Introduction to HIV/AIDS and sexually transmitted infection surveillance

MODULE 1

Overview of the HIV/AIDS epidemic with an introduction to public health surveillance
Introduction to HIV/AIDS and sexually transmitted infection surveillance

MODULE 1

Overview of the HIV/AIDS epidemic with an introduction to public health surveillance
## Contents

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Introduction

How to use this module
What you should know before the course

This training course provides an introduction to the HIV/AIDS epidemic and public health surveillance. The course is targeted primarily at HIV surveillance officers at the national and subnational levels. As a participant, you should have a basic medical understanding of HIV/AIDS 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. The modules were designed for use in training workshops. The other modules are:

- Module 2: Surveillance of HIV risk behaviours
- Module 3: Surveillance of most-at-risk-populations
- 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 Eastern Mediterranean Region.

The modules are also intended for use in the countries of the Joint United Nations Programme on HIV/AIDS (UNAIDS) Middle East and North Africa Region. For the purpose of this training course, all countries in the WHO Eastern Mediterranean Region plus Algeria are therefore the intended audience. We refer to these collectively as Eastern Mediterranean Region/Middle East and North Africa (EMR/MENA) countries.

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 manual. No one will see your answers but you. We will study and discuss the unit, and then you will have time to go back and
change your warm-up answers. At the end of the unit, the class will discuss the warm-up questions 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: Differences between public health and research methods

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

The global HIV/AIDS situation
Overview

What this unit is about

This unit focuses on the HIV/AIDS situation in the 23 countries in the Eastern Mediterranean Region/Middle East and North Africa, which for the purposes of this module we refer to as EMR/MENA. We consider recent data from country reports, UNAIDS, WHO and other agencies.

Warm-up questions

1. True or false? As of 2007, more than 33 million people were infected with HIV worldwide. Circle your answer below:

   True   False

2. In which three countries in EMR/MENA is there evidence of widespread heterosexual transmission?

3. Aside from the countries mentioned in Question 2 above, the three groups in which high prevalence of HIV infection has been found are:

4. Which of the following countries in EMR/MENA has the highest reported HIV prevalence among adults?
   a. Afghanistan
   b. Djibouti
   c. Morocco
   d. Sudan
Introduction

What you will learn

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

● describe the overall HIV/AIDS situation in the world
● describe the HIV/AIDS situation in EMR/MENA.

Worldwide epidemic

The HIV epidemic

Acquired immunodeficiency syndrome (AIDS) is unique in human history in its rapid spread, its extent and the depth of its impact. Since the first AIDS case was diagnosed in 1981, the world has struggled to come to grips with the extraordinary dimensions of this disease. Early efforts to mount an effective response were fragmented, piecemeal and vastly under-resourced. Few communities recognized the dangers ahead, and even fewer were able to mount an effective response.

As of 2007, 26 years later, approximately 30 million people have died and 33.2 million people (range: 30.6–36.1 million) globally are living with the human immunodeficiency virus (HIV). The HIV epidemic continues to grow worldwide, destroying people's lives and, in many cases, damaging the fabric of societies. In 2007, an estimated 2.5 million people became newly infected with HIV. Table 1.1, on the next page, shows statistics on the HIV/AIDS epidemic worldwide and regionally.

Success in addressing the epidemic

Uganda has often been cited as a sub-Saharan Africa success story in HIV/AIDS control.

● At major urban surveillance sites, HIV prevalence levels have been falling. In Kampala, HIV prevalence levels among antenatal clinic (ANC) attendees have declined more than 50% since the early 1990s [1]. Median HIV prevalence at clinics outside major urban areas has also been cut in half since the early 1990s.
● Population-based surveys suggest that behaviour change has been an important part of the reported decline. Condom use by single women aged 15–24 years has almost doubled, and these women are often delaying sexual intercourse or abstaining entirely [1].

The HIV/AIDS epidemic in Thailand began in the late 1980s, as it did in many other countries in Asia, but with a subsequently more rapid upsurge in HIV prevalence than occurred in other countries. Since then, Thailand has made substantial progress in the fight against HIV/AIDS.

● It is one of the very first countries to achieve the sixth Millennium Development Goal, which is to begin to reverse the spread of HIV/AIDS by 2015. In Thailand, the number of new infections has fallen from a peak of 14,000 per year in the 1990s to 16,000 in 2006 [2].
● There is evidence, however, that HIV is now spreading largely among the spouses and
partners of clients of sex workers and among marginalized sections of the population, such as injecting drug users [2].

**Prevalence of HIV/AIDS in EMR/MENA**

Prevalence is the proportion of persons in a population with a particular disease. As described in Table 1.1, there were 380,000 adults and children living with HIV in the UNAIDS Middle East and North Africa Region in 2007. While this Region is home to approximately 10% of the world’s population, it contained only 1.1% of the men, women and children living with HIV as of 2007.

Although HIV prevalence is relatively low in the Region compared to other parts of the world, recent reports suggest that transmission and prevalence is increasing in certain countries and populations.

**Table 1.1**  HIV/AIDS epidemic worldwide and in the Middle East and North Africa

<table>
<thead>
<tr>
<th>Category</th>
<th>Number worldwide</th>
<th>Number in the UNAIDS Middle East and North Africa Region</th>
<th>Percentage of global burden in the UNAIDS Middle East and North Africa Region</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults and children living with HIV</td>
<td>33.2 million</td>
<td>380,000</td>
<td>1.1%</td>
</tr>
<tr>
<td>Adults and children newly infected with HIV</td>
<td>2.5 million</td>
<td>35,000</td>
<td>1.4%</td>
</tr>
<tr>
<td>Adult and child deaths due to AIDS</td>
<td>2.1 million</td>
<td>25,000</td>
<td>1.2%</td>
</tr>
</tbody>
</table>

Data were derived from [2].
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Concentrated

Generalized

Signs of concentrated

Signs of generalized

Figure 1.1 State of the HIV epidemic in WHO Eastern Mediterranean Region, 2004 [3]
Figure 1.1 shows the state of the HIV epidemic in the countries of the WHO Eastern Mediterranean Region. In a low-level epidemic, while recorded infection is largely confined to individuals with higher risk behaviour, such as sex workers, injecting drug users and men who have sex with men, HIV prevalence levels have not yet exceeded 5% in any defined subpopulation. In a concentrated epidemic, HIV has spread rapidly in a defined subpopulation, but is not well-established in the general population; HIV prevalence is consistently over 5% in at least one defined subpopulation but below 1% in pregnant women in the general population. Finally, in a generalized epidemic, HIV is firmly established in the general population and HIV prevalence is consistently above 1% in pregnant women.

**Examples from EMR/MENA**

Examples from EMR/MENA illustrate the potential for HIV spread in the region [4]:

- In Djibouti and Sudan, prevalence levels in adults have risen to above 1%, while in Somalia the national seroprevalence is just below 1%. The pattern of transmission in these countries is predominantly heterosexual and resembles the epidemics of their sub-Saharan African neighbours.
- In Morocco, more than 65% of reported infections are among adolescents and young adults from 15 to 39 years old. Similarly, in Jordan, the majority of HIV infections are among 15 to 35-year-old adolescents and adults. Often, prevalence levels in younger adults are used as a proxy for incidence. The high proportion of cases in young adults suggests rising rates of new infection.
- In the Islamic Republic of Iran, reported HIV infections rose by 80% in 2005 alone. The vast majority of cases are among injecting drug users, in whom prevalence was estimated to be 10% in 2002. In the southern Algerian city of Tamanrasset, prevalence among commercial sex workers in 2004 was 9%.

**HIV burden in each country of EMR/MENA**

In 2006, overall adult HIV prevalence in the countries of EMR/MENA was 0.2% [5]. This prevalence is lower than sub-Saharan Africa, where the overall adult HIV prevalence is 6.7% and, much lower than some African countries, where it is as high as 30%. In the 23 countries of EMR/MENA, there were an estimated 600,000 cases and 42,000 deaths in 2005. Table 1.2 shows the HIV disease burden for each country.
<table>
<thead>
<tr>
<th>Country</th>
<th>Estimated HIV prevalence in adults (%)</th>
<th>Estimated number of PLWHA*</th>
<th>Estimated number of deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afghanistan</td>
<td>&lt;0.1</td>
<td>&lt;1 000</td>
<td>&lt;100</td>
</tr>
<tr>
<td>Algeria</td>
<td>0.1</td>
<td>19 000</td>
<td>&lt;500</td>
</tr>
<tr>
<td>Bahrain</td>
<td>&lt;0.2*</td>
<td>&lt;1 000</td>
<td>NR</td>
</tr>
<tr>
<td>Djibouti</td>
<td>3.1</td>
<td>15 000</td>
<td>1 200</td>
</tr>
<tr>
<td>Egypt</td>
<td>&lt;0.1</td>
<td>5 300</td>
<td>&lt;500</td>
</tr>
<tr>
<td>Iran, Islamic Republic of</td>
<td>0.2</td>
<td>66 000</td>
<td>1 600</td>
</tr>
<tr>
<td>Iraq</td>
<td>&lt;0.2*</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Jordan</td>
<td>&lt;0.2*</td>
<td>&lt;1 000</td>
<td>NR</td>
</tr>
<tr>
<td>Kuwait</td>
<td>&lt;0.2*</td>
<td>&lt;1 000</td>
<td>NR</td>
</tr>
<tr>
<td>Lebanon</td>
<td>0.1</td>
<td>2 900</td>
<td>&lt;100</td>
</tr>
<tr>
<td>Libyan Arab Jamahiriya</td>
<td>&lt;0.2*</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Morocco</td>
<td>0.1</td>
<td>19 000</td>
<td>1 300</td>
</tr>
<tr>
<td>Oman</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Pakistan</td>
<td>0.1</td>
<td>85 000</td>
<td>3 000</td>
</tr>
<tr>
<td>Occupied Palestinian territory</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Qatar</td>
<td>&lt;0.2*</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Saudi Arabia</td>
<td>&lt;0.2*</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Somalia</td>
<td>0.9</td>
<td>44 000</td>
<td>3 700</td>
</tr>
<tr>
<td>Sudan</td>
<td>1.6</td>
<td>350 000</td>
<td>32 000</td>
</tr>
<tr>
<td>Syrian Arab Republic</td>
<td>&lt;0.2*</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Tunisia</td>
<td>0.1</td>
<td>8 700</td>
<td>&lt;100</td>
</tr>
<tr>
<td>United Arab Emirates</td>
<td>&lt;0.2*</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Yemen</td>
<td>&lt;0.2*</td>
<td>NR</td>
<td>NR</td>
</tr>
</tbody>
</table>

NR, not reported;
* denotes high end of range when no point estimate is given.
* Persons living with HIV/AIDS.
Source: [5].
HIV prevalence

Trends

Surveillance is the systematic collection and analysis of health data for the purpose of disease prevention and control. Since several countries in EMR/MENA have very low rates of HIV infection, measuring trends in the general population may be of little use at this stage of the epidemic. Outside of Djibouti, Somalia and Sudan, the majority of HIV infections are concentrated among individuals participating in high-risk behaviours, such as injecting drug use or sex work, and the growth in the epidemic is primarily due to rising rates of infection in these subpopulations.

HIV surveillance data from the region are limited. However, available data show that prevalence varies by country and population. Djibouti and Sudan have generalized HIV epidemics, and national seroprevalence is estimated at 3.1% and 1.6%, respectively. Data from Somalia show increasing trends in 15 to 24 year-old ANC attendees between 2004 and 2007, concentrated in the north-west zone of Somalia (Figure 1.2).

![HIV prevalence graph](image)

Source: [6].

**Figure 1.2** HIV seroprevalence among 15 to 24 year-old ANC patients, north-west zone of Somalia, 1999–2007

The Islamic Republic of Iran and Libyan Arab Jamahiriya have concentrated epidemics (or have signs of concentrated epidemics) among injecting drug users, and infection may now be spreading to other groups. For instance, surveys among incarcerated injecting drug users in the Islamic Republic of Iran have shown prevalence levels of 23%. Injecting drug users may also be significant contributors to the epidemic in Afghanistan, and high levels of needle sharing have been reported in Algeria, Egypt, Lebanon and Morocco.

Other high-risk groups have also been found to have increased levels of HIV infection.
For instance, in Sudan, female commercial sex workers in Khartoum had a prevalence of 4.4% in 2002, and men who have sex with men had a prevalence of 9.2% in 2006. In Morocco, prevalence in commercial sex workers was 2.2%, and in Egypt, prevalence among men who have sex with men was 6.2% in the same year.

**Conflict, displacement and population mobility**

Among the main factors driving the epidemic in some EMR/MENA countries are conflict, displacement and extensive population mobility across national borders. This is because:

- Away from their community and their regular sexual partners, men are more likely to engage in commercial sex.
- Due to coercion or the need to provide a source of income for themselves and their families, girls and women may engage in sex work or transactional sexual relationships, in which money or gifts are exchanged for sex.
- The psychological and social trauma associated with conflict and displacement may lead to increased drug use.
- War and civil unrest may increase the incidence of sexual attacks against women and girls, heightening their risk of HIV infection.

Examples of such factors include:

- In Sudan, due to both internal and external conflict, a higher-than-expected HIV prevalence was seen in displaced populations. For instance, there were prevalence levels of 4% among refugees from Eritrea and Ethiopia and 1.1% among internally displaced people.
- In the north-west zone of Somalia, internally displaced women attending ANCs had a higher prevalence of infection compared to women in the general population.
- In Yemen, migrants entering the country accounted for almost 40% of all positive HIV tests.
- In the Islamic Republic of Iran, conflict in Afghanistan led to a restriction of the supply of opiates, which in turn led to a change from opium smoking to heroin injecting and subsequent HIV transmission through shared needles.

**Factors that affect HIV prevalence**

Various factors may account for the regional and the subregional variations in prevalence of HIV. The situation in Djibouti and parts of Somalia and Sudan resembles that of generalized heterosexual epidemics in other parts of Africa. In other subregions, major factors driving the epidemic are commercial sex, injecting drug use and men having sex with men. Often these groups are marginalized and put at increased risk for infection due to isolation and stigmatization.

Away from their communities and their regular sexual partners, migrant and mobile workers (such as truckers) are more likely to become clients of female sex workers. The involvement of girls and women in sex work often results from coercion and/or the need to provide a source of economic survival for themselves and their families. Internally displaced persons and refugees, especially from areas with generalized HIV epidemics, have increased risks of ongoing transmission among themselves and to others.
Other factors accounting for the prevalence rate in the region may include:

- high prevalence of other sexually transmitted infections (STIs), increasing the risk of acquiring and transmitting HIV
- lack of care-seeking for STIs due to the associated stigma
- illicit drug trafficking
- poverty
- unmarried men frequenting sex workers
- cultural taboos preventing open discussion and sex education of youth
- limited access to or social unacceptance and unavailability of condoms
- women’s low status and their inability to influence partner behaviour
- low literacy rates
- lack of awareness and access to HIV and STI prevention information
- increasing urbanization, migration, mobilization and separation of families as a result of economic and/or social circumstances.

