WHO-EM/STD/133/E

Introduction to HIV, AIDS and sexually transmitted infection surveillance

MODULE 3

Surveillance of most-at-risk and vulnerable populations

World Health Organization
Regional Office for the Eastern Mediterranean

UNAIDS
JOINT UNITED NATIONS PROGRAMME ON HIV/AIDS
UNHCR UNICEF WFP UNDP UNFPA
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Contents

Introduction 7
How to use this module 7
Additions, corrections, suggestions 8
Acknowledgements 9

UNIT 1 Introduction to surveillance in most-at-risk populations 11
Overview 13
What this unit is about 13
Warm-up questions 13
Introduction 14
Sampling methods 18
Measures and indicators 24
Ethical considerations 28
Summary 32
Exercises 32
Appendix A.1.1 Formula for sample size calculation 33
Appendix A.1.2 Estimating the size of your target population 35
Methods of estimating the size of your target population 35
Census and enumeration methods 35
Multiplier method 36
Capture-recapture 38
Appendix A.1.3 Choosing an HIV test 42
Selecting an HIV antibody test 42
HIV testing algorithms 44
Selection of HIV testing algorithms for surveillance 46
Ensuring quality in the laboratory 47
Summary 50
Appendix A.1.4 Examples of verbal and written consent to participate in a survey 51

UNIT 2 Sex workers 55
Overview 57
What this unit is about 57
Warm-up questions 57
Introduction 58

Conducting a formative assessment 61
Selecting a sampling method 62
Measures 64
Special ethical considerations 65
Summary 66
Exercises 66

UNIT 3 Injecting drug users 71
Overview 73
What this unit is about 73
Warm-up questions 73
Introduction 74
Conducting a formative assessment 78
Selecting a sampling method 80
Measures 81
Special ethical considerations 84
Summary 84
Exercises 85

UNIT 4 Men who have sex with men 89
Overview 91
What this unit is about 91
Warm-up questions 91
Introduction 92
Conducting a formative assessment 94
Selecting a sampling method 96
Male sex workers 97
Measures 98
Special ethical considerations 99
Summary 100
Exercises 101

UNIT 5 Mobile populations 105
Overview 107
What this unit is about 107
Warm-up questions 107
Introduction 109
Conducting a formative assessment 113
Select a sampling method 115
Measures 117
Special ethical considerations 118
Summary 119
Exercises 119

UNIT 6 Street children 127
Overview 129
What this unit is about 129
Warm-up questions 129
Introduction 130
Conducting a formative assessment 132
Selecting a sampling method 134
Measures 136
Special ethical considerations 137
Summary 139
Exercises 139

UNIT 7 Prisoners 145
Overview 147
What this unit is about 147
Warm-up questions 147
Introduction 149
Conducting a formative assessment 150
Selecting a sampling method 151
Measures 152
Special ethical considerations 154
Summary 156
Exercises 156

Module summary 163

References 167

Annex 1 Glossary 171

Annex 2 Useful links 185

Annex 3 Answers to warm-up questions and case studies 191
Unit 1 answers 193
Unit 2 answers 194
Unit 3 answers 196
Unit 4 answers 201
Unit 5 answers 204
Unit 6 answers 209
Unit 7 answers 213

Annex 4 Laboratory tests available for measuring biological outcomes among most-at-risk populations 217

Introduction

How to use this module

What you should know before the course

This training course provides an introduction to surveillance in populations at high risk for HIV transmission. It builds upon the information provided in *Module 2: Surveillance of HIV risk behaviours*. This course is targeted primarily at those involved in the planning and implementation of human immunodeficiency virus (HIV) surveillance in most-at-risk populations (MARPs). As a participant, you should have an understanding of the basic epidemiology of HIV and public health surveillance before taking the course.

This module is part of a set of four modules that have been designed with a focus on the World Health Organization's (WHO) Eastern Mediterranean Region (EMR) and the Joint United Nations Program on HIV/AIDS (UNAIDS) Middle East and North Africa (MENA) Region. We refer to these collectively as EMR/MENA countries. The modules were designed for use in training workshops. The other modules are:

- Module 1: Overview of the HIV/AIDS epidemic with an introduction to public health surveillance
- Module 2: Surveillance of HIV risk behaviours
- Module 4: Introduction to respondent-driven sampling.

Similar training modules have been developed for WHO's African, Americas, European and South-East Asia regions. Although the overall framework of the modules is the same, each region has different patterns of HIV epidemics and distinct social and cultural contexts. Also, different countries may have different HIV surveillance capacities and different needs. Thus, these modules were developed taking into account the specific context of the HIV epidemic in the countries of the Region.

Module structure

This 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 be just a guess. Answer the questions as best you can. You will keep your answers to the warm-up questions in this module. 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 and you can check your work.

As you study this module, you may come across terms and acronyms that are unfamiliar. In Annex 1, you will find a glossary that defines many of these.

Annexes

More information is provided in the following annexes:

Annex 1: Glossary

Annex 2: Useful links

Annex 3: Answers to warm-up questions and case studies

Annex 4: Laboratory tests available for measuring biological outcomes among most-at-risk populations

Additions, corrections, suggestions

We welcome feedback on this training module. Please send your suggestions for any changes or additional information that might be included to the following address for possible inclusion in future editions.

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Unit 1

Introduction to surveillance in most-at-risk populations

Overview

What this unit is about

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

Warm-up questions

1. Which of the following groups are at increased risk for HIV infection in EMR/MENA?
   a. sex workers
   b. injecting drug users
   c. men who have sex with men
   d. all of the above

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

   True False

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

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

Introduction

What you will learn

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

- discuss the importance of surveillance in most-at-risk populations in different epidemic settings
- identify most-at-risk populations in EMR/MENA
- discuss the advantages and disadvantages of different sampling approaches, especially in the context of surveillance among most-at-risk populations
- understand the special ethical issues of surveillance of most-at-risk populations.

HIV surveillance

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

Second-generation surveillance

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

For the purpose of HIV surveillance and strategic HIV program planning the concepts of risk and vulnerability are important:

Risk is defined as the probability that a person may become infected with HIV. Unprotected sex, multiple sexual partnerships involving unprotected sex and injecting drug use with contaminated injecting equipment are the most important risk behaviours. Risk increases with the prevalence of HIV in the sexual or drug-using network.

Vulnerability to HIV is defined as the extent to which individuals are able to control their risk. Factors that make people vulnerable include: a lack of knowledge about HIV or lack of skills to avoid risk behaviours; inability to access condoms, clean needles, or other protection; gender and income inequality that prevents sexual negotiation or contributes to forced sex; and discrimination and stigma, which deter people from changing risk behaviours. These factors, alone or in combination, when shared throughout a community, create collective or community vulnerability. Vulnerability is independent of whether HIV is highly present. Where HIV vulnerability is high it is likely that an individual or community will be less resilient to HIV risk if or when HIV increases within the network.

Populations of interest in HIV surveillance

Populations of interest in HIV surveillance include the general population, most-at-risk populations, bridging populations and vulnerable populations. The definitions of these populations used in this module are the following:

- **General population:** The general population encompasses all people living in a defined community, e.g. a country, a province or a city. If surveillance data on the general population exclude certain subpopulations, e.g. specific age-groups of the population, foreign workers, refugees or others, this should be stated clearly. The general population is at relatively low risk of HIV exposure in low-level and concentrated HIV epidemics.
- **Most-at-risk population (MARP)**, **priority population** or **key population at increased risk:** The terms most-at risk population, priority population and key population at increased risk are used interchangeably. These are populations that experience the highest probability of being exposed to HIV and include injecting drug users, men who have sex with men (including male sex workers) and female sex workers.
- **Bridging populations:** Bridging populations are populations at intermediate risk of exposure to HIV and provide links between most-at-risk populations and the low-risk general population. Bridging populations may include the sexual partners of injecting drug users, sex workers and men who have sex with men. For example, a client of an HIV-infected sex worker may become infected with HIV. He may then have unprotected sex with his wife, transmitting the virus to her. In this scenario, he has acted as a bridge by which HIV infection has passed from the sex worker to his wife.
- **Vulnerable populations:** Vulnerable populations form a subset of the general population and are generally at low risk of HIV exposure, but under certain circumstances are vulnerable to practices that may put them at a higher risk of HIV. Depending on the context, prisoners, youth and mobile populations belong to vulnerable populations. Once these vulnerable populations adopt high-risk practices they become part of most-at-risk or bridging populations.

  Vulnerable populations are found in all settings. Their risk of acquiring HIV depends on the prevalence of HIV in their networks and their ability to adopt safer behaviours and access prevention and treatment commodities and services. For that reason, populations such as people affected by humanitarian emergencies and migration, young people, women, prisoners and people living with disabilities may be at high risk in some places but not in others. Once these vulnerable populations adopt high-risk practices they become part of most-at-risk or bridging populations
- **Key populations:** Key populations include most-at-risk, bridging and vulnerable populations, who, while being important to the dynamics of HIV transmission in a setting, are essential partners for an effective response to the epidemic, i.e. they are key to the epidemic and key to the response. Key populations will vary depending on the epidemic and community/country context.

Populations considered priority for HIV surveillance in EMR/MENA

An important part of second-generation surveillance system is determining HIV prevalence and risk behaviours in most-at-risk, bridging and vulnerable populations. In particular, most-at-risk populations are often important in establishing, accelerating or sustaining

the HIV epidemic. most-at-risk populations are likely to be the first to become infected in a new epidemic. They are also infected at higher rates than the general population.

Throughout the world, sex workers, injecting drug users and men who have sex with men are considered most-at-risk populations. During the development of this training course, public health experts emphasized that potentially vulnerable populations in EMR/MENA include, but are not limited to, the following:

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

Therefore this training module includes specific guidance on HIV surveillance for mobile populations, street children and prisoners, as well as for most-at-risk populations (injecting drug users, men who have sex with men and sex workers).

For information on the issues unique to a specific population, refer to the unit related to the populations that interest you (see Table 1.1).

Table 1.1 Most-at-risk and vulnerable populations discussed in Units 2–7

Group	Unit
Most-at-risk populations	
Sex workers	2
Injecting drug users	3
Men who have sex with men	4
Populations frequently considered as vulnerable in EMR/MENA	
Mobile populations	5
Street children	6
Prisoners	7

A central role of most-at-risk populations

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

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

HIV is then transmitted quickly to other members of these groups through their networks of sexual and drug-injecting 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.

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

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

Epidemic states

Data from HIV surveillance in most-at-risk populations are used differently at different epidemic states. This use is illustrated in Table 1.2.

Discussing the table

Looking at Table 1.2, answer the following questions:

a. How is HIV surveillance in most-at-risk populations used in low-level epidemics?
b. What are the characteristics of a concentrated epidemic?
c. In generalized epidemics, do decreases in HIV prevalence occur first in most-at-risk populations or in the general population?

More on epidemic states

Figure 1.1 shows the state of the HIV epidemic in EMR/MENA.

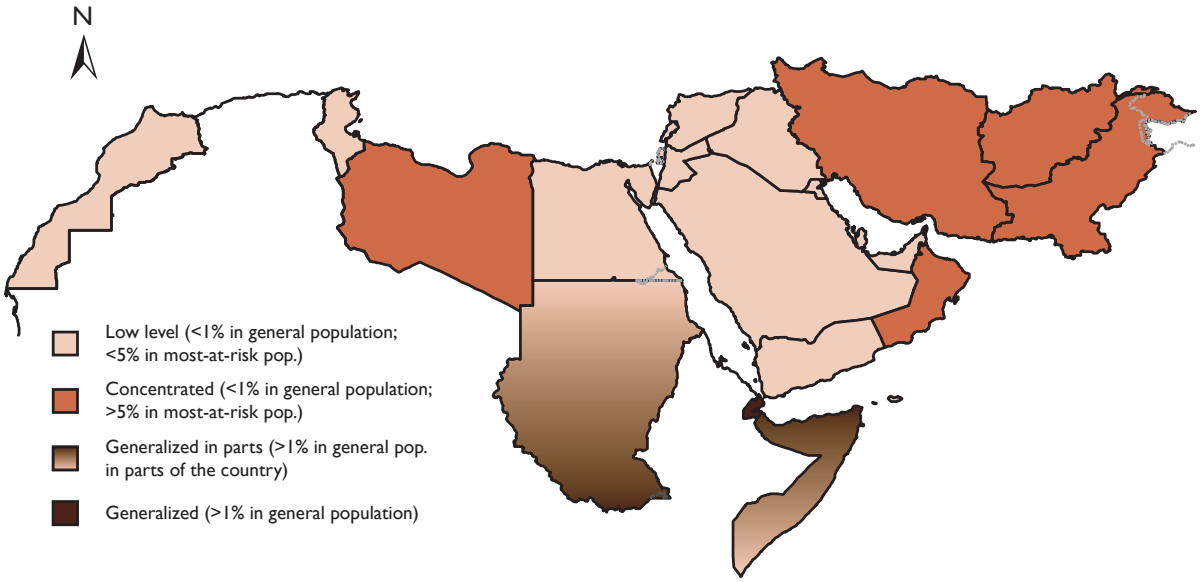


Figure 1.1 State of the HIV epidemic in EMR/MENA countries [1]

Discussing the figure

Looking at Figure 1.1, answer the following questions:

a. Which countries in EMR/MENA have the lowest prevalence of HIV?
b. What might explain the differences in HIV prevalence between different EMR/MENA countries?

HIV prevalence among various most-at-risk and vulnerable populations

Surveillance in populations at increased risk has varied from country to country in EMR/MENA. Most countries have been successful in gathering HIV surveillance data from sex workers and patients attending STI clinics. Several countries have been able to survey men who have sex with men, injecting drug users, prisoners, mobile populations and uniformed personnel. Examples of surveillance methods are shown below, and examples of the specific groups surveyed are given in Units 2–7 of this module.

Sampling methods

Conventional sampling techniques

Various sampling methods are used to collect data and measure certain characteristics. Table 1.3 provides a brief summary of conventional sampling techniques and their advantages and disadvantages.

These techniques include simple random sampling, systematic sampling, stratified sampling and cluster sampling.

Table 1.3 Summary of conventional sampling techniques

Sampling technique	Steps	Advantages	Disadvantages
Simple random	1. Construct sampling frame for survey population 2. Select people randomly from sampling frame using random numbers table or lottery draw	1. Concept is easy to understand and analyse	1. Requires sampling frame of entire target population 2. Difficult to carry out if sample is geographically dispersed 3. Using random number/ lottery is time consuming
Systematic	1. Create a list of the target population 2. Calculate sampling interval (SI) 3. Select random start between 1 and SI and select that person 4. Add SI to random start and select person, and so on.	1. Random numbers or lottery not required 2. Easy to analyse	1. Requires sampling frame of entire target population 2. Difficult to carry out if sample is geographically dispersed
Stratified	1. Define the strata and construct a sampling frame for each stratum 2. Take a simple or systematic sample from each stratum 3. Calculate indicator estimates for each stratum and for population	1. Produces unbiased estimates of indicators for the strata 2. Can increase precision of indicator estimates	1. Requires sampling frame of entire survey population 2. Difficult to carry out if sample is geographically dispersed 3. Requires sample large enough to make precise estimates for each stratum 4. Population estimates require weighting
Cluster: Probability proportional to size (PPS) or equal probability sampling	1. Construct sampling frame of clusters 2. Calculate SI, select random start between 1 and SI 3. Select cluster whose cumulative size contains the random start 4. Add SI to random start and select cluster 5. Sample equal numbers of people from selected clusters	1. Only need sampling frame of clusters and individuals in selected clusters 2. Sample concentrated in geographical areas	1. Decreases precision of estimates, thus requiring larger sample size 2. Size of clusters required prior to sampling
Cluster: Equal probability, fixed cluster size	1. Construct sampling frame of clusters 2. Select clusters using simple or systematic sampling 3. Sample equal numbers of people from selected clusters	1. Only need sampling frame of clusters and individuals in selected clusters 2. Sample is concentrated in geographical areas 3. Do not need cluster sizes before sampling	1. Decreases precision of estimates, thus requiring larger sample size 2. Weighted analysis required for unbiased estimates 3. Size of clusters required for weighted analysis

Table 1.3 (continued) Summary of conventional sampling techniques

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

Discussing the table

Looking at Table 1.3 answer the following questions:

a. What are the advantages to using a systematic sampling method?
b. What are the steps to take when using a cluster: equal probability, fixed cluster-size sampling method?
c. What is the disadvantage of using the stratified sampling method when it comes to making population estimates?

Newer sampling methods

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

RDS

In snowball sampling, investigators do not seek potential participants actively, but have current participants refer them. RDS combines the methods of snowball sampling with a mathematical model to weigh the sample. This method compensates for the non-random way in which the sample was collected. It is an experimental sampling method that does not require a sampling frame. It is especially useful to help us find hard-to-reach groups, which are small compared to the general population. A more detailed description of the methods and statistical tests used in RDS can be found at: http://www.respondentdrivensampling.org

TLS

TLS combines the methods of targeted sampling and cluster sampling to produce a probability sample. TLS is like conventional cluster sampling, but it solves the problem of

everyone in the target population not being in the same place at the same time. It solves this problem because clusters are defined by location and time. TLS requires extensive ethnographic mapping to prepare a sampling frame that reflects the variety in time periods, locations of behaviours and number of group members.

TLS:

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

How TLS works

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

- Sex workers often gather at brothels, massage parlours and street corners
- Men who have sex with men may gather in bars, parks and other meeting areas
- Injecting drug users tend to congregate at injecting locations, such as parks and deserted buildings or under bridges.

TLS lessons learned

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

TLS methods

There are four stages of the TLS method:

Step 1: Prepare for TLS

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

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

Step 2: Construct the sampling frame

Staff will use the list of venues to construct monthly sampling frames of venues and day/time periods (four-hour blocks of time that would yield at least 8 participants). Standardized enumerations of eligible participants are used to help select which venues and day/time periods are included in the sampling frames.

Table 1.4 Comparing time-location and respondent-driven sampling

Time-location sampling (TLS)	Respondent-driven sampling (RDS)
Steps: ● Write the procedures and calculate the required sample size ● Conduct formative assessment ● Identify clusters using ethnographic mapping ● Construct a sampling frame of clusters. Define clusters by both location and time if the population is floating ● Select clusters and individuals in clusters using equal probability sampling	**Steps:** ● Write the procedures and calculate the required sample size ● Conduct formative assessment ● Start with initial contacts or seeds who are surveyed and who then become recruiters ● Each recruiter invites up to three people from their own high-risk group to be interviewed ● The new recruits become the recruiters ● Several recruitment waves occur
Requirements: ● Needs extensive mapping and ethnographic work ● Need to create a sampling frame of location and time (clusters) and individuals in selected clusters ● Needs coordination with gatekeepers, such as bar owners and pimps ● The interviewers should be able to identify and approach members of the target population ● Adjusting the estimates during data analysis is important because estimating cluster size in advance is difficult	**Requirements:** ● The target population must be in networks ● Need to keep track of links between recruiters (who are members of the target population) and recruits ● The size of group members' networks must be documented ● Sample must reach equilibrium ● Special statistical software must be used to adjust the final data. The most commonly used software is RDSTAT
Special considerations: ● To some extent, TLS lets us do a probability sample of populations whose members go to certain venues and sites ● It is difficult to maintain randomness while selecting respondents within clusters ● Clusters and sites can close quickly ● Samples can be concentrated in geographical areas	**Special considerations:** ● Can reach subgroups who do not visit certain venues or clinics ● If conducted correctly, can provide unbiased estimates ● There is much less need for ethnographic mapping. Field operations can be done in office settings ● Because the target population does the recruiting, it still works when it is hard to identify members of the target population

Step 3: Construct the sampling plan

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

Step 4: Sample the participants

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

Comparing RDS and TLS

The sampling steps and the comparison of TLS and RDS are summarized in Table 1.4.

Discussing the table

Looking at Table 1.4, answer the following questions:

a. How are clusters identified in TLS?
b. At the beginning of a study using RDS, what is the role of new recruits?
c. What are the special considerations when using TLS?

Choosing the sampling approach

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

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

Detailed information on the sampling and survey methods used to do surveillance among most-at-risk populations is provided in *Module 2: Surveillance of high-risk behaviours*. Detailed information on the survey methods applicable to behavioural and biological surveillance of most-at-risk populations is presented later in this module.

Calculating sample size

Appendix A.1.1 provides pre-calculated sample-size estimates for a range of possible scenarios in behavioural and biological surveillance.

In many situations you may not know the size of your target population. Methods on how to estimate the size of a specific population are described in Appendix A.1.2.

Measures and indicators

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

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

You should choose indicators for surveying most-at-risk populations based on the data your country needs. Essential indicators for sex workers, injecting drug users and men who have sex with men are shown in Table 1.5.

Further information and the specific wording and definitions of questions and indicators that are used internationally can be found in *Module 2: Surveillance of high-risk behaviours* and at the following websites:

- United Nations General Assembly Special Session on HIV/AIDS (UNGASS) has developed a set of core indicators. *Monitoring the Declaration of Commitment on HIV/AIDS guidelines on construction of core indicators* is available online at: http://www.ua2010.org/index.php/en/ungass/meeting-ungass-targets/ungass-core-indicators
- Family Health International (FHI) publishes guidelines for repeated behavioural surveys in populations at risk of HIV, including indicators that are key to the spread of HIV among high-risk groups. These guidelines are available online at: http://www.fhi.org (English) or http://www.fhi.org/ar/fhiag.html (Arabic).
- The HIV/AIDS Survey Indicators Database of MEASURE 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.
- The UNAIDS Indicator Registry, developed by the Country Response Information System (CRIS) Unit in collaboration with monitoring and evaluation experts, is a facility for harmonizing and publishing indicator definitions and sets on the internet. Further information is available at: http://www.unaids.org/en/knowledgecentre/hivdata/cris/cris_data.asp or www.indicatorregistry.org.
- The technical guide for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users is available at: http://www.who.int/hiv/pub/idu/targetsetting/en.

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

It is usual for data to be collected on background information and on factors such as alcohol or drug use that promote high-risk behaviours. In this way, indicators can be compared across different sociodemographic groups.

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

Injecting drug users	Sex workers	Men who have sex with men
Percentage of injecting drug users who report the use of sterile injecting equipment the last time they injected	Percentage of sex workers who report the use of a condom with their most recent client	Percentage of men who report the use of a condom the last time they had anal sex with a male partner

Discussing the table

Looking at Table 1.5, answer the following questions:

a. What is one common indicator for behavioural surveillance found in all three populations?
b. What do you think are the reasons for defining risk behaviours that are to be measured so exactly?

Further information on the behavioural measures used in surveillance of most-at-risk populations is provided later in this module and in *Module 2: Surveillance of high-risk behaviours*.

Deciding whether to test for HIV and STI

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

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

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

Questions to ask when planning biological sampling are:

- Is there adequate space at the site for counselling and testing?
- Are there enough supplies and personnel for collecting specimens?
- What is the organization required for laboratory capabilities, transportation and storing specimens?
- How do we make sure that ethical matters are taken care of: maintaining confidentiality, approval by ethical review board, adaptation of consent form?
- Will testing cause refusal to participate and lead to participation bias?

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

Information on the different options for HIV testing is provided in Appendix A.1.3.

Biological measures

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

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

Type of transmission	Infections to test for
Sexual	• Syphilis • Gonorrhoea • *Chlamydia* • Herpes simplex virus type 2 (HSV-2) • Hepatitis B virus (HBV) • Trichomoniasis • Human papilloma virus (HPV) • *Haemophilis ducreyi* (chancroid) • *Treponema pallidum*
Parenteral (bloodborne)	• Hepatitis C virus (HCV) • Syphilis

Discussing the table

Looking at Table 1.6, answer the following questions:

a. Which infection is characterized by both sexual and parenteral (bloodborne) transmission?
b. What type of transmission characterizes *T. pallidum*?

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

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

Sexually transmitted infections

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

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

- sex workers
- patients of STI clinics
- men who have sex with men
- mobile populations, such as truck drivers, fishermen and migrant labourers
- prisoners
- uniformed personnel.

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

Testing for STIs

STIs that are most frequently measured are:

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

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

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

- gonorrhoea
- *Chlamydia*
- syphilis (high-titre reactivity of rapid plasma reagin test means new infection, low titre means past infection)
- trichomoniasis.

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

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

Tests for syphilis, HSV-2 and HBV require blood samples. Although 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). Because it is easy to collect urine for detection of gonorrhoea and *Chlamydia*, these infections are often measured in surveys of most-at-risk populations.

High-titre syphilis (for example, a positive rapid plasma reagin test 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 participants back in for treatment and for management of their sexual contacts.

Parenterally transmitted infections

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

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

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

It should be noted that in some countries, the reuse of needles in medical settings and piercing and scarification practices contribute to parenteral transmission of HCV.

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

Ethical considerations

Including most-at-risk populations in surveillance

Most-at-risk populations 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 about the HIV situation in a country or district. It is essential to reach these most-at-risk populations to understand the spread of HIV among them. Additionally, surveillance data can contribute to advocacy for improved treatment and care for these vulnerable populations.

Potential harms

Many most-at-risk populations are marginalized and their behaviour is illegal in most countries. Most-at-risk populations that have legitimate fears both of surveillance and of the reactions of the larger society include the following:

- sex workers
- injecting drug users
- men who have sex with men
- refugees and internally displaced persons
- prisoners.

However, some level of risk probably exists for all most-at-risk populations. A list of potential harms from surveillance, if their status is disclosed, is listed in Table 1.7.

Table 1.7 Potential harms caused by HIV and behavioural surveillance in most-at-risk populations

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

Discussing the table

Looking at Table 1.7, answer the following questions.

a. What are two potential harms facing injecting drug users who participate in HIV surveillance activities?

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

WHO ethical guidelines

In 2003, the WHO published a set of guidelines specifically directed toward ethical considerations involved in second-generation surveillance (available at http://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 serosurveillance
- consent to participate in studies
- use and dissemination of data
- participants' right to access test results.

Confidentiality

Confidentiality protects participants from problems 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 and may even be subject to criminal charges. Be aware of any part of your country's laws that may make participation difficult. This may include:

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

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

Approaches to HIV testing

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

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

Linking

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

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

- informed consent
- pre- and post-test counselling
- confirmatory testing as indicated in national HIV testing strategies
- referral to needed health care and other services.

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

Unlinked anonymous testing (UAT) refers to removing identifying information or means

to link HIV test results to participants. Although unlinking HIV test results from someone's personal identifying information makes certain of confidentiality and reduces participation bias, it prevents post-test counselling and returning results to the people tested.

When using UAT, it is recommended that you refer people who are tested and wish to know their HIV status to other services where they can receive HIV testing and counselling.

Informed consent

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

Whenever informed consent is obtained, it is important to watch for participation bias. It may be useful to add a check box on consent forms to indicate people who choose not to participate so that you can evaluate participation bias. If this is not possible, you can use other ways to collect information on non-participants during data collection. For example, you may write into the protocol that you will ask people who refuse to participate a few questions regarding their sociodemographic characteristics such as age, gender, religion, etc., in order to see if there is any difference between those who participate and those who refuse to participate.

Written consent forms and surrogate consent

Written consent forms are generally needed to document that informed consent has occurred. The appropriate reading level for consent forms is middle school or lower. When literacy is low, consent can be obtained verbally, but it needs to be documented. Examples of written and verbal consent forms are included in Appendix A.1.4. Suggestions for wording and language for what is required in consent forms are available at the CDC website: http://www.cdc.gov/od/ads/docs/consent.pdf.

When people are not capable of giving written or verbal informed consent, surrogate consent can be obtained. Examples of this are when a parent gives consent for a child or a guardian gives consent for an adult with severe illness. Countries may also have laws about the age at which an adolescent can participate in research without their parents' consent and who may provide surrogate consent for orphans or street children. You should familiarize 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 lower ranking members of uniformed serves are especially vulnerable to the belief that if they do not participate, they will be punished. In these situations, you must make sure that effective communication and understanding is involved in the informed consent process.

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

Further information on the ethical issues related to surveillance of high-risk groups is provided in Units 2–7 in this module.

Summary

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

In EMR/MENA, populations at increased risk include sex workers, injecting drug users, men who have sex with men, mobile populations, street children, prisoners and uniformed personnel. There are a number of conventional probability sampling methods that can be used. Because many populations at increased risk are also hard to reach, RDS and TLS methods are ideal for surveys of these groups. Many populations at increased risk are also vulnerable to a variety of social factors, and, as a result, surveillance and special studies in these groups raises several ethical issues.

Exercises

Warm-up review

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

Small group discussion

Get into small groups to discuss these questions.

1. In your country, what populations are recognized as most-at-risk populations for HIV infection? Are there estimates of the sizes of these populations?
2. Does your country conduct HIV surveillance among most-at-risk populations? How frequently?

Appendix A.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: 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 that particular brothel. Choosing a design effect is difficult without prior survey data. Design effects from 1 (that is, none) to 2 (moderate) cover a 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: These 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 practice, it is usually set at the smallest change you

think is meaningful. For example, a 10% increase in condom use would be considered a meaningful improvement, whereas a 1% increase would not be considered meaningful. The smaller the change you wish to detect, the larger the sample size you will need. Also, the closer P_1 and P_2 are to 50%, the larger the sample size you will need.

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

Table A.1.1.1 provides precalculated sample size estimates for a range of possible scenarios in behavioural and serosurveillance.

Table A.1.1.1 Sample size needed per survey wave to detect a change in the proportion of an indicator between survey waves, using a 95% confidence level, 80% power and a design effect of 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

Appendix A.1.2

Estimating the size of your target population

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

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

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

Methods of estimating the size of your target population

Estimation options

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

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

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

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

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

Defining your target population

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

Census and enumeration methods

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

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

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

Multiplier method

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

Using the multiplier method requires:

- Having good institutional record-keeping
- Behavioural surveillance instruments that include questions related to your target population (e.g., number of males in the general population that frequent sex workers, number of clients per week per sex worker).

Multiplier method exercise 1

As the National AIDS Programme manager of Menaland you want to estimate the number of sex workers in the country.

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

How would you estimate the number of sex workers in Menaland?

Exercise 1 solution

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

12% × 1.45 million = 174 000

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

174 000 × 26 = 4 524 000

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

11 × (52 - 3) = 539

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

4 524 000 ÷ 539 = 8400

You estimate that there are 8400 sex workers in Menaland.

Exercise 2

As the National AIDS Programme manager of Menaland you want to estimate the number of injecting drug users in the country.