Summary

By the end of 2007, there were 33.2 million people living with HIV/AIDS (PLWHA) worldwide, including more than 2 million children. Of these, approximately 530,000 lived in EMR/MENA. Although EMR/MENA accounts for only 1.2% of all infections worldwide, there is evidence of rising rates of infections in certain groups and countries.

Unit 1 exercises

Warm-up review

Take a few minutes to review your answers to this unit’s warm-up questions and make any necessary changes.

Small group discussion

Form small groups to discuss these questions. Choose a speaker for your group who will report back to the class.

1. Which regions of your country are most affected by the HIV/AIDS epidemic?
2. What might be the factors contributing to the high rate of HIV in these regions?
3. Which population groups are most affected by the HIV/AIDS epidemic in your country?

Apply what you have learned/case study

Try this case study individually. We will discuss the answers in class.

Menaland, a country in EMR/MENA, had its earliest cases of AIDS recognized in 1984. Data below are based on estimates of HIV prevalence by district. Study the data and answer the questions that follow.
HIV prevalence (%) by district, Menaland, 1998–2004

<table>
<thead>
<tr>
<th>District</th>
<th>1998</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>2.10</td>
<td>2.30</td>
<td>1.56</td>
<td>1.60</td>
<td>1.18</td>
<td>1.06</td>
<td>1.05</td>
</tr>
<tr>
<td>Southern</td>
<td>2.11</td>
<td>2.43</td>
<td>1.84</td>
<td>1.65</td>
<td>1.64</td>
<td>1.44</td>
<td>1.34</td>
</tr>
<tr>
<td>Eastern</td>
<td>2.19</td>
<td>2.33</td>
<td>2.19</td>
<td>1.67</td>
<td>1.49</td>
<td>1.51</td>
<td>0.99</td>
</tr>
<tr>
<td>Western</td>
<td>1.30</td>
<td>1.24</td>
<td>1.08</td>
<td>1.11</td>
<td>0.91</td>
<td>1.18</td>
<td>0.95</td>
</tr>
<tr>
<td>Central</td>
<td>1.99</td>
<td>2.03</td>
<td>1.58</td>
<td>1.50</td>
<td>1.72</td>
<td>1.06</td>
<td>0.96</td>
</tr>
</tbody>
</table>

a. In 2004, which district had the highest prevalence of HIV?
b. Comment on the HIV infection trends.
Unit 2

Impact of the HIV/AIDS epidemic in the Eastern Mediterranean Region/Middle East and North Africa
Overview

What this unit is about

IN THIS UNIT, we will discuss the impact of HIV in EMR/MENA in terms of mortality, demographics and the economic situation. We will provide a few examples from other regions to show how profound the impact can be. To begin this unit, try the questions below.

Warm-up questions

1. True or false? Nearly 100,000 people die every year in EMR/MENA because of AIDS. Circle your answer below.

   True          False

2. What is the impact of HIV/AIDS on children?

3. What is the economic impact of HIV/AIDS on individuals, families and nations?

4. What is the burden of HIV/AIDS in terms of DALYs and deaths in EMR/MENA countries?

5. List some of the effects stigma has on HIV prevention, care and support for individuals with HIV and their families.
Introduction

What you will learn

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

● describe the impact of HIV/AIDS on individuals and families
● describe the impact of HIV/AIDS on sustainable development.

Impact of HIV/AIDS in EMR/MENA

Increase in annual AIDS deaths

Using UNAIDS’s 20-country regional estimates, there were 36 000 deaths due to HIV in the Middle East and North Africa Region in 2006. This is about a 10% increase from 2004. When additional countries in EMR/MENA are added, such as Afghanistan, Djibouti, Islamic Republic of Iran, Pakistan and Somalia, the number of deaths is closer to 42 000. Because of the stigma attached to HIV and AIDS, deaths due to HIV may be reported as due to other causes, notably tuberculosis (TB) and pneumonia.

To date, the high mortality observed in neighbouring regions has not yet been experienced by countries in EMR/MENA. However, experience from other countries that had similar types of HIV epidemics suggests that mortality rates may not always remain low. For example, in high HIV prevalence countries in Asia (Cambodia, Myanmar, Thailand and some states in India), it is estimated that deaths due to AIDS could account for a substantial proportion of deaths in the 15 to 49-year-old population [7].

HIV-related adult mortality in the five Asian and Pacific countries (India, Malaysia, Nepal, Papua New Guinea and Viet Nam) with estimated HIV prevalence levels between 0.1% and 1% of the 15 to 49-year-old population will also increase up to 5% during the coming decade. These prevalence levels are similar to those in several EMR/MENA countries. Most of these AIDS deaths will occur in young male injecting drug users and male clients of female sex workers [7].

Projections to 2010

In affected countries, HIV can have a profound effect on life expectancy. Examples from South-East Asia are illustrative. By 2010, life expectancy is projected to be two years lower in Thailand and four years lower in Cambodia and Myanmar (Figure 2.1).
**AIDS as a cause of death**

AIDS is the fourth leading cause of death in the world. It is the fifteenth leading cause of death in the countries of the WHO Eastern Mediterranean Region, as shown in Figure 2.2.

Although HIV/AIDS is the fifteenth leading cause of death in the WHO Eastern Mediterranean Region, it is plausible that some of the incidence of other leading causes of death, such as lower respiratory infections and diarrhoea, is HIV/AIDS-related. Additionally, in view of the current limitations of HIV surveillance in the Region, HIV-associated diseases may contribute significantly to the overall disease burden.
**Loss of work**

Globally, HIV/AIDS accounts for 84.5 million disability-adjusted life years (DALYs). DALYS are a measure of burden of disease in a population obtained by combining “years of life lost” and “years lived with disability”. In the WHO Eastern Mediterranean Region, around 1.3 million DALYS were lost due to HIV/AIDS in 2004, making HIV/AIDS the fifteenth-leading cause of DALYs in the Region (Table 2.1). Just as HIV/AIDS is an underappreciated cause of death in the Region, it may also be an underappreciated cause of DALYS lost.

**Table 2.1** Leading causes of DALYs lost in the WHO Eastern Mediterranean Region, 2004

<table>
<thead>
<tr>
<th>Disease</th>
<th>Disability-adjusted life years (DALYS) lost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lower respiratory tract infections</td>
<td>9,949,000</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>8,093,000</td>
</tr>
<tr>
<td>Ischaemic heart disease</td>
<td>3,956,000</td>
</tr>
<tr>
<td>Other unintentional injuries</td>
<td>3,815,000</td>
</tr>
<tr>
<td>Unipolar depressive disorder</td>
<td>3,754,000</td>
</tr>
<tr>
<td>Tuberculosis</td>
<td>2,928,000</td>
</tr>
<tr>
<td>Road traffic accidents</td>
<td>2,732,000</td>
</tr>
<tr>
<td>Measles</td>
<td>2,470,000</td>
</tr>
<tr>
<td>Malaria</td>
<td>2,158,000</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>1,954,000</td>
</tr>
<tr>
<td>Pertussis</td>
<td>1,878,000</td>
</tr>
<tr>
<td>Cataracts</td>
<td>1,873,000</td>
</tr>
<tr>
<td>Protein-energy malnutrition</td>
<td>1,869,000</td>
</tr>
<tr>
<td>Hearing loss, adult onset</td>
<td>1,497,000</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>1,351,000</td>
</tr>
<tr>
<td>Falls</td>
<td>1,212,000</td>
</tr>
<tr>
<td>Tetanus</td>
<td>1,192,000</td>
</tr>
<tr>
<td>Meningitis</td>
<td>1,134,000</td>
</tr>
<tr>
<td>Vision loss, age-related and other</td>
<td>1,127,000</td>
</tr>
<tr>
<td>War</td>
<td>1,115,000</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>1,037,000</td>
</tr>
</tbody>
</table>

Source [9].

**Family impact**

**Impact on household income**

The impact of HIV/AIDS goes far beyond individual suffering and death. The high case fatality rate can have a major impact on families. As studies have shown in other parts of the world, the impact of HIV/AIDS on a household’s income and family structure is disastrous:
Those who contract the virus are generally from the most productive age groups in society, between 15 and 49 years of age. At these ages, people are usually earning at the peak of their capacities, so the loss of their income has a major impact on the household.

- At the same time, family incomes are eroded because other family members stop working to care for the sick.
- The death of parents increases the burden on the extended family. Grandparents are often left to care for young children.
- There is an increased burden on society to provide orphanages, health-care facilities and schools for these orphans.

**Study data**

A study from India has shown the changes in the average pattern of monthly expenditure in Delhi and Manipur after HIV is detected in a patient (Figure 2.3). Individuals and families usually cope with the increase in expenditure for care by using savings, borrowing money, and selling and mortgaging assets.

![Figure 2.3 Monthly household expenditure after detection of HIV status, Delhi and Manipur, India, 2003](image)

Children’s education suffers when a family member is infected with the HIV virus. The children are likely to be kept home to care for sick family members or to take over their domestic duties. As a result, their education is affected:

- Children are often forced to leave school because reduced household income means that families can no longer pay school fees.
- World Bank studies show that school attendance by young people is reduced by half when the household has lost an adult family member to HIV/AIDS in the previous year.
- Girls’ education may be placed at particular risk in this context.

In many parts of the world, the increasing number of child deaths due to AIDS threatens to reverse many of the recent gains of child survival programmes. Moreover, the socioeconomic impact of HIV/AIDS on children is profound.
A study conducted in Kenya in 2001 found that raised HIV prevalence in a community was associated with an increase in child mortality and that HIV was a key component of the 25% increase in under-five mortality in Kenya between the late 1980s and the mid-1990s. Another study, in Malawi, measured mortality of children born to HIV-infected women versus those born to HIV-uninfected women. This study found significant differences in under-five mortality levels between HIV-infected mothers (46%) and HIV-uninfected mothers (16%). This increased mortality is likely due to both vertical transmission of HIV and the negative impacts of an ill parent [11].

As their parents fall sick and die of AIDS, children may undergo a long trail of painful experiences, including the following:

- economic hardship
- withdrawal from school
- lack of love, attention and affection
- psychological distress, stigma, discrimination and isolation
- malnutrition and illness.

**Workforce and health services impact**

**Effect on the workforce**

Employers in several countries will bear a large cost of the epidemic. These are the indirect costs of:

- absenteeism
- loss of productivity
- the need to train and replace skilled workers
- increasing benefits payments.

Economic wealth in the form of gross national product could drop in some areas of the world by as much as 40% by 2020. In EMR/MENA, such losses could be economically significant if HIV continues to spread in the region.

**Pressure on health services**

The increasing number of persons with symptomatic HIV infection (exhibiting symptoms), AIDS and AIDS-related diseases has in many areas of the world dramatically increased the demand for treatment and care, putting extreme pressure on health services.

In Sudan, the cost of caring for an HIV-infected patient with TB was 50% higher than caring for an HIV-uninfected patient with TB. As the number of HIV-TB coinfections increases in the country, this cost difference will likely have a significant impact on TB control activities.

Research conducted in Papua New Guinea found that, even when HIV affected just 0.2% of the population, patients with HIV-related illnesses occupied 5% of beds in Port Moresby General Hospital. This level of infection is roughly equivalent to that in several EMR/MENA countries.
**Social stigma**

AIDS-related stigma remains one of the greatest obstacles to the fulfilment of human rights among people living with HIV (PLHIV). Stigma is also a major barrier to creating and implementing HIV programming, and can result in discrimination. Discrimination against people with HIV infection and AIDS is an infringement of their human rights and has contributed to the various forms of abuse they have suffered in many parts of the world.

Stigma is a major barrier to individuals getting tested for HIV and engaging in protective behaviours and has its roots in attitudes towards PLHIV. For example, a recent survey in Egypt found that only approximately 25% of women were willing to care for a family member with HIV, and more than half would not want the HIV status of the family member known (see Figure 2.4).

![Figure 2.4 Attitudes toward people living with HIV, Egypt](image)

Data derived from [12].

**Figure 2.4 Attitudes toward people living with HIV, Egypt**

Stigma is not only directed toward PLHIV. In many cases, it has attached itself to pre-existing stigmas—to racial and ethnic stereotypes and to discrimination against women and sexual minorities. At the same time, long-standing patterns of racial, ethnic and sexual inequality increase vulnerability to HIV.

Despite the overwhelming evidence that AIDS is everywhere, the impulse to say AIDS is only a problem “somewhere else” is still strong. In such a climate, marginalized people, such as injecting drug users and men who have sex with men, are often badly served by prevention programmes. In some countries, their care and support needs are systematically ignored. Knowledge of HIV status is the gateway to AIDS treatment and has documented prevention benefits; however, the current reach of HIV testing services is poor, largely because of fear of stigma and discrimination.
Summary

The burden of HIV/AIDS has had a significant impact on several aspects of life in many parts of the world. The death of productive family members has a strong impact on many lives and families, and puts a strain on the workforce and health services. These factors will have negative effects on development. While many of the examples cited here are not from EMR/MENA, there is no reason to believe that HIV will not have a similar impact in this region, should its prevalence reach comparable levels. Even at lower levels, HIV will likely have a substantial impact on health-care systems and will have a profound effect on the people and families affected.

Unit 2 exercises

Warm-up review

Take a few minutes to review your answers to this unit’s warm-up questions and make any necessary changes.

Small group discussion

Get into small groups to discuss these questions.

1. Describe the impact of HIV and AIDS on the health system in your country.
2. Is there any evidence of stigma and discrimination against HIV-infected persons in your country? If yes, provide examples.
3. Discuss how stigma can hamper HIV prevention and treatment interventions in your country.

Apply what you have learned/case study

Try this case study individually.

The five districts in Menaland have had different experiences with the HIV/AIDS epidemic. Examine the following data:

<table>
<thead>
<tr>
<th>Measures of HIV impact by district, Menaland, 2006</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>District</strong></td>
</tr>
<tr>
<td>Northern</td>
</tr>
<tr>
<td>Southern</td>
</tr>
<tr>
<td>Eastern</td>
</tr>
<tr>
<td>Western</td>
</tr>
<tr>
<td>Central</td>
</tr>
</tbody>
</table>
Now try the questions below.

a. In which district has the impact of HIV/AIDS been greatest?

b. Based on the data above, which district would you expect to have the greatest impact of HIV/AIDS by the year 2012?
Unit 3

Biology, transmission, natural history, prevention and treatment of HIV infection and AIDS
Overview

What this unit is about

Extensive research has shown that HIV is the virus that causes AIDS. This unit discusses HIV types and the prevention and treatment of HIV infection and AIDS.