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

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

Using the above data how would you estimate the number of injecting drug users in Menaland?

Exercise 2 solution

If only 2% of heroin is seized, then:

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

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

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

The total number of injectors must therefore be:

1 950 000 ÷ 54.75 = 35 616

You estimate that there are 35 616 injecting drug users in Menaland.

Capture-recapture

Introduction

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

Assumptions of capture-recapture

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

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

Limitations of capture-recapture

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

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

List dependency: People who are in list 1 (a harm reduction nongovernmental organization) might be referred by a private methadone clinic (list 2)

Population heterogeneity: People who go to a harm reduction nongovernmental organization (list 1) might be different (for example, by socioeconomic status) than people who go to a private methadone clinic (list 2).

Analyzing three or more sources using a 2 × 3 table or log-linear model eliminates much of the bias associated with capture-recapture because it eliminates the bias of independence of sources and homogeneity.

Capture-recapture analysis

In order to complete a capture-recapture analysis, two or more data sets are required. If two data sets are used, 2 × 2 tables are useful for determining the number of cases not included in either data set and thus can be used to estimate the total population (Figure A.1.2.1).

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

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

Where:

N = Estimate of total population size

M = Total number of people captured and marked on the first visit

C = Total number of people captured and marked on the second visit

R = Number of people captured on the first visit that were then recaptured on the second visit (i.e. included in both samples).

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

Figure A.1.2.1 Two-by-two table for capture recapture analysis

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

Detailed example of how to use capture-recapture data

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

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

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

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

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

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

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

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

Where Var(*N*) is calculated as:

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

Capture-recapture exercise:

The Al Rabia city Department of Public Health has decided to conduct a survey of injecting drug users in Al Rabia to gather information on the behaviours driving the epidemic among injecting drug users. Although nongovernmental organization and police reports indicate that there is a growing injecting drug user population, the Department of Public Health does not know its size.

To estimate the size of the injecting drug user population in Al Rabia, the Department of Public Health decides to enlist the support of all harm reduction nongovernmental organization clinics serving injecting drug users and all methadone maintenance clinics in the city. After describing the purpose of the surveillance activity and convincing the clinics that the patients' names and information will be kept confidential, the clinics agree to give the Department of Public Health their intake registers that include the names and birth dates of all the injecting drug users who sought services from their clinics in the past month.

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

The results of the two lists are provided below.

Number of injecting drug users in Al Rabia, Menaland, 2008

Methadone clinic list	Harm reduction nongovernmental organization clinic list		
	Present	Absent	Total
Present	296	441	737
Absent	350	—	—
Total	646	—	*N*

How would you go about estimating the number of injecting drug users in Al Rabia, Menaland?

Exercise solution:

If 646 injecting drug users are present on the methadone clinic registration list, 737 injecting drug users are present on the harm reduction nongovernmental organization clinic list, 296 are present on both lists and N = MC / R

Then the total number of injecting drug users = 646 × 737 ÷ 296 = 1608

Acknowledgements

The material provided in this appendix was adapted from the UNAIDS/WHO report *Estimating the size of populations at risk for HIV* prepared by Elizabeth Pisani [2].

Appendix A.1.3

Choosing an HIV test

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

Through reading this appendix you will be able to:

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

Selecting an HIV antibody test

Introduction

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

Conventional EIAs

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

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

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

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

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

Rapid tests

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

Advantages of rapid tests

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

The characteristics of EIAs and HIV rapid tests are compared in Table A.1.3.1.

Table A.1.3.1 Comparing EIAs and HIV rapid tests [3]

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

Discussing the table

Looking at Table A.1.3.1, answer the following questions:

a. Which test requires less laboratory equipment and is easier to perform?
b. Where refrigeration is not available, which test would be more appropriate?

Oral fluid and urine tests

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

Whichever test is chosen, it is essential that the results given to people be reliable. Additionally, in HIV surveillance, it is important to consider the step-by-step procedure,

the laboratory-testing algorithm, which will most accurately detect HIV infections in a population.

HIV testing algorithms

Definition

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

Reliability and accuracy of tests

Different algorithms have certain limitations on how well they can detect all persons who have a disease and also how well they can detect all persons who do not have a disease. These limitations are described below and in Table A.1.3.2:

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

Table A.1.3.2 True positives, false positives, true negatives, false negatives

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

Discussing the table

Looking at Table A.1.3.2, answer the following questions:

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

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

Sensitivity and specificity

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

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

Positive and negative predictive values

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

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

Table A.1.3.3 A guide for calculating sensitivity and specificity

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

In Table A.1.3.3:

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

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

How HIV prevalence affects test selection

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

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

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

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

Selection of HIV testing algorithms for surveillance

Selecting an HIV testing strategy

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

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

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

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

Testing strategy when using unlinked anonymous testing

Recently, the UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance recommended that the testing strategy of serial testing with two tests be used regardless of HIV prevalence for surveillance (Figure A.1.3.1). This concept replaces the previous options of strategies according to prevalence. The strategy states:

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

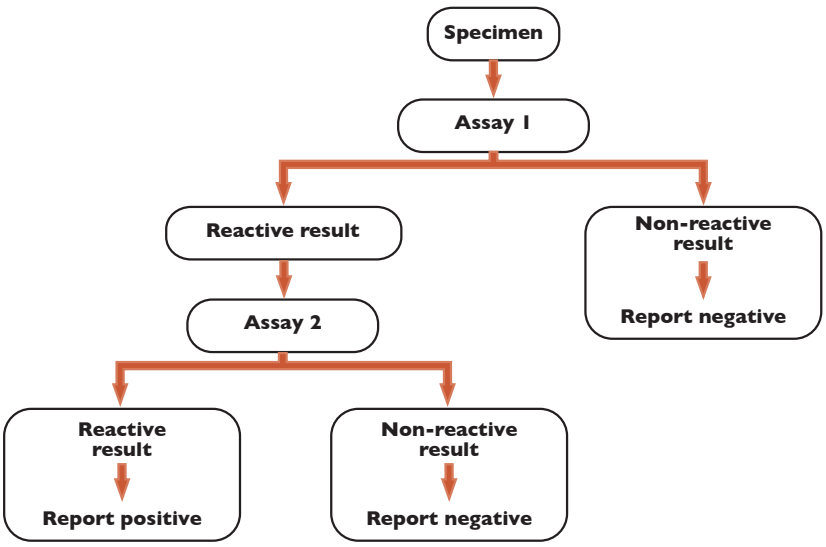


Figure A.1.3.1 Strategy for HIV testing for surveillance [4]

Testing strategy when returning results

If the test results during a surveillance survey will be returned, be sure to use a diagnostic HIV testing algorithm appropriate for the epidemic situation in your country.

In low epidemic settings WHO recommends 3 serial tests for confirming a positive HIV status, to be conducted and interpreted as follows:

Test 1: The test is reported negative if the result is non-reactive. If reactive, proceed to the next test.
Test 2: If the second test result is non-reactive, the test is reported negative. If it yields a reactive result a third test should be conducted.
Test 3: If the third test is reactive report as positive. If this test is non-reactive, report as "indeterminate" and repeat the whole process in two weeks on a fresh specimen.

In generalized epidemic settings or in specific population groups where the epidemic is concentrated, WHO recommends two serial tests for confirming a positive HIV status, to be conducted and interpreted as follows:

Test 1: The test is reported negative if the result is non-reactive. If reactive, proceed to the next test.
Test 2: If the second test is reactive report the result as positive. If it is non-reactive, report as "indeterminate" and repeat the whole process in two weeks on a fresh specimen.

Ensuring quality in the laboratory

Introduction

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

Quality control

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

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

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

Quality assurance

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

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

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

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

QA and the phases of the testing process

There are a variety of components in each phase of the testing process that should be monitored by QA programmes. These components are listed in Table A.1.3.4.

Table A.1.3.4 Components for review by QA programmes in the pre-analytical, analytical and post-analytical phases of the testing process.

Pre-analytical phase	Analytical phase	Post-analytical phase
• Training • Laboratory safety • Number of trained personnel available and capable of performing HIV testing • Specimen collection, labelling and transport conditions • Deciding on handling of specimens before testing • Deciding on the sources and types of specimens to be tested • Deciding on the number of specimens tested • Selection of test kits • Expiration dates of test kits. Kits need to be used before expiration dates. Older kits should be used before newer kits. • HIV test kit reagents. Reagents must be stored at the appropriate temperature as specified by the manufacturer. Certain reagents (such as conjugates for EIAs) may require refrigeration.	• Specimen processing and storage • Written procedure manual • Reagent preparation • Testing performance • Performance and maintenance of equipment (such as spectrophotometers and washers) • Correct use of reagents • Inclusion of internal quality controls in the test kits • Quality control monitoring procedure	• Interpreting results • Transcribing results, such as recording results on the correct identifier code • Entering data into the tracking system (computer or hard copy) • Maintaining records • Reviewing quality control

Discussing the table

Looking at Table A.1.3.4, answer the following questions:

a. In which phase are results analysed and interpreted?
b. In which phase are specimens tested?

Internal QA

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

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

External QA

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

External QA programmes may be instituted by a national or international reference laboratory, which function as a recognized centre of expertise and standardization of diagnostic techniques. The steps taken to implement an external QA programme, such as a proficiency testing programme, are listed below. Proficiency testing should be done once or twice each year.

1. The national reference laboratory sends all participating laboratories a proficiency panel of approximately six specimens to identify as HIV-positive or HIV-negative. Proficiency panels are a set of samples for which the test results are known by the reference laboratory. This panel should contain HIV-negative and HIV-positive samples of both weak and strong specimens. Samples should be representative of the HIV strains circulating in a country, and they should be from different stages of the disease (for instance, from early HIV infection to late-stage AIDS).
2. The panels are tested at the local laboratories in much the same way as they routinely test their specimens for HIV.
3. The local laboratories report their findings to the reference laboratory.
4. The reference laboratory collates the results and provides feedback to each participating laboratory.

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

QA with limited laboratory infrastructure

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

Summary

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

Appendix A.1.4

Examples of verbal and written consent to participate in a survey

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

University of Menaland

INFORMATION SHEET FOR RESEARCH PARTICIPANTS

PURPOSE AND BACKGROUND: The Minstry of Health in collaboration with the University of Menaland is conducting a survey of injecting drug users. Participants will undergo a behavioural interview, receive monetary compensation for costs 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, sexually transmitted infection testing, and other HIV- and sexually transmitted infection-related behaviours with both standard and site-specific measures. This study will be based on data from 320 injecting drug users recruited from social and sexual networks in Wadi Zohour, Menaland. 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 sexually transmitted infections and HIV
  - Utilization 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 injecting drug users and the injecting drug user community in Wadi Zohour. This information may be helpful in creating HIV prevention programmes for injecting drug users in your community.

REIMBURSEMENT: At the end of the interview, you will be reimbursed 100 Menaland 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 Menaland 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 Menaland 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 investigators at the University of Menaland.

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, Wadi Zohour Hospital 4th Floor, University of Menaland. His phone contact is xxxxxx.

CONSENT: Participation in research is voluntary. You are free to decline to be in this study and free to withdraw from it at any time. Your decision 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 2: Written consent form (requiring a written signature)

University of Menaland

CONSENT TO BE A RESEARCH SUBJECT

A research study of ways to reduce HIV transmission among injecting drug users in Wadi Zohour, Menaland

A. PURPOSE AND BACKGROUND

Dr. xxx of the University of Menaland and Dr. xxx of the Ministry of Health of Menaland are conducting a research study to learn about ways to reduce transmission of human immunodeficiency virus (HIV) among injecting drug users in Wadi Zohour, Menaland. 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 drug dependency treatment and methadone maintenance programmes in Wadi Zohour, Menaland.

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 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 or Dr. xxx at the University of Menaland at 123 College Road, Wadi Zohour, Menaland, (Telephone xxxxxxx).

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 between the hours of 08:00 and 17:00, Sunday through Thursday, by calling xxx, or by writing. The address is 123 College Road, University of Menaland, Wadi Zohour.

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 jeopardize 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

Unit 2

Sex workers

Overview

What this unit is about

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

Warm-up questions

1. True or false? Sex workers can contribute disproportionately to the sexual transmission of HIV because of their large number of sexual partners. Circle your answer below.

   True False

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

   a.

   b.

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

4. True or false? Surveillance coordinators should meet with sex workers to use their expertise in designing the approach and questionnaires for behavioural surveillance.

   True False

5. Clients of sex workers are often a _____ to low-risk populations. For example, clients of sex workers 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 brothels.

Introduction

What you will learn

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

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

Sex work

This unit focuses on the special issues in conducting behavioural surveillance and HIV serosurveillance in sex workers.

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

Table 2.1 Comparing direct and indirect sex workers

Direct sex workers	Indirect sex workers
• have little or no source of income outside of sex work	• are those who may have another source of income or do not engage in sex work full time
• are also called formal sex workers	• are also called casual sex workers or clandestine sex workers
• can be found in brothels	• may provide sex services in specific locations where they are employed, such as bars, hotels or massage parlours that are not necessarily or exclusively associated with sex work
• can be found in high concentrations in streets, hotels, bars and massage parlours	• may work by special arrangement via telephone or internet
• may work by special arrangement via telephone or internet	• are unlikely to be included in registries or lists of sex workers routinely screened at STI clinics
• 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 not identify themselves as sex workers
• may be registered in areas where sex work is legal or tolerated; registries of direct sex workers may be maintained through STI clinics to monitor routine STI screening and treatment	
• may identify themselves as sex workers	

Discussing the table

Looking at Table 2.1, answer the following questions:

a. What is another name for indirect sex workers?

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

Sex workers 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 people 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 are similar to those used with female sex workers. However, in other ways, surveillance among male sex workers is very different from surveillance among female sex workers. For example, the formative assessment phases should identify issues with accessing men who have sex with men 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 (Unit 4). You should keep in mind that not all male sex workers are men who have sex with men; in some settings male sex workers may identify as heterosexual and have female clients.

Role of sex workers in the HIV epidemic

Sex workers 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 sex partners. Factors that may increase HIV risk among sex workers include:

- a 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, which increases the spread of HIV and STIs)
- a 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 drugs
- a high frequency of sex under the influence of alcohol or drugs, which often affects the ability to negotiate condom use
- a large number of clients under the influence of alcohol or drugs
- loss of control over condom use due to financial and physical coercion or violence
- having non-client sex partners, both regular and non-regular, with whom they do not use condoms
- high levels of mobility and travel; for example, to areas that have higher or lower HIV prevalence
- difficult access to HIV and STI prevention programmes due to the illegal and stigmatized nature of sex work.

Prevalence of HIV among sex workers

In EMR/MENA, the prevalence of HIV among sex workers varies by country and region, as illustrated in the following data:

- Between 1990 and 1995, the prevalence of HIV among sex workers in Djibouti ranged from 41%–47%. Since 1996, it has remained as high as 20%–32% [5].

- HIV infection levels of 9%–10%, 2.2% and 4.4% have been found among female sex workers in Saida and Tamanrasset in Algeria, in Morocco and in Sudan, respectively [6].
- In Pakistan in 2001, 1.7% of sex workers in Sindh Province were found to be infected with HIV [7].
- Among Tunisian bar girls tested for HIV in 1989 and 1992, the prevalence of HIV was found to be 1.3% and 2.3%, respectively [8].
- Among a small group of sex workers identified by police in Yemen, an HIV prevalence of 4.5% was reported in 1998 and a prevalence of 2.7% was reported in 1999. In 2001, a study found a 7% infection rate [9].

Role of sex workers in surveillance

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

- In countries with low-level epidemics, where the HIV prevalence has not consistently exceeded 5% in any defined subpopulation, sex workers may be the first to be detected with HIV infection.
- Sex workers are often one of the first populations to reach HIV prevalence levels above 5%, leading to a country's epidemic classification as concentrated.
- In generalized epidemics, where transmission is widespread in the general population, behavioural changes in response to prevention programmes may be detected first among sex workers. For example, the results of consistent condom use may be detected first among sex workers.

Sex workers 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 serosurveillance among sex workers plays a central role in determining the magnitude and direction of the HIV epidemic in all epidemic states.

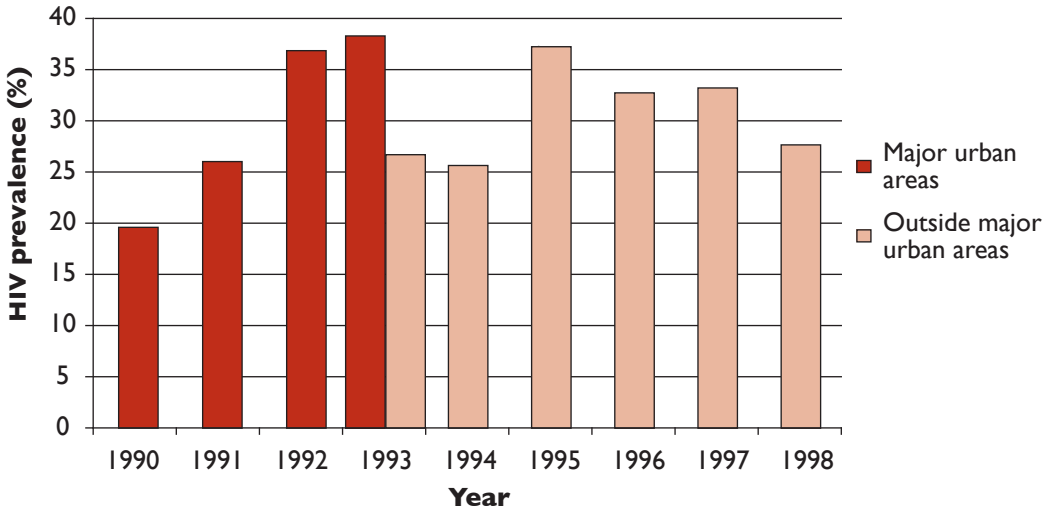


Figure 2.1 HIV Surveillance prevalence in sex workers, Djibouti, 1990–1998 [5]

Discussing the figure

Looking at Figure 2.1, answer the following question:

a. Between 1990 and 1993, did the prevalence of HIV in urban areas in Djibouti increase or decrease?

b. In 1993, was the prevalence of HIV in major urban areas higher or lower than the prevalence of HIV outside major urban areas?

What are some of the limitations of Figure 2.1?

Bridges and overlap with other populations

Clients of sex workers are often bridges to other populations. For example, male clients of female or male sex workers may transmit HIV to their wives and non-commercial sex partners who are regular and non-regular.

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

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

In some settings, sex workers also overlap with other populations covered in this module. Sex workers are found among injecting drug users, street children and prisoners.

Additionally, many sex workers 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. Sex workers may include migrants who later become sex workers and women and children who are trafficked for the purpose of sex work.

Conducting a formative assessment

Surveillance requires gaining access to the full range of sex workers subpopulations and areas. However, locating and gaining access to all areas where sex workers can be found can be difficult.

You can locate and gain access to sex workers by:

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

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

- influential current and former sex workers
- police

- handlers or other gatekeepers, such as pimps, madams and brothel managers or owners
- governmental and nongovernmental organizations conducting sex worker HIV prevention and care programmes
- international sex worker advocacy groups
- national and international organizations that broadly advocate for women's interests
- doctors and pharmacists who provide services to sex workers
- taxi drivers.

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

The places where sex workers congregate include:

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

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

- For each brothel, make a census for the number of sex workers.
- For a particular street, count the number of sex workers 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 sex workers 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 sex workers should be recorded, if possible. For example, how many sex workers are part-time versus full-time? How many are direct sex workers versus indirect sex workers?

Some sex workers do not congregate in a particular location. They are accessed by clients through other channels, such as newspaper advertisements, internet advertisements, the telephone or word of mouth. Such sex workers 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 small. The ways in which they can be included in future surveillance activities is under research.

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

Selecting a sampling method

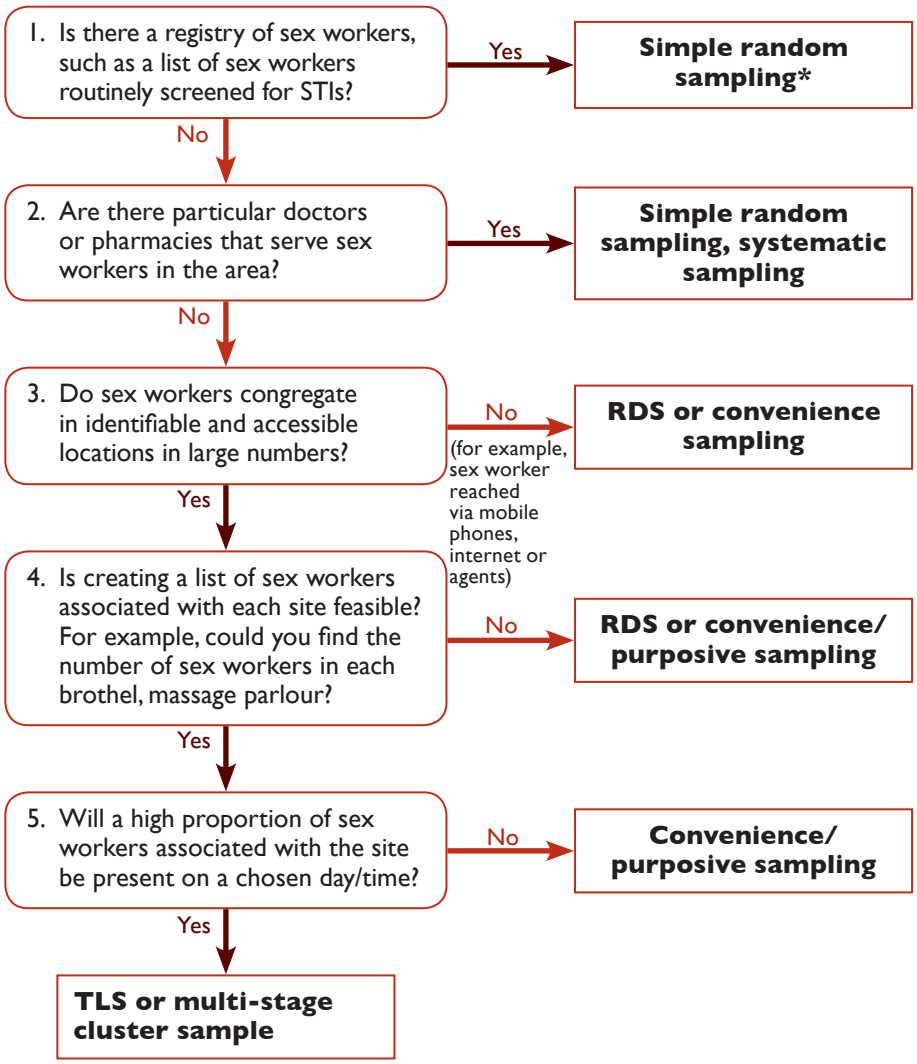
In the past, samples of sex workers and other hard-to-reach populations were convenience or non-probability samples, such as surveys of sex workers attending STI clinics, or interviews of the most visible sex workers found in certain areas. Although non-probability samples can provide some information, these data can be biased for a number of reasons. For example, HIV prevalence and risk behaviours may be different in

the most visible subpopulations of sex workers 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 sex workers.

Depending on how sex workers are organized and how easily they can be accessed, different sampling methods may be more or less feasible. Several basic strategies for sampling hard-to-reach sex worker populations are:

- consecutive sampling via UAT; for example, of male sex worker STI clinic patients
- multi-stage cluster sampling
- TLS
- RDS; for example, to obtain a sample of transgendered sex workers
- convenience/purposive sampling; for example, recruiting sex workers from an nongovernmental organization that provides services to sex workers.

Figure 2.2 will help you select an appropriate sampling method for sex workers in your area.



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

Figure 2.2 Selecting sampling methods for sex workers

Measures

Biological measures

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

- Syphilis testing is often the most efficient biological indicator, because the standard tests can be done with the same serological specimen as HIV testing. The test is 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.
- *Trichomonas vaginalis* testing with positive results is a marker of sexual risk in women. As *T. vaginalis* is usually asymptomatic in men, it is not a good marker of sexual risk in men.

In areas where there may be suspected overlap between sex workers and injecting drug users, biological markers may include HCV and HBV.

In Egypt's Nile delta region, HCV is endemic and thus may not be a good marker for injecting drug use.

Additionally, in some countries HBV is often acquired perinatally or from child-to-child contact in household settings, and may therefore be a less accurate marker for injecting 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 sex workers. In 2001, the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) developed indicators to include when conducting behavioural surveillance among sex workers. These indicators were updated in 2005, and include:

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

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

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

Reference to indicators

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

Special ethical considerations

Risks for sex workers

Because sex work is stigmatized and often illegal, sex workers 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 a sex worker
- 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 sex workers 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 injecting drug use
- laws prohibiting men having sex with men

- laws requiring the 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 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 sex workers in private settings
- keeping the names of the sex workers 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
- requiring all staff to sign confidentiality forms and undergo training in research ethics.

Note that, by design, UAT methods preclude the disclosure of participants' names or other identifying information. In settings where confidentiality cannot be guaranteed and the potential harm of being identified as a sex worker or HIV-infected person is severe, the UAT sampling method may be desired. If you decide to use UAT in your surveillance activity, you should provide participants with information on where they can go to receive voluntary HIV counselling and testing.

Summary

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

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 serosurveillance 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 will discuss the answers in class.

Formative assessment among female sex workers in Khalij-al-Akbar, Menaland

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

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

In response, the HIV programme within the Ministry of Health would like to conduct HIV behavioural surveillance among sex workers in Khalij-al-Akbar. A meeting is held with a team of epidemiologists and social workers to plan for the survey. However, since little is known about the population, they first decide to use formative assessment to lay the foundation from which data about sex workers can be collected.

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

The team discuss what they already know about sex workers in Khalij-al-Akbar. Very little secondary data exist regarding commercial sex work either in Menaland or the rest of EMR/MENA. Together, they try to find additional information and make a list of possible key informants and focus group participants. Their plan is to look for secondary data and meet with key informants in the city to find out more.

1. What are the goals of formative assessment?
2. Who are the possible key informants and participants for focus group discussions in Khalij-al-Akbar?
3. What types of questions does the team ask during their interviews?

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

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

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

The HIV programme team also meets with a diverse set of key informants, such as pimps, bar owners, taxi drivers, private doctors, pharmacists, police, a couple of high-class sex workers and nongovernmental organization managers and outreach workers. Not only will they be able to help answer questions about sex workers, including the best ways to recruit sex workers, their social networks, demographic characteristics and locations of operation, but they are also the community stakeholders of the behavioural surveillance survey. Before the interview, the key informants are taught about the need for and purpose of formative assessment in order to conduct behavioural surveillance. Afterwards, interviews are conducted using open-ended questions, and verbal assurance of their willingness to collaborate with the HIV programme team is sought. Their support will go a long way to ensuring that the activities are acceptable to the broader community once data collection begins.

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

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

First, the team decides to put a large effort into estimating the population size of mobile phone sex workers in Khalij-al-Akbar. This is difficult because so little is known about sex workers, the population seems dispersed and difficult to access, and there is a limited social network.

1. What are the possible approaches to estimating population size among sex workers in Khalij-al-Akbar?
2. Why does the team decide to concentrate on estimating the population size of the mobile phone sex worker population in Khalij-al-Akbar?

Part 3: Estimating population size

Because mobile phones seem to be the predominant mode of communication within the sex trade, the HIV programme team decides to estimate the size of the mobile phone sex worker population in Khalij-al-Akbar. Estimating the population size of sex workers will help plan for the behavioural surveillance survey as well as help to inform the resources needed to plan for any interventions that may follow pending the results. The team decides to use the capture-recapture method for estimating population size.

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

The team conducts an informal interview with 100 men in various hotel lobbies, after obtaining their consent, to ask how much text messaging spam they received during the week prior and how many different spam texts they received from potential sex workers. They can do this by looking back in their inbox. This could be any type of text messaging, including "Bluetooth" messages from sex workers that are in the area. The interviewers compile a list of the phone numbers from the spam received. A week later the team repeats the interviews and the two lists are compared. By establishing the number of individuals missing from both lists, the total population can be estimated. This enables the team to make an estimation of the number of sex workers in the city and possibly use the phone numbers in the future for an access point to the sex workers for sampling purposes.

		Week 1 list		
		Present	**Absent**	**Total**
Week 2 list	**Present**	310_R	515_b	825_M
	Absent	430_c	x	
	Total	740_C		N

Estimated values		**Formula**
Individuals missing	x	$n_b(n_c)/n_R$
Total population	N	$n_C(n_M)/n_R$

1. How many mobile phone sex workers does the team estimate are in Khalij-al-Akbar?
2. What are the limitations of this method, in terms of using cell phone numbers?
3. What are the assumptions of capture-recapture and are they met?
4. Prior to conducting formative research, what did the team need to do to make the study ethical and have a chance of publishing their findings?
5. How did the HIV programme team engage the different stakeholders for this activity?

Part 4: Obtaining institutional review board approval

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

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

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

Part 5: Epilogue

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

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

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

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

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

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 serosurveillance among injecting drug users. The unit includes a case study highlighting special issues in conducting surveillance among injecting drug users.

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 injecting drug users?
   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 injecting drug users.
   a.
   b.

4. List two interventions that can help reduce HIV transmission among injecting drug users.
   a.
   b.

5. What are the ethical issues you must consider when conducting surveillance among injecting drug users?

Introduction

What you will learn

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

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

Definitions

This unit focuses on the special issues in conducting behavioural surveillance and HIV serosurveillance in injecting drug users.

Drugs injected by injecting drug users may include:

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

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

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

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

The risk of HIV infection is greatest with intravenous injection, but the other types of injection also carry high risks of HIV transmission.

Non-injectable drug use, such as smoking marijuana, ingesting sedative-hypnotic drugs, inhaling cocaine, sniffing glue and drinking alcohol cannot lead to HIV transmission directly. These drugs can contribute indirectly to the problem of HIV because they can be associated with the necessity for sex work to acquire funds to buy the 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 drug users who inject, then efforts must be made to accurately distinguish injecting drug users from other drug users. Screening for injection may occur at the facility level, at drug treatment centres specifically for injecting drug users, for example, or by trained interviewers. Methods for identifying true injectors include physical examination for track marks and other signs of injection, or detailed interviews on how drugs are prepared for injection.

Role of injecting drug users in the HIV epidemic

Injecting drug users are at high risk for HIV infection because of the practice 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, HBV and HCV. Parenteral transmission is the term that refers to blood-to-blood transmission, such as transmission through:

- transfusion of blood
- transfusion of blood products, such as anti-haemophilia factors
- needlestick injuries, such as might occur in health-care personnel
- reuse of needles in medical settings, for blood donation and other procedures
- organ transplantation
- injection of illegal drugs intravenously, intramuscularly, subcutaneously or intradermally.

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

According to UNODC, around 10% of all new HIV infections worldwide are due to injecting drug use. In some countries in the region this is much higher, such as the Islamic Republic of Iran, where data of public health authorities suggest that nearly 70% of approximately 21 400 HIV cases reported between 1986 and June 2010 are attributable to injecting drug use.

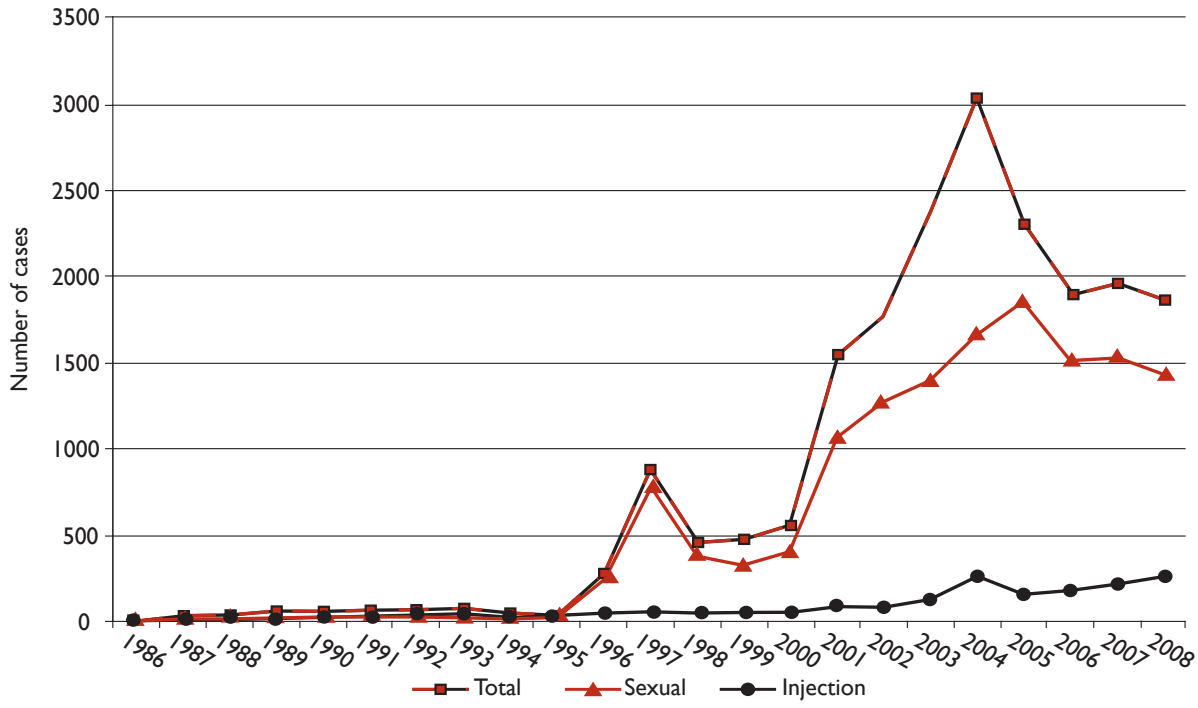


Figure 3.1 Identified HIV cases by year in the Islamic Republic of Iran (total ~ 13 000) [10]

Discussing the figure

Looking at Figure 3.1, answer the following questions:

a. What are some of the factors that may have contributed to the apparent increase in identified HIV cases in the Islamic Republic of Iran between 1995 and 2004? What may have contributed to the decrease thereafter?

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

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

Prevalence of HIV among injecting drug users

Injecting 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 EMR/MENA. In some EMR/MENA countries, injecting 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 injecting drug users.

Historically, regions where heroin trafficking takes place can have explosive HIV epidemics once HIV is introduced. Such has been the case in Afghanistan, Islamic Republic of Iran and Pakistan, which are all located in or near one of the world's major opium-producing areas (Figure 3.2).

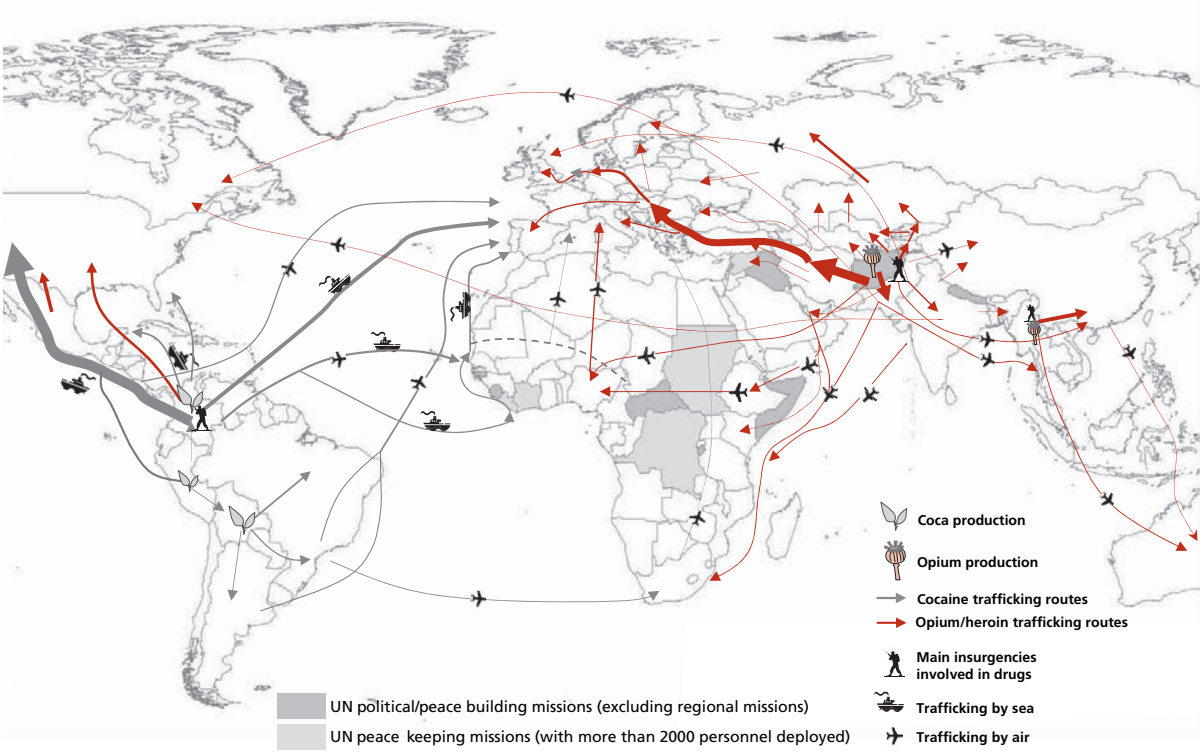


Figure 3.2 Cocaine/heroin trafficking routes and instability [11]

Prevalence of HIV among injecting drug users in EMR/MENA

According to WHO and UNAIDS, injecting drug use has also contributed substantially to the HIV epidemic in the Libyan Arab Jamahiriya and HIV has been detected among injecting drug users and many countries [13–25]. In other EMR/MENA countries, the prevalence of HIV infection among injecting drug users varies by country and region, including the following examples:

- Surveillance data from the National AIDS Control Program in Pakistan show HIV prevalence in different cities ranging from 12.3% to 28.5% [12].
- According to UNAIDS, mid-range prevalence estimates among injecting drug users are 11.8% in Oman, 6.5% in Morocco, 2.6% in Egypt [13].
- According to UNAIDS, injecting drug users accounted for 67% of all reported AIDS cases in Bahrain through 2000. Although the prevalence of HIV among injecting drug users was around 8% and 3% in 1989 and 1990, respectively, a steady decrease occurred from 1991 to a prevalence of <1% in 2000 [14].
- Fifteen per cent of injecting drug users receiving treatment at drug treatment centres in Tehran, Islamic Republic of Iran, were found to be HIV-infected [15].
- In Marvdasht, Islamic Republic of Iran , 85% of injecting drug users said they had used drugs in prison, and 19% said they had used non-sterile injecting equipment there [16].
- Among 213 injecting drug users recruited from a drop-in centre in Tehran, Islamic Republic of Iran, in 2004, the prevalence of HIV was 23.2% among male injecting drug users. A history of shared drug injection inside prison and multiple incarcerations were associated with significantly higher prevalence of HIV-1 infection [17].
- According to UNAIDS, 3.2% of the AIDS cases reported in Jordan between 1997 and 2001 were attributed to injecting drug use [18].
- Between 1997 and 2001, the transmission mode of reported HIV cases was 6% among injecting drug users in Kuwait [19].
- In Oman, in 1999, 7 of 135 injecting drug users were HIV positive (5.2%). In 2000, 5 of 60 injecting drug users screened at the psychiatric hospital and the police hospital were HIV positive [20].
- In Pakistan, the HIV prevalence in 2006 among injecting drug users varied by city; 30% in Karachi, 6.5% in Lahore, 51.3% in Sargodha, 0.0% in Rawalpindi, 5.3% in Sukker and 13.3% in Faisalabad [21].
- A study in Lahore and Karachi, Pakistan, in 2005 confirmed an injecting drug user HIV prevalence of 0.5% and 23%, respectively. More than 25% of study participants reported having shared their most recent injection with someone else [22].
- Between January 1995 and May 1996, the overall HIV prevalence among drug-dependent patients (n = 2628) in a hospital in Jeddah, Saudi Arabia, was 0.15%. The calculated HIV prevalence among injecting drug users (n = 2102) was 0.14% [23].
- Of HIV cases reported in the Syrian Arab Republic 1997–2000, 8% were attributed to injecting drug use [24].
- In Tunisia, the prevalence of HIV infection among injecting drug users was 1.6% in 1992 and 0.3% in 1997 [25].

Role of injecting drug users in surveillance and bridges with other populations

In countries with substantial numbers of injecting drug users, HIV may first appear among injecting drug users, spread rapidly and reach very high levels of HIV prevalence.. Injecting drug users may be further connected to other populations at risk for HIV. In particular, a large proportion of both male and female injecting drug users may engage in sex work to support their addictions. Other injecting drug users may have sexual partners who are not injecting drug users themselves. Finally, the mothers of HIV-infected children are often female injecting drug users or female partners of male injecting drug users in countries with low-level and concentrated epidemics.

Injecting drug users, therefore, overlap with many other most-at-risk and vulnerable populations covered in this module. Injecting drug users are found among men who have sex with men, prisoners, street children and sex workers. Therefore, HIV surveillance of injecting drug users can serve to monitor the reach, acceptance and effectiveness of intervention programmes for both injecting drug users and other populations at high risk.

An example

During the past 5 to 10 years, the number of HIV/AIDS cases reported in the Ukraine and the Russian Federation has risen dramatically due to a sharp increase in injecting drug use and subsequent spread among heterosexually active injecting drug users. In this region, injecting drug users constitute a key bridge to the general heterosexual population, especially young females. Genotyping and sequencing of the reverse transcriptase and protease gene regions performed on over 200 HIV-1 strains by Sanchez et al between 2000 and 2003 confirmed that the subtype found in the general heterosexual population was similar to the subtype found among injecting drug user networks in the region (26).

Conducting a formative assessment

Identifying points of access

As injecting drug users 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 organizations and persons trusted by injecting drug users will help you to understand more fully the culture and diversity of injecting drug users in your area.

Due to the illegal and stigmatized nature of injecting drugs, locating and accessing this population can be difficult. Individual injecting drug users may be reluctant to participate in surveillance activities if they fear arrest and criminal charges. A useful starting point for gaining access to injecting drug users is to speak with people who deal with injecting drug users through the health-care system, through prevention programmes and through the justice system. In addition, working with former and current injecting drug users can guide you to the places where injecting drug users can be found and into the social networks of different groups of injecting drug users. People to contact include the following:

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

These same people and organizations can also later assist with implementing surveillance activities. For example, former injecting drug users can be hired and trained as recruiters or interviewers. Hiring former injecting drug users gives you the added advantage of using their experience to distinguish true injecting drug users from non-injecting drug users. Alliances with institutions dealing with injecting drug users may also assist with referrals to treatment or with minimizing 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 injecting drug user population with regard to:

- the places where injecting drug users 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 injecting drug users can be found to be recruited for surveillance activities, and which subpopulations can be found in different areas. More specifically, detailed ethnographic mapping can be used to produce a sampling frame or comprehensive roster representing the injecting drug user population in your area. This sampling frame provides the basis for some probability sampling methods, such as TLS and multi-stage cluster sampling.

Consider where to find injecting drug users

In many countries in EMR/MENA injecting drug use is considered a mental health issue. Thus, injecting drug users may be found in large numbers at a variety of facilities:

- drug treatment clinics, including de-addiction and opiate substitution clinics
- needle-exchange programmes
- prisons
- social service organizations serving injecting drug users or injecting drug user drop-in centres run by nongovernmental organizations
- hospitals
- mental health facilities.

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

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

Check at drug treatment centres or opiate substitution programmes

Surveillance in injecting drug users 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 injecting drug users are easily accessed. Often, sentinel surveillance using UAT of patients is used. Other countries have relied on injecting drug users 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 injecting drug users who are not arrested or do not seek treatment. Sometimes, targeted intervention sites provided by nongovernmental organizations are used for collection of data using a voluntary counselling and testing (VCT) approach, such as those in India and Myanmar.

The illegal nature of injecting drug use means that those most at risk may avoid the official health-care system altogether. Therefore, they will be under-represented in surveillance based at drug treatment centres and other sites where surveillance is implemented. Basing measurement on injecting drug users 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 injecting drug users. Because of this, community-based sampling approaches for injecting drug users are preferred.

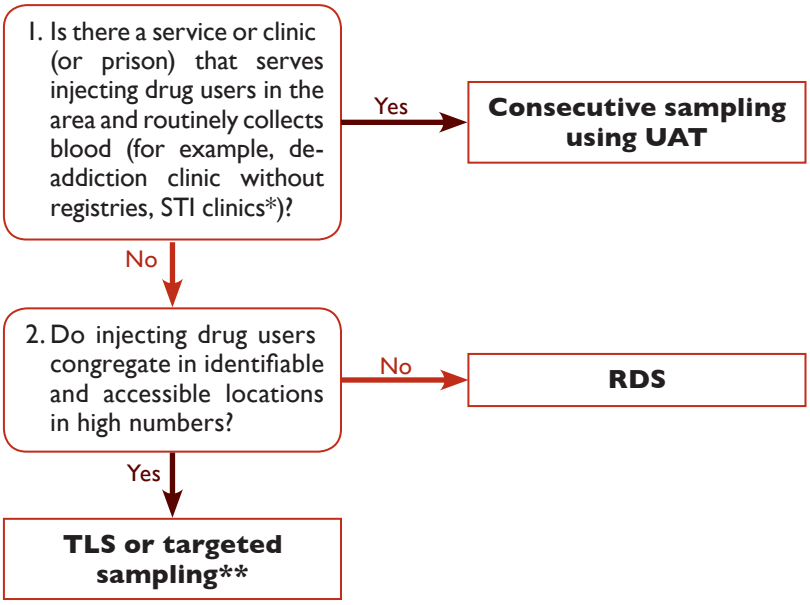
Selecting a sampling method

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

- consecutive sampling at treatment facilities, using UAT
- consecutive sampling in jails and prisons, using UAT
- RDS
- TLS
- non-probability sampling methods, such as snowball sampling.

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

Figure 3.3 will help you select an appropriate sampling method for injecting drug users in your area.



* Not all injecting drug users may enter these facilities.

** Targeted sampling may be used when, through formative assessment, you have determined the relative size of the subpopulations of injecting drug users in the different areas. For example, if you know that 35% of injecting drug users in your area are youth who congregate near the beach, 30% are men who have sex with men in the city centre and 35% are professional artists/designers who congregate in the theatre district, you can target your sampling to locations in the neighbourhoods in these proportions.

Figure 3.3 Decision tree for selecting sampling methods for injecting drug users

Safety factors

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

Measures

Biological measures

Measuring HIV seroprevalence among injecting drug users 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 antibodies (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 if infected as children or with weak immune systems, such as people with AIDS, chronic infection with HBV may occur and HBsAg remains positive.
- Hepatitis C antibody is a nonspecific marker of acute, chronic or resolved HCV infection. These tests cannot tell if you still have an active viral infection, only that you were exposed to the virus in the past.
- Injecting drug users are also at risk of HIV through sexual behaviour. Biological markers for STIs also may be considered in surveillance for injecting drug users.

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

Limitations

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

In areas where both HBV and HCV are endemic, a biological marker for parenteral exposure may not be available. Before including HBV and HCV as markers for injecting drug use in your surveillance activity, determine the current and historical modes of HBV and HCV transmission in your country.

Behavioural measures

Measuring changes in injecting and sexual behaviour among injecting drug users helps explain trends in HIV and STI seroprevalence data. The sharing of needles and syringes is a very efficient means for the parenteral spread of HIV infection. The probability of HIV infection among injecting drug users is proportional to the frequency of needle- and syringe-sharing and the number of partners with whom needles/syringes are shared. The more frequent the sharing, and the more partners needles/syringes are shared with, the higher the risk.

Some drugs may result in more frequent injecting than others. For example, cocaine and methamphetamine injecting may become more frequent than heroin injecting in many cases. Consequently, the type of drug, too, determines the frequency of injecting and, hence, the risk of HIV. In addition, HIV can also be transmitted through unprotected sex among injecting drug users and from them to their non-injecting sexual partners.

In broad strokes, behavioural surveillance of injecting drug users attempts to measure:

- the number of needle/syringe sharing partners
- the frequency of needle- and syringe-sharing
- the frequency of unprotected sex.

Several international organizations have sought to standardize a set of "core" or basic indicators of HIV risk among injecting drug users. In 2001, the UNGASS developed indicators to include when conducting behavioural surveillance among injecting drug users. These indicators were updated in 2005. Further indicators to monitor and evaluate interventions for injecting drug users have been defined by WHO, UNODC and UNAIDS in 2009 and have been published in the document Technial Guide for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users. These indicators include:

- the percentage of injecting drug users who received HIV testing in the last 12 months and who know the results
- the percentage of injecting drug users reached by opiate substitution programmes
- the percentage of injecting drug users reached by needle/syringe exchange programmes
- the percentage of injecting drug users reporting the use of sterile injecting equipment the last time they injected
- the percentage of injecting drug users reporting the use of a condom the last time they had sexual intercourse.

These basic indicators should be included when conducting behavioural surveillance among injecting drug users in EMR/MENA, and may be supplemented with local measures of particular importance in your area, as determined by your formative assessment phase. Additional information of interest may include:

- injecting locations, such as abandoned buildings
- frequency of injecting
- types of drugs injected
- type and number of people with whom injecting drug users share needles and syringes
- size of social network
- condom use
- history of incarceration
- history of sex work
- contact with 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 websites listed in Unit 1 of this module.

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

Special ethical considerations

Risks for injecting drug users

Because drug use is stigmatized and usually illegal, injecting drug users 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 injecting drug user
- inadvertent disclosure of HIV status
- negative reaction and consequences in response to publicized results
- arrest and incarceration.

Another special ethical consideration when conducting surveillance among injecting drug users 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 injecting drug users to participate.

Assuring confidentiality

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

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

Injecting drug users 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 minimize the threats.

Ensuring interviewer safety

Conducting HIV surveillance among injecting drug users requires face-to-face contact with drug-dependant people 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. Additionally, injecting drug users who are high or in withdrawal should not be interviewed.

Summary

Due to unsafe injecting practices and unsafe sex, injecting drug users are at high risk for acquiring and transmitting HIV and other bloodborne illnesses. In many countries with

low-level and concentrated epidemics, HIV has spread most rapidly among injecting drug users.

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

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

Apply what you have learned/case study

Behavioural surveillance among injecting drug users in Al-Rabia, Menaland

Part 1: Collecting information to plan surveillance activities

You are the HIV surveillance officer for Al-Rabia, a medium-sized city in northern Menaland and a major transit point on the drug-trafficking route between central Asia and western Europe. There have been increasing reports of local injecting drug use, particularly among youth in your area, that have alerted you to a potential for increased HIV transmission among this population.

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

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

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

1. What are the advantages and limitations of this approach? (i.e. collecting information from the city's detoxification centres)
2. Describe the steps you take to conduct this survey. How do you ensure confidentiality?
3. What biological markers do you include? Why?
4. How might HIV prevalence estimated from injecting drug users in detoxification centres differ from that in injecting drug users outside of detoxification centres?

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

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

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

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

Part 3: Choosing approaches to combined behavioural and biological surveillance

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

A brief meeting is organized, at which you, the HIV surveillance officer, inform the stakeholders about the need for and purpose of combined HIV behavioural and biological surveillance of injecting drug users in Al-Rabia. You also gather information from the stakeholders on the local population including any subgroups of injecting drug users.

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

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

1. What sampling schemes might be appropriate for conducting community-based sampling of injecting drug users in Al-Rabia?
2. What are the advantages and disadvantages of using TLS versus RDS?
3. Given the limited information available at this point, which method do you think will work best in Al-Rabia?

Part 4: Implementing RDS

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

1. What types of characteristics of injecting drug users do you think would be important for seeds to have based on the information given by the stakeholders? Why?
2. How would you go about finding what kind of incentive would be most appropriate for this population? Other than cash, can you think of other types of incentives that injecting drug users might prefer?
3. Can you think of any ethical considerations of providing incentives?
4. What questions do you want to include in your survey?

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

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

5. What are your options for reaching the older injecting drug users now?

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

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

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

Part 5: Analysis

Your team exceeds your calculated sample size of 600 and successfully recruits 680 injecting drug users. It is now time to prepare a report on your findings.

1. What data analysis software do you use?
2. What information did you collect in order to analyse these data? Do you recall if you mentioned collecting these variables when planning the survey?

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

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

Part 6: Epilogue

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

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

1. Expand drug treatment programmes in Al-Rabia.
2. Establish a needle-exchange programme.

Unit 4

Men who have sex with men

Overview

What this unit is about

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

   True False

2. List two possible points of access where men who have sex with men can be found.

   a.

   b.

3. Given that men who have sex with men 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 men who have sex with men?

5. What are some possible behavioural indicators to include when conducting HIV surveillance among men who have sex with men?

6. What are some possible biological measures to include when conducting HIV surveillance among men who have sex with men?

Introduction

What you will learn

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

- describe the special considerations associated with surveillance in men who have sex with men
- list the possible organizations that can assist in surveillance of men who have sex with men
- describe options for sampling and surveillance methods among men who have sex with men.

Definitions

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

Another group that has historically been included in men who have sex with men 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. Keep in mind that some people self-identify as transgendered without having undergone any sort of surgery or treatment. In some cultures, particularly in Asia, there are also culturally endorsed roles for persons identifying as neither male nor female. These people are considered a third gender.

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

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

Role of men who have sex with men in the HIV epidemic

Men who have sex with men do not contribute a substantial proportion to reported HIV cases in most EMR/MENA countries. However recent data suggest emerging epidemics among men who have sex with men in some countries of the Region.

Men who have sex with men 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, many men who have sex with men 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 men who have sex with men at higher risk in general. Men who have sex with both men and

women may be an important bridge group between a subpopulation at high risk for HIV infection and a larger population at lower risk for infection.

In EMR/MENA, marriage pressure (that is, family pressure on sons to marry to provide stability for parents and the continuation of the family name) may be greater than in other parts of the world. Marriage pressure may be a factor that contributes to the higher rates of bisexual behaviour seen in EMR/MENA.

Prevalence of HIV among men who have sex with men

The data below illustrate the range of HIV prevalence among men who have sex with men in EMR/MENA 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 men who have sex with men.

Very little data exist regarding the prevalence of HIV among men who have sex with men in EMR/MENA, and what little information there is varies by country, including the following examples:

- A bio-behavioural survey from Egypt in 2006 indicated a 6.2% HIV seroprevalence among men who have sex with men [27].
- HIV prevalence among men who have sex with men in Lebanon was 3.6% in a bio-behavioural survey [18].
- In Oman, among the cases reported between 1997 and 2001, 11% occurred in men who have sex with men [20].
- A 2007 study found an HIV prevalence of 7.8% among insertive men who have sex with men, slightly lower than the 9.3% found among receptive men who have sex with men from an earlier study (2005) in Khartoum State, Sudan [28, 29].
- Between 1997 and 2000, of all the HIV cases reported in the Syrian Arab Republic, 8% were among men who have sex with men [24].
- In Tunisia, among 1178 men who have sex with men who were recruited at six sites for a bio-behavioural survey, HIV prevalence was 4.9%.

Role of men who have sex with men in HIV surveillance

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

The purposes of HIV surveillance in men who have sex with men 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 men who have sex with men.

Table 4.1 summarizes how HIV is affecting men who have sex with men throughout the world.

Table 4.1 HIV burden among men who have sex with men

Region of the world	Men who have sex with men HIV burden
• North America • Australia • New Zealand • Most western European nations	Men who have sex with men are the most affected population
• Asia • Latin America	Depending on the country, men who have sex with men constitute a large proportion of persons affected by HIV
• Sub-Saharan Africa • North Africa • Middle East	Data on the burden of HIV among men who have sex with men are limited

Discussing the table

Looking at Table 4.1, answer the following question:

a. Why are data on the burden of HIV among men who have sex with men so limited in EMR/MENA?

Bridges and overlap with other populations

In EMR/MENA, as in the rest of the world, a proportion of men who have sex with men also have sex with women. The potential for men who have sex with men to bridge HIV infection to heterosexual women is an issue that deserves monitoring and investigation. Surveys of men who have sex with men should always ask about all types and genders of partners the men may have. Men who have sex with men can also be members of other most-at-risk and vulnerable populations covered in this module including injecting drug users, patients of STI, street children, prisoners and male sex workers. Engaging in sex work and/or injecting drug use obviously increases the risk of HIV infection for men who have sex with men.

Conducting a formative assessment

Consider where to find men who have sex with men

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

Surveillance activities should enlist the assistance of:

- health authorities

- the Ministry of Interior
- social services
- men who have sex with men groups
- organizations that represent the interests of men who have sex with men
- existing public health prevention programmes
- the police and other law enforcement personnel.

Surveillance officers should also enlist the support of people whom the men who have sex with men community trust as sources of information:

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

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 men who have sex with men community is an essential part of surveillance for this group, as for any other hard-to-reach group.

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

Conducting ethnographic mapping

Conduct ethnographic mapping to create a comprehensive description of:

- the social geography of men who have sex with men
- the places where men who have sex with men congregate
- time periods when men who have sex with men congregate.

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

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

- restaurants
- cafes
- beaches
- dance clubs
- gyms
- parks
- bathhouses
- social organizations

- beauty salons
- other cruising areas.

Cruising areas are public spaces, such as parks, bathhouses and dance clubs, where men who have sex with men meet, congregate and arrange or engage in sexual activity.

Other points of access

Men who have sex with men venues in countries without well-developed gay communities will be more difficult to identify. This is the case in most EMR/MENA countries. Some men who have sex with men do not congregate in particular locations. They may be deliberately elusive due to stigmatization of homosexual behaviour. Other points of access may be through gay websites or gay-focused services, internet chat rooms and clinics specializing in men who have sex with men health.

Organizations providing HIV prevention or HIV and STI treatment services to men who have sex with men should not be included as venues because such inclusion has the potential to inflate estimates of HIV infection and/or HIV risk behaviour.

Selecting a sampling method

Although surveillance of men who have sex with men 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 been used successfully to monitor HIV prevalence and risk behaviours in men who have sex with men are:

- TLS
- RDS

In some circumstances, neither TLS nor RDS will be appropriate for men who have sex with men in your area. In this case, using traditional snowball sampling or mixed methods may be the only appropriate option. Figure 4.1, will help you select an appropriate sampling method for men who have sex with men in your area.

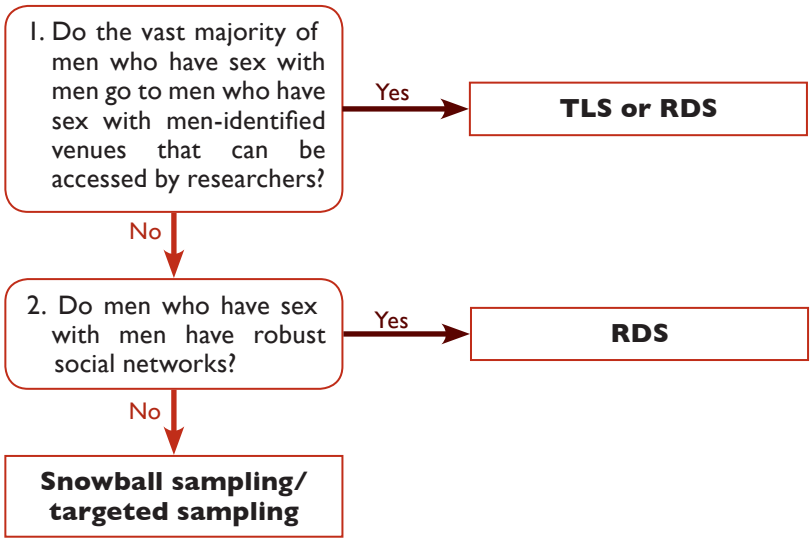


Figure 4.1 Appropriate sampling methods for men who have sex with men

Discussing the figure

Looking at Figure 4.1, answer the following questions:

a. If men who have sex with men do not congregate in identifiable venues and do not have robust social networks, which sampling methods may be most appropriate?
b. Is this sampling method a probability sampling or non-probability sampling method?

Male sex workers

Male sex workers are a highly mobile and often invisible subpopulation of men who have sex with men. Male sex workers are men who sell sex to women as well as men who sell sex to men. Male sex workers in EMR/MENA primarily sell sex to men.

Male sex workers have been found for example in Moroccan tourist centres such as Marrakesh and Tangier, as well as in cities such as Casablanca. In Morocco, two distinct types of male sex workers have been identified.

- gigolos (hustlers)—usually self-identify as being heterosexual and tend to have foreign, often European, clients
- *prostitués homosexuels* (homosexual prostitutes)—usually self-identify as homosexual or gay.

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

Measures

Introduction

Comprehensive HIV surveillance among men who have sex with men includes surveillance of:

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

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

Biological measures

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

The biological measures to include in surveys of men who have sex with men are similar to those for female sex workers:

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

In areas where there may be suspected overlap between men who have sex with men and injecting drug users, HCV may also be a useful biological marker.