Warm-up questions

1. Which body cells does HIV primarily infect?
   a. respiratory cells
   b. skin cells
   c. red blood cells
   d. white blood cells

2. How many major types of HIV exist?

3. Which of the following is not a mode of HIV transmission?
   a. sexual intercourse
   b. casual physical contact
   c. blood transfusion
   d. mother to foetus

4. What type of infectious agent is HIV?
   a. bacterium
   b. virus
   c. prion
   d. none of the above

5. True or false? HIV infection and the onset of AIDS occur simultaneously. Circle your answer.
   True       False
6. Which of the following is associated with increased risk of sexual transmission of HIV?
   a. failure to use a male or female condom
   b. a greater number of sexual partners
   c. a higher viral load in an infected partner
   d. all of the above

7. List the three main types of antiretroviral drugs used to treat HIV infection.
   a.
   b.
   c.

8. True or false? The presence of existing STIs increases the risk of acquiring HIV during sexual intercourse.

   True   False

9. Which of the following opportunistic infections commonly occurs in AIDS patients?
   a. herpes zoster
   b. cryptococcosis
   c. TB
   d. all of the above

10. True or false? A vaccine for the prevention of HIV infection is currently available.

    True   False

11. True or false? Some STIs, such as Chlamydia, are biologically more easily acquired by young women, making them more susceptible to HIV infection.

    True   False

13. _________________is the term used to describe the treatment to prevent or suppress infection.
Introduction
What you will learn

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

● explain the basic biology of HIV
● describe HIV transmission routes
● understand the importance of concurrent STIs in increasing the risk of HIV transmission
● discuss the natural history of HIV and list the major opportunistic infections
● describe the major elements of HIV prevention and control programmes
● recognize that HIV is treated with antiretroviral drugs and that HIV case management also involves prevention and treatment of opportunistic infections.

Biology of HIV

The virus

Extensive research has shown that HIV is the virus that causes AIDS. HIV is a retrovirus, a family of viruses that carry their genetic information on a single strand of RNA. HIV infects a number of different cells in the body. Most important are two classes of white blood cells that are involved with protecting the body against infection:

● CD4+ T lymphocytes
● Macrophage cells.

CD4+ T lymphocytes are a type of white blood cell that fights infections in the body. The CD4+ T lymphocyte is the cell that HIV infects and destroys. Macrophage cells are tissue cells derived from monocytes (a type of white blood cell) that protect the body against infections.

As the number of these T-cells is depleted because of viral destruction, patients become immunodeficient, meaning their immune systems are insufficient to ward off infections. They develop opportunistic infections and certain cancers that may be infectious in origin. Opportunistic infections are illnesses that usually do not occur in persons with healthy immune systems.

HIV types

The epidemiology of the distribution and evolution of HIV subtypes worldwide is critical for several reasons:

● for vaccine development
● to trace transmission among individuals and track the spread of the virus through countries.

Two major types of HIV have been recognized, HIV-1 and HIV-2. The following table (Table 3.1) summarizes the differences between the two types:
Introduction to HIV/AIDS and sexually transmitted infection surveillance

Table 3.1 Characteristics of HIV-1 and HIV-2

<table>
<thead>
<tr>
<th></th>
<th>HIV-1</th>
<th>HIV-2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geographic distribution</td>
<td>Worldwide</td>
<td>Primarily confined to West Africa, although cases have been reported in Europe, Asia and Latin America</td>
</tr>
<tr>
<td>Subtypes</td>
<td>Major group, M, is classified into 10 subtypes; additional highly divergent strains are known as group O</td>
<td>Five genetic subtypes</td>
</tr>
<tr>
<td>Natural history</td>
<td>More easily transmitted, and faster progression to AIDS</td>
<td>Less easily transmitted than HIV-1, and slower progression to AIDS</td>
</tr>
</tbody>
</table>

Differences in distribution

At present, specific subtypes are found more frequently in certain countries or regions of the world. Because people move within and between countries, it is likely that multiple subtypes of HIV-1 will appear in most countries:

- In Djibouti, Somalia and Sudan, subtype C predominates. This is the same subtype found in much of eastern and southern Africa.
- Elsewhere in the region, there is a remarkable heterogeneity of subtypes. Subtypes C, G, B, D, A and CRF02_AG have been reported from Saudi Arabia. Subtype A appears to be the dominant subtype in the Islamic Republic of Iran, subtypes A and B in Lebanon and subtypes B and C among Indian and Ethiopian expatriates in Kuwait.
- In North Africa, the European subtype B predominates in Morocco and Tunisia, but there is evidence of recombinant virus CRF02_AG in Algeria (genetic mixing of two or more HIV subtypes in individuals who are simultaneously infected with different subtypes can result in what is known as a circulating recombinant form, or CRF).

HIV transmission and natural history

How HIV is transmitted

All types, subtypes and strains of HIV are transmitted in the same ways:

- The predominant route of transmission in EMR/MENA is through heterosexual intercourse. However, there are areas where the HIV epidemic has emerged among injecting drug users and men who have sex with men.
- HIV is also transmitted through blood, blood products and donated organs or semen. Bloodborne, or parenteral, transmission occurs primarily through the use of inadequately sterilized needles, syringes or other skin-piercing instruments and through the transfusion of infected blood.
- HIV may be transmitted from an infected mother to her foetus or infant during pregnancy, delivery or when breastfeeding. This type of transmission is often called perinatal or vertical transmission.

Examples of how the different modes of HIV infection are distributed in a country are shown in the figure below from the Islamic Republic of Iran (Figure 3.1).
Figure 3.1 Modes of HIV transmission, Islamic Republic of Iran, 2007 [13]

Discussing the figure

Looking at Figure 3.1, answer the following questions:

a. What is the most common mode of transmission in the Islamic Republic of Iran?

b. What does perinatal mean?

Increased risk of infection

A number of factors increase the risk of becoming infected with HIV through sexual intercourse. These fall into two broad categories.

First, the risk of acquiring HIV is proportionate to one’s risk of being exposed sexually to HIV. This means that a person’s risk of HIV is determined primarily by the risk of having an infected partner:

● Persons whose primary sexual partner is infected have the greatest probability of infection through repeated sexual exposure.
● Among persons with multiple sexual partners, the greater the number of partners an individual has, the greater his or her likelihood of having intercourse with someone with HIV infection.

Second, a variety of biological and behavioural factors appear to increase the risk of becoming infected. These include the following:

● the viral load of the infected partner (the amount of virus present in blood, semen and cervicovaginal fluids)
● type of intercourse (anal intercourse is riskier than vaginal intercourse, and vaginal intercourse is substantially riskier than oral intercourse)
● the coexistence of inflammatory (such as gonorrhea or Chlamydia) or ulcerative (such as syphilis, chancroid or herpes simplex virus type 2) STIs

● failure to use prevention methods, such as condoms.
Role of STIs

STIs are of particular importance in the rapid transmission of HIV during the growth phase of an epidemic in a country. There is ample evidence that viral STIs, such as herpes simplex virus type 2 (HSV-2) and acute bacterial STIs, are cofactors in HIV transmission:

- STIs cause inflammation and ulceration. This leads to an increased risk of acquiring infection through recruitment of uninfected lymphocytes to the site of the inflammation or from disruption of the genital epithelium and endothelium.
- Some STIs, such as Chlamydia, are more easily acquired by adolescent women, making young women also more susceptible.

Aggressive STI control

Several interventions have integrated and examined the potential role of aggressive STI control on HIV infection. One study, conducted in the Mwanza province of Tanzania, an area with rising HIV incidence and high levels of STIs, found that aggressive STI control programmes could lead to a decline in HIV incidence. Subsequent studies, conducted in areas with high HIV prevalence but low HIV incidence and low levels of STIs, were unable to confirm the findings of this study. Nonetheless, it appears that STI control programmes can decrease HIV incidence at a community level under circumstances of high HIV transmission and high rates of STIs.

At the individual level, STIs are an important risk factor for acquiring HIV infection, and both ulcerative STIs, such as HSV-2, syphilis and chancroid, and inflammatory STIs, such as gonorrhoea and Chlamydia, have been clearly associated with increased risk of transmission, both from infected individuals and to uninfected individuals. For this reason, screening and treatment of STIs remain important strategies for HIV control.

Role of male circumcision

Male circumcision has consistently been shown to decrease the risk of HIV acquisition for men. In three randomized controlled trials of male circumcision that were published in 2006 and 2007, circumcision was associated with a 50%–60% decreased risk of acquiring HIV infection. There is no evidence so far, however, that circumcised men are less likely than uncircumcised men to transmit HIV to women. Given the impressive reduction in risk shown in these trials, however, WHO has recommended circumcision for uncircumcised adolescent and adult men living in areas with high transmission of HIV. Because HIV transmission is likely to be relatively low in most parts of EMR/MENA, and given that, as Muslims, the vast majority of men in the region are already circumcised, the impact of this intervention will probably not be high regionally.

Natural history

AIDS is the late stage of HIV infection. AIDS is characterized by a severely weakened immune system that can no longer ward off life-threatening infections and cancers. The risk of developing AIDS is related to the length of time a person has had HIV infection. The vast majority of HIV-infected individuals will eventually develop AIDS.
A review of cohort studies in developing countries found that the median interval from HIV infection to death is 11 years in the absence of any treatment interventions [2]. Cohort analyses involve following groups of subjects—in this case HIV-infected persons—over time.

The advent of effective antiretroviral therapy (ART) has considerably reduced the rate of progression to AIDS in areas where these drugs are accessible and has been associated with changes in the types of opportunistic infections that appear with AIDS. For example, in Brazil, survival following an AIDS diagnosis increased from 18 months to 58 months between 1995 and 1996, the first year in which highly active antiretroviral therapy was introduced.

**Preventing transmission of HIV/AIDS**

**Basic approach to prevention**

The best long-term solution for controlling the HIV/AIDS epidemic is a low-cost, highly effective vaccine. However, one will not be available in the near future.

In the absence of an effective and safe vaccine, other approaches to prevention are critical. The goal of prevention is to decrease the risk for HIV transmission from infected to uninfected individuals. The basic approach to prevention involves:

- decreasing the risk of being exposed through sexual intercourse or sharing injecting equipment with an infected person
- decreasing the risk of transmission, if exposed.

**Preventing sexual transmission**

The most basic approach to prevention of sexual transmission, other than abstinence, is to promote:

- delay in age of sexual debut (first time a person has sexual intercourse)
- decrease in the number of sexual partners
- consistent use of male or female condoms
- voluntary counselling and testing (VCT) so that individuals can know their HIV status
- treatment of STIs
- male circumcision in high-incidence countries.

VCT is an intervention that provides both counselling and testing services to individuals and communities, allowing persons who are tested to obtain emotional and medical support before and after their HIV tests.

**Preventing bloodborne transmission**

Bloodborne, or parenteral, transmission of HIV may account for many of the new HIV transmissions in EMR/MENA countries. It typically occurs in injecting drug users through reuse and sharing of injecting equipment without sterilization.

HIV can be transmitted in medical settings through transfusion, reuse of needles and surgical equipment without sterilization, and needle-stick injuries to health-care workers.
Parenteral transmission can be prevented by sterilizing or not reusing needles, screening blood and blood products for HIV prior to administration, sterilization of surgical instruments and universal precautions for health-care workers.

**Injecting drug use**

In some parts of EMR/MENA, the principal means of parenteral transmission has been people who share needles and syringes when injecting illegal drugs. Sharing injecting equipment is a very efficient way of passing on HIV.

Because of this, HIV prevalence can rise rapidly among injecting drug users who share needles. Data show that, in many settings in the region, sharing needles and syringes is very common.

- In the Islamic Republic of Iran, surveys done in 2001 and 2004 found an increase in seroprevalence among injecting drug users from 15% in 2003 to 23% in 2004, although the studies were done in somewhat different injecting drug user populations. At the same time, another study found that between 30% and 100% of injecting drug users in five districts in Tehran routinely shared needles and syringes [14].
- In Pakistan, the HIV prevalence among injecting drug users varies 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 [15].

The evidence suggests that large-scale programmes that provide substitutes (such as methadone) for injected drugs and that increase access to clean needles and syringes can reduce new HIV infections among injectors.

While HIV prevention services for drug injectors remain controversial politically, there are now good examples from the Islamic Republic of Iran to suggest that these programmes can be effective in other EMR/MENA countries. If injectors are to avoid contracting or passing on HIV, they must have easy access to clean injecting equipment.

Clean injecting equipment and condoms are the two things that can most immediately interrupt HIV transmission among injecting drug users. Table 3.2 outlines how to prevent bloodborne and injecting drug use-related transmission of HIV.

**Table 3.2 Prevention of bloodborne and injecting drug use-related transmission of HIV**

<table>
<thead>
<tr>
<th>Method of transmission</th>
<th>How to prevent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transfusion</td>
<td>● sterilizing or not reusing needles</td>
</tr>
<tr>
<td></td>
<td>● screening blood and blood products for HIV prior to administration</td>
</tr>
<tr>
<td></td>
<td>● selection of volunteer blood donors at low risk for HIV</td>
</tr>
<tr>
<td>Reuse of needles and surgical instruments without sterilization</td>
<td>● sterilization of surgical instruments</td>
</tr>
<tr>
<td></td>
<td>● sterilizing or not reusing needles</td>
</tr>
<tr>
<td>Needle-stick injuries to health-care workers</td>
<td>● universal precautions for health-care workers (for example, use of gloves and eyewear, proper disposal of needles)</td>
</tr>
<tr>
<td></td>
<td>● post-exposure prophylaxis</td>
</tr>
</tbody>
</table>
Preventing mother-to-child transmission

Perinatal HIV transmission may contribute to increasing trends in HIV infection in EMR/MENA. Effective interventions are now available to prevent mother-to-child transmission (MTCT) of HIV. These include:

1. preventing HIV infection among women of childbearing age;
2. preventing unintended pregnancies among women living with HIV;
3. preventing HIV transmission from a woman living with HIV to her infant, including HIV testing and counselling of pregnant women attending ANC, providing antiretroviral therapy (ART) to eligible pregnant women with HIV infection or short course of antiretrovirals to women not yet eligible for ART and infants, safe obstetric procedures and safe infant feeding practices; and
4. providing appropriate treatment, care and support to mothers living with HIV and their children and families. [11,16,17]

HIV/AIDS treatment

Antiretroviral drugs

Antiretroviral drugs are used to treat HIV infection. In the past, the high cost of these drugs caused them to be infrequently used in EMR/MENA. The Global Fund to Fight AIDS, Tuberculosis and Malaria and other organizations are now making funds available for antiretroviral and other therapies. There are several classes of antiretroviral drugs: The three main classes are:

- nucleoside reverse-transcriptase inhibitors
- non-nucleoside reverse-transcriptase inhibitors
- protease inhibitors.

The regimens include a combination of three antiretroviral drugs, according to the WHO recommendations [18]. Clinical staging and CD4+ T cell count are used for deciding on when to start antiretroviral therapy. Treatment is started when patients develop clinical symptoms from their immunodeficiency (WHO stage 3 or 4) or reach a CD4+ cell count of less than 350 cells per mm³.