Behavioural measures

Measuring changes in sexual behaviour among men who have sex with men helps explain trends in seroprevalence data on HIV and STIs.

Behavioural surveillance of men who have sex with men attempts to determine:

- the frequency of unprotected sex
- the characteristics of partners of men who have sex with men
- the frequency of injecting drug use.

When conducting behavioural surveillance of men who have sex with men, core UNGASS indicators include:

- percentage of men who have sex with men who received HIV testing in the last 12 months and who know the results

- percentage of men who have sex with men reached by prevention programmes
- percentage of men who have sex with men who correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission
- percentage of men reporting the use of a condom the last time they had anal sex with a male partner
- percentage of male sex workers reporting the use of a condom with their most recent client.

Behavioural surveillance of men who have sex with men may collect information on:

- condom use
- number of partners
- type of partners
- frequency of unprotected insertive anal intercourse (UIAI)
- 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
- men who have sex with men venues.

Reference to indicators

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

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

Special ethical considerations

Risks for men who have sex with men

Due to the covert nature of life for many men who have sex with men in many developing countries, men who have sex with men 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 a man who has sex with men
- inadvertent disclosure of HIV status
- negative reaction and consequences in response to publicized results

- physical abuse
- imprisonment
- rejection by family members.

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

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

Differing language, social perspectives and taboos apply to homosexual activity 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 injecting drug use
- laws requiring reporting of individuals who have 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 investigators will take to minimize the threats. Explaining these issues to potential subjects is part of the informed consent process. Steps you can take to minimize threats to confidentiality may include:

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

Summary

Men who have sex with men include self-identified gay and bisexual men, men who have engaged in male-male sex but who self-identify as heterosexual and transgendered people. Men who have sex with men are at high risk of acquiring HIV and other STIs due to their high risk sexual behaviours and may make up an increasing proportion of the HIV burden in EMR/MENA. Behavioural and HIV serosurveillance of men who have sex with men is particularly important in countries and regions, such as EMR/MENA, where little is known about these populations. RDS and TLS are well-suited for sampling men

who have sex with men when men who have sex with men have either identifiable venues or robust social networks. As men who have sex with men are often stigmatized and as their behaviour may be criminalized, you must consider and address the special ethical issues of conducting surveillance among this group.

Exercises

Warm-up review

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

Small group discussion

Get into small groups to discuss these questions:

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

Apply what you have learned/case study

Biological and serosurveillance of men who have sex with men in Bluecoast, Menaland

Part 1: Collecting information to plan surveillance activities

Bluecoast is a cosmopolitan city with a population of three million in southern Menaland.

Because Bluecoast is the financial and cultural centre of the country, many men are drawn to the city. However, homosexuality is officially prohibited and the men who have sex with men population is hidden to avoid fines, physical abuse, imprisonment, deportation or death.

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

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

Nevertheless, due to substantial evidence, the Ministry of Health has decided to conduct biological and behavioural HIV/STI surveillance among men who have sex with men this year.

As the HIV surveillance officer of Bluecoast, you are tasked with designing and conducting this activity.

1. What information is required for planning the survey?
2. What research activity would you use to obtain this information?

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

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

1. How would you gain the trust of members of the men who have sex with men community?

Part 3: Mapping the men who have sex with men network and choosing a sampling approach

Enlisting the support of popular men who have sex with men in Bluecoast, you form a partnership with the local underground nongovernmental organization working with the men who have sex with men community and establish a working group or a community advisory board to help gain access to other men who have sex with men. 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 men who have sex with men who participate.

Through formative research, you find that a local men who have sex with men commercial scene does exist. After conducting focus group discussions and in-depth interviews with men who have sex with men, you find out that men who have sex with men in Bluecoast do not often congregate in visible and accessible locations and that there are few specific locations where men who have sex with men can be found in large numbers. However, although it is hidden, there is a large network and solidarity exists within it. Most men who have sex with men find each other through websites, friends, night clubs, bath houses, salons and beaches. Sex takes place in some of these areas. There are also a range of men who have sex with men subpopulations, including male sex workers, transgendered people and married men who have sex with men.

1. What sampling scheme is most appropriate?
2. What are the advantages and disadvantages of the sampling scheme you have chosen?

Part 4: Collecting biological and behavioural data

You decide to conduct HIV prevalence and risk behaviour surveys of men who have sex with men every other year, using the RDS method. There are advantages and disadvantages to RDS. RDS is still in the early stages of development; however, it has been shown to reduce in-group affiliation, where initial study participants tend to list people of similar demographics, such as socioeconomic status and educational levels. RDS also improves random probability of selection and the cooperation of surveillance participants because it uses a peer-referral method and a dual incentive structure. Now that you have chosen your sampling strategy, it is time to prepare for the survey instrument and implementation of the survey.

1. What biological variables do you include?
2. What behavioural variables do you include?
3. What additional steps are needed to test for HIV?
4. What are some of the special ethical considerations for this surveillance activity?

Part 5: Preparing for the surveillance activity

To prepare for the surveillance activity, you hold a few focus group discussions with men who have sex with men and your community advisory group to discuss a location in the city to conduct the survey, common language used to identify sexual behaviours, the design of the coupon and the types of incentives to offer. From this preparation, you are also able to come up with six seeds (initial survey participants) and surveillance staff for the sites, including nurses, counsellors, interviewers and greeters.

1. What subpopulations did you include in selecting seeds?
2. What characteristics would you look for in selecting a site to conduct your surveillance activity?

Part 6: Analysing and disseminating data

You decide to assess the prevalence of HIV, syphilis, gonorrhoea, *Chlamydia* and HSV-2, the types and number of partners and the frequency of unprotected anal sex and vaginal sex.

You need a site that is easy to find, affordable to get to and private. There should be enough space to store all the surveillance materials, and it should be comfortable and clean for the participants.

To acquire the behavioural and biological data, you will need to obtain voluntary informed consent from men who have sex with men who agree to participate in the study. Ethical issues you should consider include maintaining participants' confidentiality and ensuring that interviewers are sensitive to issues facing men who have sex with men. Additionally, as you will be testing for HIV, you should establish a mechanism in which persons who test positive for HIV are referred to counselling and treatment.

The study produces the following results:

- HIV prevalence of 5%.
- Syphilis prevalence of 12%.
- HSV-2 prevalence of 16%.
- Gonorrhoea prevalence of 5%.
- *Chlamydia* prevalence of 6%.

- Eighty-five percent of men who have sex with men report unprotected anal sex with male partners.
- Some men who have sex with men engage exclusively in homosexual activity, while others consider themselves to be heterosexual and are married.

1. Describe how you would use the data collected to develop men who have sex with men-focused prevention programmes?

Part 7: Epilogue

Bluecoast has a large population of men who have sex with men, including male sex workers, men who identify as homosexual and men who are married and identify as heterosexual or lead covert lives. Because homosexuality is prohibited, there is a lack of services for men who have sex with men in Bluecoast and they can be fearful of the authorities. Due to the stigma associated with being men who have sex with men, they often do not seek medical care when it is needed.

The findings suggest men who have sex with men in Bluecoast are at high risk of acquiring and transmitting HIV. Some men who have sex with men have high rates of partner turnover and low rates of condom use; many do not seek treatment for STIs or other health problems; many are injecting drug users, and many have been incarcerated and beaten. Targeted interventions are needed to reduce stigma and promote safer sex practices among men who have sex with men in Bluecoast.

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

1. Engage peer and nongovernmental organization outreach workers, as well as STI clinic staff, to educate men who have sex with men about the need for consistent condom use with non-regular and regular partners.
2. Distribute condoms to men who have sex with men through peers, workers at nongovernmental organizations and STI clinics, night clubs, saunas and salons.
3. Establish education and outreach programmes to encourage men who have sex with men to seek treatment for STIs.

Unit 5

Mobile populations

Overview

What this unit is about

This unit describes the background and special considerations associated with conducting HIV/STI and behavioural surveillance among mobile populations. It explains sampling and surveillance methods and recommends specific surveillance methods for this group.

Warm-up questions

1. Which of the following terms is used to describe migrant labourers, fishermen and truck drivers?
   a. involuntary migrants
   b. voluntary migrants
   c. military personnel
   d. none of the above

2. Which of the following terms is used to describe refugees and internally displaced people?
   a. involuntary migrants
   b. voluntary migrants
   c. military personnel
   d. none of the above

3. Of the following, which is not a reason why migrants are especially vulnerable to HIV?
   a. Female migrants may sell "survival sex" when they have no other source of income.
   b. Migrants usually have only one sexual partner.
   c. Migrants have limited access to health care.
   d. Migrants often live in settings where they are more likely to adopt risk behaviours.

4. Mobile persons often serve as a _____ between female sex workers and the general population. Additionally, due to migration patterns, mobile populations may bring HIV from high-prevalence areas to low-prevalence areas.

5. List two possible locations where mobile persons may be found in high numbers.

   a.

   b.

6. What are some of the ethical issues to consider when conducting HIV surveillance among refugees or internally displaced persons?

Introduction

What you will learn

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

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

Definitions

This unit focuses on the special issues involved with conducting behavioural surveillance and HIV serosurveillance in mobile populations. "Mobile populations" is the term used to refer collectively to groups of people who move from one place to another. They may move temporarily, seasonally or permanently, and for either voluntary or involuntary reasons. Migration is one of many social factors that have contributed to the HIV epidemic. Migration refers to people moving from one area to another and does not imply permanent resettlement. Many migrant groups with increased risk of HIV are temporary migrants and may move for only a few weeks at a time.

Migration can be divided into two broad categories:

- voluntary and job-related migration, which includes truckers, uniformed personnel, skilled and unskilled labourers, and fishermen
- involuntary migration, which includes refugees and internally displaced people.

Voluntary migration

Although there are many different types of migration, a common mode of migration in EMR/MENA is circular or oscillating migration. This type of migration is characterized by young men and women who leave their rural communities to work in urban areas or at 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 also commonly migrate from rural areas to seek employment as domestic helpers or factory workers in urban centres.

Some examples of migration include the following:

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

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

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

Role of voluntary migrants in the epidemic

Voluntary 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 risky behaviour may be occurring, including multiple sex partners and drug use.
- Female migrants may sell sex when they arrive at a new location and have no other sources of income.
- Migrants have limited access to health services, including HIV services.
- Several studies have demonstrated the importance of major drug transportation corridors in the spread of HIV.

In some countries, sex work may be common in border towns and port areas, where truckers or uniformed personnel congregate. This sex work is often based in bars, cafés or nightclubs. In some settings, sex workers may 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 form of HIV transmission among migrants. Both male and female migrants are often at risk for parenteral transmission because of injecting drug use, traditional medical practices and unsafe therapeutic injections. The trafficking of illegal drugs is also an important driver of the epidemic among migrants.

Bridges and overlap with other populations

Mobile men may 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. 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.

Involuntary migration

In EMR/MENA, civil unrest is a major reason for involuntary migration. There are many people who are involuntary migrants, including refugees and internally displaced persons. By legal definition, refugees are people who are outside their country of nationality and who are unable or unwilling to return to that country due to a well-founded fear of persecution because of race, religion, political opinion or membership in a social group.

As of 1 January, 2007, the United Nations High Commission on Refugees (UNHCR) reported over 2.5 million individuals in the Middle East and nearly 140 000 individuals in North Africa falling under their mandate.

This term "refugee" only applies to people who have been displaced from their homeland and who 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 not crossed an internationally-recognized state border.

The number of internally displaced persons in EMR/MENA varies by country, including the following United Nations figures:

- Afghanistan: 232 000 [30]
- Iraq: 2 647 300 [30]
- Pakistan: 155 800 [30]
- Somalia: 1 277 200 [30]
- Sudan: 1 201 000 [30]

In addition, Lebanon hosts 425 000 displaced Palestinians as of 31 December 2009 [31]

Role of involuntary migrants in the epidemic

Studies have suggested that the longer-term ramifications of war and civil unrest have increased risk of transmission of HIV and other STIs in refugee and internally displaced populations in some contexts and in others not. However, there have been only a few published studies of the prevalence of HIV and other STIs in these populations, particularly of those in Africa. Such information is crucial for the development and implementation of effective programmes that address the needs of displaced populations.

In terms of the factors associated with transmission, complex emergency settings may differ substantially from the more stable environments in which HIV research and prevention programmes have traditionally taken place. Vulnerability factors for HIV and STIs differ from context to context, but can include:

- massive population displacement
- disruption of family and social structures and ways of life
- disruption of sexual networks
- sexual interaction between military or paramilitary personnel and people affected by the emergency
- economic vulnerability of women and unaccompanied minors
- frequency of commercial sex work
- frequency of sexual violence, coercive sex and rape
- psychological trauma
- disruption of preventive and curative health services
- unsafe blood transfusion practices at a time of increased need for blood transfusions due to trauma
- increased use of illicit drugs, often due to psychological trauma.

It is best to think about HIV and STI surveillance within the larger context of the medical, social, economic and political needs of refugee and internally displaced populations. HIV

and STIs will seldom be considered the highest priority item on the list of the myriad problems facing refugees and those who serve them. Nonetheless, these people are particularly vulnerable to engaging in high risk behaviours and have real needs for HIV and STI prevention. To be successful, HIV surveillance needs to be closely coordinated with and through onsite medical and social relief programmes. It can then be integrated into the broader context of information-gathering about the refugees and their situation.

The risk of sexual transmission of HIV between local peoples and refugees/internally displaced populations depends on the following factors:

- the relative HIV prevalence in the two populations and the extent the two groups interact
- the prevalence of STIs in the vicinity
- whether displaced populations are housed in camps or are integrated into the community, which means more opportunity for sexual interaction.

An example

Although the non-injecting use of opium is a traditional practice in Afghanistan, injecting is a new behaviour trend. As reported in a 2003 UNODC study, 50% of the injectors surveyed in Kabul reported that they started injecting heroin while seeking asylum in the Islamic Republic of Iran or Pakistan [32].

Since 2001, the population of Kabul, Afghanistan has dramatically increased as refugees have begun returning to Afghanistan. It is thought that some refugees may have acquired high-risk behaviours, such as injecting drug use, while displaced, which may place Afghan communities at risk upon their return [33].

Prevalence of HIV among mobile populations

In EMR/MENA, the prevalence of HIV infection among mobile populations varies by country and region. Consider the following examples:

- HIV prevalence as high as 4.4% has been found among some formerly displaced adults in Yei in southern Sudan, along the Ugandan border [15].
- In Sudan a high prevalence of HIV (4%) was found among refugees mostly from Eritrea and Ethiopia [34].
- In Somalia's north-west zone, internally displaced women attending antenatal clinics had a higher HIV prevalence than women in the general population [35].
- In Yemen, among migrants entering the country, those seeking Yemini residency visas had an HIV prevalence of 0.77% in 1998 and 0.53% in 2000 [36].

Role of mobile populations in HIV surveillance

There is a large and increasing number of migrant workers moving from rural villages to cities, as well as to other countries, in EMR/MENA. 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 mobile populations.

Conducting a formative assessment

Consider where to find mobile populations

Conducting surveillance in mobile populations requires gaining access to the full range of subpopulations in the area. Due to the diversity of these subpopulations, locating all areas where mobile persons can be found and gaining access to them is challenging. You can locate and access mobile persons by:

- visiting the locations and venues where they congregate or work
- interviewing and working with people who have regular contact with mobile persons
- collaborating with organizations that provide services to these groups.

HIV prevalence may be highest in busy border towns, ports and in areas where refugees and internally displaced people seek refuge. These sites may therefore be appropriate and convenient for surveillance. Possible locations where mobile persons may be found in large numbers include:

- truck stops and roadside hotels
- neighbourhoods known as refugee areas, such as particular slum communities
- refugee settings
- health clinics that serve refugees or internally displaced people.

Before deciding on a sampling method you should decide whether to sample at the point of origin or the point of destination of the migrant and mobile populations. This decision will depend on the aggregation of people at one end or the other, as well as whether the effect of the epidemic is being assessed for the geographical region that is the point of origin or the point of destination.

UNHCR provides information on assessing, monitoring, evaluating, planning and lessons learnt regarding HIV/AIDS and refugee programmes in the field as well as information on behavioural surveillance and workshops related to HIV/AIDS among refugees and internally displaced persons. Further information is available at: http://www.unhcr.org/protect/459e13fc2.html

The Family Health International (FHI) report *Protecting people on the move: applying lessons learned in Asia to improve HIV/AIDS interventions for mobile people,* further discusses how to identify sites that fuel the spread of HIV or create conditions that make mobile people vulnerable to HIV [37].

The Fafo Institute 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 organizations and individuals that are concerned with and trusted by the segment of the migrant community in which you are interested, such as:

- UNHCR
- border patrol staff, immigration police, customs agents and harbour masters
- employers
- employment agencies
- cafe owners
- union officials
- operators of truck stops, fish markets and other places where these groups may congregate
- nongovernmental organizations, such as the Red Crescent Society
- department of transportation
- local community leaders, such as town mayors and advocates within the migrant communities themselves

Forming alliances is an ongoing process that must be developed over time and will help in each stage of preparing for surveillance. When planning and implementing surveillance activities, it is important to understand the power structures that influence the movement and behaviour of mobile populations. It will also be helpful to enlist the support of any currently existing intervention programmes for migrant workers and populations. This will be extremely helpful in setting up the infrastructure for the surveillance system and disseminating results of the surveillance activity.

Obtaining community approval

Community approval promotes trust and confidence among community members who will be involved. It also reflects respect for local community customs. Given this, it is recommended that 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 community advisory 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
- community leaders
- Ministry of Labour
- Ministry of Interior
- nongovernmental organizations and community-based organizations
- other relevant partners identified through formative assessment.

Identifying the migrant populations that are of greatest interest to you and the best ways to approach these groups is an important first step, and the core of your formative assessment.

Select a sampling method

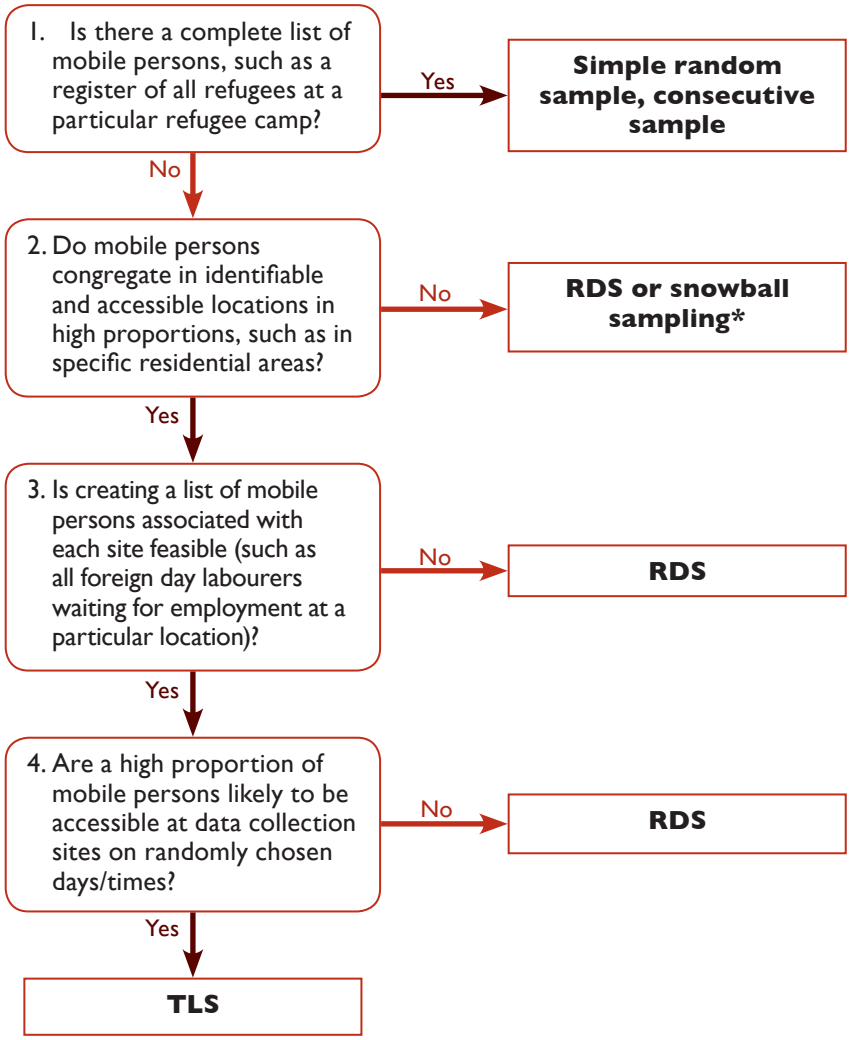
Sampling methods

Methods for surveillance in migrants are similar to those used in other populations in this module:

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

Figure 5.1 will help you select an appropriate sampling method for mobile populations in your area.

There is no one "best" sampling method for use in all situations. In some situations, when neither TLS nor RDS is appropriate, a facility-based sampling method may be the



* *Note:* Persons must be highly networked to use RDS. If they are not highly networked, snowball sampling or another non-probability sampling techniques may be the most appropriate. Your formative assessment will help you determine whether the community is networked enough to conduct RDS.

Figure 5.1 Sampling methods for mobile populations or displaced persons

Table 5.1 Possible methods of surveying various mobile populations

Mobile population	Possible survey methods
Truck drivers and their assistants	• Simple random sampling, cluster sampling or systematic sampling, if trucking companies provide lists of their employees
Miners, factory and construction workers	• During regular occupational health check-ups • If housed by a company, lists or maps can be used for simple random sampling or multi-stage cluster sampling
Self-employed mobile persons, such as truck drivers and fishermen	• TLS, used, for example, among truck drivers stopping for dinner along a specific highway
Merchant sailors	• Simple random sampling; for example, if a list of seamen exists at a union hall
Refugees and internally displaced people in closed camps	• Household-based surveys within refugee camps • Systematic survey of refugees as they enter the camp or from the camp registry
Refugees and internally displaced people in community settings	• Household-based surveys • TLS of day labourers in areas where they congregate

most viable option. The best way to sample these groups will depend on which specific groups of workers you wish to survey and the best places to find them.

The following table summarizes some of the possible methods of surveying various mobile populations.

An example: sampling migrant workers

An important element of these studies relates to the sexual networks and sexual behaviours of migrant workers. 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 through colleagues in the workplace.

Thus, to provide a good sampling frame for migrant populations, the following steps are suggested:

- List all working sites of migrants, by geography or time location; for example, all large industrial facilities with dormitories for migrant workers or all highway stops that cater to long-distance truck drivers.
- Based on HIV prevalence or the potential for instituting prevention programmes, choose the type of site of interest to you.
- Select sites for surveillance from the list you generate. If the number of people working at the sites is small (for example, 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

Introduction

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 area and what is acceptable in the context of cultural and societal norms.

Biological measures

As in most other surveillance systems, biological specimens should be drawn for testing for prevalence of HIV and other STIs. The high sexual risk among mobile persons also makes STI testing a useful and feasible indicator for surveillance. For a description of the available STI and HIV tests, refer to the WHO test kit evaluation programme (http://www.who.int/diagnostics_laboratory/evaluations/en/).

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

If, during formative assessment, you found that some mobile persons also inject drugs, biological markers of injecting drug use include hepatitis B core antibody (HBcAb) and HCV antibody.

Behavioural measures

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

Core UNGASS indicators for mobile populations include:

- percentage of target mobile population, such as refugees or truck drivers, that received HIV testing in the last 12 months and know the results
- percentage of target population reached by prevention programmes
- percentage of target population that correctly identify ways of preventing the sexual transmission of HIV and that reject major misconceptions about HIV transmission.

Where appropriate, these indicators may be supplemented with the following additional behavioural indicators:

- knowledge of HIV and STIs

- number and types of sexual partners
- condom use with sexual partners
- sex between men
- injecting 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
- length of time spent away from home/regular sex partners
- where they travel and how often
- city/region/country of origin
- whether they cluster in communities that mimic their home/living conditions, types of social support.

Other indicators may also be appropriate. Your formative assessment will help you determine which measures are of particular importance in your area.

Reference to indicators

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

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

Special ethical considerations

Risks for mobile popultions

There are special ethical issues you must consider when conducting surveillance activities in mobile populations. Being identified as HIV-infected or an injecting drug user could result in firing or deportation.

An additional ethical concern when including mobile populations in surveillance activities are the consequences that may result when a particular social, religious or ethnic group is identified as having a high prevalence of HIV or risk behaviours. This is particularly important when a high prevalence of HIV is discovered in a refugee, internally displaced or immigrant population in an otherwise low-prevalence country or area.

Obtaining informed consent

You should consider your ability to obtain true informed consent when mobile persons may be coerced to participate or not participate by their employer or by their community leaders.

Assuring confidentiality

Confidentiality protects subjects from adverse consequences that may arise from participating in a study or survey. If a person's HIV infection becomes known, he or she may suffer discrimination or stigma, or be subject to criminal charges in some situations. Be aware of any particular provisions in your country's laws that may complicate participation. These may include:

- laws prohibiting men having sex with men
- laws prohibiting injecting 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 the threats. Explaining these issues to them is part of the informed consent process.

Summary

Mobile populations are vulnerable to engaging in behaviours that put them at risk of both getting and transmitting HIV and STIs. 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 mobile populations you wish to survey and the places in which 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 unit. 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 that are vulnerable to engaging in high risk behaviour that may put them at increased risk for HIV in your country.
2. Does your country conduct behavioural and/or serosurveillance of mobile populations, such as refugees, undocumented labourers or truck drivers?
3. In your country, who are the gatekeepers of this population?
4. In your country, what methods have been used to sample mobile populations?
5. In your country, what behavioural and biological measures have been used when conducting surveillance of mobile populations?
6. In the past five years, has the prevalence of HIV among mobile populations increased, decreased or remained about the same?

Apply what you have learned/case study

Case study 1: Biological and behavioural surveillance among Jamilistani refugees in Menaland

Part 1: Collecting information to plan surveillance activities

Al Aniram, with a total population of 10 million people, is a large port city in Menaland, a country with a low-level HIV epidemic. Due to civil unrest in the neighbouring country of Jamilistan, a country with a generalized HIV epidemic, thousands of documented and undocumented Jamilistanis migrate to Menaland each year; many more transit through Al Aniram on their way to Europe.

Although the UNHCR in Menaland administers two closed refugee camps each for approximately 20 000 Jamilistani refugees, many undocumented migrants settle in the slum neighbourhoods of Al Aniram, where there is a large Jamilistani community. The following information has been reported:

- Results from routine antenatal clinic surveys in Jamilistan and Menaland in 2006 indicate that the prevalence of HIV is significantly higher in Jamilistan than in Menaland.
- Police reports indicate that some female Jamilistanis are selling sex to support themselves.
- Information from service providers indicate that many Jamilistanis do not seek care at hospital and clinics for fear that their illegal immigration status may result in deportation back to Jamilistan.

The HIV programme manager decides to conduct a survey among Jamilistanis in Al Aniram to gather information to design interventions to curb the spread of HIV among Jamilistanis and prevent HIV from spreading to the general population in Al Aniram.

The HIV programme manager decides to focus on Jamilistanis in the slum communities because of their potential as a bridging population, bringing HIV infection from high-prevalence areas to an area of lower prevalence. The programme manager decides to undertake a combined biological/behavioural survey among Jamilistanis in Al Aniram, 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, and reports from UNHCR, the Red Crescent Society and other organizations that provide services to Jamilistani migrants. Several key informants are also contacted, including prominent members of the Jamilistani community in Al Aniram, persons from the Ministry of the Interior, persons from the Ministry of Immigration and cafe and other business owners in Jamilistani communities. Interviews of key informants are conducted using open-ended questions.

The HIV surveillance team discovers that:

- The UNHCR camps are closed camps and no mixing occurs between Jamilistanis in the camps and the general population of Al Aniram.
- A UNHCR study at one of the closed camps found the prevalence of HIV among antenatal clinic attendees was 1.5%.

- There are three neighbourhoods in Al Aniram that are primarily inhabited by Jamilistanis.
- Many Jamilistani immigrants work as day labourers and congregate on specific street corners to wait for employment.
- There are many Jamilistani-owned cafes and restaurants in these neighbourhoods that Jamilistani immigrants patronize.
- Some Jamilistani women work as sex workers and have Jamilistani and non-Jamilistani clients.
- Injecting drug use is not common among Jamilistanis.

1. What sampling scheme can be used to select representative respondents to be included in the survey?

Part 3: Sampling and collecting biological and behavioural data

A variety of sampling approaches are appropriate for sampling Jamilistani immigrants in Al Aniram. The team weighs the pros and cons of each sampling approach. Because the team was able to learn that many Jamilistani migrants congregate in identifiable locations in large numbers, they decide to employ TLS.

1. What are the advantages and disadvantages of this approach?
2. If only men congregate in identifiable locations, what are the limitations of using TLS?
3. If the surveillance team were to include Jamilistani refugees in the closed refugee camps, which sampling approaches would be appropriate?
4. What behavioural variables should be collected?
5. What biological variables should be collected?

Part 4: Collecting survey information

Although TLS requires mapping and time-consuming ethnographic work and may only reach a subset of the target population, it allows for a probability sample of the Jamilistani immigrants.

Had the surveillance team decided to include the refugees in the closed UNHCR camps, the team could have employed simple random sampling or systematic sampling, provided that UNHCR granted the team access to the camp and the refugees.

After explaining the purpose of the surveillance activity and obtaining informed consent, members of the surveillance team collect urine and blood samples from participants, which are then tested for:

- HIV-1
- HSV-2—a marker of lifetime sexual risk, for example, of multiple sexual partners
- syphilis
- gonorrhoea.

Interviewers administer semi-structured questionnaires to the refugees to assess sexual risk behaviours. Variables collected include:

- sociodemographic information, such as age, marital status, employment history, point of origin
- types of female sex partners in the past year

- men having sex with men
- condom use
- history of diagnosis with STIs and current symptoms of STIs.

The survey produces the following biological results:

- HIV prevalence: 2.75% (11/400)
- HSV-2 prevalence: 40% (160/400)
- syphilis prevalence: 5% (20/400)
- gonorrhoea prevalence: 3% (12/400).

Test results are returned to survey participants and those with positive test results are referred to appropriate services.

The survey produces the following behavioural results:

Risky sexual behaviour is common, including low condom use with non-marital partners. Premarital and extramarital sex are both common. Both married and non-married Jamilistanis report multiple sex partners, with a small number of female Jamilistanis involved in sex work with Jamilistani and non-Jamilistani clients. Only 20% of those engaged in sex work reported having ever used a condom and only 5% consistently used condoms with non-cohabitating, non-marital partners.