Preventing and treating opportunistic infections

In addition to antiretroviral drugs, the clinical management of HIV infection includes diagnosis, prophylaxis (treatment to prevent or suppress infection) and treatment of opportunistic infections.

- TB is the most common opportunistic infection.
- Cotrimoxazole prophylaxis and isoniazid prophylaxis have been used successfully to prevent the onset or recurrence of some opportunistic infections in HIV patients such as Pneumocystis jiroveci infection, cerebral toxoplasmosis, some bacterial infections and TB.
- Vaccines are available for some potential opportunistic infections.
Introduction to HIV/AIDS and sexually transmitted infection surveillance

**Summary**

HIV is a virus that can be transmitted sexually, parenterally or perinatally. There are means to prevent each mode of transmission, including condom use, using new and disposable needles and syringes, and short-course antiretroviral treatment during pregnancy. Treatment includes antiretroviral drugs and the prevention and treatment of opportunistic infections.

**Unit 3 exercises**

**Warm-up review**

Take a few minutes to review your answers to this unit’s warm-up questions and make any necessary changes.

**Small group discussion**

Get into small groups to discuss these questions. Choose a speaker for your group who will report back to the class.

1. What is the predominant subtype of HIV-1 in your country?
2. What are the risk factors associated with sexual transmission of HIV in your country?
3. What are the most common opportunistic infections in your country?
4. What are the major HIV prevention programmes that are operating in your country? What proportion of the population do these programmes reach?

**Apply what you have learned/case study**

Work on this case study independently.

The Western District in Menaland has experienced rapid expansion of the HIV epidemic. Examine the data and answer the questions below.

**Incidence of various STIs over time, Western District**

<table>
<thead>
<tr>
<th>STI</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gonorrhoea*</td>
<td>5.0</td>
<td>12.8</td>
<td>23.5</td>
</tr>
<tr>
<td>Syphilis*</td>
<td>2.1</td>
<td>4.5</td>
<td>16.4</td>
</tr>
<tr>
<td>Reported cases of urethritis from STI clinic</td>
<td>2987</td>
<td>3452</td>
<td>6784</td>
</tr>
<tr>
<td>HIV incidence (estimated)</td>
<td>2%</td>
<td>4.3%</td>
<td>5.0%</td>
</tr>
</tbody>
</table>

*a Cases per 1000 population 15–49 years old

a. Do you think that STIs may be playing an important role in the spread of HIV infection? Why?
b. Would an STI prevention programme be an important part of the district’s HIV control efforts?
c. Given the HIV incidence in the Western District, what do you think will happen with TB rates in the next few years and why?
Unit 4
Overview of public health surveillance
Overview

What this unit is about

To achieve HIV prevention and control, AIDS control programmes need information on infection trends and on demographic and behavioural characteristics of the affected population in a geographic area. This information is collected through surveillance systems. This unit discusses the techniques of public health surveillance.

Warm-up questions

1. Which of the following terms indicates the number or proportion of persons in a population who have a disease at a given point in time?
   a. sensitivity
   b. prevalence
   c. negative predictive value
   d. none of the above

2. True or false? One-time cross-sectional surveys are valid methods of HIV/AIDS surveillance. Circle your answer.
   True
   False

3. Match the following terms with their definitions:

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>sentinel surveillance</td>
<td>a. a surveillance system in which the reports of cases come from clinical laboratories as opposed to healthcare practitioners or hospitals</td>
</tr>
<tr>
<td>laboratory-based reporting</td>
<td>b. clinical and laboratory characteristics that a patient must have to be counted as a case for surveillance purposes</td>
</tr>
<tr>
<td>case definition</td>
<td>c. a surveillance system in which reports are obtained only from certain selected facilities and populations</td>
</tr>
</tbody>
</table>
4. Which of the following terms indicates the number of persons who newly develop a disease within a specified time period?
   a. specificity
   b. positive predictive value
   c. incidence
   d. none of the above
Introduction

What you will learn

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

- describe the components of a surveillance system
- define sentinel surveillance, laboratory-based surveillance and case definitions
- define incidence and prevalence.

What is surveillance?

Surveillance is the systematic, regular collection of information on the occurrence, distribution and trends of a specific infection, disease or other health-related event. Surveillance must occur on an ongoing basis with sufficient accuracy and completeness for analysis and dissemination of data. It should lead to effective prevention and control of the infection, disease or health-related event.

Types of activities included in HIV surveillance are:

- HIV case reporting
- HIV seroprevalence surveys
- second generation surveillance
- behavioural/high-risk surveillance.

Public health surveillance

Surveillance events

Surveillance involves the following main components:

- the systematic collection, analysis and evaluation of morbidity and mortality reports and other relevant data
- timely and regular distribution of information about the trends and patterns of disease to those who need to know
- use of the information for disease prevention and control.

An important part of the definition is that surveillance systems involve ongoing collection and use of health data. In other words, one-time cross-sectional surveys, which are conducted at a given point in time (such as during a specific year rather than studying a group over time), are not considered surveillance activities.

Information loops

A surveillance system is an information loop or cycle that involves:

- health-care providers
- public health agencies
- persons with disease under surveillance.

The cycle begins when cases of disease occur. It is complete when information about these cases is made available and used for prevention and control of the disease.
Analysed and interpreted data must be communicated to the people and agencies that need to use them.

Figure 4.1 shows the information loop. As you look at the figure, think about how HIV and AIDS surveillance (or surveillance of a different disease) is conducted in your country.

**Figure 4.1** The flow of surveillance data

**Discussing the figure**

Think about how HIV/AIDS surveillance is conducted in your country or choose a different disease. Then for each block in the loop, write two events that might occur. “Collection” has been done as an example.

**Collection:**
1. ANC hands out forms to midwives.
2. ANC technician draws blood and sends it for testing.

**Collation:**
1. 
2. 

**Analysis/interpretation:**
1. 
2. 

**Dissemination/utilization:**
1. 
2. 
**Surveillance terms**

Information from surveillance is used to make decisions about the best ways to prevent and control disease. The term surveillance implies information used to perform an action. Let us review some basic surveillance terms.

- Universal case reporting—a surveillance system in which all cases of a disease are supposed to be reported.
- Sentinel surveillance—a surveillance system in which reports are obtained from selected facilities or populations. Sentinel surveillance can apply both to reports of cases of disease or to periodic surveys, such as antenatal HIV surveys.
- Laboratory-based reporting—a surveillance system in which the reports of cases come from clinical laboratories instead of physicians, other health-care practitioners or hospitals.
- Case definition—the clinical and laboratory characteristics that a patient must have to be counted as a case for surveillance purposes.
- Prevalence—the proportion of persons in a population who have a disease or condition at a given point in time.
- 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.
- Passive surveillance—a passive system refers to data generated without solicitation, intervention or contact by the health agency carrying out the surveillance; other agencies initiate reporting. Example: normal HIV case reporting by health facilities.
- Active surveillance—the organization conducting surveillance initiates procedures to obtain reports. Example: making telephone calls or visits to health facilities to obtain information.

**Relationship between disease and case definition**

There is a relationship between disease and case definition. Study Table 4.1 and the four terms that follow it.

<table>
<thead>
<tr>
<th>Case definition</th>
<th>True disease</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Present</td>
<td>Absent</td>
<td>Total</td>
</tr>
<tr>
<td>Definition met</td>
<td>$a$</td>
<td>$b$</td>
<td>$a+b$</td>
</tr>
<tr>
<td>Definition not met</td>
<td>$c$</td>
<td>$d$</td>
<td>$c+d$</td>
</tr>
<tr>
<td>Total</td>
<td>$a+c$</td>
<td>$b+d$</td>
<td>$n$</td>
</tr>
</tbody>
</table>

**Sensitivity**—referring to Table 4.1 above, the ability of a case definition to predict true disease ($a/(a+c)$). The term “sensitivity” may be more familiar to you as it is used for laboratory tests. In that situation, sensitivity is the ability of a positive laboratory test to predict true disease.

**Specificity**—the ability of a case definition or laboratory test to predict absence of true disease ($d/(b+d)$).
Positive predictive value—proportion of persons meeting a case definition or having a positive laboratory test that have true disease \( \frac{a}{a+b} \).

Negative predictive value—the proportion of persons not meeting a case definition or having a negative laboratory test that do not have true disease \( \frac{d}{c+d} \).

Examine the table and definitions above and answer the following questions:

Determine the specificity of this case definition:
\[ a = 10, \ b = 10, \ c = 30 \text{ and } d = 150. \]

Using these numbers, what is the negative predictive value of the case definition? What does this figure represent?

Past approaches

In the past, national communicable disease surveillance systems in many regions have not approached surveillance in an effective way. Here are some of the problems:

- Duplication of effort. Vertical or categorical surveillance systems were established to report a single disease as a component of specific disease intervention programmes. This has resulted in duplication of effort and resources. Different programmes approached the same agency for similar surveillance activities.
- Delay in reporting. Health workers failed to report on time the first cases of epidemic-prone diseases that fitted standard case definitions. This delay in reporting the earliest suspected cases significantly slows identification of outbreaks and impedes the effectiveness of response.
- Inadequate data collection, analysis, use and dissemination. Collection, analysis, utilization and dissemination of surveillance data at the subnational level have been inadequate. Usually, surveillance data are passed from district to national level without adequate analysis. Feedback has also generally been inadequate at each level.
- Lack of integrated training. Little attention has been given to seeking opportunities to combine surveillance training activities to increase efficiency. As a result, each programme organizes programme-specific training courses (including surveillance) for the same health personnel, especially at subnational and health facility levels.
- Lack of evaluation. Inadequate attention has been given to the evaluation of programmes using surveillance data. Many resources are invested in interventions that are not adequately evaluated.
- Lack of laboratory involvement and coordination. Involvement of laboratories in the surveillance system has been inadequate. Neither national nor intercountry laboratory networks have been established to fulfil important public health functions, including the confirmation of cases and outbreaks when the specificity of clinical diagnosis is low.
- Lack of supervision. Supervisory support and the completeness and timeliness of reporting have been generally inadequate.
Integrated disease surveillance

IDSР strategy defined

The integrated disease surveillance and response (IDSР) strategy integrates priority communicable disease surveillance activities at the district level, with support for training, supervision and resources from all programmes, streamlined and delivered in an integrated way. It was developed by the WHO as an approach to strengthen communicable disease surveillance [19].

The district level is the focus for integrating surveillance functions because it is the first level in the health system with full-time staff dedicated to all aspects of public health, such as:

- monitoring health events in the community
- mobilizing community action
- encouraging national assistance
- accessing regional resources to protect the health of people in the district.

Rather than using scarce resources to maintain separate activities, resources are combined to collect information to a single focal point at each level. All surveillance activities are coordinated and streamlined.

WHO encourages the adoption of the IDSР strategy. Toward this goal, a strategic document has been prepared for implementation of IDSР in Member States. Countries currently utilizing the IDSР strategy in EMR/MENA include the Islamic Republic of Iran, Libyan Arab Jamahiriya and Sudan.

IDSР goals

The IDSР strategy aims to provide a basis for decision-making and implementing public health interventions for priority diseases. The strategy seeks to:

- strengthen the capacity of countries to conduct effective surveillance activities
- integrate multiple surveillance systems so that forms, personnel and resources can be used more efficiently and effectively
- improve the use of information for decision-making
- improve the flow of surveillance information between and within levels of the health system
- improve laboratory capacity in identification of pathogens and monitoring of drug sensitivity
- increase the involvement of clinicians in the surveillance system
- emphasize community participation in detection of and response to public health problems
- strengthen the involvement of laboratory personnel in epidemiological surveillance.
Priority diseases

The priority communicable diseases that have been identified under the strategy are divided into three categories:

- **Epidemic-prone diseases**
  Examples: cholera, acute diarrhoea, bacillary dysentery, meningococcal meningitis, plague, anthrax, malaria, viral hepatitis, viral haemorrhagic fever, enteric fever, measles, leptospirosis, visceral leishmaniasis, diphtheria and any other cluster of syndromes.

- **Diseases targeted for elimination/eradication**
  Examples: acute flaccid paralysis/polio, leprosy, neonatal tetanus, measles, lymphatic filariasis and yaws.

- **Other priority communicable diseases**
  Examples: TB, HIV/AIDS and rabies.

Summary

Surveillance is the ongoing collection of data relevant to public health which can be analysed to guide prevention and treatment programmes. Sentinel surveillance involves the collection of more detailed data from a smaller sample of sites, while laboratory-based reporting occurs when case reports come from laboratories instead of health facilities. Prevalence is the proportion or number of persons in a certain population who have a particular disease, while incidence measures new infections during a specific time period.

Unit 4 exercises

Warm-up review

Take a few minutes to review your answers to this unit’s warm-up questions and make any necessary changes.

Small group discussion

Get into small groups to discuss these questions.

1. Using the HIV or AIDS surveillance systems in your country, outline how surveillance data flow. Compared with Figure 4.1, are there elements missing in your system?
2. A case definition has a sensitivity of 80% and a specificity of 90%. Describe what these numbers mean in words.

Apply what you have learned/case study

Try this case study. We will discuss the answers in class.

Background:

Until 2006, Menaland reported AIDS using the 1994 WHO AIDS case definition, so only patients with AIDS were reported.
In 2006, WHO expanded AIDS case reporting to include all clinical stages of HIV. Also in 2006, WHO developed new clinical staging of adult and paediatric HIV disease and new HIV surveillance case definitions.

The WHO is sponsoring a pilot project in Menaland to examine the sensitivity, specificity and positive predictive value of the 1994 case definition using the newer 2006 case definition for advanced HIV disease as a “gold standard”.

One hundred patients were evaluated using the 1994 AIDS case definition and the 2006 case definition for advanced HIV infection.

Examine the comparison data in the following table.

### Number of patients who meet the 2006 WHO case definition for advanced HIV disease and the 1994 WHO AIDS case definition

<table>
<thead>
<tr>
<th>1994 case definition</th>
<th>2006 WHO case definition</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Present</td>
</tr>
<tr>
<td>Definition met</td>
<td>65</td>
</tr>
<tr>
<td>Definition not met</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>71</td>
</tr>
</tbody>
</table>

a. If the 2006 WHO case definition is defined as the “gold standard”, what are the sensitivity and specificity of the 1994 AIDS case definition to detect advanced HIV disease?

b. What is the positive predictive value of the 1994 AIDS case definition in patients similar to those in this study?

c. What proportion of the patients in this study actually has advanced HIV disease, as defined by the 2006 WHO case definition?
Unit 5

Core elements of HIV surveillance
Overview

What this unit is about

The two core elements of HIV/AIDS surveillance include:

- Reporting of HIV cases and cases of advanced HIV disease requiring treatment
- HIV seroprevalence surveys in selected clinic populations, such as ANC attendees and patients with STIs, and in selected high-risk groups such as injecting drug users and sex workers.

These two elements provide basic information on the distribution of HIV, very basic data on trends in the epidemic and data that can be used to evaluate prevention programmes.