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

Part 5: Epilogue

The findings of this study are consistent with the results of other studies. Many male Jamilistani migrants engage in high-risk behaviours and many did not have their last genital symptoms treated. Additionally, a subset of Jamilistani women work as sex workers in Al Aniram with non-Jamilistani clients, thus serving as a bridging population to the general population of Menaland.

Given the very low levels of HIV in Menaland, targeting Jamilistani immigrants and refugees with behaviour-change interventions could be an important means of avoiding an HIV epidemic.

Based on these findings, the Menaland Minister of Health directs the HIV programme manager to implement the following measures in Al Aniram:

- Create condom-use campaigns by engaging peers and nongovernmental organization outreach workers to educate Jamilistani immigrants about consistent condom use with sex workers and regular partners.
- Engage migrant populations in knowledge-building activities regarding the modes of HIV transmission.
- Improve the service provided to refugees by:
  - establishing VCT, reproductive health services, STI treatment programmes and psychosocial counselling programmes for migrants
  - hiring medical professionals who speak the language(s) of the migrant populations
  - ensuring that information gathered by people seeking treatment and care is not used by the Ministry of Immigration for deportment purposes.

1. What are some of the risks Jamilistanis living in Al Aniram face if the results of this study are published and made available to the general population?

Case study 2: Biological and behavioural surveillance among truck drivers in Menaland

Part 1: Collecting information to plan surveillance activities

Al-Rabia, with a total population of 15 million people, is the capital of Menaland. The Northern District of Menaland borders Jamilistan and is thought to be a common drug trafficking area. Khalij-al-Akbar, to the south, is Menaland's major deep-water port and a docking place for merchant marines, cruise ships and local fishing vessels.

Seroprevalence surveys conducted in Al-Rabia have consistently found low HIV prevalence. However, similar surveys conducted over the past five years have found that prevalence levels of HIV among injecting drug users in the Northern District and STIs among female sex workers in Khalij-al-Akbar are rising at an alarming rate.

The Menaland 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 Menaland 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 nongovernmental organizations, reports from trucking companies and clinic records from roadside health centres. Several key informants are 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 health centres. Interviews of key informants are conducted using open-ended questions.

Through interviews with key informants and a review of the available literature, the surveillance team discovers that there are 140 trucking companies in Menaland, employing approximately 20 000 truck drivers. All trucking companies have offices in Al-Rabia, 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 Al-Rabia and the Northern District, which borders Jamilistan
- a medium-distance route between Al-Rabia and the deep-water port of Khalij-al-Akbar in the south of the country
- local routes between Al-Rabia and the surrounding areas.

The HIV surveillance team conducts a census of the trucking companies in Menaland 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 4000 medium-distance drivers and 20 companies employ a total of 6000 local-route drivers.

1. 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 A.1.1.1 with the sample size options).
2. 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

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. A variety of sampling approaches are appropriate for sampling truck drivers in Menaland. A sample size of 400 per survey year is decided upon. Because the team was able to construct a list of all the trucking companies, as well as information on how many drivers each company employs, the HIV surveillance team decides to employ a probability proportional to size (PPS) sampling scheme, in which types of truck drivers are sampled proportionate to the size of the different groups of truck drivers (long-distance, medium-distance or local).

In stage 1, the team 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 2, 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 only employs one type of driver, all 20 long-distance trucking companies are contacted, eight medium-distance companies are randomly selected and 12 local-route companies are contacted.

With help from the selected trucking companies, the surveillance team randomly selects 10 truck drivers from each selected trucking company. A total of 400 truckers are successfully recruited.

1. Describe how you would randomly sample 10 truck drivers from each company.
2. What behavioural variables should be collected?
3. What biological variables should be collected?

Part 4: Collecting survey information

Between January and April of 2008, the team of fieldworkers visits the selected trucking companies' offices at the Al-Rabia truck stand to recruit subjects. The Al-Rabia truck stand is selected as the best site for recruitment as all companies have offices at the Al-Rabia truck stand and all drivers must visit their office to receive their trip assignments. Assuring the participants that confidentiality will be maintained, the fieldworkers explain the purpose of the study to the drivers and obtain verbal informed consent.

Members of the surveillance team escort the recruited drivers to the local roadside STI clinic for biological and behavioural data collection.

Male clinic staff members collect urine and blood samples from participants, which are then tested for:

- HIV-1
- HSV-2, a marker of lifetime sexual risk, for example, having had multiple sex partners
- syphilis
- gonorrhoea
- hepatitis C, a marker for injecting drug use.

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

- sociodemographic information, such as age, marital status, employment history
- alcohol and drug use
- types of female sex partners in the past year
- men having sex with men
- condom use
- history of diagnosis with STIs, current symptoms of STIs
- injecting drug use behaviours, such as types of drugs injected, frequency, needle-sharing and use of sterile equipment.

The survey produces the following biological results:

- HIV-1 prevalence: 2.75% (11/400)
- HSV-2 prevalence: 40% (160/400)
- syphilis prevalence: 5% (20/400)
- gonorrhoea prevalence: 3% (12/400)
- hepatitis C prevalence: 12% (48/400).

The survey produces the following behavioural results:

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

Nearly 10% report male-male sex ever and 15% report injecting drug use within the last year. Overall, condom use with non-marital partners is low. Only 20% reported ever having used a condom and only 5% consistently used condoms with non-cohabitating, non-marital partners. No subject reporting having sex with another man reported using condoms.

Marked differences are found between the three categories of truckers.

Long-distance drivers (n = 200):

- mostly single and young
- high rates of injecting drug use
- reported sharing of syringes and other injecting equipment
- some sexual contact with sex workers along trucking route
- 24% prevalence of hepatitis C (48/200)
- 5% prevalence of HIV-1 (10/200)
- three cases of HCV/HIV coinfection.

Medium-distance drivers (*n* = 80):

- single and married
- high level of interaction with sex workers in port of Khalji-al-Akbar
- high prevalence of HSV-2 (80%), gonorrhoea and syphilis
- no reported injecting drug use
- 1.25% HIV prevalence (1/80)
- Most with HIV also had HSV-2; many also had other STIs.

Local-route drivers (*n* = 120):

- mostly married and many with multiple wives and/or regular sex partners in different locations
- little contact with sex workers
- high prevalence of untreated gonorrhoea and syphilis
- no reported injecting drug use
- no HIV cases.

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

Part 5: Epilogue

Findings of this study are consistent with the results of other studies. Most trucker drivers surveyed engaged in high-risk behaviours and many did not have their last genital STI symptoms treated.

Given the very low levels of HIV in Menaland, targeting truck drivers with behaviour-change interventions could be an important means of avoiding an HIV epidemic.

Based on these findings, the Menaland Minister of Health directs the HIV programme manager to:

- create 100% condom-use campaigns in port area brothels and engage peers and nongovernmental organization outreach workers to educate truck drivers about consistent condom use with sex workers and regular partners.
- establish harm reduction programmes for injecting drug users and provide sterile injecting equipment to injecting drug user truck drivers at the large truck stops along the trucking routes between Al-Rabia and the Northern District.
- establish workplace-based STI screening and HIV education for local-route drivers.
- improve the service provided at roadside STI clinics by ensuring drug supply and training staff on proper STI management.

Unit 6

Street children

Overview

What this unit is about

This unit describes the background and special considerations for conducting behavioural and biological HIV surveillance among street children.

Warm-up questions

1. What are some of the reasons why street children may be considered vulnerable to HIV?

   a.

   b.

2. List three possible places where you would expect to find large numbers of street children.

   a.

   b.

   c.

3. List two organizations with which you can form alliances as you develop your HIV surveillance system for street children.

   a.

   b.

Introduction

What you will learn

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

- understand the role of street children in the HIV epidemic
- describe options for the sampling of street children for surveillance
- describe the special ethical considerations associated with conducting HIV surveillance activities among street children.

Definitions

The term "street children" is often used to describe children who live and/or work on the streets. The United Nations Children's Fund (UNICEF) has defined two main categories of street children:

- Children on the street—those engaged in economic activity, such as begging or vending. The children belonging to this group often return home to their families at the end of the day and contribute to the family income.
- Children of the street—those who actually live on the streets.

Children belonging to the second group often do not have strong familial ties. For the purpose of surveillance, street children may include all persons who are under the age of 18, or only those between ages 12 and 18 years. Depending on the laws in your country about research with minors, conducting biological surveillance and/or behavioural surveillance may not be possible among all age groups. Conducting a formative assessment and investigating your country's laws about research with minors will help you determine the age groups you can and should include in your surveillance activity.

Street children often live under challenging conditions and are marginalized from mainstream services and society. In EMR/MENA, subpopulations of street children at risk for HIV infection include orphaned, homeless, runaway or neglected children who live chiefly in the streets without adequate protection, supervision or direction from responsible adults.

Contributing factors

Factors that can contribute to children being on the street include:

- economic hardship—begging to support oneself or ones family
- the lure of cities—youth may run away from families in rural areas
- social conflict and emergencies—natural disasters, political conflicts and war may generate street children
- orphan status—parents may have died from war and conflict
- divorce or separation of parents—illegitimate children may also become street children.

Role of street children in the HIV epidemic

Street children have a higher risk of acquiring HIV, as they:

- do not receive reproductive health education and other school-based services
- may have low self-esteem, which can lead to risk behaviours
- face stigma and discrimination that prevent them from adopting risk-reduction behaviours
- may have access to drugs, which increases the likelihood of risk taking
- are more likely to experiment with drugs and alcohol
- may be sexually exploited or involved in sex work.

Street children are often more likely than their elders to engage in high-risk behaviour, making them more susceptible to HIV 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 street children are varied. Street children are at risk of acquiring HIV because they:

- are often sexually active
- may have multiple sex partners, including sex workers
- may sell sex in exchange for goods or money
- may be sexually abused
- may sniff glue and/or smoke hashish or marijuana
- may inject drugs
- have less access to prevention information through schools
- may be involved in gangs and/or drug trafficking
- are unlikely to receive appropriate medical care.

By targeting street children through behaviour-change interventions, several countries have successfully decreased national HIV prevalence levels. To create appropriate interventions, HIV surveillance of high-risk youth is crucial.

Prevalence of HIV among street children

Little data exists regarding the prevalence of HIV among street children in EMR/MENA. The following data are two studies with HIV prevalence information, both showing zero HIV prevalence. However, more data are needed to understand the true picture of street youth in EMR/MENA:

- Of 102 street children (<15 years old) included in a cross-sectional study in Tehran, Islamic Republic of Iran, all were HIV-negative, three were positive for hepatitis B surface antigen and 15 were positive for hepatitis B surface antibody (38).

- In Cairo, Egypt, among the 600 street children (ages 12–17 years) surveyed between May and August 2006, the prevalence of HIV was zero (27).

Role of street children in surveillance

In EMR/MENA, persons under the age of 18 years account for the largest portion of the population. It is crucial to identify and track the most vulnerable 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 street children and other youth. These programmes include:

- mass media campaigns
- promotion of youth-friendly health services
- condom promotion use and life skills
- VCT for HIV and STIs.

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.

Conducting a formative assessment

Consider where to find street children

Because street children are composed of a number of different subgroups, HIV prevalence may differ considerably among groups existing relatively closely within a country or even within a city. Identifying points of access and forming alliances with organizations and persons trusted by the different subgroups will help you understand more fully the culture and diversity of street children in your area.

Surveillance requires gaining access to a full range of street children and to areas where street children can be found. This may be difficult when considering each subgroup's different characteristics. Findings from the pre-surveillance assessment should prove helpful in focusing the search. To aid in locating and accessing street children, consider:

- identifying and interviewing people known to have regular contact with street children
- visiting areas where the children are known to congregate
- collaborating with organizations that provide education, food and/or shelter to street children, such as religious organizations and civil society organizations.

Possible organizations that can help you locate and access street children include:

- local and international nongovernmental organizations that work with street children
- governmental bodies, such as the Ministry of Social Development and the Ministry of Youth and Sports
- UNICEF
- the United Nations Populations Fund (UNFPA)
- the Red Cross and Red Crescent societies

- Save the Children
- day centres for street children
- youth scouts
- OXFAM International
- local sports clubs.

Other subgroups of street children, such as child sex workers, factory workers and soldiers, may require more extensive formative assessment before they are located. These subgroups may be more easily accessed by forming alliances with adults or older youth who are in charge. Some examples include:

- governmental organizations and nongovernmental organizations that have youth-targeted HIV prevention and care programmes
- influential current and former sex workers
- factory workers
- police
- leaders of youth gangs and begging groups
- national and international advocacy groups dealing with issues relating to street children.

These people and organizations can also assist later on in implementing surveillance activities. For example, former adolescent sex workers can be hired and trained as recruiters or interviewers in difficult-to-access areas.

Conduct ethnographic mapping

This comprehensive description is used to broadly guide where and when street children can be found and recruited for surveillance activities and what subgroups can be found in different areas. More specifically, detailed ethnographic mapping can be used to produce a sampling frame or comprehensive roster representing street children or a particular subgroup in your area. This sampling frame provides the basis for some probability-based sampling methods.

The locations where street children spend most of their time will differ by subgroup. To locate street children, identify areas where young people tend to congregate. These include:

- parks
- markets and shopping centres
- city centres and squares
- tourist sites
- train and bus stations
- around mosques
- near restaurants
- near religious ceremonies
- street corners
- busy intersections
- under bridges
- drop-in centres for street children.

Due to various legal issues surrounding many of the subgroups, it is unlikely that

there is any formal registration system for street children. However, depending on the country or region, street children may be registered as sex workers or labourers. Rosters of street children also may be available from nongovernmental organizations, religious organizations, drop-in centres and other agencies that provide services to street children. It is important to note that these lists are rarely separated into adult and youth categories, making it difficult to obtain a representative sample.

Selecting a sampling method

Introduction

Vulnerable groups that are hard to reach, such as street children, may be sampled using either probability sampling or non-probability sampling (also referred to as convenience sampling). Depending on the organization and accessibility of the streetchildren, and the extent to which they are networked, different sampling methods may be more or less feasible. Although non-probability sampling, such as snowball sampling, is easier to conduct than probability sampling because a sampling frame is not needed, data collected through non-probability methods can introduce bias into the data. This can occur due to differences in HIV prevalence or risk behaviours between different subpopulations or subgroups. Probability and quasi-probability sampling methods can be used to obtain more representative samples of street children.

Probability sampling techniques like time-location sampling (TLS) and respondent-driven sampling (RDS) may be used to sample hard-to-reach street children.

TLS

TLS may be used to sample street children when they tend to gather or congregate in identifiable and accessible locations, such as certain street corners, markets and transportation centres. In TLS, the sites known to be frequented by street children, which are found through ethnographic mapping or pre-surveillance activities, are used to develop a sampling frame from which a probability sample of sites and time periods are chosen. Because the locations where street children congregate may change over time, you should develop a new sampling frame for each round of surveillance.

Mapping the locations where street children can be found also will help you decide where to implement future interventions.

RDS

Certain subpopulations of street children do not congregate in identifiable and accessible locations, and are not adequately represented by TLS. RDS, an adaptation of chain-referral sampling, is based on a dual incentive structure in which participants are rewarded for being interviewed and for recruiting their peers. When using RDS to sample hard-to-reach or mobile street children, incentives should not be too weak or too strong.

- If incentives are too weak, participants may 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, clothing and other useful in-kind (non-monetary) 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 street children may vary, your inclusion and exclusion criteria should be very clear in the first wave of recruitment so that youth understand which other youth to recruit.

RDS may not work in all settings. In settings where street children neither congregate in identifiable locations nor have strong social networks, using a non-probability sampling approach, such as snowball sampling, may be your only option. Your formative assessment will provide you with the information necessary to determine which sampling approaches are feasible.

Priorities for Local AIDS Control Efforts

The Priorities for Local AIDS Control Efforts (PLACE) protocol is a new rapid assessment tool used to identify areas of high HIV transmission. It formalizes the collection of information in high-transmission areas. PLACE uses key informants to identify locations where people meet new sex partners, then conducts interviews at the site to characterize the people who congregate there and to map sites. Identifying high-transmission areas and places where people meet new sex and injecting partners will also help you determine where to implement behaviour-change interventions and other programmes targeted at street children.

Figure 6.1 will help you select an appropriate method for sampling street children in your area.

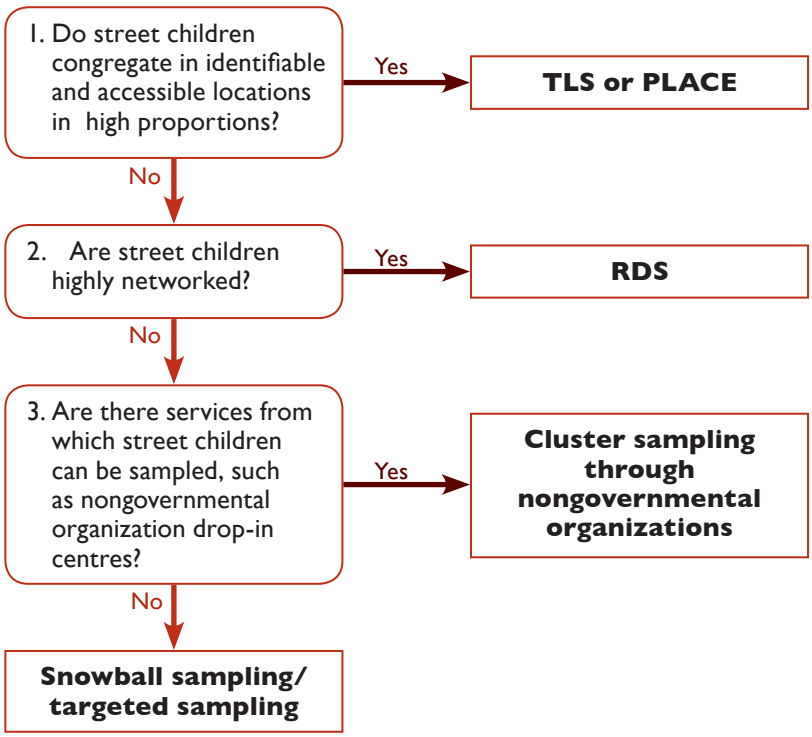


Figure 6.1 Selecting sampling methods for street children

Additional information on the sampling methods that may be used to sample street children is discussed in *Module 2: Surveillance of HIV risk behaviours*.

Measures

Biological measures

Measuring HIV prevalence among street children is important for surveillance. The high sexual risk among many of the subgroups makes STI testing a good indicator for surveillance. For information on the available STI and HIV tests, refer to the WHO test kit evaluation programme at: http://www.who.int/diagnostics_laboratory/evaluations/en/

- Syphilis testing is often the most efficient biological indicator of unprotected sexual intercourse; the standard tests can be done with the same serological specimen used for HIV testing. The test is relatively inexpensive and widely available.
- Gonorrhoea and *Chlamydia* tests usually require a urine, rectal or pharyngeal specimen.

Behavioural measures

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

Behavioural variables that assess sexual risk include:

- correct identification of ways to prevent the transmission of HIV and rejection of major misconceptions about HIV transmission
- age of sexual debut
- history of coerced sex
- condom use during last sex
- sex with multiple partners
- exposure to interventions
- access to HIV services and health care
- psychological indicators to assess history of trauma
- the use of transactional sex.

In areas where there is suspected overlap between street children and other most-at-risk populations, such as sex workers, men who have sex with men or injecting drug users, consider using indicators that assess high-risk behaviours among these groups.

The behavioural variables that may be appropriate in situations where there is suspected overlap between street children and other high-risk groups are presented in Table 6.1.

Table 6.1 Additional behavioural variables to include when there is suspected overlap between street children and most-at-risk populations

Group	Behavioural variable
Sex workers	• venue of sex work • number of paying customers • condom use with paying customers
Injecting drug users	• frequency of injecting drug use • sharing of needles, syringes and other injecting equipment • types of drugs injected • history of imprisonment
Men who have sex with men	• number of male sex partners • frequency of unprotected insertive anal intercourse • frequency of unprotected receptive anal intercourse

Reference to indicators

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

Special ethical considerations

Risks for street children

Because street children are young and often involved in activities such as prostitution or child labour, they are often stigmatized and are considered a vulnerable population. Their participation in surveillance activities may place them at risk of 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 consequences in response to publicized results.

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

Assuring confidentiality

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

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

People asked to participate in a survey or study should understand potential threats to their anonymity. They should also understand the steps that the investigators will take to minimize the threats. 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 street children in private settings
- collecting no identifying information about street children
- 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. Familiarize yourself with these laws in your country as part of your initial formative assessment 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 street children may be considered minors and obtaining consent from their parents may be difficult.

The World Medical Association has developed the Declaration of Helsinki as a statement of ethical principles to provide guidance to persons participating in research involving human subjects. The Declaration of Helsinki provides ethical guidance for research activities involving minors and states that:

- When a minor child is able to give assent to decisions about participation in research, the investigator must obtain that assent in addition to the consent of the legally authorized representative.

Further information on the ethical principles included in the Declaration of Helsinki is available at: http://www.wma.net/en/30publications/10policies/b3/index/html

Summary

Depending on the organization and accessibility of street children in your area, different sampling methods may be more or less feasible. Additionally, appropriate behavioural indicators will vary depending on the situation and subpopulations of street children in your area. You should be aware that different countries will have different laws and standards about when an adolescent can participate in research involving sexual behaviours and when parental consent is required. If you plan to include children under the age of 15 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 serosurveillance of street children?
2. In your country, who are the gatekeepers of this population?
3. In your country, what methods have been used to sample street children?
4. In your country, what behavioural and biological measures have been used when conducting surveillance of street children?
5. In the past five years, has the prevalence of HIV among street children increased, decreased or remained about the same?

Apply what you have learned/case study

Conducting behavioural surveillance among street children in Al Muri, Menaland

Part 1: Collecting information to plan surveillance activities

Al Muri, with a total population of 5 million, is the economic and administrative capital of Menaland, a large country in EMR/MENA.

In 2007, data from STI surveillance found that the number of new diagnoses of *Chlamydia* among adolescents had doubled since 2000. Alarmed by these results, the Ministry of Health developed a package of youth-targeted evidence-based interventions to reduce HIV, including a national multi-media prevention campaign of billboards, leaflets, and radio and television broadcasts.

The Commissioner of Public Health for the Al Muri metropolitan area is alarmed by recent nongovernmental organization reports that an increasing number of street children, 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 children and/or have not been effective in preventing HIV infection among these youth.

The Commissioner of Public Health directs the HIV Programme Manager to undertake a survey of street children in Al Muri 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 HIV team obtain this information?

Part 2: Building key alliances with community networks involved with street children

Prior to conducting the survey, the HIV team 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, nongovernmental organization reports, clinic records of the public and private clinics and reports from the police department. Several key informants are contacted, including current and former street children, railway station employees, shop keepers, police, nongovernmental organization managers and outreach health workers. The HIV team collects information on the locations where street children sleep, work and congregate, and the public health services and nongovernmental organizations operating in the area.

Through discussions with current and former street children, the HIV team realizes that street children are highly distrustful of outsiders, including researchers, and are fearful that involvement in research activities may lead to the destruction of their illegal squatter settlements and/or to their arrest. The team decide that to access street children, they must enlist the support of gatekeepers whom the street children know and trust.

1. Who are important gatekeepers that can help the HIV team gain access to the street children in Al Muri?
2. What actions can the HIV team take to address the street children's distrust?

Part 3: Ethical considerations

Through discussions with current and former street children and managers of nongovernmental organizations working with street children, the HIV team learn that many of the street children are organized in cliques (or groups), with certain cliques living and working as a team and hanging out in certain areas. Using the contacts of the current and former street children, the HIV team meets with "senior" street children who have influence among other street children.

The HIV team also meets with nongovernmental organization 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 that they will not arrest street children participating in the survey or destroy their settlements, the HIV team can move to the next step.

1. What are the special ethical considerations related to conducting HIV surveillance among street children?
2. What actions can you take to safeguard the well-being of the street children whom you want to participate in your surveillance activity?
3. What kinds of incentives should the HIV team offer the street children who participate in the survey?

Part 4: Choosing a sampling approach

Through their pre-surveillance activities, the HIV programme manager learns a lot about street children and writes a brief report. Included in the report is information about where the street children sleep, work and congregate. Though funds for the surveillance activity were used for the pre-surveillance activity, the information gained will ensure resources for the resulting surveillance are not wasted.

1. What sampling methods are appropriate for sampling street children in Al Muri?
2. What are the advantages and disadvantages of each approach?
3. How would the HIV team construct their sampling frame?

Part 5: Collecting behavioural data

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

- conduct targeted sampling
- conduct TLS at the locations where street children congregate
- use snowball sampling
- conduct RDS.

The team weighs the pros and cons of each approach and 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 resources than TLS or RDS, because it does not require a sampling frame. Like targeted sampling, snowball sampling is not a probability-based sampling method.
- RDS and TLS are probability-based sampling methods that have more external validity than either snowball sampling or targeted sampling.

Given that street children sleep, work and congregate in identifiable and accessible locations, the availability of adequate resources and the strengths of TLS as a probability sampling method, the team decides to conduct TLS to obtain a representative sample of street children in Al Muri.

The HIV team constructs a list of sites where street children live, work and meet. These sites include squatter settlements where many street children sleep, bus stations, train stations, busy intersections, markets where street children beg and sell goods, and parks where they congregate. The team visits these venues and counts the numbers of street children present at specific times.

The team statistician determined that the HIV team needs to survey a total of 600 street children; thus, the HIV team decides to use a two-stage cluster sampling design. In Stage I, 20 locations are randomly selected using a list of random numbers. In Stage II, a fixed number of 30 street children are selected from each selected site at a randomly selected three-hour time period on a randomly selected day of the week.

Although the HIV team discusses providing financial incentives, for ethical reasons they decide to give a packet of biscuits and a hot meal as the incentive to participate.

1. What behavioural variables should be collected?

Part 6: Results

At the randomly selected locations and times, trained interviewers explain the purpose of the study to the youth and obtain verbal consent. Confidentiality is assured. The interviews are conducted in private and in a non-coercive manner. Personal identifiers are not collected.

Trained interviewers administer a pretested, 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, current school attendance and highest grade completed. Participants are asked about lifetime history of sexual intercourse, age of first intercourse, frequency of condom use, if they had ever exchanged sex for money, had experienced any kind of sexual abuse in the streets or had experienced any kind of sexual abuse in the home. They are asked about their alcohol and illicit drug use. They are also asked about the number of sexual partners they had in the previous year, whether they were diagnosed with any STIs, and whether they had any unprotected sex under the influence of drugs or alcohol. The HIV-related knowledge and information section included items asking about any HIV testing history and whether they could correctly identify condom use as a means of preventing HIV transmission. To assess the youths' recognition and exposure to HIV/STI prevention interventions, including the national mass-media prevention campaign, campaign logos and campaign audio recordings are presented to participants. 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 Public Health Commissioner of Al Muri.

Although the study cannot afford to provide HIV or STI testing, referrals and vouchers for these services are offered to all street children who participate in the survey.

The survey produces the following results:

Demographics

- The sample included 600 street children (480 boys and 120 girls).
- Median age of those who participated was 16 years (range 12–19).
- Boys were significantly older than girls (median age 17 vs. 14, $p < 0.01$).
- Girls were more likely to be in contact with their families 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.
- Forty-five per cent (267) of respondents were literate (50% of boys; 22.5% of girls).
- Five per cent of those surveyed reported having run away from home as a result of sexual or physical abuse in their home (with girls more frequently reporting this occurrence, $p < 0.05$).

- Fifteen per cent reported growing up on the street as a result of being born out of wedlock.
- Ten reported having run away from home because of a forced marriage (girls more frequently reported this occurrence, $p < 0.05$).

Sexual behaviours

- A significantly higher proportion of boys (67%) than girls (30%) reported ever having had sexual intercourse ($p < 0.01$).
- Median age of sexual debut was 15 for boys and 13 for girls.
- Fifteen per cent of female respondents reported having performed sex or sexual favours for money within the previous year, compared to only 4% of male respondents.
- An additional 10% of female respondents reported having exchanged sex for food or other goods, mostly with other street children.
- Five per cent of male respondents reported having provided female street children with food or protection in exchange for sex or sexual favours.
- Eleven per cent of female respondents reported having been raped while living on the streets.
- Twenty-six per cent of those who were sexually active reported a history of condom use "in general", while 72% reported using a condom during most recent sexual intercourse.

Drug use

- Hashish was the substance most frequently used within the last year among boys (85%) and girls (79%).
- Girls were less likely than boys to report having used hashish, marijuana, inhalants and/or methamphetamines in the last year ($p < 0.05$).
- Injecting drug use was reported by 15% of participants, all male.

HIV knowledge

- Nearly all respondents had heard about HIV/AIDS, but only 32% mentioned that consistent use of condoms could prevent transmission of HIV and other STIs.
- Fifty-six per cent of respondents believed that they would never get HIV.
- Eleven per cent of the participants reported having been tested for HIV; only one respondent reported that he/she was HIV-infected.

Exposure to interventions

- Only 12% of those surveyed had been exposed to the government's mass-media HIV prevention campaign.
- All those who had been exposed to it had heard the radio component of the campaign.
- Nearly all of the youth surveyed knew the locations of the public health centre that served street children, yet only 10% reported having utilized these services.
- Fear of being arrested or "sent home" was the most commonly cited reason why street children did not utilize public health services.

1. Based on the community survey, what are the main factors that put street children at risk of transmitting and acquiring HIV?
2. What interventions should be initiated based on these results?

Part 7: Epilogue

Based on the community survey, street children were at high risk of acquiring and transmitting HIV, HIV-related knowledge was low, many female street children had performed sex work and had been raped or abused, and many children had run away from home to escape abusive relationships or forced marriages. Injecting drug use was alarmingly high, although glue sniffing and smoking hashish were also common. Street children surveyed did not utilize the public health centres, although they knew they existed. Urgent targeted interventions were needed to increase safe sex practices and HIV-knowledge among street children in Al Muri.

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

1. Design interventions specifically targeted at street children.
2. Engage peers and nongovernmental organization outreach workers to educate street children about HIV/STI transmission and prevention.
3. Disseminate "best practices" to researchers and practitioners who have worked with street children across different cities.
4. Work with local police and public health centres to establish times when street children can visit public health centres without fear of being arrested or persecuted.

Unit 7

Prisoners

Overview

What this unit is about

This unit describes the background and special ethical considerations associated with conducting HIV surveillance in populations of prisoners. It presents sampling options and recommends specific surveillance methods for this group.

Warm-up questions

1. Which of the following is a reason for high HIV prevalence among prisoners?
   a. the over-representation of injecting drug users among prisoners
   b. male-to-male sex during long periods of incarceration
   c. sexual relations between prison staff and prisoners
   d. high concentration of female sex workers in some prisons
   e. the sharing of needles for drug use in prison
   f. all of the above

2. 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

3. 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

4. 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

5. Because of their inability to give true voluntary _____, prisoners are a vulnerable population and need special ethical protection.

Introduction

What you will learn

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

- understand the factors that contribute to the increased risk 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.

Definitions

Both male and female prisoners are at increased risk for HIV infection.

For the purpose of this unit, we define a prisoner as any person involuntarily confined or detained in a penal institution, including persons detained pending arraignment, trial or sentencing. We use the term "prison" broadly for any place of detention, including:

- reform centres
- police stations and jails
- centres for pre-trial and convicted prisoners
- centres for juvenile offenders
- centres for refugees, illegal immigrants and/or asylum seekers
- mandatory re-education and rehabilitation centres, such as those for injecting drug users.

Role of prisoners in the HIV epidemic

In many EMR/MENA countries, such as the Islamic Republic of Iran and Sudan, prison settings have contributed to the rapid spread of HIV infections. There are multiple and powerful factors contributing to the high prevalence of HIV in prisons. These include:

- the high concentration of arrested injecting drug users and sex workers
- consensual and non-consensual male-to-male sex, especially during long periods of incarceration
- syringe sharing with multiple injectors
- tattooing with unsafe needles; this factor is theoretical, although there is clearly a risk for HBV and HCV infection.

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

Female prisoners are often incarcerated for sex work and therefore can have a higher prevalence of HIV than do male prisoners. Additionally, sexual relations between correctional staff and female prisoners may contribute to the high prevalence of HIV among female prisoners.

Prevalence of HIV among prisoners

HIV seroprevalence levels have reached alarming levels in many prison populations in some EMR/MENA counties and elsewhere in the world. The high HIV prevalence levels in prisoners are the result of both the high rates of HIV infection before persons enter prison and the high transmission rates within prisons. Transmission within prisons is likely the result of both high-risk sex and the sharing of syringes and needles for injecting 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 seroprevalence studies are more difficult to conduct in prisons than in community settings, due to the difficulty of gaining access to prison populations.

In EMR/MENA, the prevalence of HIV infection among prisoners varies by country and area. Consider the following examples:

- In Iran, among 4543 prisoners HIV prevalence was 2.09% in 2009. HIV prevalence was higher among prisoners with a history of drug injection (8.11%) (39).
- Among 764 prisoners tested in Kuwait in 1999, 4 (<1%) tested positive for HIV (19).
- One study found an HIV prevalence of 18% among prisoners in the Libyan Arab Jamahiriya (15).
- In Morocco, prison sites reported a prevalence of 0.61% among male prisoners (n = 2289) and 1.2% among female prisoners (n = 167) in 2003 (40).
- Data from the Sudan National AIDS Programme indicate that the prevalence among prisoners increased from 2.0% in 2002 to 8.63% in 2006 (41).

Bridges and overlap with other populations

Prisoners overlap with other most-at-risk populations, i.e. injecting drug users and sex workers. Due to the illegal nature of sex work and injecting drug use, sex workers and injecting drug users 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 most-at-risk population 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 a formative assessment

Building alliances

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

Building alliances with the community networks involved with prisoners, including prison administrations and staff, and health-care workers at prisons, will help you design and conduct surveillance activities and do your formative assessment. Prison wardens are important gatekeepers who can provide access to prisoners. Involving the Ministry of Justice would also assist with gaining access to prisons and support for the surveillance.

Formative assessment questions

Conducting a formative assessment will help you identify important indicators to measure the diversity of the subpopulations of prisoners and the structure and procedures of prisons for surveillance purposes. Information gathered during your formative assessment will help you answer the following questions:

- What are the different types of facilities for incarceration in your country: city, subnational and national-level prisons and penitentiaries?
- What are your country's policies for testing prisoners for HIV at each level?
- Are HIV-infected prisoners kept at separate facilities?
- Are prisoners routinely screened on admission or at some other time during incarceration?
- Are surveys of currently incarcerated prisoners practical and ethical?
- Are surveys of prisoners at the time of, or immediately following, release feasible?

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

- persons from the Ministry of Interior
- persons from the Ministry of Justice
- prison wardens and correctional officers
- human rights organizations
- prisoner rights organizations
- Nongovernmental organizations that provide social services programmes for prisoners.

Selecting a sampling method

WHO/UNAIDS discourage mandatory testing of prisoners. However, 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 carried out and for more complex surveys, such as surveys of prisoners who are currently incarcerated or surveys of prisoners at the time of release, some form of random sampling may be appropriate. One approach, for example, is to conduct combined biological surveillance and behavioural surveillance on a consecutive or systematic sample of prisoners after their intake or at an initial health assessment. As with all surveillance activities, surveillance must be regular and ongoing to be effective.

Information gathered during your formative assessment will guide you in selecting sampling approaches that are appropriate and practical.

As the prevalence of HIV, STIs and risk behaviour varies between facilities, it is important to keep in mind that results of a study conducted in a particular facility may not be generalizable to the entire prisoner population of a country.

Measures

Introduction

Ideally, seroprevalence studies should be combined with behavioural surveillance. This will allow you to understand the behaviours that affect the prevalence of HIV, STIs and parenterally transmitted infections.

Surveys that collect behavioural and biological information on HIV, STIs and risk behaviours should include informed consent. The focus of the questions may vary based on gender, as summarized in Table 7.1.

Table 7.1 Focus of behavioural surveillance, by prisoner gender.

Prisoner gender	Focus of surveillance
Male	• injecting drug use before and during incarceration • male-to-male sex in prison • heterosexual sex before incarceration
Female	• injecting drug use before and during incarceration • heterosexual sex before and during incarceration

Discussing the table

Looking at Table 7.1, answer the following question:

a. What foci of surveillance are common to both male and female prisoners? In which group is heterosexual sex during incarceration more important?

Biological measures

Measuring HIV seroprevalence among prisoners is a possible component of surveillance. The high sexual risk among prisoners also makes STI testing a useful and feasible indicator for surveillance. For information on the available STI and HIV tests, refer to the WHO test kit evaluation programme: http://www.who.int/diagnostics_laboratory/evaluations/en/

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

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

Table 7.2 Possible biological measures

Biological measure	Notes
Syphilis	Syphilis testing is often the most efficient biological indicator, because the standard tests can be done with the same serological specimen as with the HIV testing. The test is relatively inexpensive and widely available.
Gonorrhoea	Accurate tests for gonorrhoea are expensive and usually require a urine specimen.
Chlamydia	Accurate tests for *Chlamydia* are expensive and usually require a urine specimen.
Herpes simplex virus type 2 (HSV-2)	HSV-2 testing is a marker for lifetime sexual risk. However, it is less readily available. To be an indicator for sexual risk, the test needs to distinguish HSV-2 from HSV-1.
Hepatitis C virus (HCV)	HCV is a good marker for injecting drug use.

In rare cases, and where permitted by law, urine specimens may also be tested for the presence of opiates and methamphetamines.

Behavioural measures

Behavioural measures should focus on sexual and parenteral risk behaviours. Because sex workers and injecting drug users may be present in high numbers in 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 injecting drug users are discussed in Unit 2 and Unit 3.

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 transmission (UNGASS).

These basic indicators may be supplemented with local measures of particular importance in your area, as determined by your formative assessment phase. These additional variables may include:

- reason for incarceration
- drug use, injecting and non-injecting
- marital status
- occupation before incarceration
- term of sentence in years or months
- history of attending a drug abuse treatment clinic.

Reference to indicators

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

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

Estimating incidence

Because prisoners are a relatively stationary group, calculating the incidence of HIV in prisons may be possible. Cohort studies provide the most exact measurements of incidence, but are only possible if correctional staff members allow public health workers access to prisoners for HIV testing during their incarceration. A few studies have surveyed prisoners as they are released and calculated the incidence of HIV in prisons. Additionally, recidivists (persons who are repeatedly arrested for criminal behaviour) form dynamic cohorts for HIV incidence studies. Ideally, incidence studies should be combined with behavioural surveillance to aid in understanding the specific risk behaviours contributing to HIV incidence.

Tuberculosis testing

The prevalence of tuberculosis (TB) is up to 100 times higher in prisons than in the general population. HIV/TB coinfected 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 coinfection among prisoners in your country, you should consider entrance-point tuberculin skin testing or chest X-ray of prisoners and periodic testing of prisoners and prison staff. This testing is done for clinical purposes, 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

Risks for prisoners

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 http://www.wma.net/en/30publications/10policies/b3/index.html. The Helsinki Declaration states:

> *Medical research is subject to ethical standards that promote respect for all human beings and protect their health and rights. Some research populations are particularly vulnerable and need special protection. These include those who cannot give or refuse consent for themselves and those who may be vulnerable to coercion or undue influence.*

As prisoners are unable to give true voluntary informed consent, they are a vulnerable population and need special ethical protection.

Because of their unique situation, special efforts are required to ensure the privacy, rights and safety of prisoners participating in HIV testing, the provision of adequate care if they are found to be infected and the safety and security of the staff conducting the study. Most prevalence studies require that the investigators alert the potential study participants to the possible consequences, legal or otherwise, of admitting drug use or having sex in prison. Furthermore, some IRBs require the input of a prisoner advocate.

Informed consent

Informed consent is required when conducting prevalence studies and other activities involving the non-routine collection of data. In every area of life, prisoners bargain for privileges and better conditions. Because of their incarceration, prisoners are under unique constraints that affect their ability to make a truly voluntary and uncoerced 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.

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 from uninfected prisoners, ensuring confidentiality is not possible.

If the correction facility has isolation for HIV-infected prisoners, then:

- prisoners must be informed about the treatment options available in the facility
- prisoners must be made aware of who has access to their medical records
- prisoners' rights must be considered by IRBs.

When confidentiality cannot be guaranteed and the potential harm of being identified as HIV-infected is severe, UAT may be a more desirable option. By design, UAT precludes the disclosure of participants' names or other identifying information.

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 injecting drug use are illegal in many countries, large numbers of these most-at-risk groups may be present in prisons.

Special ethical considerations must be made when conducting surveillance activities among prisoners. Ethically, prisoners are considered a special population due to their potential 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 serosurveillance 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 the central prison, Menaland

Part 1: Introduction

The central prison is the largest adult male correctional facility in Menaland and houses prisoners from all regions of the country. The HIV surveillance team of the National AIDS Control Programme (NACP) recently received a report from a nongovernmental organization that found previous incarceration to be one of the strongest predictors of HIV infection among males in Menaland. The NACP is concerned that released prisoners are a potential source of HIV transmission to the general population.

The surveillance team, in collaboration with the Ministry of Justice, decides to conduct a seroprevalence assessment of prisoners at the central prison. It is estimated that approximately 50% of all prisoners are incarcerated on drug-related offences. The minimum stay for the prison is 12 months; persons sentenced to less time are held in local jails.

Previous studies showed an HIV prevalence of 5% among the prisoners tested. Biological data suggest that persons entering prison 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.

1. What are the possible approaches to conducting a behavioural survey among prisoners at the 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 pre-incarceration sexual and injecting behaviour of 700 prisoners. Although blood and urine are routinely collected at intake, behavioural data are not routinely collected. In addition, 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 first 700 male prisoners who arrived at the central prison between January and April and explain the purpose of the behavioural survey. After receiving assurance that confidentiality will be maintained, 525 prisoners provide informed consent and agree to participate in the survey. The HIV surveillance team administers a baseline questionnaire that includes the following variables:

- sociodemographic information:
  - age
  - marital status
  - occupation prior to incarceration

  - monthly income
  - residence prior to incarceration
- arrest/incarceration information:
  - type of offence and whether drug related
  - duration of sentence
  - past history of incarceration
- injecting behaviour:
  - which drugs
  - sharing of injecting equipment
- sexual behaviour:
  - sex with regular 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.
- Thirty-eight per cent of respondents injected prior to incarceration.
- Heroin was the most commonly injected drug.
- Twenty-two per cent reported having shared injecting equipment, such as needles and syringes, in the month prior to their incarceration.
- Three per cent reported sex with men before incarceration
- Many have a history of prior incarceration.

Although the survey data suggest that many inmates engaged in high-risk behaviour prior to their incarceration, engaging in high-risk behaviours within the prison is also prevalent. The HIV surveillance team decides to assess the incidence of HIV inside the central prison.

1. Describe how the HIV surveillance team could measure HIV incidence among the central prison inmates.
2. What behaviours could explain an increase in HIV among the prisoners?

Part 3: Estimating incidence

To determine the incidence of HIV during incarceration in the central prison and the behaviours related to infection, the HIV surveillance team follows 500 HIV-uninfected prisoners for 12 months. After 12 months, the 500 HIV-uninfected prisoners are retested for HIV and their in-prison risk behaviours are assessed.

Behavioural data from follow-up surveys produce the following results:

- Fifteen per cent (75/500) inject heroin while in prison, all of whom report sharing needles and other injecting equipment due to the unavailability of sterile injecting equipment.
- Five per cent (25/500) inject heroin, share injecting equipment and engage in unprotected male-male sex while in prison.
- Five per cent (25/500) do not inject heroin but do engage in unprotected male-male sex while in prison.
- Four per cent (20/500) seroconverted in the 12-month period.

- Eighteen reported injecting while in prison (HIV incidence among injectors was 24% per year).
- Two reported male-male sex but no injecting (HIV incidence among those reporting male-male sex but no injection was 8% per year).

The HIV surveillance team concludes that many prisoners who are uninfected when they enter the central prison are contracting the virus while incarcerated through sharing of injecting equipment with HIV-infected prisoners and, to a lesser extent, through unprotected male-male sex.

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

Part 4: Epilogue

Based on these findings, the NACP directs the Ministry of Justice to increase the funding for prison-based drug treatment programmes and HIV interventions. The NACP directs the Ministry of Justice to consider the following options and consider the practicality of implementing them:

- provide prison-based HIV education
- initiate antiretroviral therapy for prisoners according to national guidelines
- establish drug treatment and methadone programmes for prisoners who are injecting drug users
- establish condom programmes within the prisons
- distribute sterile injecting equipment to prisoners.

Module summary

Module summary

- In EMR/MENA, most-at-risk populations (MARPs) include sex workers, injecting drug users and men who have sex with men. Mobile populations, street children and prisoners are considered vulnerable populations.
- Most-at-risk and vulnerable populations play a central role in the spread of HIV infection. At the beginning of an HIV epidemic, the first infections appear in these groups because they have more higher-risk behaviours. These behaviours include:
  - having sex without using a condom (unprotected sex) with multiple partners and/or having a large number of new partners
  - injecting drugs with shared needles and syringes.
- Understanding the spread of HIV in most-at-risk and vulnerable populations is essential and of highest priority. Surveillance among vulnerable populations is of lower priority. Surveillance data can contribute to advocacy for improved care and treatment for most-at-risk populations and evaluate the success of HIV and STI control programmes.
- The first step in planning HIV surveillance in most-at-risk and vulnerable 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 subpopulations and the geographical areas and venues where most-at-risk and vulnerable populations may be found in large numbers.
- There are several conventional probability sampling methods that can be used for sampling most-at-risk and vulnerable 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 most-at-risk and vulnerable populations.
- 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 most-at-risk and vulnerable populations should be determined by your country's data needs. The formative assessment phase

should be used to determine the local questions of greatest relevance to the epidemic in your area.

- Behavioural surveillance indicators should measure behaviours that are essential to the spread of HIV and that are targeted by HIV prevention programmes, including:
  - behaviours that increase the chance that an uninfected person will come into contact with an infected person
  - behaviours that increase the chance that HIV will be transmitted if contact with an HIV-infected person occurs.
- 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 injecting drug users, have increased risk of other blood-borne infections. Hepatitis C virus is the blood-borne infection most typically measured.
- Many most-at-risk and vulnerable populations are marginalized and sometimes their behaviour is illegal. It is important to understand your country's laws regarding sex workers, injecting drug users, men who have sex with men and the required reporting of individuals with HIV infection, as these laws may complicate the participation of some at-risk populations.

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Annex I

Glossary

Glossary

Accuracy	Refers to how well the sample reflects (nearest to the truth) the study population.
Acquired immunodeficiency syndrome (AIDS)	see **Advanced HIV infection**
Advanced HIV infection	The late stage of HIV infection that includes development of one or more opportunistic illnesses (illnesses that occur because of low levels of CD4 lymphocytes, or immunodeficiency). **Advanced HIV infection** is the term now used for AIDS in updated WHO guidelines.
Agent	A factor, such as a microorganism, chemical substance,or form of radiation, whose presence is essential for the occurrence of a disease.
Algorithm	Step-by-step procedure for decision-making; a recipe for achieving a specific goal.
Aliquot	A portion of a sample; for example, an aliquot of a 100 millilitre sample of blood might be a 5 millilitre portion of that sample.
Alliances	Partnerships created to assist with formative assessment. These partnerships differ based on the type of most-at-risk group being sampled, but usually include gatekeepers, governmental or non-governmental organizations, influential members of the target group, advocates and physicians and others who provide health care to the target group.
Anonymous	Having no known name or identity. For example, removing all personally identifying information from a sample that will be tested for HIV, in order to protect the patient's identity.
Antibodies	Molecules in the blood or secretory fluids that tag, destroy or neutralize bacteria, viruses or other harmful toxins.
Antiretroviral therapy (ART)	Treatment with drugs that inhibit the ability of HIV to multiply in the body.
Asymptomatic	Without symptoms.
At-risk groups	Groups of people that are at increased risk for passing HIV on to others or for being infected by others.
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 sample selection and the collection or interpretation of data.

Biological surveillance Surveillance that involves regular and repeated cross-sectional surveys, but collects biological samples that are tested for HIV and other related illnesses, such as sexually transmitted diseases and tuberculosis.

Bridging population Bridging populations are populations at intermediate risk of exposure to HIV and provide links between the most-at-risk populations and the low-risk general population. Bridging populations are for example sexual partners of injecting drug users, men who have sex with men (including male sex workers) and female sex workers.

Carrier A person or animal without apparent disease who harbours a specific infectious agent and is capable of transmitting the agent to others.

Case An individual in the population or sample with a particular disease of interest.

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

Cluster Any aggregate of the population of interest (for example, departments, villages, health facilities, etc.)

Confidentiality Protecting information that concerns a study participant or patient from release to those who do not need to have the information.

DHS Acronym for "demographic and health surveys".

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

Distribution The frequency and pattern of health-related characteristics and events in a population. In statistics, the observed or theoretical frequency of values of a variable.

EIA See **enzyme immunoassay**.

ELISA See **enzyme-linked immunosorbent assay**.

EMR/MENA Acronym for the "Eastern Mediterranean Region/Middle East and North Africa" created explicitly for use in this module series. It includes: Afghanistan, Algeria, Bahrain, Djibouti, Egypt, Islamic Republic of Iran, Iraq, Jordan, Kuwait, Lebanon, Libyan Arab Jamahiriya, Morocco, Oman, Pakistan, occupied Palestinian territory, Qatar, Saudi Arabia, Somalia, Sudan, Syrian Arab Republic, Tunisia, United Arab Emirates and Yemen. EMR/MENA does not refer to an official UNAIDS or WHO region.

Enzyme immunoassay (EIA) A type of test that identifies antibodies to an organism such as HIV. EIAs rely on a primary antigen-antibody interaction and can use whole viral lysate of HIV or one or more antigens from the virus.

Enzyme-linked immunosorbent assay (ELISA) A type of enzyme immunoassay (EIA) to determine the presence of antibodies to an infectious agent such as HIV in the blood or oral fluids.

Epidemic The occurrence of a disease (or other health-related event) at a greater than expected level of increase to a baseline. For example, the high prevalence of HIV found in many parts of the world today, including sub-Saharan Africa, Latin America, and South and South-East Asia.

Epidemic state The prevalence the epidemic has reached in a country or region. Can be low-level, concentrated or generalized within a subpopulation or within the general population.

Epidemiology The study of the distribution and determinants of the frequency of health-related states or events in specified populations, and the application of this study to the control of health problems.

Equilibrium In RDS, the point in the recruitment process where a variable is not expected to change by more than 2% with each successive wave.

Ethnographic mapping Collecting information on the geographical location, temporal movement of, and interactions among, members of the study population.

Factor An intrinsic factor (age, race, sex, behaviours, etc.) which influences an individual's exposure, susceptibility or response to a causative agent.

False positive Test results that are positive when the patient does not actually have the disease that is being tested for.

False negative Test results that are negative when the patient actually has the disease that is being tested for.

Formative assessment Research conducted before the study begins. Researchers use qualitative methods, such as focus groups, in-depth interviews, mapping or observations of the target population and the individuals who work with them to ensure that the research team sufficiently understands the community.

Female sex worker Females who engage in sex work, or the exchange of sex for money, which includes many practices 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.

Focus group A group setting in which people are asked by a facilitator about their views about a topic. Participants are free to talk with other group members as well as the facilitator. Focus groups allow interviewers to study people in a more natural setting than they can in a one-to-one interview.

Gatekeepers Persons who can provide access to a most-at-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 The general population encompasses all people living in a defined community, e.g. a country, a province or a city. If surveillance data on the general population exclude certain subpopulations, e.g. specific age-groups of the population, foreign workers, refugees or others, this should be stated clearly. The general population is relatively at low risk of HIV exposure in low-level and concentrated HIV epidemics.

Gigolo Male sex workers who identify as straight. They tend to have foreign clients and engage in male-male sexual activity.

Gonorrhoea An infection caused by *Neisseria gonorrhoeae* bacteria. Although gonorrhoea is considered primarily an STI, it can also be transmitted to newborns during the birth process.

High-risk behaviours Behaviours that increase the risk that a person will contract a disease.

HIV See **human immunodeficiency virus**.

HIV-negative Showing no evidence of infection with HIV (for example, absence of antibodies against HIV) in a blood or tissue test.

HIV-positive Showing indications of infection with HIV (for example, presence of antibodies against HIV) based on a test of blood or tissue.

Human immunodeficiency virus (HIV) A retrovirus that causes AIDS by infecting T-cells of the immune system.

Impact indicators A standardized set of indicators developed by UNAIDS to help monitor HIV prevalence in particular populations.

Incentive A reward or reimbursement given to participants in a study. In RDS surveys, there are typically two levels of incentive—primary incentive and secondary incentive. A participant receives the primary incentive for enrolling in the study and completing an interview. The same participant receives secondary incentive(s) for recruiting his or her peers into the study. Incentives are not absolutely necessary in every situation and should be determined during formative research.

Incidence A measure of the frequency with which an event, such as a new case of illness, occurs in a population over a period of time. The denominator is the population at risk; the numerator is the number of new cases occurring during a given time period.

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 a way to compare levels of risk behaviours between different population groups.

Infectivity The proportion of persons exposed to a causative agent who become infected by an infectious disease.

Informed consent The permission granted by a patient or a participant in a research study after he or she has received comprehensive information about a research study or medical procedure. Informed consent protects the person's freedom of choice and respects his or her autonomy with regard to decisions affecting his or her body and health.

In-group affiliation In RDS, what homophily measures (group similarity based on ethnicity, age, socioeconomic status and so forth).

Injecting drug user (IDU) Injecting drug users are persons who use needles or syringes to inject drugs. Injecting drug use is considered a high-risk behaviour.

Institutional review board (IRB) The committee designated to approve, monitor and review biomedical and behavioural research involving humans with the aim of protecting the rights and welfare of research participants. Also known as an ethics committee.

Internally displaced person (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.

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.

Isolate A population of bacteria or other cells that has been isolated and cultured.

Key informant Members of the target group, who can often become informal assistants.

Key populations	Key populations include most-at-risk, bridging and vulnerable populations, who, while being important to the dynamics of HIV transmission in a setting, are essential partners for an effective response to the epidemic, i.e. they are key to the epidemic and key to the response. Key populations will vary depending on the epidemic and community/country context.
Lessons learnt	Information from actual studies that will help you make decisions when planning your study.
Linking	Refers to whether a tested individual's names or identifying information is associated with his or her HIV test results. Also whether non-identifying demographic or other information is associated with the test results.
Low-level epidemic	The epidemic state in which HIV has never spread to significant levels in any subpopulation, although HIV infection may have existed for many years; HIV prevalence is less than 1% in pregnant women and has not consistently exceeded 5% in any defined subpopulation. This state suggests that networks of risk are rather diffuse or that the virus has only been recently introduced.
Male sex worker	Males who engage in sex work, or the exchange of sex for money, which includes many practices and occurs in a variety of settings.
Mandatory testing	Testing that is required of a patient if he or she is to obtain certain services; for example, mandatory HIV testing of individuals who request marriage certificates.
Marriage pressure	Family pressure on sons to marry to provide stability for parents and the continuation of the family name as well as to avoid the stigma of being a man who has sex with men.
Most-at-risk population (MARP), priority population or key population at increased risk	The terms most-at risk population, priority population and key population at increased risk are used interchangeably. These are populations that experience the highest probability of being exposed to HIV and include injecting drug users, men who have sex with men (including male sex workers) and female sex workers.
Men who have sex with men (MSM)	Men who have sex with men are considered at increased risk of HIV if they engage in high-risk behaviours such as unprotected anal sexual intercourse. For the purposes of this module, we also consider male sex workers, transvestites and transgendered persons in the men who have sex with men category.
Mobile populations	Refers collectively to groups of people who move from one place to another (migrants). They may move temporarily, seasonally or permanently and for either voluntary or involuntary reasons.
Monitoring	Evaluating a programme's performance over time.
Monitoring and evaluation (M&E)	Collecting and analysing accurate and reliable information that can be used to improve programme performance and planning.
MSM	Acronym for "men who have sex with men".
MSW	Acronym for "male sex worker".
Negative controls	Specimens known to be negative and term used to ensure that a laboratory reagent is working properly prior to testing specimens from patients.
Negative predictive value	In HIV testing, the probability that a person with a negative test result is not infected. Also known as "predictive value negative".

Network sampling A sampling method that 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 (see **seed**) who act as entry points to the network.

Non-probability sampling When the sampling units are selected through a non-randomized process; therefore, the probability of selecting any sampling unit is not known.

Optical density The intensity of colour as measured by a machine in an EIA HIV antibody test, indicating whether the patient's sample is HIV-positive.

Parenteral transmission Transmission of an infectious agent through blood. Parenteral transmission of HIV can occur from the sharing of injecting drug equipment, from transfusions with infected blood or blood products, or from needle stick injuries.

Participation bias Error in results from a study that is due to differences in characteristics between those who participate in a survey and those who do not. For example, persons who already know they are HIV-infected may find testing unnecessary; those who suspect they are HIV-infected may decline testing in order to avoid stigma.

Partner concurrency Having extensive sexual network connections to many persons at the same time, which increases the spread of HIV and STIs.

PLACE See **Priorities for Local AIDS Control Efforts**.

Population The total number of inhabitants of a given area or country. In sampling, the population may refer to the unit from which the sample is drawn, not necessarily the total population of people.

Positive controls Specimens known to be positive, as used in proficiency testing.

Positive predictive value The probability that a person with a positive test result is infected; in surveillance this refers to the proportion of cases reported by a surveillance system or classified by a case definition which are true cases. Also known as "predictive value positive".

PPS See **probability proportional to size sampling**.

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

Pre-surveillance assessment Describes a set of activities that occur prior to beginning formal HIV and behavioural surveillance in high-risk groups. These activities include developing detailed plans and reviewing and collecting information that will help in planning and designing surveillance activities.

Prevalence The proportion of persons in a given population with a disease or condition at a given point in time; a specific group infected. Prevalence is a direct measurement of the burden of disease in a population.

Prevalence assessment Surveys that determine prevalence of a disease in a population.

Prisoner Any person involuntarily confined or detained in a penal institution, including persons detained pending arraignment, trial or sentencing.

Probability sampling A sampling scheme that ensures that each entity in a population has a known, non-zero chance of being selected.

Prostitués homosexuels Homosexual prostitutes. Male sex workers who identify as homosexual or gay.

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 characterize the site in each area and map sites, and, finally, interviews individuals socializing 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.

RDS See **respondent driven sampling**.

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 of an ethnic or social group.

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

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 subpopulation themselves can most efficiently identify and encourage the participation in surveillance of other subgroup 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.

RIBA Acronym for "recombinant immunoblot assay", also known as Western blot. Immunoblot assays confirm anti-HCV reactivity. Serum is incubated on nitrocellulose strips on which four recombinant viral proteins are blotted. Colour changes indicate that antibodies are adhering to the proteins. A positive result is if two or more proteins react and form bands. An indeterminate result is if only one positive band is detected.

Sample A selected subset of a population. There are specific types of samples used in surveillance and epidemiology such as convenience, systematic, population-based and random.

Sample size The number of subjects to be used in a given study.

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

Sampling bias Also called selection bias. This refers to errors in sampling that decrease accuracy and lead to incorrect estimates. We also use the term "biased samples" to mean that errors were made in choosing the people in the sample.

Sampling interval	The standard distance between elements selected in the sample population.
Sampling scheme	Procedure for choosing individuals to be included in a sample.
Sampling units	Refers to individual members of the population whose characteristics are to be measured.
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 serosurveys and uses additional sources of data to gain additional understanding of the epidemic. It includes biological surveillance of HIV and other STIs, as well as systematic surveillance of the behaviours that spreads them.
Secondary incentive	The incentive a participant gets for recruiting his or her peers into the study.
Seed	Non-randomly selected (by the investigators) members of the target population who will initiate the RDS recruitment process by recruiting members of his or her peer group. From each seed, a recruitment chain is expected to grow.
Sensitivity	The proportion of persons with disease who are correctly identified by a screening test or case definition as having disease.
Sentinel population	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 STI patients or truck drivers.
Sentinel sites	Sites at which sentinel surveillance activities take place, including clinics attended by individuals who may or may not be representative of the general population but are likely to represent groups initially infected or at higher risk for infection than the general population.
Sentinel surveillance	A surveillance system in which a pre-arranged sample of reporting sources at "watch post" or "sentinel" sites agrees to report all cases of one or more notifiable conditions. Often designed to provide an early indication of changes in the level of disease. Depending on the nature of the population surveyed, these data may be representative of the general population, or they may simply give more detailed information about the populations tested.
Seroprevalence	The proportion of a population that is infected, as determined by testing blood for the appropriate antibody. For example, the proportion of a population that is infected with HIV, as determined by testing for HIV antibodies in blood samples.
Sexual transmission	Transmission of an infectious agent, such as HIV, that occurs predominately through unprotected vaginal or anal intercourse, and less frequently through oral intercourse.
Sexually transmitted infection (STI)	Infections that are spread by the transfer of organisms from person to person during sexual contact.