Warm-up questions

1. True or false? HIV surveillance can be used to identify groups or geographic areas for targeted interventions. Circle your answer.
   
   True  False

2. True or false? HIV seroprevalence surveillance is more likely to underreport the status of an epidemic than HIV case reporting is.
   
   True  False

3. _______________ provides detailed, high-quality data about a more specific population by using a smaller, more reliable system.
   
   a. Universal HIV case reporting
   b. Sentinel surveillance

4. True or false? Prevalence and incidence data can be directly compared.
   
   True  False
5. Which of the following is not a direct objective of HIV surveillance?
   a. providing an accurate assessment of the distribution of disease by person, place and time
   b. distributing antiretroviral medications to patients with advanced HIV disease
   c. providing information to evaluate the effectiveness of prevention efforts
   d. providing data for prevention programme management
   e. none of the above

6. Name two sentinel populations that can be sampled for HIV sentinel surveillance activities.

7. _________________ is the rate at which new HIV infections occur in a population in a given period of time, while prevalence is a unitless proportion that measures the level of HIV infection in a population.

8. Which of the following is/are core elements of an HIV surveillance system?
   a. case reporting of advanced HIV disease
   b. HIV seroprevalence surveys in selected populations
   c. both a and b
   d. neither a nor b
Introduction

What you will learn

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

● discuss the purpose of HIV surveillance
● describe the core elements of an HIV surveillance system
● explain the difference between prevalence and incidence
● discuss the two approaches to HIV surveillance.

The purpose of HIV surveillance

The primary objective of epidemiological surveillance is to detect trends in incidence and prevalence of a disease over time. HIV surveillance serves several purposes, including the following:

● to monitor trends in the prevalence of HIV infection over time
● to assess the prevalence of HIV infection in population subgroups (for example, by person and place)
● to identify behaviours and risk factors for HIV transmission
● to provide data to assist with public health decision-making, including:
  ○ advocacy
  ○ targeting and prioritizing prevention and care programmes
  ○ monitoring and evaluating prevention and care programmes
  ○ resource allocation and programme planning
  ○ mobilization of political commitment.
● to educate the public on HIV
● to guide scientific research
● to make estimates and projections for new and total HIV infections, AIDS cases, AIDS deaths, HIV infected pregnancies and births, number of orphans and other strategic information, such as ART need, survival on ART, and so on.

One standardized package for making these sorts of projections in low-level and concentrated epidemics is the Spectrum® software package. Spectrum® takes a variety of HIV prevalence inputs and projects the number of people living with HIV and AIDS by age and sex, the number of AIDS deaths and the number of orphans as a result of AIDS. It also provides other outputs, such as life expectancy and child mortality.

HIV surveillance systems

Core elements

Historically, the core elements of HIV/AIDS surveillance included the following:

● AIDS case reporting, which involves routine reporting of specific data elements for persons diagnosed with AIDS in all or selected health facilities in the country. The goal of AIDS case reporting is to monitor AIDS morbidity in the general population and identify needs for ART, to plan appropriate health system response. In some
countries, HIV cases (including those HIV cases that have not progressed to AIDS) are also reported.

- In contrast, HIV seroprevalence surveillance seeks to estimate the prevalence of HIV infection in selected populations, such as ANC attendees, patients with STIs and blood donors, by conducting seroprevalence surveys in these populations on an ongoing basis. Seroprevalence surveys estimate HIV prevalence by testing blood for HIV antibodies.

- More recently, WHO has begun to emphasize HIV case reporting, especially in countries with lower levels of HIV infection, and reporting of cases of advanced HIV disease i.e. persons who should be receiving ART. For surveillance purposes, advanced HIV disease is defined as HIV infection with fewer than 350 CD4+ cells or HIV infection in the presence of stage 3 (advanced) or stage 4 (severe) clinical disease. CD4+ criteria for children less than 5 years old are based on CD4 percentage (≤11 months, 25%; 12–35 months, 20%; 36–59 months, 15%). Surveillance for advanced HIV disease is largely replacing AIDS case surveillance in much of the world. Diseases meeting the clinical definitions for stage 3 and 4 clinical disease are shown in Table 5.1.

**Table 5.1** WHO clinical staging of HIV/AIDS for adults and adolescents with confirmed HIV infection, stages 3 and 4 only, 2007

<table>
<thead>
<tr>
<th>Clinical stage 3</th>
<th>Clinical stage 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unexplained severe weight loss (&gt;10% of presumed or measured body weight)</td>
<td>Severe bacterial infections (for example, pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteraemia)</td>
</tr>
<tr>
<td>Unexplained chronic diarrhoea for longer than one month</td>
<td>Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis</td>
</tr>
<tr>
<td>Unexplained persistent fever (intermittent or constant for longer than one month)</td>
<td>Unexplained anaemia (&lt;8g/dl), neutropenia (&lt;0.5 × 10^9/L) and/or chronic thrombocytopenia (&lt;50 × 10^9/L)</td>
</tr>
<tr>
<td>Persistent oral candidiasis</td>
<td>Pulmonary tuberculosis</td>
</tr>
<tr>
<td>Oral hairy leukoplakia</td>
<td>Lymph node tuberculosis</td>
</tr>
<tr>
<td>Pulmonary tuberculosis</td>
<td>Severe bacterial infections (for example, pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteraemia)</td>
</tr>
<tr>
<td>Lymph node tuberculosis</td>
<td>Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis</td>
</tr>
</tbody>
</table>

1 Unexplained refers to cases in which the condition is not explained by other conditions.
2 Assessment of body weight in pregnant woman must consider the expected weight gain of pregnancy.
3 Some additional specific conditions also can be included in regional classifications (for example, American trypanosomiasis reactivation in the Americas Region).
AIDS case reporting, which is now defined as HIV infection and either clinical stage 4 disease or <200 CD4+ cells remains an option (Figure 5.1), and in countries that have long-standing and accurate AIDS case surveillance, remains a reasonable option for measuring the disease burden of severe HIV.

HIV case surveillance and HIV seroprevalence surveillance are complementary. Each type of surveillance has advantages and disadvantages (Table 5.2 below).

Table 5.2  Comparison of HIV case surveillance and HIV seroprevalence surveillance

<table>
<thead>
<tr>
<th>HIV case surveillance</th>
<th>HIV seroprevalence surveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Advantages</strong></td>
<td><strong>Advantages</strong></td>
</tr>
<tr>
<td>● Provides information on relative importance of HIV transmission categories</td>
<td>● High specificity of case definition</td>
</tr>
<tr>
<td>● Case surveillance for advanced HIV disease measures clinical disease burden (the size of the health problem in the area) and corresponds roughly to the size of the population that should be on antiretroviral therapy</td>
<td>● HIV has a very short latent period</td>
</tr>
<tr>
<td>● Provides information on people accessing care</td>
<td>● Underreporting not a problem</td>
</tr>
<tr>
<td>● Advanced HIV infection has a long latent period</td>
<td>● Better measures prevalence and trends in HIV infection in population groups</td>
</tr>
<tr>
<td>● Underreporting of both HIV and advanced HIV infection may be severe</td>
<td>● Provides no information on morbidity</td>
</tr>
<tr>
<td>● Does not necessarily indicate levels of HIV infection in people who have not tested for HIV</td>
<td>● Less information on the relative importance of HIV transmission categories</td>
</tr>
</tbody>
</table>
Discussing case reporting for advanced HIV disease

When case reporting for advanced HIV disease is comprehensive and thorough (currently it is not in many countries in the region), it describes:

- clinical disease burden caused by the HIV epidemic
- relative importance of various HIV transmission modes, such as injecting drug use and heterosexual transmission (this is also true of HIV case reporting).

Estimating the ratio of the number of advanced HIV cases to HIV cases helps in analysing the trends of the epidemic. However, because of the long period of unapparent infection, or latent period, from HIV infection to the development of advanced HIV disease that is severe enough to require antiretroviral therapy:

- advanced case surveillance alone may severely underrepresent the magnitude of the epidemic, especially when the HIV epidemic is emerging in a location
- advanced cases may rise for a long time, even when prevention efforts have greatly reduced the rate of new HIV infections.

HIV seroprevalence surveillance may provide a more accurate description of current levels and trends in HIV prevalence because it does not require voluntary testing for HIV.

Prevalence and incidence

It is essential to have a clear understanding of the difference between prevalence and incidence.

- Incidence is 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.
- Prevalence measures the level of HIV infection in a population. It is measured as a unitless proportion, such as the percentage infected or the number of infections per thousand persons tested. The prevalence level is influenced by both the rate of new infections (incidence) and the rate that infected people leave the population by death, cure or migration.

Because the units of measurement are different for prevalence and incidence, they cannot be directly compared. For example, it makes no sense to say that the prevalence is four times the incidence in a population. This would be the equivalent of saying that 80 kilometres is four times 20 kilometres per hour.

Approaches to case reporting

Two approaches

There are two distinct approaches for organizing case reporting systems for HIV and STIs, universal case reporting and sentinel surveillance. Both approaches are recommended under the IDSR strategy. Table 5.3, below, describes each system and its advantages.
Table 5.3  Overview of two common surveillance systems

<table>
<thead>
<tr>
<th>Description</th>
<th>Advantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Universal case reporting</td>
<td>Provides data that can be generalized to the entire population of a country</td>
</tr>
<tr>
<td>Sentinel surveillance</td>
<td>Provides detailed, high-quality data about a more specific population by using a smaller, more reliable system</td>
</tr>
</tbody>
</table>

Because the two types of data are so different, countries in the region should establish both systems to obtain a comprehensive picture of the spread of HIV, AIDS and STIs.

**Summary**

The purpose of HIV/AIDS surveillance is to provide an accurate picture of the epidemic which will then help to guide prevention and treatment programmes. It helps to identify population subgroups that are at higher risk for infection. Also, more information is provided on the distribution of disease over time and space.

**Unit 5 exercises**

**Warm-up review**

Take a few minutes to review your answers to this unit’s warm-up questions and make any necessary changes.

**Small group discussion**

Get into small groups to discuss these questions.

1. What is the approximate HIV prevalence in your country?
2. What type of HIV case reporting and/or seroprevalence surveillance is being conducted in your country?
**Apply what you have learned/case study**

Try this case study. We will discuss the answers in class.

In the Northern District of Menaland, the Ministry of Health has conducted a long-term cohort study of 1000 residents who were originally uninfected with HIV in 1997. The goal is to measure the incidence and prevalence of HIV infection. Examine the data in the table below.

<table>
<thead>
<tr>
<th>HIV infection status</th>
<th>1998</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td>New HIV infections</td>
<td>10</td>
<td>25</td>
<td>50</td>
<td>80</td>
<td>114</td>
</tr>
<tr>
<td>Total HIV infections</td>
<td>10</td>
<td>35</td>
<td>85</td>
<td>165</td>
<td>279</td>
</tr>
<tr>
<td>Population at risk (non-infected)</td>
<td>1000</td>
<td>990</td>
<td>965</td>
<td>915</td>
<td>835</td>
</tr>
<tr>
<td>Total population (infected and non-infected)</td>
<td>1000</td>
<td>1000</td>
<td>1000</td>
<td>1000</td>
<td>1000</td>
</tr>
</tbody>
</table>

a. What is the prevalence of HIV infection in 2002?
b. What is the incidence of HIV infection in 2002?
c. In which year was the incidence rate the highest?
Unit 6

Second-generation HIV/AIDS surveillance
Overview

What this unit is about

SECOND-GENERATION HIV SURVEILLANCE systems are designed to collect and integrate data reported from a variety of sources, such as behavioural surveillance, HIV case reporting, death registration and STI surveillance. Additional data are added to HIV seroprevalence surveillance and HIV case reporting to provide a more complete picture of the HIV/AIDS epidemic. This unit discusses elements of the second-generation surveillance approach.

Warm-up questions

1. Which of the following is the goal of second-generation HIV surveillance?
   a. better understanding of behaviours driving the epidemic
   b. surveillance more focused on subpopulations at highest risk for infection
   c. surveillance of the children of patients who acquired HIV in the first wave of infections
   d. a and b
   e. none of the above

2. The types of elements included in second-generation surveillance vary according to the type of epidemic. List the three types of HIV/AIDS epidemics.

3. True or false? Second-generation surveillance is flexible and can change with the needs and state of the epidemic in a particular country. Circle your answer.

   True  False

4. Which of the following is not yet a regular element of second-generation HIV surveillance?
   a. screening of donated blood
   b. behavioural surveillance
   c. surveillance for coexisting opportunistic infections
   d. HIV case reporting
Introduction

What you will learn

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

● describe the concept of second-generation surveillance
● discuss the various elements of a second-generation HIV surveillance system.

Second-generation HIV surveillance

Definition

The HIV/AIDS epidemic is spreading and becoming more complex. Surveillance efforts must become more sophisticated if they are to be effective. Recognizing this, UNAIDS and WHO have developed second-generation HIV surveillance.

Second-generation HIV surveillance is designed to collect and integrate data reported from a variety of sources, including the following:

● behavioural surveillance, which involves asking a sample of people about their sexual behaviour and, sometimes, their drug-injecting behaviour
● HIV case reporting
● HIV seroprevalence surveillance
● death registration
● STI surveillance.

Additional data provide a comprehensive understanding of trends in the epidemic (particularly incidence, which is difficult to determine from HIV case reporting and HIV seroprevalence surveillance alone) as well as serving to inform control and prevention measures. Figure 6.1 summarizes the components of second-generation surveillance.

![Diagram of second-generation surveillance](image-url)

Figure 6.1 The components of second-generation surveillance
Goals

The goals of second-generation HIV surveillance are:

- better understanding of trends over time
- better understanding of the behaviours driving the epidemic in a country
- increased focus on subpopulations at highest risk for infection
- flexibility to change with the state of the epidemic.

Major indicators

The major indicators shown in Table 6.1 include biological indicators, behavioural indicators and sociodemographic indicators. These form a relatively standard set of data elements that allow for comparison across time and between geographic areas.