Sex worker (SW) Persons who engage in sex work, or the exchange of sex for money, which includes many practices and occurs in a variety of settings. These may include "direct" or "formal" sex workers, who are sometimes included in registries and often found in brothels, and "indirect" or "casual" sex workers, who do not engage in sex work full time and are unlikely to be included in registries. The term "sex worker" can be used to refer to female, male and transgendered sex workers.

Simple random sampling (SRS) Sampling where everyone has an equal chance of being randomly selected (a non-zero probability) and we know what that chance is.

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 network Members of a peer group who know each other.

Specificity The proportion of persons without disease who are correctly identified by a screening test or case definition as not having disease.

Stakeholders (or stakeholder's group) Those with an interest in the results of surveillance activities. Includes public health practitioners, health-care providers, data providers and users, representatives of affected communities, governments at the district, province and national levels, and members of professional and private non-profit and donor organizations.

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.

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

Strata A subgroup in stratified sampling.

Stratification The classification of a survey population into subgroups or strata on the basis of selected characteristics.

Stratified sampling Stratified sampling is generally used to obtain a representative sample when the population is heterogeneous, or dissimilar, where certain homogeneous, or similar, subpopulations can be isolated (strata). A stratified sample is obtained by taking samples from each stratum or subgroup of a population.

Street children Children who live and/or work on the streets, including orphaned, homeless, runaway or neglected children who live chiefly in the streets without adequate protection, supervision or direction from responsible adults.

Subcutaneously Below the skin, as in an injection.

Surveillance The systematic collection, analysis, interpretation and dissemination of health data on an ongoing basis, to gain knowledge of the pattern of disease occurrence and potential in a community, in order to control and prevent disease in the community.

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).

Survival sex To barter sex for the necessities of living, such as food, shelter, goods or money. Engaged in by vulnerable populations such as displaced women, street children and transgendered people who are marginalized and discriminated against.

Susceptible Vulnerable or predisposed to a disease.

Symptomatic Exhibiting symptoms.

Symptom Any perceptible, subjective change in the body or its functions that indicates disease or phases of disease, as reported by the patient.

Systematic sampling A sampling method that consists of randomly selecting the initial patient who meets the inclusion criteria and then selecting every "*n*th" (for example, third or fifth) eligible patient thereafter until the predetermined sample size is reached or the survey period is over.

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 characterizing the target population; 2) sampling may be biased and difficult to replicate; 3) geographical 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 sampling frame more than once (for example, at different times of the day or different days of the week).

Table A set of data arranged in rows and columns.

Transactional sex Distinct from other forms of commercial sex. Includes the receipt of gifts or services in exchange for sex.

Transgendered persons Persons who identify with or express a gender and/or sex different from their biological sex.

Transmission Any mode or mechanism by which an infectious agent is spread through the environment or to another person.

Trend A long-term movement or change in frequency, usually upwards or downwards.

Treponema pallidum The bacterial causative agent of syphilis.

Trichomonas vaginalis A sexually transmitted protozoan parasite that causes the vaginal infection, trichomoniasis, characterized by itching, burning and vaginal discharge. Reinfection is common if sexual partners are not treated simultaneously.

True positives Test results that are positive when the patient actually has the disease that is being tested for.

True negatives Test results that are negative when the patient actually does not have the disease that is being tested for.

UAT See **unlinked anonymous testing**.

UNGASS Acronym for United Nations General Assembly Special Session on HIV/AIDS.

Unlinked anonymous testing (UAT) Testing that occurs when a sample of blood originally collected for other purposes is tested for HIV after being anonymized. The person whose blood is taken does not know that his/her blood will be tested for HIV. All information that could identify the person is removed from the sample so that the results of the test cannot be linked back to them.

Unprotected sex Having sex without using a condom as protection against HIV and other sexually transmitted infections.

Validity The validity of a measure is the extent to which it actually measures what it is suppose to measure—the truth.

Values Magnitude of measurements (statistics).

Variable Any characteristic or attribute that can be measured.

VCT See **voluntary counselling and testing**.

Virus Microorganisms that typically contain a protein coat surrounding nucleic acid (RNA or DNA) that are capable of growth only within living cells.

Voluntary counselling and testing (VCT) A programme that provides both counselling and testing services to communities, allowing persons who are tested to obtain emotional and medical support before and after their HIV tests.

Vulnerable population Vulnerable populations form a subset of the general population and are generally at low risk of HIV exposure, but under certain circumstances are vulnerable to practices that may put them at a higher risk of HIV. Depending on the context prisoners, youth and mobile populations belong to vulnerable populations. Once these vulnerable populations adopt high-risk practices they become part of most-at-risk or bridging populations.

Western blot A type of HIV test, Western blot uses an electro-blotting method in which proteins are transferred from a gel to a thin, rigid support and detected by binding of labelled antibody to HIV.

WHO Acronym for the "World Health Organization".

Annex 2

Useful links

Useful links

The Body

An AIDS and HIV information resource based in New York City, USA. Provides information on various questions related to HIV/AIDS. Available at: http://www.thebody.com

Cochrane HIV/AIDS Group

An affiliate of the International AIDS Society and the University of California, San Francisco (UCSF) CSF AIDS Research Institute, the Cochrane Collaborative Review Group on HIV Infection and AIDS is an international network of health-care professionals, researchers and consumers working to prepare, maintain and disseminate systematic reviews on the prevention and treatment of HIV infection and AIDS. Available at: http://www.igh.org/cochrane

Council for International Organizations of Medical Sciences (CIOMS)

The Council for International Organizations of Medical Sciences (CIOMS) has prepared the *International Ethical Guidelines for Biomedical Research Involving Human Subjects*, in collaboration with the WHO. Available at: http://www.cioms.ch/frame_guidelines_nov_2002.htm

Family Health International (FHI)

FHI 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. Available at: http://www.fhi.org/en/hivaids (English) or http://www.fhi.org/ar/fhiag.html (Arabic).

The Global Fund to Fight AIDS, Tuberculosis and Malaria

The Global Fund was created to finance a dramatic turnaround in the fight against AIDS, TB and malaria. These three diseases kill more than six million people a year. This massive scaling-up of resources is already supporting aggressive interventions against all three. Available at: http://www.theglobalfund.org

HIV InSite

HIV InSite is developed by the Center for HIV Information (CHI) at UCSF. HIV InSite's mission is to be a source for comprehensive, in-depth HIV/AIDS information and knowledge. Available at: http://www.hivinsite.ucsf.edu

HIV/AIDS rapid assessment guide

FHI has prepared an HIV/AIDS rapid assessment guideline. Available at: http://www.fhi.org/en/hivaids/pub/guide/RapidAssessmentGuide/index.htm

HIV/AIDS Survey Indicators Database

The HIV/AIDS Survey Indicators Database is overseen by a technical advisory committee that includes representatives from USAID, UNICEF, CDC, UNAIDS, WHO, US Census Bureau, FHI, MEASURE Evaluation, The Synergy Project and MEASURE DHS+ (the implementing organization). USAID is currently the primary funder for the initiative, with UNAIDS and UNICEF providing additional support. There are 180 surveys available in the database. Available at: http://www.measuredhs.com

Multiple Indicator Cluster Survey (MICS), UNICEF

The 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. Available at: http://www.childinfo.org

Prevention and Public Health Group, Global Health Sciences (University of California, San Francisco)

The Prevention and Public Health Group (PPHG) within Global Health Sciences (GHS) at the University of California, San Francisco (UCSF), is dedicated to improving health and reducing the burden of disease in the world's most vulnerable populations. Areas of focus are applied public health research, education and programme improvement. PPHG works with academic, government and community partners throughout the world using evidence-based methods to build capacity in surveillance, monitoring and evaluation, epidemiology, clinical care and scientific best practices. More information is available at http://globalhealthsciences.ucsf.edu/pphg/index.html

Respondent-Driven Sampling (Cornell)

Defines RDS and provides information on minimum data requirements, sampling references, intervention references and downloads. Available at: http://www.respondentdrivensampling.org

UNAIDS (Joint United Nations Programme on HIV/AIDS)

As the main advocate for global action on HIV/AIDS, UNAIDS leads, strengthens and supports an expanded response aimed at preventing the transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS and alleviating the impact of the epidemic. Available at: http://www.unaids.org

UNAIDS epidemiological information on HIV/AIDS

Available at: http://www.unaids.org/en/resources/epidemiology.asp

UNAIDS surveillance information on HIV/AIDS

Available at: http://www.unaids.org/en/in+focus/topic+areas/surveillance+and+reporting.asp

United Nations Children's Fund (UNICEF)

UNICEF is one of the United Nations' key agencies in the fight against HIV/AIDS, mobilizing financial resources and helping persuade governments to put HIV/AIDS at the top of their agendas and to treat the epidemic as a national emergency. UNICEF is working in 160 countries around the world to combat the epidemic. Available at: http:// www.unicef.org/aids

United Nations General Assembly Special Session (UNGASS)

This site is dedicated to tracking compliance with the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), which in 2001 concluded with a declaration of commitment signed by 189 Member States to take actions to reduce the spread and impact of HIV/AIDS. As part of this effort, UNAIDS reports on progress toward achieving this goal every two years. To measure progress, UNAIDS developed a set of 25 indicators called the UNGASS indicators. Available at: http://www.ua2010.org/index.php/en/ungass

United Nations Office on Drugs and Crime (UNODC)

UNODC is a global leader in the fight against illicit drugs and international crime. UNODC is involved in HIV/AIDS programming in regions, such as the Middle East and North Africa, where injecting drug use is known to drive the HIV/AIDS epidemic. Available at: http:// http://www.unodc.org

U.S. Centers for Disease Control and Prevention (CDC)

CDC serves as the national focus for developing and applying disease prevention and control, environmental health and health promotion and education activities designed to improve the health of the people of the United States. Available at: http://www.cdc.gov

The CDC Global AIDS Program (GAP) surveillance team has developed an interactive sampling selection tool for use in surveillance study sampling design. Proper sampling design is critical to the success of a study. The tool is available at: http://globalhealthsciences.ucsf.edu/pphg/surveillance/sampling_tool.html

U.S. National Institutes of Health (NIH)

The National Institutes of Health is the federal focal point for medical research in the United States. The NIH, comprising 27 separate institutes and centres, is one of eight health agencies of the Public Health Service, which, in turn, is part of the U.S. Department of Health and Human Services. Simply described, the goal of NIH research is to acquire new knowledge to help prevent, detect, diagnose and treat disease and disability. Available at: http://www.nih.gov

World Bank, Global HIV/AIDS Program

The Global HIV/AIDS Program was created in 2002 to support the World Bank's efforts to address the HIV/AIDS pandemic from a cross-sectoral perspective. The Program offers global learning and knowledge sharing on approaches and best practices to addressing HIV/AIDS. Available at: http://www1.worldbank.org/hiv_aids/globalprogram.asp

World Health Organization (WHO)

The WHO is the United Nations specialized agency for health. WHO's objective, as set out in its Constitution, is the attainment by all peoples of the highest possible level of health. WHO is governed by 192 Member States through the World Health Assembly. Available at: http://www.who.int

WHO Department of HIV/AIDS

The HIV/AIDS Department coordinates a strategic, organization-wide response to the HIV/AIDS epidemic and enables WHO to provide enhanced technical support in HIV/AIDS to countries and regional offices. Available at: http://www.who.int/hiv/en

WHO Regional Office for the Eastern Mediterranean

The WHO Regional Office for the Eastern Mediterranean coordinates WHO activities for the Eastern Mediterranean Region. The Region includes: Afghanistan, Bahrain, Djibouti, Egypt, Islamic Republic of Iran, Iraq, Jordan, Kuwait, Lebanon, Libyan Arab Jamahiriya, Morocco, Oman, Pakistan, occupied Palestinian territory, Qatar, Saudi Arabia, Somalia, Sudan, Syrian Arab Republic, Tunisia, United Arab Emirates and Yemen. The web site provides a variety of information specific to the Eastern Mediterranean Region and links to partner and regional government websites.

Available at: http://www.emro.who.int

WHO Test Kit Evaluations Programme

The WHO test kit evaluation programme aims to provide Member States, UN agencies and other partners with technical information and advice on the quality of currently available test kits and technologies. Additional information is available at: http://who.int/diagnostics_laboratory/evaluations/en/

Annex 3

Answers to warm-up questions and case studies

Answers to warm-up questions and case studies

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. Which of the following groups are at high risk for HIV infection in EMR/MENA?
   a. sex workers
   b. injecting drug users
   c. men who have sex with men
   d. all of the above
   In EMR/MENA, groups at increased risk of HIV infection include sex workers, injecting drug users and men who have sex with men.

2. True or false? In low-level epidemics, surveillance of most-at-risk populations can serve as an early indicator of the presence of HIV in a country. Circle your answer below.
   True. At the beginning of an epidemic, the first infections often appear in most-at-risk populations because they have greater risk behaviours than the general population.

3. List the two sampling methods that are commonly used in HIV surveillance of most-at-risk populations.
   Respondent-driven sampling (RDS) and time-location sampling (TLS) are ideally suited for surveys of most-at-risk populations, especially those that are harder to find.

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

Potential consequences of not protecting participants' privacy and confidentiality include physical, psychological, legal and social harms. 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.

Unit 2 answers

Warm-up questions

1. True or false? Sex workers can contribute disproportionately to the sexual transmission of HIV because of their large number of sexual partners. Circle your answer below.

   True. Because their clients can infect others in the general population, sex workers can contribute greatly to sexual HIV transmission.

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

   Direct sex workers can be based in streets, hotels and bars.

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

   Indirect sex workers. Indirect sex workers sell sex to supplement their primary income and can often be found in bars or massage parlours or work from apartments.

4. True or false? Surveillance coordinators should meet with sex workers to use their expertise in designing the approach and questionnaires for behavioural surveillance.

   True. Sex workers often have inside information that could help you design a more effective approach to surveillance.

5. Clients of sex workers are often a *bridge* to low-risk populations. For example, clients of sex workers 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 population. A bridging population is a group that serves to facilitate the spread of HIV from a most-at-risk population to the general population.

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

   RDS can be used to sample highly mobile sex workers.

Case study: Formative assessment among female sex workers in Khalij-al-Akbar, Menaland

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

1. What are the goals of formative assessment?

   The goals of the formative assessment phase should be to determine the questions relevant to the epidemic and collect background information that will aid in designing the behavioural survey. This includes identifying and characterizing the sex worker population of interest, reviewing what is already known about sex workers in this region, locating and gaining access to all areas where sex workers can be found and gaining participation and buy-in from key members of the community. An additional component of formative assessment entails an assessment of how networked, or interconnected, sex workers are with each other and mapping the venues or locations where they work based on the types of sex work in which they are involved.

2. Who are the possible key informants and participants for focus group discussions in Khalij-al-Akbar?

   Possible key informants and participants for focus group discussion include a diverse mix of sex workers, pimps, bar owners, taxi drivers, private doctors, pharmacists, police and nongovernmental organization managers and outreach workers.

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

   The key informants and focus group participants should be asked open-ended questions about sex workers, including demographic characteristics, locations where they live and work, population-specific health risk behaviours and the best ways to recruit sex workers. These individuals can also provide input on local vocabulary to be used in the questionnaire, key people who have access to sex workers, possibilities for incentives, information about their social networks and give an idea of the population's willingness to participate.

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

1. What are the possible approaches to estimating population size among sex workers in Khalij-al-Akbar?

   Possible approaches to estimating population size among sex workers in Khalij-al-Akbar include capture-recapture, various multiplier methods, and census and enumeration methods.

2. Why does the team decide to concentrate on estimating the population size of the mobile phone sex worker population in Khalij-al-Akbar?

   The HIV programme team decides to estimate the size of the mobile phone sex worker population in Khalij-al-Akbar because mobile phones seem to be the predominant mode of communication within the sex trade. Estimating the population size of sex workers will help plan for the behavioural surveillance survey as well as help to inform the resources needed to plan for any interventions that may follow pending the results.

Part 3: Estimating population size

1. How many mobile phone sex workers does the team estimate are in Khalij-al-Akbar?

   The team estimates that there are about 1970 mobile phone sex workers in the city. N = (740)(825)/310 = 1970

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

   This information is limited because some sex workers may have multiple cell phones.

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

   The capture-recapture assumptions include the following: 1) the population is closed, sex workers would not be migrating in and out of the city in a week; 2) the sources of data are independent, meaning new lists were made each week although different teams were used to collect the phone numbers each week; 3) the sex workers had the same chance of being listed in each data source; 4) individual phone numbers were matched. These assumptions were met.

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

   Prior to conducting their formative research activities, the team must submit their application to their ethics committee or institutional review board (IRB) and obtain approval to conduct their formative research activities.

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

   The HIV programme team engaged various stakeholders through key informant interviews and focus groups. The team may continue to engage stakeholders by holding stakeholder input meetings, discussing the results of the formative assessment and involving stakeholders in planning for next steps. The HIV programme team can also have stakeholders participate in implementation of the surveillance activity.

Part 4: Obtaining institutional review board approval

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

   Because sex work is stigmatized and often illegal, sex workers are a vulnerable population. Their participation in surveillance activities may place them at risk for harm and discrimination. Specific issues to consider include how informed consent will be obtained, how confidentiality will be protected and the benefits of the survey, as well as the possible risks to participants.

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 reuse in medical settings, injection of illegal drugs, etc.

2. Which of the following sampling methods can be used for surveillance in injecting drug users?

   a. time-location sampling

   b. multi-stage cluster sampling

   c. convenience sampling

   d. simple random sampling from a drug treatment clinic registry

   Along with RDS, TLS is an ideal method for surveying hard-to-reach populations.

3. List two organizations with which you can form alliances as you develop your HIV surveillance system for injecting drug users.

   Examples include treatment clinics, needle-exchange programmes, prisons, social service organizations, etc.

4. List two interventions that can help reduce HIV transmission among injecting drug users.

   Interventions that can help to reduce HIV transmission among injecting drug users include promoting sterilization of injecting equipment, providing sterile needles, treating drug addiction, promoting condom use, etc.

5. What are the ethical issues you must consider when conducting surveillance in injecting drug users?

   Ethical issues to consider when conducting surveillance in injecting drug users include the inability of injecting drug users to provide true informed consent when under the influence of drugs or withdrawing from drugs, and that participation in surveillance activities may place injecting drug users at risk for harm and discrimination due to inadvertent identification as an injecting drug user or as HIV-infected.

Case study: Behavioural surveillance among injecting drug users in Al-Rabia, Menaland

Part 1: Collecting information to plan surveillance activities

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

   One advantage of conducting surveillance in injecting drug users at drug treatment centres and other centres of care is that these facilities are places where injecting drug users are easily accessed. One limitation, however, is that the illegal nature of injecting drug use means that those more at risk who avoid the official health-care system altogether, and the important group of injecting drug users who are not arrested or do not seek treatment will not be captured using this approach.

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

   In conducting this survey, you would first construct a sampling frame for the survey population using the four detoxification centres, then select people randomly or systematically within that sampling frame.

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

   - *conducting surveillance among injecting drug users anonymously*

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

3. What biological markers do you include? Why?

   Measuring HIV seroprevalence among injecting drug users is an integral component of surveillance. Given that the primary route of transmission would be from injecting drug use, you should also consider including the following markers that are related to parenteral infection:

   - *Anti-hepatitis B core antigen (anti-HBc), a non-specific marker of acute, chronic or resolved HBV infection.*
   - *Hepatitis B surface antigen (HBsAg), a marker of infectivity, the presence of which indicates either acute or chronic HBV infection.*
   - *Hepatitis C antibody, a nonspecific marker of acute, chronic or resolved HCV infection.*

   Injecting drug users are also at risk of HIV through sexual behaviour. Biological markers for STIs may also be considered in surveillance for injecting drug users.

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

   The illegal nature of injecting drug use means that those most at risk may avoid the official health-care system altogether. Therefore, they will be under-represented in surveillance based at drug treatment centres and other sites where surveillance is implemented. Basing measurement on injecting drug users 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 injecting drug users.

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

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

   A useful starting point for gaining access to injecting drug users is to speak with people who deal with injecting drug users through the health-care system, through prevention programmes and through the justice system. In addition, working with former and current injecting drug users can guide you to the places where injecting drug users can be found and into the social networks of different groups of injecting drug users.

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

   The HIV programme team can engage various stakeholders to gain a better understanding of the culture and diversity of injecting drug users in the area and gain access to injecting drug users. This includes engaging stakeholders through key informant interviews and focus

groups during the formative assessment. The team may continue to engage stakeholders by holding stakeholder input meetings to discuss the results of the formative assessment and plan for next steps. The stakeholders can also later assist with implementing surveillance activities.

Part 3: Choosing approaches to combined behavioural and biological surveillance

1. What sampling schemes might be appropriate for conducting community-based sampling of injecting drug users in Al-Rabia?

   RDS and TLS are ideally suited for surveys of high-risk groups, especially those that are harder to find, like injecting drug users in Al-Rabia.

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

   TLS combines the methods of targeted sampling and cluster sampling to produce a probability sample. TLS is like conventional cluster sampling, but it solves the problem of everyone in the target population not being in the same place at the same time. This method can be applied to populations that are visible and congregate in venues that are accessible to researchers.

   Disadvantages of TLS may include the following: In TLS, only the more visible "hidden" populations are reached. TLS requires extensive ethnographic mapping to prepare an appropriate sampling frame. Because sampling is done at a variety of venues, coordination with gatekeepers such as bar owners is essential. There are staffing concerns such as safety, late hours, time, transportation and field set-up. Finally, there are ethical concerns regarding the use of venues to conduct TLS for stigmatized populations. This may draw unwanted attention to the population and expose safe havens.

   Some advantages of RDS are that it enables you to reach members of the population that are not visible and it does not require extensive mapping in the formative assessment. RDS has been shown to reduce in-group affiliation, where initial study participants tend to list people of similar demographics, such as socioeconomic status and educational levels. RDS also improves random probability of selection and the cooperation of surveillance participants because it uses a peer referral method and a dual incentive structure.

   Disadvantages of RDS include: the requirement that the population be sufficiently networked; recruitment is dependent on participants and can be unpredictable; data on links between participants and network size must be accurately recorded; the sample must reach equilibrium; and special statistical software must be used to analyse the data.

3. Given the limited information available at this point, which method do you think will work best in Al-Rabia?

   Based on the information provided, RDS may be the most feasible method for sampling injecting drug users in Al-Rabia.

Part 4: Implementing RDS

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

   You should ensure that you select seeds from each distinct group of injecting drug users (young injectors, older injectors, injecting sex workers, etc.) to increase your chances of recruiting injecting drug users from each of these groups in your study. The people you select as seeds should be well respected and highly connected in the injecting drug user

community to ensure that they are able to encourage support for the study and recruit others to participate.

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

   You should gather information on appropriate incentives during the formative assessment phase. Incentives should be large enough that participants feel it is worth the time and effort to participate and recruit their peers, but small enough that participation does not become biased by the inclusion of the incentive. You may give cash incentives or other incentives such as gift certificates, vouchers or other non-monetary gifts for participation.

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

   Providing monetary incentives for injecting drug users for participation in a study presents some ethical concerns. Given that injecting drug users may use cash to purchase drugs, monetary incentives may place inappropriate motivation on them to participate. You may want to consider non-monetary incentives with this population. Given that this is a vulnerable population, you should consider if the value of the incentive could introduce the potential for coercion for participation.

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

   Behavioural surveillance of injecting drug users should measure the frequency of needle and syringe sharing as well as the frequency of unprotected sex. If you are conducting your study using RDS, you will also want to include questions about network size.

   You should be sure to include core UNGASS indicators for injecting drug users. These indicators are used to estimate the percentage of injecting drug users who received HIV testing in the last 12 months and who know the results, the percentage of injecting drug users reached by opiate substitution therapy programmes, the percentage of injecting drug users reached by needle/syringe exchange programmes and the percentage of injecting drug users who both correctly identify ways of preventing the sexual transmission of HIV and reject major misconceptions about HIV transmission.

   You may want to supplement with questions on injecting locations, frequency of injecting, types of drugs injected, people with whom injecting drug users share needles and syringes, size of social network, condom use, history of incarceration, history of sex work and contact with sex workers.

5. What are your options for reaching older injecting drug users now?

   Your options for reaching older injecting drug users include giving your seeds more time to grow, contacting your existing seeds to encourage recruitment among their peers or finding new older injecting drug user seeds, if needed.

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

   You end recruitment by reducing the number of coupons you give to participants to give to their peers, and eventually by giving out no more coupons. Given that participants receive secondary incentives for recruiting their peers, one problem you might encounter when trying to end recruitment is resentment from participants for reducing their opportunities to earn secondary incentives.

Part 5: Analysis

1. What data analysis software do you use?

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

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

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

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. Circle your answer below.

   False. Men who have sex with men often have sex with both men and women, meaning that it is possible that they may transmit any infections they have to both their female and male partners.

2. List two possible points of access where men who have sex with men can be found.

   Although men who have sex with men 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. Given that men who have sex with men are often hard to reach because of discrimination and stigmatization, two successful sampling methods in this group are

   _____*TLS*_____ and _____*RDS*_____.

4. What are some of the ethical issues to consider when conducting HIV surveillance of men who have sex with men?

   Men who have sex with men 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 a man who has sex with men, inadvertent disclosure of HIV status, negative reactions and a backlash in response to publicized results, physical abuse and imprisonment.

5. What are some possible behavioural indicators to include when conducting HIV surveillance among men who have sex with men?

   Behavioural indicators to incorporate in surveys of men who have sex with men may include information on condom use, number of partners, type of partners, frequency of unprotected insertive anal intercourse (UIAI), frequency of unprotected receptive anal intercourse (URAI), STI treatment-seeking, migration patterns, marital status, history of sex work, etc.

6. What are some possible biological measures to include when conducting HIV surveillance among men who have sex with men?

   Biological measures to incorporate in surveys of men who have sex with men may include syphilis, gonorrhoea, Chlamydia, HSV-2 and syndromic proctitis.

Case study: Biological and serosurveillance of men who have sex with men in Bluecoast, Menaland

Part 1: Collecting information to plan surveillance activities

1. What information is required for planning the survey?

   To plan for the survey, you must identify and characterize the population of men who have sex with men you want to study, including any subpopulations. You will also want to determine locations where men who have sex with men can be found, how visible or hidden the population is, to what extent men who have sex with men congregate in venues that are identifiable and accessible to the investigators, and if the community is networked. Gatekeepers in the community should be identified.

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

   You should conduct a formative assessment to obtain this information. This may include gathering information from websites, key informant interviews, focus group discussions, observation and ethnographic mapping.

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

1. How would you gain the trust of members of the men who have sex with men community?

   You can gain the trust of members of the men who have sex with men community by forming alliances with members of the community and organizations that work with them. You can establish a working group or a community advisory board to obtain local input on the study and ensure acceptability in the community. You can let the community know that data will be 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 the men who participate.

Part 3: Mapping the men who have sex with men network and choosing a sampling approach

1. What sampling scheme is most appropriate?

   The most appropriate sampling scheme would be RDS since the population of men who have sex with men is hidden, but sufficiently networked. Since men who have sex with men in Bluecoast do not often congregate in visible and accessible locations, and there are few specific locations where they can be found in large numbers, TLS would not be an appropriate sampling scheme.

2. What are the advantages and disadvantages of the sampling scheme you have chosen?

   Some advantages of RDS are that it enables you to reach members of the population that are not visible, and it does not require extensive mapping in the formative assessment. RDS has been shown to reduce in-group affiliation, where initial study participants tend to list people of similar demographics, such as socioeconomic status and educational levels.

RDS also improves random probability of selection and the cooperation of surveillance participants because it uses a peer-referral method and a dual incentive structure.

Disadvantages of RDS include that: there is a requirement that the population be sufficiently networked; recruitment is dependent on participants and can be unpredictable; data on links between participants and network size must be accurately recorded; and special software must be used to analyse the data.

Part 4: Collecting biological and behavioural data

1. What biological variables do you include?

   Biological markers that you may want to include are HIV and syphilis. Additionally, if funding permits and the participants seem interested you could also include gonorrhoea (urethral, rectal and pharyngeal), Chlamydia (urethral, rectal and pharyngeal), HSV-2 and syndromic proctitis (inflammation of the anus). However, make sure that individuals can be treated on site or referred for treatment if a positive result occurs.

2. What behavioural variables do you include?

   Behavioural surveillance of men who have sex with men should measure the frequency of unprotected sex, the number of and types of partners, the frequency of drug use and access to prevention services.

   You should be sure to include core UNGASS indicators for men who have sex with men. These indicators are used to estimate the percentage of men who have sex with men who received HIV testing in the last 12 months and who know the results, percentage of men who have sex with men reached by prevention programmes, percentage of men who have sex with men who correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission, percentage of men reporting the use of a condom the last time they had anal sex with a male partner and percentage of male sex workers reporting the use of a condom with their most recent client.

   Behavioural surveillance of men who have sex with men may collect information on condom use, number of partners, type of partners, frequency of unprotected insertive anal intercourse, frequency of unprotected receptive anal intercourse, 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, and men who have sex with men venues.

3. What additional steps are needed to test for HIV?

   When testing for HIV or other STIs where treatment is available, you should establish a mechanism in which persons who test positive are referred to counselling and treatment.

4. What are some of the special ethical considerations for this surveillance activity?

   Ethical issues you should consider include maintaining participants' confidentiality and ensuring that interviewers are sensitive to issues facing men who have sex with men.

Part 5: Preparing for the surveillance activity

1. What subpopulations did you include in selecting seeds?

   In your formative research you identified subpopulations of men who have sex with men, including male sex workers, transgendered people and married men who have sex with men. You should be sure to include some seeds from each of these subpopulations.

2. What characteristics would you look for in selecting a site to conduct your surveillance activity?

   In choosing a site to conduct the surveillance activity, you should ensure that the site is easily accessible, considered safe by men who have sex with men and has private rooms for conducting interviews and counselling and testing. There should be enough space to store all the surveillance materials, and it should be comfortable and clean for the participants.