Table 6.1  Major indicators used in second-generation HIV surveillance

<table>
<thead>
<tr>
<th>Biological indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV prevalence</td>
</tr>
<tr>
<td>STI incidence and prevalence</td>
</tr>
<tr>
<td>TB incidence and prevalence</td>
</tr>
<tr>
<td>number of adult cases of HIV infection and advanced HIV disease</td>
</tr>
<tr>
<td>number of paediatric cases of HIV infection and advanced HIV disease</td>
</tr>
<tr>
<td>prevalence and trends of mother-to-child transmission</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Behavioural indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>sex with a non-regular partner in last 12 months</td>
</tr>
<tr>
<td>condom use at last sex with a non-regular partner</td>
</tr>
<tr>
<td>age at first sex</td>
</tr>
<tr>
<td>use of unclean injecting equipment reported by injecting drug users</td>
</tr>
<tr>
<td>number of clients in the last week reported by sex workers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sociodemographic indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>age</td>
</tr>
<tr>
<td>sex</td>
</tr>
<tr>
<td>socioeconomic and educational status (may include occupation)</td>
</tr>
<tr>
<td>residency or migration status</td>
</tr>
<tr>
<td>parity (for antenatal sites)</td>
</tr>
<tr>
<td>marital status</td>
</tr>
</tbody>
</table>

Behavioural indicators

In addition to surveillance for cases of HIV and advanced HIV disease, and HIV seroprevalence surveys, a number of other types of data are collected and examined in second-generation surveillance. Behavioural surveillance is an example of these additional data sets. Behavioural surveys can be done both in smaller populations, such as most-at-risk populations (MARPs), and in the general population. When surveying the general population at a national level, one of two survey methods designed by Measure Evaluation (http://www.unc.edu/measure) is often used. These are the AIDS Indicator Survey (AIS) and the Demographic and Health Survey (DHS).
AIS is a survey designed to provide data for the reporting requirements of HIV/AIDS programmes, including the collection of the President’s Emergency Plan for AIDS Relief (PEPFAR), United Nations General Assembly Special Session (UNGAASS) and other indicators, while ensuring comparability of findings across countries and over time. It consists of two parts:

- a household survey to identify eligible men and women
- a survey of eligible individuals within those households.

The individual questionnaire contains questions on background characteristics, pattern of marital unions, age at sexual debut, patterns of sexual behaviour in the last 12 months, condom use, experience with STIs and treatment response to self-reported STIs, knowledge and attitudes related to HIV/AIDS, and coverage of HIV testing. AIS takes about nine months to complete. It has been carried out in five countries worldwide. Additionally, Sudan is in the process of planning a household survey modeled on the AIS conducted in other countries.

DHS surveys are, in contrast, very large household-based surveys of entire countries. They are designed not just for HIV programmes, but also to provide data on population, health and nutrition. DHS surveys occur at fairly broad intervals, typically every five years; they take 18–20 months from start to finish. DHS surveys can be combined with drawing blood for biological markers, such as HIV, herpes simplex type 2 or syphilis. If accompanied by biological markers, DHS is called DHS+. DHS surveys have been conducted in more than 75 countries, including six from EMR/MENA—Egypt, Jordan, Morocco, Pakistan, Sudan and Yemen.

**Data collection methods**

Various data collection methods can be used for second-generation HIV surveillance. These include:

- expanded biological surveillance for HIV (primarily seroprevalence surveys in defined and general populations)
- serial behavioural surveys in defined and general populations
- other sources of information.

An overview of data collection methods is shown in Table 6.2.
Table 6.2  Data collection methods for second-generation HIV surveillance

<table>
<thead>
<tr>
<th>Basic components</th>
<th>Additional components</th>
</tr>
</thead>
<tbody>
<tr>
<td>● sentinel HIV seroprevalence surveillance in defined subpopulations (such as ANC</td>
<td>● regular screening of occupational cohorts or other subpopulations (for example, factory</td>
</tr>
<tr>
<td>attendees, STI clinic patients, sex workers)</td>
<td>workers, military recruits)</td>
</tr>
<tr>
<td>● serial cross-sectional behavioural surveys in high-risk groups</td>
<td>● HIV screening of specimens taken in general population surveys</td>
</tr>
<tr>
<td>● regular HIV screening of donated blood</td>
<td>● HIV screening of specimens taken in special population surveys</td>
</tr>
<tr>
<td>● case surveillance for advanced HIV disease</td>
<td>● serial cross-sectional behavioural surveys in general populations</td>
</tr>
<tr>
<td></td>
<td>● data from other programmes, such as voluntary counselling and testing</td>
</tr>
<tr>
<td></td>
<td>● death registration and mortality surveillance</td>
</tr>
<tr>
<td></td>
<td>● STI surveillance</td>
</tr>
<tr>
<td></td>
<td>● TB surveillance</td>
</tr>
<tr>
<td></td>
<td>● data from HIV care and treatment programmes</td>
</tr>
</tbody>
</table>

UNGASS indicators

The UNGASS in 2001 concluded with a Declaration of Commitment signed by 189 Member States to take action to reduce the spread and impact of HIV/AIDS [20]. 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 (Table 6.3), which are called the UNGASS indicators. Subsets of the UNGASS indicators also measure progress on the HIV-related Millennium Development Goals (4 of 25) and the goal of universal access to HIV treatment and care (8 of 25).

UNGASS indicators are divided into four categories: national indicators, national programme indicators (such as blood safety, ART coverage, prevention of mother-to-child transmission (PMTCT), comanagement of TB and HIV treatment, HIV testing, prevention programmes, services for orphans and vulnerable children, and education), knowledge and behavioural indicators and impact indicators.
### Table 6.3 UNGASS indicators

<table>
<thead>
<tr>
<th>National indicators</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Domestic and international AIDS spending by categories and financing sources</td>
<td></td>
</tr>
<tr>
<td>2. National Composite Policy Index (areas covered: gender, workplace programmes, stigma and discrimination, prevention, care and support, human rights, civil society involvement, and monitoring and evaluation)</td>
<td></td>
</tr>
<tr>
<td>3. Percentage of donated blood units screened for HIV in a quality assured manner</td>
<td></td>
</tr>
<tr>
<td>4. Percentage of adults and children with advanced HIV infection receiving antiretroviral therapy</td>
<td></td>
</tr>
<tr>
<td>5. Percentage of HIV-positive pregnant women who received antiretrovirals to reduce the risk of mother-to-child transmission</td>
<td></td>
</tr>
<tr>
<td>6. Percentage of estimated HIV-positive incident TB cases that received treatment for TB and HIV</td>
<td></td>
</tr>
<tr>
<td>7. Percentage of women and men aged 15–49 who received an HIV test in the last 12 months and who know their results (UNGASS indicators, 2008)</td>
<td></td>
</tr>
<tr>
<td>8. Percentage of most-at-risk populations that have received an HIV test in the last 12 months and who know their results</td>
<td></td>
</tr>
<tr>
<td>9. Percentage of most-at-risk populations reached with HIV prevention programmes</td>
<td></td>
</tr>
<tr>
<td>10. Percentage of orphaned and vulnerable children aged 0–17 whose households received free basic external support in caring for the child</td>
<td></td>
</tr>
<tr>
<td>11. Percentage of schools that provided life-skills-based HIV education in the last academic year</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Knowledge and behaviour</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Current school attendance among orphans and among non-orphans aged 10–14</td>
<td></td>
</tr>
<tr>
<td>13. Percentage of young women and men aged 15–24 who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission</td>
<td></td>
</tr>
<tr>
<td>14. Percentage of most-at-risk populations who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission</td>
<td></td>
</tr>
<tr>
<td>15. Percentage of young women and men aged 15–24 who have had sexual intercourse before the age of 15</td>
<td></td>
</tr>
<tr>
<td>16. Percentage of women and men aged 15–49 who have had sexual intercourse with more than one partner in the last 12 months</td>
<td></td>
</tr>
<tr>
<td>17. Percentage of women and men aged 15–49 who had more than one sexual partner in the past 12 months reporting the use of a condom during their last sexual intercourse</td>
<td></td>
</tr>
<tr>
<td>18. Percentage of female and male sex workers reporting the use of a condom with their most recent client</td>
<td></td>
</tr>
<tr>
<td>19. Percentage of men reporting the use of a condom the last time they had anal sex with a male partner</td>
<td></td>
</tr>
<tr>
<td>20. Percentage of injecting drug users reporting the use of a condom the last time they had sexual intercourse</td>
<td></td>
</tr>
<tr>
<td>21. Percentage of injecting drug users reporting the use of sterile injecting equipment the last time they injected</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Impact</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>22. Percentage of young women and men aged 15–24 who are HIV infected</td>
<td></td>
</tr>
<tr>
<td>23. Percentage of most-at-risk populations who are HIV-infected</td>
<td></td>
</tr>
<tr>
<td>24. Percentage of adults and children with HIV known to be on treatment 12 months after initiation of antiretroviral therapy</td>
<td></td>
</tr>
<tr>
<td>25. Percentage of infants born to HIV-infected mothers who are infected</td>
<td></td>
</tr>
</tbody>
</table>

Source: [21].
How the data are used

STI prevalence can sometimes be used as a proxy for high-risk behaviours, and higher risk translates directly into a greater number of STIs, and over time into higher HIV levels. Figure 6.2, below, is an example of how data from multiple biological surveillance systems can be used together. The figure shows national-level data on the total reported cases of HIV and other STIs from 1987–2005 in the fictitious country of Menaland.

Figure 6.2. Trend of reported ulcerative STIs, genital discharge and newly identified HIV-infected patients, Menaland, 1987–2005

Low, concentrated and generalized HIV epidemics

Epidemic classification

To choose the most appropriate surveillance systems, UNAIDS and WHO suggest a classification that describes the HIV epidemic by its current state: low-level, concentrated or generalized. Epidemics may shift from one state to another over time, but such a shift is not inevitable. Although the issues for planning HIV surveillance are similar for each state of the epidemic, the actual surveillance needs will differ.

For each epidemic classification, the pages that follow:
- describe the characteristics and give examples
- provide a surveillance approach in table form (Tables 6.4, 6.5, 6.6).

Low-level epidemic

Characteristics of low-level epidemics include the following:
- Although HIV infection may have existed for many years, it has never spread to significant levels in any subpopulation.
- Recorded infection is largely confined to individuals with higher risk behaviour, such as sex workers, injecting drug users and men who have sex with men.
This epidemic state suggests that networks of risk are rather diffuse (with low levels of partner exchange or sharing of drug injecting equipment) or that the virus has been introduced only very recently.

HIV prevalence has not consistently exceeded 5% in any defined subpopulation.

Examples of low-level epidemics in EMR/MENA include those in the following countries: Afghanistan, Algeria, Bahrain, Egypt, Iraq, Jordan, Kuwait, Lebanon, Morocco, Oman, occupied Palestinian territory, Qatar, Saudi Arabia, Syrian Arab Republic, Tunisia, United Arab Emirates and Yemen.

Table 6.4  Surveillance approaches to low-level epidemics

<table>
<thead>
<tr>
<th>Main questions</th>
<th>Basic second-generation HIV surveillance activities</th>
<th>Additional second-generation HIV surveillance activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there groups with risk behaviour?</td>
<td>• formative research and mapping of groups with potential risk behaviour</td>
<td>• mapping to cover a larger geographical area and to be conducted more frequently</td>
</tr>
<tr>
<td></td>
<td>• analysis of available STI surveillance data</td>
<td>• estimate size of groups with potential risk behaviour</td>
</tr>
<tr>
<td>What are the main risk behaviours?</td>
<td>• risk behaviour surveys in groups considered at high risk for HIV infection</td>
<td>• increased geographical coverage of risk behaviour surveys</td>
</tr>
<tr>
<td></td>
<td>• HIV seroprevalence surveillance in identified groups with risk behaviour</td>
<td>• STI prevalence and incidence studies in groups with risk behaviour</td>
</tr>
<tr>
<td>How much HIV infection is there?</td>
<td>• analysis of available blood donor screening data</td>
<td>• larger coverage and increased frequency of HIV seroprevalence surveillance in identified groups with risk behaviour</td>
</tr>
<tr>
<td></td>
<td>• HIV case reporting</td>
<td>• HIV sentinel seroprevalence surveillance in pregnant women in urban areas</td>
</tr>
<tr>
<td>Who else might be affected and to what extent?</td>
<td>• Risk behaviour surveys focused on potential bridging populations</td>
<td></td>
</tr>
</tbody>
</table>

Concentrated epidemic

Characteristics of concentrated epidemics include the following:

- HIV has spread rapidly in at least one defined subpopulation(s), but is not well-established in the general population.
- Active networks of risk exist within the subpopulation(s).
- HIV prevalence is consistently over 5% in at least one defined subpopulation. HIV prevalence is below 1% in pregnant women in urban areas.

Examples of concentrated epidemics (or epidemic which show signs of concentration) in EMR/MENA include those in the following countries: Islamic Republic of Iran, Libyan Arab Jamahiriya and Pakistan.
Table 6.5  Surveillance approaches to concentrated epidemics

<table>
<thead>
<tr>
<th>Main questions</th>
<th>Basic second-generation HIV surveillance activities</th>
<th>Additional second-generation HIV surveillance activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much HIV infection is there?</td>
<td>● HIV seroprevalence surveillance in groups with risk behaviour</td>
<td>● wider geographical coverage and increased frequency of HIV seroprevalence surveillance in identified groups with risk behaviour</td>
</tr>
<tr>
<td></td>
<td>● annual sentinel seroprevalence surveillance in pregnant women in urban/high-exposure areas</td>
<td>● HIV surveillance in bridging populations (such as clients of sex workers) and pregnant women</td>
</tr>
<tr>
<td></td>
<td>● analysis of available blood donor screening data</td>
<td></td>
</tr>
<tr>
<td>What are the main risk behaviours and how do they change over time?</td>
<td>● repeated risk behaviour surveys in groups with risk behaviour</td>
<td>● wider geographical coverage and increased frequency of repeated behavioural surveys in groups with risk behaviour and bridging populations</td>
</tr>
<tr>
<td></td>
<td>● repeated risk behaviour surveys in bridging populations</td>
<td>● surveys of health-seeking behaviour for STI</td>
</tr>
<tr>
<td></td>
<td>● analysis of STI data in groups with risk behaviour and bridging populations</td>
<td></td>
</tr>
<tr>
<td>Who else might be affected and to what extent?</td>
<td>● repeated risk behaviour surveys in the general population in urban/high-exposure areas</td>
<td>● repeated risk behaviour surveys in the general population in all areas</td>
</tr>
<tr>
<td></td>
<td>● HIV case reporting</td>
<td>● HIV case reporting</td>
</tr>
</tbody>
</table>

Generalized epidemic

Characteristics of generalized epidemics include the following:

● HIV is firmly established in the general population.
● Although subpopulations at high risk may continue to contribute disproportionately to the spread of HIV, sexual networking in the general population is sufficient to sustain an epidemic independent of subpopulations at higher risk for infection.
● HIV prevalence is consistently over 1% in pregnant women.