Part 6: Analysing and disseminating data

1. Describe how you would use the data collected to develop men who have sex with men-focused prevention programmes?

   Depending on the surveillance results, you may decide to:

   - *Engage peer and nongovernmental organization outreach workers, as well as STI clinic staff, to educate men who have sex with men about the need for consistent condom use with non-regular and regular partners.*
   - *Distribute condoms to men who have sex with men through peers, workers at nongovernmental organizations and STI clinics, night clubs, saunas and salons.*
   - *Establish education and outreach programmes to encourage men who have sex with men to seek treatment for STIs.*

Unit 5 answers

Warm-up questions

1. Which of the following terms is used to describe migrant labourers, fisherman and truck drivers?

   a. involuntary migrants

   b. voluntary migrants

   c. military personnel

   d. none of the above

   Voluntary migrants are often young men and women who leave their rural communities to work in urban areas or construction sites. Voluntary migrants also include people in the transportation industry, such as truck drivers and merchant seamen, who travel frequently across long distances.

2. Which of the following terms is used to describe refugees and internally displaced persons?

   a. involuntary migrants

   b. voluntary migrants

   c. military personnel

   d. none of the above

   Involuntary migrants include refugees and internally displaced persons. The term "refugee" only applies to persons who have been displaced from their homelands and have sought refuge in a second country. Internally displaced persons are persons who have left their homes due to civil unrest, natural disasters, political and/or religious persecution, but have not crossed an internationally recognized state border.

3. Of the following, which is not a reason why migrants are especially vulnerable to HIV?
   a. Female migrants may sell "survival sex" when they have no other source of income.
   b. Migrants usually have only one sexual partner.
   c. Migrants have limited access to health care.
   d. Migrants often live in settings where they are more likely to adopt risk behaviours.

   As they are often away from home for extended periods of time, migrants often have multiple sexual partners.

4. Mobile persons often serve as a *bridge* between female sex workers and the general population. Additionally, due to migration patterns, mobile populations may bring HIV from high-prevalence areas to low-prevalence areas.

   The role of migration in the spread of HIV has been described primarily as a result of men becoming infected while they are away from home, often by contact with infected sex workers and infecting their wives or regular partners when they return.

5. List two possible locations where mobile persons may be found in high numbers.

   Possible locations where mobile persons may be found in high numbers include truck stops and roadside hotels, neighbourhoods known as refugee areas, refugee settings and health clinics that serve refugees or internally displaced persons.

6. What are some of the ethical issues to consider when conducting HIV surveillance among refugees or internally displaced persons?

   One of the ethical concerns surrounding HIV surveillance among refugees or internally displaced persons is the backlash that may result when these groups are identified as having a high prevalence of HIV or risk behaviours. This is particularly important when a high prevalence of HIV is discovered in a refugee population in an otherwise low-prevalence country.

Case study 1: Biological and behavioural surveillance among Jamilistani refugees in Menaland

Part 1: Collecting information to plan surveillance activities

1. What information is required for planning the survey?

   To plan for the survey, you will want to review any background information such as published literature and reports from UNHCR. With this information and information obtained from key informant interviews, you will need to identify and characterize the population of Jamilistanis in Al Aniram you want to study, including any subpopulations such as youth. You will want to determine how visible or hidden the population is, locate all areas where the Jamilistani refugees can be found and determine how networked the population is. You should also identify gatekeepers in the community to help gain access to the population.

2. How might the HIV surveillance team obtain this information?

   Key informants should be identified and interviewed, for example, members of the

Jamilistani community in Al Aniram, persons from the Ministry of the Interior, persons from the Ministry of Immigration and business owners in Jamilistani communities. Through referrals, other people can be found to be interviewed.

Part 2: Choosing a sampling approach

1. What sampling scheme can be used to select representative respondents to be included in the survey?

   A variety of sampling approaches may be appropriate for sampling Jamilistani immigrants in Al Aniram such as cluster sampling or TLS. Given that many Jamilistani migrants congregate in identifiable locations in large numbers, TLS may be the most appropriate method.

Part 3: Sampling and collecting biological and behavioural data

1. What are the advantages and disadvantages of this approach?

   TLS combines the methods of targeted sampling and cluster sampling to produce a probability sample. TLS is like conventional cluster sampling, but it solves the problem of everyone in the target population not being in the same place at the same time. This method can be applied to populations that are visible and congregate in venues that are accessible to researchers.

   Disadvantages of TLS may include the following: In TLS, only the more visible "hidden" populations are reached. TLS requires extensive ethnographic mapping to prepare an appropriate sampling frame. Because sampling is done at a variety of venues, coordination with gatekeepers such as bar owners is essential. There are staffing concerns such as safety, late hours, time, transportation and field set-up. Finally, there are ethical concerns regarding the use of venues to conduct TLS for stigmatized populations. This may draw unwanted attention to the population and expose safe havens.

2. If only men congregate in identifiable locations, what are the limitations of using TLS?

   If only men congregate in identifiable locations and TLS is used, then the survey will only capture men and so would only reach a subset of the population of interest.

3. If the surveillance team were to include Jamilistani refugees in the closed refugee camps, which sampling approaches would be appropriate?

   Had the surveillance team decided to include the refugees in the closed UNHCR camps, the team could have employed simple random sampling or systematic sampling, provided that UNHCR granted the team access to the camp and the refugees.

4. What behavioural variables should be collected?

   Behavioural surveillance of refugees should collect sociodemographic information, such as age, marital status, employment history, point of origin, types of sexual partner in the past year, gender of sexual partners, exchange of sex for money or gifts, condom use, history of diagnosis with STIs and current symptoms of STIs.

   You should be sure to include core UNGASS indicators for mobile populations. These indicators include the percentage of the target mobile population that received HIV testing in the last 12 months and know the results, percentage of target population reached by prevention programmes and the percentage of target population that correctly identify

ways of preventing the sexual transmission of HIV and that reject major misconceptions about HIV transmission.

5. What biological variables should be collected?

   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 if those with a positive test can be referred to appropriate services for treatment.

   Since the formative assessment suggested that injecting drug use was not common among Jamilistanis, biological markers of injecting drug use including hepatitis B core antibody (HBcAb) and HCV antibody may not be necessary.

Part 4: Collecting survey information

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

   Some examples of interventions that can be initiated include:

   - *Create condom-use campaigns by engaging peers and nongovernmental organization outreach workers to educate Jamilistani immigrants about consistent condom use with sex workers and regular partners.*
   - *Engage migrant populations in knowledge-building activities regarding the modes of HIV transmission.*
   - *Improve the service provided to refugees by: establishing VCT, reproductive health services, STI treatment programmes and psychosocial counselling programmes for migrants, hiring medical professionals who speak the language(s) of the migrant populations and ensuring that information gathered by people seeking treatment and care is not used by the Ministry of Immigration for deportation purposes.*

Part 5: Epilogue

1. What are some of the risks Jamilistanis living in Al Aniram face if the results of this study are published and made available to the general population?

   If the results of this study are published and made available to the general population, the Jamilistanis living in Al Aniram may suffer discrimination and stigma.

Case study 2: Biological and behavioural surveillance among truck drivers in Menaland

Part 1: Collecting information to plan surveillance activities

1. What information is required for planning the survey?

   To plan for the survey, you must identify and characterize the population of truck drivers you want to study, including any subpopulations. You will want to determine how visible or hidden the population is, locate all areas where the truck drivers can be found and determine how networked the population is. You should also identify gatekeepers in the community to help gain access to the population.

2. How might the HIV surveillance team obtain this information?

   To obtain background information for designing a behavioural survey, the HIV surveillance team can review published literature, reports of nongovernmental organizations, reports from trucking companies and clinic records from roadside health centres. Key informants should be identified and interviewed, 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 health centres.

Part 2: Choosing a sampling approach

1. 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 A.1.1.1 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.

2. What sampling scheme can be used to select representative respondents to be included in the survey?

   A variety of sampling approaches are appropriate for sampling truck drivers in Menaland. Because the team was able to construct a list of all the trucking companies, as well as information on how many drivers each company employs, it may be most appropriate to use the probability proportional to size (PPS) sampling scheme, in which types of truck drivers are sampled proportionate to the size of the different groups of truck drivers (long-distance, medium-distance or local).

Part 3: Sampling and collecting biological and behavioural data

1. Describe how you would randomly sample 10 truck drivers from each company.

   Since the selected trucking companies all have offices at the Al-Rabia truck stand and all drivers must visit their office to receive their trip assignments, the Al-Rabia truck stand would be the best site for recruitment. Ten subjects from each company can be randomly sampled from the Al-Rabia truck stand.

2. What behavioural variables should be collected?

   Behavioural surveillance of truck drivers should collect sociodemographic information, such as age, marital status, alcohol and drug use, types of sex partners in the past year, paid sex, sex with men, condom use, history of diagnosis with STIs, current symptoms of STIs and injecting drug use behaviours, such as types of drugs injected, frequency, needle-sharing and use of sterile equipment.

   You should be sure to include core UNGASS indicators for mobile populations. These indicators include the percentage of the target mobile population that received HIV testing in the last 12 months and know the results, percentage of target population reached by prevention programmes and the percentage of target population that correctly identify ways of preventing the sexual transmission of HIV and that reject major misconceptions about HIV transmission.

3. What biological variables should be collected?

   As in most other surveillance systems, biological specimens should be drawn for testing for prevalence of HIV and other STIs, such as HSV-2, syphilis and gonorrhoea. The high sexual risk among mobile persons also makes STI testing a useful and feasible indicator for surveillance.

Since injecting drug use may be prevalent in this population, biological markers of injecting drug use including hepatitis B core antibody (HBcAb) and HCV antibody should be considered.

Part 4: Collecting survey information

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

   Some examples of interventions that can be initiated include:

   - *To create 100% condom-use campaigns in port area brothels and engage peers and nongovernmental organization outreach workers to educate truck drivers about consistent condom use with sex workers and regular partners.*
   - *To establish harm reduction programmes for injecting drug users and provide sterile injecting equipment to injecting drug user truck drivers at the large truck stops along the trucking routes between Al-Rabia and the Northern District.*
   - *To establish workplace-based STI screening and HIV education for local-route drivers.*
   - *To improve the service provided at roadside STI clinics by ensuring drug supply and training staff on proper STI management.*

Unit 6 answers

Warm-up questions

1. What are some of the reasons why street children may be considered vulnerable to HIV?

   Street children may be more vulnerable to HIV infection for any of the following reasons: they do not receive reproductive health education and other school-based services; they are not exposed to the structure that the school environment would otherwise provide; they face stigma and discrimination that may prevent them from adopting risk-reduction behaviours; they are more likely to experiment with drugs and alcohol; and they may be sexually exploited, trafficked or involved in the sex industry.

2. List three possible places where you would expect to find large numbers of street children.

   Locations where street children spend most of their time will differ by subgroup. To locate street children, identify areas where young people tend to congregate. These include the places listed on page 145. Depending on the focus of the surveillance, other subgroups, such as sex workers or injecting drug users may be included. In these cases, also consider brothels/massage parlours, bars/discos, places where people gather to use drugs, etc.

3. List two organizations with which you can form alliances as you develop your HIV surveillance system for street children.

   Possible organizations that can help you locate and access street children include governmental bodies such as the Ministries of Social Development,Youth and Sports,as well as UNICEF, UNFPA, the Red Cross and Red Crescent societies, Save the Children, day centres for street children, youth scouts, OXFAM International, local sports clubs and nongovernmental organizations that work with street children.

Case study: Conducting behavioural surveillance among street children in Al Muri, Menaland

Part 1: Collecting information to plan surveillance activities

1. What information is required for planning the survey?

   To plan for the survey, you must identify and characterize the population of street children in Al Muri you want to study, including any subpopulations. You will want to determine how visible or hidden the population is, locate all areas where street children can be found and determine how networked is the population. You should also identify gatekeepers in the community to help gain access to the population.

2. How will the HIV team obtain this information?

   A formative assessment should prove helpful in obtaining this information.

   The HIV team should first review published articles, government reports, nongovernmental organization reports, clinic records of public and private clinics, and reports from the police department. Key informants should be identified and interviewed, including current and former street children, railway station employees, shop keepers, police, nongovernmental organization managers and outreach health workers.

   They may want to conduct 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.

Part 2: Building key alliances with community networks involved with street children

1. Who are important gatekeepers that can help the HIV team gain access to the street children in Al Muri?

   Possible organizations and individuals that can help the HIV team gain access to the street children include:

   - *local and international nongovernmental organizations that work with street children*
   - *governmental bodies, such as the Ministry of Social Development and the Ministry of Youth and Sports*
   - *UNICEF*
   - *UNFPA*
   - *the Red Cross and Red Crescent societies*
   - *Save the Children*
   - *day centres for street children*
   - *youth scouts*
   - *OXFAM International*
   - *local sports clubs*
   - *current and former street children.*

2. What actions can the HIV team take to address the street children's distrust?

   The HIV team can meet with nongovernmental organization managers and the police in the area. Verbal assurance of the cooperation of the stakeholders and assurance from the police that they will not arrest street children participating in the survey or destroy their settlements will aid in addressing the street children's distrust. Using their contacts, the HIV team can also establish alliances with "senior" street children who have influence among other street children.

Part 3: Ethical considerations

1. What are the special ethical considerations related to conducting HIV surveillance among street children?

   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. If it is necessary to include children under the age of 15, special guidance on research with children should be sought. It may be necessary to check your country's laws regarding parental consent and the age of majority, as some street children may be considered minors and obtaining consent from their parents may be difficult. It may also be difficult to obtain true informed consent from street children, due to the lower education and literacy levels common among them.

   Additionally, because street children are young and often involved in activities such as prostitution or child labour, they are often stigmatized and are considered a vulnerable population. Their participation in surveillance activities may place them at risk of harm and discrimination.

2. What actions can you take to safeguard the well-being of the street children whom you want to participate in your surveillance activity?

   Steps you can take to minimize threats to anonymity may include conducting anonymous interviews with street children in private settings, collecting no identifying information about street children, limiting access to all survey data to authorized survey personnel only, keeping survey documents in a locked, limited-access room and having all staff sign confidentiality forms and undergo training in research ethics.

   Additionally, getting assurance from the police that they will not arrest street children participating in the survey or destroy their settlements will provide added protection for the well-being of the street children in your survey.

3. What kinds of incentives should the HIV team offer the street children who participate in the survey?

   For ethical reasons, the HIV team may not want to offer financial incentives to the street children who participate in the survey. Food items, clothing and other useful in-kind (non-monetary) items are often used as incentives when conducting studies among children and adolescents.

Part 4: Choosing a sampling approach

1. What sampling methods are appropriate for sampling street children in Al Muri?

   A variety of sampling approaches are appropriate for sampling street children in Al Muri. Possible sampling methods include targeted sampling, snowball sampling, RDS and TLS.

   Given that street children sleep, work and congregate in identifiable and accessible locations, the availability of adequate resources and the strengths of TLS as a probability sampling method, TLS may be the most appropriate method to sample of street children in Al Muri.

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

   - *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 resources than TLS, 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.*

3. How would the HIV team construct their sampling frame?

   If the TLS method is used, the HIV team would construct a list of sites where street children live, work and meet. The team would visits these venues and count the numbers of street children present at specific times.

   In the first stage of sampling, a certain number of sites are randomly selected from the "universe" of sites that was compiled. In the second stage, a fixed number of street children are selected from each selected site at a randomly selected time period on a randomly selected day of the week.

Part 5: Collecting behavioural data

1. What behavioural variables should be collected?

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

   Indicators that assess sexual risk include:

   - *correct identification of ways to prevent the transmission of HIV and rejection of major misconceptions about HIV transmission*
   - *age of sexual debut*
   - *history of coerced sex*
   - *condom use during last sex*
   - *sex with multiple partners*
   - *sex with partners 10 years or older*
   - *exposure to interventions*
   - *access to HIV services and health care*
   - *psychological indicators to assess history of trauma*
   - *the use of transactional sex.*

   In areas where there is suspected overlap between street children and other most-at-risk populations, such as sex workers, men who have sex with men or injecting drug users, consider using indicators that assess high-risk behaviours among these groups.

Part 6: Results

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

   Based on the community survey, street children were at high risk of acquiring and transmitting HIV, HIV-related knowledge was low, many female street children had performed sex work and had been raped or abused and many children had run away from home to escape abusive relationships or forced marriages. Injecting drug use was alarmingly high, although glue sniffing and smoking hashish were also common. Street children surveyed did not utilize the public health centres, although they knew they existed.

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

   Some examples of interventions that can be initiated include:

   - *Design interventions specifically targeted at street children.*
   - *Engage peers and nongovernmental organization outreach workers to educate street children about HIV/STI transmission and prevention.*
   - *Disseminate "best practices" to researchers and practitioners who have worked with street children across different cities.*
   - *Work with local police and public health centres to establish times when street children can visit public health centres without fear of being arrested or persecuted.*

Unit 7 answers

Warm-up questions

1. Which of the following is a reason for high HIV prevalence among prisoners?

   a. the over-representation of injecting drug users among prisoners

   b. male-to-male sex during long periods of incarceration

   c. sexual relations between prison staff and prisoners

   d. high concentration of female sex workers in some prisons

   e. the sharing of needles for drug use in prison

   f. all of the above

   Depending on whether prisoners are male or female, these reasons will differ.

2. 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. TLS

   A systematic random sample is the easiest and most appropriate method for this situation, since prisoners are not a mobile or hidden population.

3. True or false? High HIV prevalence among prisoners is a result of HIV infection both before and after entering the criminal justice system.

   True. There are multiple factors contributing to the high prevalence of HIV in prisons. These include the high concentration of arrested injecting drug users and sex workers, consensual and non-consensual male-to-male sex (especially during long periods of incarceration), injecting equipment sharing with multiple injectors and tattooing with unsafe needles.

4. 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 staff allow public health workers access to prisoners for HIV testing during their incarceration.

5. 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 uncoerced decision about whether to participate as a research subject. For this reason, it is important to take special precautions when obtaining informed consent from prisoners.

Case study: Biological and behavioural surveillance of prisoners at the central prison, Menaland

Part 1: Introduction

1. What are the possible approaches to conducting a behavioural survey among prisoners at the central prison?

   As access to prisoners is regulated, you must obtain permission from governmental authorities and/or prison administrators before conducting any surveillance activities. One approach is to conduct combined biological surveillance and behavioural surveillance on a consecutive or systematic sample of prisoners after their intake or at an initial health assessment.

2. What are some of the ethical issues you must consider prior to conducting a behavioural survey in a prison population?

   Some of the ethical issues you must consider prior to conducting a behavioural survey in a prison population are:

   - *the inability of prisoners to give true informed consent*
   - *issues surrounding confidentiality*
   - *issues around giving incentives for participating.*

   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 IRBs require the input of a prisoner advocate.

3. What behavioural variables should be collected?

   Behavioural measures in surveys of prisoners should focus on sexual and parenteral risk behaviours. Because sex workers and injecting drug users may be present in high numbers in prisons, measures used in community-based surveys of these populations may be appropriate when conducting behavioural surveillance among prisoners. These indicators can be supplemented with the following:

   - *reason for incarceration*
   - *drug use, injecting and non-injecting*

- *marital status*
- *occupation before incarceration*
- *term of sentence in years or months*
- *history of attending a drug abuse treatment clinic.*

You should be sure to include core UNGASS indicators for prisoners. These indicators include having received HIV testing in the last 12 months and knowing the results, and correctly identifying ways of preventing the sexual transmission of HIV and rejecting major misconceptions about HIV transmission.

Part 2: Collecting behavioural data

1. Describe how the HIV surveillance team could measure HIV incidence among the central prison inmates.

   Cohort studies provide the most exact measurements of incidence, but are only possible if correctional staff members allow public health workers access to prisoners for HIV testing during their incarceration.

   To determine the incidence of HIV during incarceration in the central prison and the behaviours related to infection, the HIV surveillance team can follow a cohort of HIV-uninfected prisoners for a specified amount of time. After that time, the cohort of HIV-uninfected prisoners can be retested for HIV and their in-prison risk behaviours can also be assessed.

2. What behaviours could explain the increase in HIV among the prisoners?

   Possible reasons for the increase in HIV among the prisoners could be the sharing of injecting equipment and unprotected sex between men in the central prison.

Part 3: Estimating incidence

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

   Some examples of interventions that can be initiated include:

   - *prison-based HIV education*
   - *antiretroviral therapy for prisoners according to national guidelines*
   - *drug treatment and methadone programmes for prisoners who are injecting drug users*
   - *condom programmes within prisons*
   - *distribution of sterile injecting equipment to prisoners.*

Annex 4

Laboratory tests available for measuring biological outcomes among most-at-risk populations

Laboratory tests available for measuring biological outcomes among most-at-risk populations [1]

Table 1 Characteristics of HIV detection assays

	Antibody detection		Antigen detection	DNA detection	RNA detection
	EIA	*Dot*		*PCR*	*Quantitative*
Sensitivity	100%	100%	detect earlier than antibody tests	as sensitive as culture	earliest detection
Specificity	95.8%–100%	99%–100%	100%	100%	100%
Advantages	sensitive, inexpensive automated	sensitive, specific, differentiate HIV-1 and 2	early detection	perinatal diagnosis, sensitive	monitor HIV levels
Disadvantages	false–positive results, no serotyping	expensive	insensitive	expensive, time-consuming	expensive, time-consuming
Level of use	intermediate lab	on-site lab, intermediate lab	referral lab	intermediate lab, referral lab	referral lab
Training	moderate	minimal	moderate	moderate	extensive
Equipment	centrifuge, microwell plate reader	none	centrifuge, microwell plate reader	microfuge, thermal cycler, microwell plate reader	depends on method[1]
Ease of performance	moderate	easy	moderate	moderate	extensive
Cost	US$ 2.00–US$ 3.00	US$ 6.00–US$ 7.00	US$4.00–US$ 5.00	US$ 12.00	US$ 60.00

1 For RT-PCR: microfuge, thermal cycler, incubator, microwell plate reader. For bDNA: ultracentrifuge, luminometer. For NASBA: microfuge, luminometer.

Source: WHO Regional Office for the Western Pacific. *Laboratory tests for the detection of reproductive tract infections*. Geneva, World Health Organization, 1999.

Table 2 Characteristics of *Chlamydia* detection assays

	Microscopy	Antigen detection		DNA detection	Amplification and detection
	DFA	*EIA*	*Rapid*	*Chemoluminescent DNA probe*	*Nucleic acid amplified tests*
Sensitivity [1]	74%–90%	71%–97%	52%–85%	75–%85%	90%–100%
Specificity [1]	98%–99%	97%–99%	> 95%	98%–99%	99%–100%
Advantages	rapid, easy	can batch samples	rapid, easy	also detects *N. gonorrhoeae*, automated	high sensitivity, allow non-invasive sampling (urine and vaginal swabs), can detect *N. gonorrhoeae* in same specimen, no special storage or transport conditions as viable organisms not required
Disadvantages	labour intensive, subjective	requires confirmation	insensitive, requires confirmation	less sensitive than PCR, requires confirmation	expensive, requires technical expertise, may yield false negative results due to inhibition, may yield false positive results due to contamination
Level of use	on-site lab, intermediate	intermediate, referral lab	exam room, onsite lab	intermediate, referral lab	intermediate, referral lab
Training	moderate to extensive	moderate	minimal	moderate	moderate
Equipment	fluorescent microscope	microwell plate reader	none	heat block, luminometer	requires dedicated instrument
Ease of performance	moderate	moderate	easy	moderate	moderate
Cost	US$ 6.00	US$ 6.00	US$ 13.00– US$ 16.00	US$ 8.00	US$ 11.00– US$ 15.00(US$ 14.00– US$ 25.00 for *N. gonorrhoeae* detection also)

1 Sensitivity and specificity are for detection of *C. trachomatis* by culture or by DNA amplification test.

Table 3 Characteristics of *N. gonorrhoeae* detection assays

	Microscopy	Antigen detection		DNA detection	Amplification and detection
	DFA	*EIA*	*Rapid*	*Hybridization assay*	*Nucleic acid amplified tests*
Sensitivity [1]	90%–95%	81%–100%	52%–85%	86%–100%	85%–100%
Specificity [1]	98%–100%		> 95%	99%	99%–100%
Advantages	rapid, inexpensive	gold standard, isolates available for further testing	rapid, easy	rapid, viable organisms not required	high sensitivity, allow non-invasive sampling (urine and vaginal swabs), can detect *Chlamydia* in same specimen, no special storage or transport conditions as viable organisms not required
Disadvantages	insensitivefor females	stringent handling, requires up to 3 days	insensitive, requires confirmation	expensive	expensive, requires technical expertise, may yield false negative results due to inhibition, may yield false positive results due to contamination
Level of use	on-site lab	on-site lab, intermediate	exam room, onsite lab	intermediate, referral lab	intermediate, referral lab
Training	moderate	moderate	moderate	moderate	moderate
Equipment	light microscope	incubator, light microscope, candle jar	none	water bath, luminometer	requires dedicated instrument
Ease of performance	easy	moderate	easy	moderate	moderate
Cost	US$ 0.50	US$ 1.00 (+1–3 to confirm positive isolates)	US$ 13.00– US$ 16.00	US$ 6.00	US$ 11.00– US$ 15.00(US$ 14.00– US$ 25.00 for *N. gonorrhoeae* detection also)

1 Sensitivity and specificity are for detection of *N.gonorrhoeae* urethral and endocervical samples by culture except for microscopy, which is for detection in urethral samples from symptomatic men.

Table 4 Characteristics of syphilis detection assays

	Microscopy	Antibody Detection		Antigen Detection	DNA Detection
	dark–field	*nontreponema RPR*	*treponemal EIA/TPHA/TPPA*		*multiplex PCR*
Sensitivity [1]	74%–86%	72%–100%	80%–100%	81%	91%
Specificity [1]	97%–100%	93%–98%	98%–100%	89%	99%
Advantages	positive early, rapid, specific, inexpensive	inexpensive, rapid, easy, antibody titer to follow treatment	specific, confirms non treponemal tests	detects *T. Pallidum* before antibodies are positive	sensitive, specific, allows self–collected sample
Disadvantages	insensitive, no oral sample, requires live treponemes	false positives, less sensitive for early disease	more difficult, more expensive	time consuming, expensive	inhibitors of PCR reaction cause false negative results, complex, expensive
Level of use	exam room, on-site lab	on–site lab, intermediate lab	intermediate lab, referral lab	intermediate lab, referral lab	referral lab
Training	extensive	minimal	moderate	moderate	extensive
Equipment	light microscope with dark-field condenser	centrifuge, rotator	centrifuge	spectrophotometer	microfuge, thermal cycler, incubator, microwell plate reader
Ease of performance	easy	easy	moderate	moderate	complex
Cost	US$ 0.40	US$ 0.50	US$ 1.50– US$ 3.00	US$ 3.00	US$ 14.00 (includes detection of *H. ducreyi* and HSV)

1 Sensitivity and specificity are for detection of primary syphilis. The sensitivity of both nontreponemal and treponemal antibody detection increases for detection of secondary syphilis. The sensitivity of nontreponemal antibody detection decreases for detection of latent and tertiary syphilis. The tests for *T. pallidum* are only relevant when lesions are present in primary and secondary syphilis. But these tests can detect latent untreated infection which can be important for patient outcomes, such as in pregnancy.

Table 5 Characteristics of genital herpes detection assays

	Culture	Antigen detection	DNA detection
			multiplex PCR
Sensitivity [1]	gold standard	70%–95%	more sensitive than culture
Specificity [1]	100%	90%–100%	98%–100%
Advantages	sensitive, specific	rapid, relatively inexpensive, more sensitive than culture for detection in late-stage lesions	very sensitive, specific, allows self-collected sample
Disadvantages	expensive, timeconsuming, requires expertise	less sensitive	inhibitors of PCR cause false negative results, complex, expensive
Level of use	referral lab	intermediate lab, referral lab	referral lab
Training	extensive	moderate	extensive
Equipment	CO_2 incubator, microscope, (centrifuge)	fluorescent microscope or light microscope or microwell plate reader	microfuge, thermal cylcer, incubator, microwell plate reader
Ease of performance	complex	moderate	complex
Cost	US$ 40.00	US$ 4.00– US$ 8.00	US$ 14.00 (includes detection of *T. Pallidum* and *H. ducreyi*)

1 The sensitivity of culture varies depending on the type of medium used and can only be estimated since there is no gold standard on which to base the diagnosis of chancroid.

Table 6 Characteristics of chancroid detection assays

	Culture	Antigen detection	DNA detection
			PCR
Sensitivity [1]	56%–90%[1]	not determined	77%–98%[2]
Specificity [1]	100%	not determined	98%–100%
Advantages	isolates available for further testing	faster	very sensitive
Disadvantages	insensitive, proper medium difficult to obt	not commercially available	inhibitors of PCR cause false negative results, complex, expensive
Level of use	on-site lab	referral lab	referral lab
Training	moderate	moderate	extensive
Equipment	incubator, light microscope, candle j ar	fluorescent microscope or microwell plate reader	microfuge, thermal cycler, incubator, microwell plate reader
Ease of performance	difficult	moderate	complex
Cost	US$ 2.00 (without confirmation)	not available	US$ 14.00 (also detects *T. Pallidum* and HSV)

1 The sensitivity of culture varies depending on the type of medium used and can only be estimated since there is no gold standard on which to base the diagnosis of chancroid.

2 Resolved sensitivity of PCR vs *H. ducreyi* culture.

Surveillance is the systematic, regular collection of information on the occurrence, distribution and trends of a specific infection, disease or other health-related event.

Second generation HIV surveillance is designed to collect and integrate data reported from a variety of sources including behavioural surveillance, HIV case reporting, HIV seroprevalence surveillance, and sexually transmitted infections surveillance. The goals of second generation HIV surveillance are to help countries better understand the HIV epidemic trends over time, to better understand the behaviours driving the epidemic, to focus on subpopulations at highest risk for infection and to better use surveillance data for planning the response to HIV epidemic.

HIV surveillance in the Eastern Mediterranean Region needs to be strengthened in order to fill the gaps in our understanding of the dynamics of the epidemic and to be in a better situation to plan appropriately for an effective response.

This training module is one of four selected from a series originally developed by University of California, in San Francisco. The selected modules were adapted to the regional context through a long process involving consultations with HIV regional experts. These modules are expected to provide a good tool for training staff working in HIV surveillance at country level. Countries are free to further adapt these modules or to translate them into local use.