Djibouti and Sudan are examples of countries in EMR/MENA with a generalized epidemic. Somalia, however, shows signs of a generalized epidemic in some of its areas. Figure 6.3 depicts HIV prevalence among ANC attendees at sentinel sites in Somalia.
**Table 6.6** Surveillance approaches to generalized epidemics

<table>
<thead>
<tr>
<th>Main questions</th>
<th>Core HIV surveillance activities</th>
<th>Expanded (second-generation) HIV surveillance activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are the trends in HIV infection?</td>
<td>• annual sentinel seroprevalence surveillance in pregnant women in urban and rural areas</td>
<td>• HIV sentinel seroprevalence surveillance in pregnant women in a larger number of sentinel sites</td>
</tr>
<tr>
<td></td>
<td>• increase sample size in high-volume sites to enable analysis by age groups</td>
<td>• HIV seroprevalence surveillance in groups considered at high risk</td>
</tr>
<tr>
<td></td>
<td>• HIV disease case reporting</td>
<td>• population-based prevalence studies to validate surveillance data</td>
</tr>
<tr>
<td>Is behaviour changing?</td>
<td>• repeated behavioural surveys in groups considered at high risk for HIV infection</td>
<td>• larger coverage of behavioural surveys by expanding populations and age groups</td>
</tr>
<tr>
<td>Do recorded changes help explain trends in</td>
<td>• analysis of STI surveillance data in groups considered at high risk for HIV infection</td>
<td></td>
</tr>
<tr>
<td>HIV infection?</td>
<td>• repeated risk behaviour surveys in the general population with a focus on young people</td>
<td></td>
</tr>
<tr>
<td>What is the impact of HIV?</td>
<td>• vital registration data</td>
<td>• other death data (census and studies)</td>
</tr>
<tr>
<td></td>
<td>• surveillance of TB and other HIV/AIDS-related illnesses</td>
<td>• studies of access to care</td>
</tr>
</tbody>
</table>

Source: Data were derived from [22].

**Figure 6.3** HIV prevalence among ANC attendees in Somalia, 2004 and 2007
Discussing the figure

Looking at Figure 6.3, answer the following questions:

a. Did the prevalence of HIV among ANC attendees in north-west zone increase or decrease between 2004 and 2007?

b. Which region(s) of Somalia was/were experiencing a generalized epidemic in 2004 and in 2007?

Future surveillance systems

With the widespread use of ART, additional surveillance systems will be developed to assist in:

- the management of diagnostic programmes, such as VCT
- treatment programmes, including:
  - PMTCT programmes
  - clinical monitoring of antiretroviral use and associated laboratory tests
  - adherence monitoring (adherence is the extent to which a patient takes his/her medications according to the prescribed schedule)
  - antiretroviral drug resistance monitoring (resistance is the ability of a pathogen, such as HIV, to overcome the inhibitory effect of a drug).

Surveillance for opportunistic infections, especially TB, will become more important as access to care improves. These changes will take place in the future.

Summary

Second-generation HIV surveillance systems are designed to collect and integrate data reported from a variety of other sources, such as behavioural surveillance, HIV case reporting, HIV seroprevalence surveillance, death registration and STI surveillance. Second-generation HIV surveillance allows for better understanding of the behaviours driving the epidemic in a country, increased focus on subpopulations at highest risk for infection, and better understanding of trends over time. To choose the most appropriate surveillance systems, UNAIDS and WHO suggest a classification that describes the HIV epidemic by its current state: low-level, concentrated or generalized.
Unit 6 exercises

Warm-up review

Take a few minutes to review your answers to this unit’s warm-up questions and make any necessary changes.

Small group discussion

Get into small groups to discuss these questions.

1. What stage of the epidemic is your country in (low-level, concentrated, generalized)? On what data do you base your assessment?
2. What second-generation HIV surveillance activities have been implemented in your country? How has the information generated from these activities been integrated and used in your HIV control programme? Suggest some second-generation HIV surveillance activities that could be incorporated into your current system.

Apply what you have learned/case study

Try this case study individually.

Ormeland has a concentrated HIV epidemic, but has yet to move beyond HIV case reporting, research projects and an occasional HIV prevalence survey. There is limited funding from the World Bank to expand surveillance activities in the capitol city, Orme, where HIV incidence and STI rates are reported to be increasing in sex workers.

a. How would you suggest investing these funds?

b. What is your goal, and what benefits do you expect from an investment in surveillance?
Unit 7

Ethical considerations in HIV surveillance
Overview

What this unit is about

People with HIV/AIDS and persons and groups at increased risk for HIV/AIDS are vulnerable to a number of social, legal and physical harms. Because of this, surveillance and special studies need to address a unique set of ethical issues. This unit discusses those issues and facilitates a more uniform approach to common ethical issues relating to HIV/AIDS surveillance.

Warm-up questions

1. True or false? Because of the urgent need to treat and prevent HIV/AIDS, issues such as confidentiality and informed consent do not need to be addressed. Circle your answer.
   
   True  False

2. The principle of beneficence refers to minimizing risk to individuals in the areas of:
   a. physical risk
   b. psychological harm
   c. stigmatization
   d. all of the above

3. True or false? Providing large monetary or in-kind incentives is an ethical way to ensure that more participants agree to give informed consent. Circle your answer below.

   True  False

4. True or false? In low-level epidemics, information about HIV infection in high-risk or marginalized groups should be widely publicized to prevent further spread of the disease.

   True  False

5. The process by which potential threats to confidentiality are discussed with subjects before they decide to participate is known as ___________________________.

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6. List three potential risks to participants in a behavioural surveillance study.
   a. 
   b. 
   c. 

7. List two types of programmes or services that can be developed as a result of surveillance activities.
   a. 
   b. 

8. Fill in the blank with one of the choices below. If ______________________ about HIV infection is violated, subjects may suffer discrimination and stigmatization. They may even be subject to criminal charges.
   a. privacy 
   b. informed consent 
   c. confidentiality 
   d. beneficence 

9. True or false? In unlinked anonymous testing, informed consent is obtained. Some information identifying the sample with the patient remains.
   True  False
Unit 7 Ethical considerations in HIV surveillance

Introduction

What you will learn

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

- discuss the ethical principles of respect for persons, beneficence and justice in the context of HIV surveillance of high-risk groups and general populations
- correctly use the terms related to ethical treatment of participants
- identify potential harms caused by HIV and behavioural surveillance
- identify potential benefits resulting from HIV and behavioural surveillance
- describe issues of confidentiality and how they relate to HIV surveillance
- explain issues of informed consent and institutional review boards and how they relate to HIV surveillance among high-risk groups and general populations.

Addressing ethical issues

What are the issues?

People infected with HIV and groups with increased risk for HIV/AIDS are vulnerable to a number of social, legal and physical harms. Because of this vulnerability and the stigma attached to the disease, surveillance and special studies need to address a unique set of ethical issues. These include:

- elevated risk of harm for people in high-risk groups, especially if their behaviour is illegal or stigma surrounds the behaviour
- stigma
- confidentiality (protecting personal information of a study participant)
- informed consent (the permission granted by a participant after he or she has been informed about the details of the study)
- access to prevention and care services.

Three ethical principles

Ethical issues do not always have clear right or wrong answers, but three universally accepted ethical principles exist:

1. “Respect for persons” requires public health officers and biomedical research investigators to see study subjects not just as passive sources of data, but as persons whose rights and welfare must be protected.
2. “Beneficence” refers to balancing the benefits and risks to individuals. This includes not only physical risk, but also risk of psychological harm and stigmatization.
3. “Justice” means that risks and benefits from studies should be distributed fairly and evenly in populations.

These ethical principles should be applied within the context of public health surveillance for HIV/AIDS.
Introduction to HIV/AIDS and sexually transmitted infection surveillance

Surveillance ethics terms

When you plan HIV seroprevalence surveillance, there are ethical considerations and issues to consider. Some of those issues were listed above. The terms below are used throughout this unit to describe how to protect individuals from harm, while ensuring that surveillance results are accurate.

“Participation bias” is error due to differences in characteristics between those who participate in a survey and those who do not.

“Informed consent” is based on the principle that competent persons are entitled to make decisions on whether or not they want to participate in studies or surveillance events. Informed consent protects the person’s freedom of choice and respects his/her autonomy with regard to decisions affecting his/her body and health.

“Unlinked anonymous testing” (UAT) is a type of testing in which a sample of blood is tested for HIV after all information that could identify the source of the blood is eliminated from the sample.

- UAT without consent is ethically acceptable if:
  - the blood is routinely collected for a reason other than HIV testing
  - all information that could potentially link the source of the blood to an individual has been removed before the blood is tested for HIV
  - no other non-routine interventions are carried out.

- UAT with informed consent is used if:
  - the testing is solely for surveillance purposes
  - all information that could potentially link the source of the blood to an individual is removed before the blood is tested for HIV.

“Linked anonymous HIV testing” is a type of testing in which the HIV result is linked to a patient’s other clinical data, such as STI data, or to behavioural data in biobehavioural surveillance studies (like AIS or DHS+). As in unlinked anonymous testing, in linked anonymous testing the HIV test results of individuals should not be able to be identified, either directly or indirectly. Patients should provide informed consent for linked anonymous testing.

In both unlinked and linked anonymous testing, it is ideal for VCT to be available.

Ethical considerations in HIV and AIDS case reporting

In many regions and countries, especially those with low-level and concentrated epidemics, the central surveillance activity is reporting cases of HIV and/or AIDS. Countries may consider implementing or modifying their HIV/AIDS surveillance reporting systems. To do so, they must decide whether or not such systems should employ names, unique identifiers or anonymous codes. The UNAIDS guidelines for public health and HIV surveillance asks you to consider the following questions:

- Who will be required to report? What clinical information and personal identifiers will they report? To whom will they report?
- How will the proposed system contribute to a more accurate characterization of the HIV/AIDS epidemic?
● What is known about the completeness of reporting for other notifiable conditions, including those that bear some stigma? How can such experience be used to anticipate the willingness to cooperate on the part of those who will be required to report?
● Given the limits of all reporting systems (such as error rates and failures to report), how will data derived from the proposed reporting system be merged with those derived from other sources, such as blinded seroprevalence studies, to provide the most accurate epidemiological picture that is achievable given the available resources?

Balancing risks and benefits

Fear of stigmatization

Infected persons in the general population and both infected and uninfected persons in high-risk groups have a legitimate fear of the reaction of the larger society based on past reactions. These groups may include:

● sex workers
● injecting drug users
● prisoners
● mobile populations
● men who have sex with men.

If people fear that information about their behaviour or their HIV status will be used against them, they will either try to confuse investigators or refuse to participate in monitoring studies. Successful surveillance in marginalized populations depends on minimizing participation bias by ensuring:

● informed consent
● absolute confidentiality
● thoughtful plans about how data that is generated will be used and disseminated.

In countries in which behaviours practiced by certain high-risk groups are illegal, consideration must be given to how any information gathered during surveillance activities will be protected from discovery by law enforcement agencies. Ideally, law enforcement agencies can be engaged to assist in surveys (for instance, by suggesting locales where individuals in high-risk groups congregate), but the confidentiality of respondents must be ensured and protected from disclosure that could result in their harm. In some countries, there may be specific laws that require public health officials to report illegal activities (for example, sex work or injecting drug use) to police, and these requirements must be considered before starting surveillance.

Low-level and concentrated epidemic considerations

One of the greatest challenges for surveillance in low-level and concentrated epidemics is gaining access to high-risk groups to track behaviour and infection. High-risk group members very often are socially marginalized. Sometimes their behaviour is illegal.

An effective surveillance system requires that populations with elevated incidence or prevalence of HIV be identified and be accessible for monitoring the following:
risk behaviour
- risk markers (for example, syphilis, herpes simplex virus type 2, hepatitis C)
- HIV infection.

In high-risk groups, many successful surveillance efforts centre on clinics and educational programmes designed to meet the needs of people most vulnerable to HIV and its impact.

These clinics provide services to the high-risk group. In doing so, they provide a sentinel site where seroprevalence surveillance can be conducted.

Where sentinel sites do not exist, community members may advise and participate in designing and carrying out cross-sectional, biological and behavioural surveys. Such efforts have been invaluable to successful surveillance in the past.

In low-level epidemics, give careful consideration to whether or not to publicize information about marginalized groups' HIV infection rates and related behaviour to a wider audience.

Experience has shown that in the early stages of the epidemic, the general public’s reaction to information about HIV infection in populations that have high-risk behaviours may be to call for restrictive and prohibitive measures. Such measures simply drive risk behaviour further underground, making prevention and care programmes more difficult and encouraging the spread of the virus. Table 7.1 describes some of the potential harms caused by HIV surveillance.

### Table 7.1 Potential harms caused by HIV surveillance

<table>
<thead>
<tr>
<th>Type of harm</th>
<th>Result</th>
</tr>
</thead>
</table>
| Physical     | - public attack  
              | - spousal/partner abuse  
              | - domestic violence |
| Legal        | - arrest  
              | - prosecution (especially with high-risk groups) |
| Social       | - disruption of family  
              | - workplace discrimination  
              | - loss of employment  
              | - isolation  
              | - loss of health-care services  
              | - refusal of care by health-care workers |

**Generalized epidemic considerations**

In surveillance of generalized epidemics, there is less focus on highest-risk populations, such as sex workers. In countries where monitoring is done primarily through anonymous unlinked seroprevalence surveillance activities, threats to confidentiality are typically low.
Given the stigmatized nature of HIV infection in many countries, risk of social discrimination and violence are quite real. Case reporting or surveys and programmatic activities, such as VCT, may diagnose individuals with HIV infection and give them their results.

Individuals may disclose these results themselves or be identified during programme activities. This may put them at risk for social harm and violence from spouses, sexual partners or others. Surveillance activities must protect data that individually identifies infected patients. Great care must be taken to protect such data from public release.

More subtle is the risk of labelling certain subgroups within the general population, such as members of a particular ethnic group or subregion who have increased infection rates of HIV/AIDS. This can lead to discrimination, stigmatization and other forms of harm. Take care to avoid inadvertently stigmatizing groups or subregions.

**Benefits**

Participation in surveillance has benefits for society as a whole, and especially for populations highly affected by HIV/AIDS and to HIV-infected individuals. Surveillance is not an academic exercise. It is intended to be used as part of a comprehensive programme to prevent and treat HIV. Participating investigators often become advocates for additional prevention and treatment services for the communities they are surveying.

HIV surveillance has numerous potential benefits to a community, including:

- guiding HIV prevention and care programmes
- guiding STI, drug treatment and other services
- raising public awareness of and sympathy for the burden of disease in the population
- helping to reduce stigma and effect social change, especially around HIV infection
- supporting the provision of special services for certain high-risk groups, such as STI clinics specifically for men who have sex with men or sex workers
- supporting the provision of HIV treatment services for prisoners.

**Confidentiality**

**Why it is important**

Confidentiality protects subjects from adverse consequences that may arise if their personal information is known, such as their:

- sexual preference
- drug use
- HIV infection status.

If confidentiality about HIV infection is violated, subjects may suffer discrimination, stigma or arrest. Public health officers must maintain the confidentiality of individuals’ records to guard against inadvertent disclosure.
Laws and confidentiality

Much of HIV surveillance entails special studies. In some countries, laws may exist that protect individually identified research results from discovery during legal proceedings. This is done to encourage participation in research on high-risk behaviour. Be aware of the particular provisions in your country’s laws that may:

- complicate participation by certain individuals—for example, the age of legal adulthood may affect results from sex workers under a certain age
- require reporting of individuals with HIV infection
- minimize risk to participants, such as those that protect study results, including risk behaviour, from discovery.

Discuss directly with participants potential threats to confidentiality and measures that you will take to minimize them. This is part of the informed consent process.

Unlinked anonymous testing without informed consent

Definition and approach

UAT without informed consent is conducted only in clinical settings. Earlier in this unit, UAT without informed consent was described. A specimen of blood originally collected for other purposes, such as syphilis testing at an ANC, is used as follows:

- all information that could potentially link the source of the blood to an individual is removed from the specimen
- the blood is tested for HIV.

Thus, the test result may not be traced back to the patient and he or she will not be informed of the test results.

Ethics and UAT

The ethical debate over UAT without informed consent has shifted over time. UAT is no longer conducted in several countries, but continues to be the backbone of ANC HIV surveillance in many countries with generalized epidemics. UAT has been deemed ethical if:

- no interaction takes place with the survey participant solely for the purpose of the survey
- information that may inadvertently identify a person is not kept
- no other non-routine interventions are carried out
- there are alternative methods or sources of obtaining linked HIV testing.

UAT is no longer conducted in several countries because it was determined to be unethical to have knowledge of a person’s HIV status and not share it with him or her, thereby denying that person the opportunity to receive treatment and information on how to prevent transmission. However, in many developing countries, UAT continues to be the backbone of ANC HIV surveillance.
In some countries, no routine blood samples are taken outside the period in which UAT is being done. This does not meet the requirement for “no other non-routine interventions” since the intervention (that is, blood drawing) is not being carried out routinely. However, the introduction of policies that require routine testing of blood (for example, for syphilis testing) may take several years to become routinely implemented. In this situation, UAT can be conducted ethically because it is consistent with the policy.

**Advantages and disadvantages**

The advantages of UAT without consent are:

- testing is anonymous, so the privacy of the individual is maintained
- the accuracy of HIV prevalence results is improved as participation bias is minimized.

The primary disadvantage is that tested individuals are not aware that they are being tested. They cannot obtain counselling and receive their test results and be referred for treatment if found to be infected. This disadvantage can be overcome by offering alternative VCT at the sentinel site with links to treatment and care.

**Informed consent**

**What information to provide**

Occasionally, surveillance activities require the formal informed consent of subjects. In these situations, investigators should disclose information that will be relevant to the subject’s decision on whether or not to participate. Such information should include:

- the nature of the surveillance system
- the procedure the project will entail (such as interview, obtaining a blood specimen, etc.)
- potential risks and benefits
- assurance that participation is voluntary and confidential.

Whenever informed consent is obtained, participation bias is an important issue and should be considered in the analysis. When HIV test results are to be given to individual subjects, confirmatory testing is required for positive specimens.

**Written consent forms**

Written consent forms are generally required to document that the process of informed consent has occurred.

- In some situations, such as work with populations with a low literacy rate or cases in which the procedure is deemed to be very low risk to the participant psychologically and physically, verbal consent documented by the investigator may be adequate.
- When individuals are not capable of giving informed consent, surrogate consent should be obtained. For example, a parent should give consent for a child or a guardian should give consent for an adult with severe mental illness.

Different countries have different laws and standards about the conditions under which an adolescent can participate in research (including biological testing) about sexual
behaviour, with his or her parents’ consent. Familiarize yourself with these laws in your country as part of your initial formative research efforts.

**Are participant gifts ethical?**

Providing incentives for study participants may raise ethical issues in some special HIV surveillance studies. Incentives for participation may consist of cash payments or small gifts, such as T-shirts. In general, incentives are appropriate for compensating study participants for time away from work and out-of-pocket expenses, such as transportation.

However, excessive payments create both ethical and methodological problems:

- Participants may choose to participate in a study merely for economic reasons. By providing excessive incentives, investigators create a situation in which an individual’s weighing of risks and benefits has been unduly influenced by money or gifts.
- When incentives for participation are created, the sample may not be fully representative. The sample may include individuals with higher rates of infection who have a greater need for money or health care.

Respondent-driven sampling is a special case. In respondent-driven sampling, modest incentives are provided to participants to recruit additional members of the high-risk group to the study. This is part of the methodology and may require explanation.

**Summary**

When conducting HIV surveillance, be mindful of patient confidentiality. Persons with HIV/AIDS are often subject to physical, legal and social harms. Try to take advantage of the potential benefits of surveillance, such as reducing stigma and guiding prevention and treatment programmes.

**Unit 7 exercises**

**Warm-up review**

Take a few minutes to review your answers to this unit’s warm-up questions and make any necessary changes.

**Small group discussion**

Get into small groups to discuss these questions.

1. What are the current regulations for surveillance studies involving minors in your country?
2. Do you know of cases where violence or other problems have occurred when an individual was identified as HIV-infected? What happened in that case?
3. What high-risk groups have been identified in your country? What are some special considerations in dealing with high-risk groups?
Apply what you have learned/case study

Try this case study individually.

You are the health officer in charge of HIV surveillance for the Northern District in Menaland. You have been asked to design and implement a special HIV seroprevalence survey among male patients with acute urethritis attending the STI clinic at the provincial referral hospital.

You are weighing two options:

1. The first would entail a self-administered questionnaire and an additional blood test for HIV and syphilis.

2. The second would entail a blinded survey of all patients who have blood drawn for syphilis serologies. Approximately 50% of patients who present with acute urethritis have serum samples drawn for syphilis; syphilis serologies are done at the clinician’s discretion, and there is no standard protocol for when to order these serologies.

   a. For which option would you need informed patient consent?

   b. How likely are the two options to yield an accurate estimate of the prevalence of HIV infection in this patient population?

   c. In which option would patient confidentiality be better protected?

   d. If you were to offer an incentive (such as reimbursement for transportation) to participants in option 1, would this be considered ethical?
Unit 8

Presenting data in charts, graphs and tables
Overview

What this unit is about

Data derived from public health surveillance systems are analysed to show trends over time and distribution of cases by demographic and geographic variables. This unit discusses how to display data in charts and graphs.

Warm-up questions

1. List two demographic variables by which surveillance data can be analysed.

2. True or false? Compiling all the data into one comprehensive chart or graph is more effective than including many simpler diagrams. Circle your answer.

   True    False

3. Which of the following can be extracted from public health surveillance data?
   a. changes over time
   b. changes by geographic distribution
   c. differences according to subject’s sex
   d. all of the above
4. Match the type of chart/graph with its example:

a. [Diagram of a pie chart showing breakdown of global funding for HIV/AIDS by region.]

   - Eastern Europe, Central Asia: US$ 20m (0.45%)
   - Latin America, Caribbean: US$ 550m (12.39%)
   - South and South-East Asia: US$ 670m (15.09%)
   - East Asia, Pacific: US$ 80m (1.80%)
   - North Africa, Middle East: US$ 50m (1.13%)
   - Sub-Saharan Africa: US$ 3070m (69.14%)

   - Scale line graph
   - Area map
   - Pie chart
   - Histogram

   1. Scale line graph
      answer:_______

   2. Area map
      answer:_______

   3. Pie chart
      answer:_______

   4. Histogram
      answer:_______
**Introduction**

**What you will learn**

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

- list the variables for analysing surveillance data
- identify the types of charts and graphs and when the use of each is appropriate.

**Analysis focus**

Data derived from public health surveillance systems are typically analysed to show trends over time and distribution of cases by demographic and geographic variables. The analyses focus on:

**Person**

- Who has developed the condition (for example, by age group or sex)?
- Are these distributions changing over time?

**Place**

- Where are cases occurring?
- Is the geographical distribution of cases changing over time?

**Time**

- Is the number of reported cases changing over time?

**Displaying data**

**Purpose**

The purpose of developing clearly understandable tables, charts and graphs is to facilitate:

- analysis of data
- interpretation of data
- effective, rapid communication on complex issues and situations.

Those who analyse surveillance data must be able to develop effective tables, charts and graphs that clearly present the important characteristics of complex epidemiological and programmatic issues.

**Types of variables**

There are two general types of variable: categorical and continuous. They are described below, along with examples.

- “Categorical variables” refer to items that can be grouped into categories. These include marital status, occupation, level of education and district of residence. These variables
can further be divided into ordinal variables and nominal variables.
  ○ “Ordinal variables” are those that have a natural order, such as level of education.
  ○ “Nominal variables” represent discrete categories without a natural order, such as marital status or occupation. A special type of nominal variable is a dichotomous variable. A dichotomous variable has only two categories, such as yes/no or male/female.

  ● “Continuous variables” are items that occur in numerical order, such as height, weight and age.
  ○ If a continuous variable has fewer than ten values, such as parity or number of wives, it should be treated as an ordinal variable.
  ○ Continuous variables are sometimes divided into groups and treated as ordinal variables. Examples of these are age groups (less than one year, one to five years, five to nine years) and numbers of sexual partners in the last three months (less than five, five to 10, 10 to 50, greater than 50).

General rules for tables, charts and graphs

  ● Simpler is better. Complicated tables, charts and graphs often are not read or understood, especially by policy-makers or others who are not experts in the subject matter.
  ● Tables, charts and graphs are often used together very effectively. For example, data tables often contain important points that can be illustrated using a graph.
  ● All tables, charts and graphs should have clear, descriptive titles and labels so the reader knows what data are being presented. The titles should include the variables “person”, “place” and “time”.
  ● Provide a descriptive narrative explanation of the highlights of the table, chart or graph to decrease the likelihood that the data will be misinterpreted. However, the major points should be understood without a verbal presentation.
  ● Ideally, identical data should not be presented in both tables and figures. You should choose which one most effectively displays the data and use it.
  ● If the table, chart or graph will be reproduced, ensure that the data points or groups will be distinguishable following multiple reproductions of the original.
  ● Be careful about comparing variables with different scales of magnitude; using a double y-scale, log scale or interrupted scale can help.

Graphs

Purpose

Graphs are generally used to display quantitative data (discrete or continuous variables). A graph is a diagram that shows a series of one or more points, lines, line segments, curves or areas. The graph represents variations of a variable in comparison with variations of one or more other variables.

A scale line graph represents frequency distributions over time where the y-axis represents frequency and the x-axis represents time (Figure 8.1, below).
Figure 8.1 Trends in HIV prevalence among direct sex workers in Menaland, 1997–2006

**Rules**

The y-axis (vertical axis) should be selected using the following criteria:

- the y-axis should be shorter than the x-axis
- start the y-axis with 0
- determine the range of values needed
- select an interval size.

**Charts**

**Purpose**

Charts are usually used to display qualitative variables.

**Bar charts**

A bar chart uses bars to represent different classes. The y-axis represents frequency, such as HIV prevalence or number of AIDS cases. The x-axis may represent time or different classes.

Figure 8.2 HIV prevalence in sex workers, Menaland, 1996–1999
Rules for bar charts

- Arrange categories that define the bars in a natural order if such an order exists, such as by age group or educational level.
- If a natural order does not exist, define categories by name, such as country, sex or marital status.
- Position the bars either vertically or horizontally.
- Make bars the same width.
- Length of bars should be proportional to the frequency of the event.

Clustered or stacked bar charts

Bars can be presented as clusters of subgroups. These are referred to as clustered bar charts or stacked bar charts, and are useful to compare values across categories. For example, you can present HIV prevalence levels by region, with subgroups by year, as in Figure 8.3.

![Figure 8.3](image)

**Figure 8.3** HIV prevalence levels among injecting drug users at four clinic sites, Al-Rabia, Menaland, 2001–2003: clustered bar chart

Rules for stacked bar charts

Some rules for clustered or stacked bar charts include:

- show no more than three sub-bars within a group of bars
- leave a space between adjacent groups of bars
- use different colours or patterns to show different subgroups for the variables being shown
- include a legend that interprets the different colours and patterns.
**Histogram**

A histogram represents a frequency distribution using rectangles. In a histogram, the frequency is represented on the y-axis and the ordinal variables are displayed on the x-axis. The widths of the bars are proportional to the widths of the variable. The frequency of the variables is represented by the area of the rectangle.

For instance, in Figure 8.4, below, the width of the variable bar for the 5- to 9-year-old age group, which represents a five-year interval, is five times as wide as the width of the bar for the 4-year-old age group, which is only a one-year interval.

![Histogram of children living with HIV, Menaland 2002](image)

**Figure 8.4** Children living with HIV, Menaland 2002
**Pie chart**

A pie chart is a circular graphic representation that compares subclasses or categories to the whole class or category using different coloured or patterned segments (Figure 8.5).

![Pie chart](image)

**Figure 8.5** Projected annual expenditure requirements for HIV/AIDS care and support by 2005, by region [23]

**Area map**

An area map is used to plot variables by geographic location (Figure 8.6).

![Area map](image)

**Figure 8.6** State of the HIV epidemic in WHO Eastern Mediterranean Region countries, 2004 [3]
Tables

Purpose

A table is a rectangular arrangement of data in which the data are positioned in rows and columns.

Rules for tables

- Each row and column should be labelled.
- Rows and columns with totals should be shown in the last row or in the right-hand column (Table 8.1).

Table 8.1 Adults and children living with HIV/AIDS by region in country Y, year X

<table>
<thead>
<tr>
<th>Region</th>
<th>Adults and adolescents ≥15 years</th>
<th>Children &lt;15 years</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>14 800</td>
<td>2</td>
<td>14 802</td>
</tr>
<tr>
<td>2</td>
<td>4 000</td>
<td>200</td>
<td>4 200</td>
</tr>
<tr>
<td>3</td>
<td>9 970</td>
<td>30</td>
<td>10 000</td>
</tr>
<tr>
<td>4</td>
<td>9 850</td>
<td>150</td>
<td>10 000</td>
</tr>
<tr>
<td>5</td>
<td>14 600</td>
<td>400</td>
<td>15 000</td>
</tr>
<tr>
<td>6</td>
<td>4 650</td>
<td>350</td>
<td>5 000</td>
</tr>
<tr>
<td>7</td>
<td>9 400</td>
<td>100</td>
<td>9 500</td>
</tr>
<tr>
<td>8</td>
<td>3 800</td>
<td>2 200</td>
<td>6 000</td>
</tr>
<tr>
<td>9</td>
<td>9 000</td>
<td>6 000</td>
<td>15000</td>
</tr>
<tr>
<td>10</td>
<td>5 450</td>
<td>50</td>
<td>5 500</td>
</tr>
<tr>
<td>Total</td>
<td>85 520</td>
<td>9 482</td>
<td>95 002</td>
</tr>
</tbody>
</table>

Source: Ministry of Health, country Y. Annual HIV/AIDS report, year X.

Looking at Table 8.1, answer the following questions:

- How does the information given by the “Total” column differ from that given by the “Total” row?
- Describe how you would use the information in this table to create a pie chart with subdivisions based on region.

Summary

Surveillance data can be analysed to describe distribution by person, place or time. Depending on your data, you can choose from a variety of chart and graph formats, including pie charts, histograms, tables, etc. Using several simpler graphics is more effective than attempting to combine all of the information into one figure.
Unit 8 exercises

Warm-up review

Take a few minutes to review your answers to this unit’s warm-up questions and make any necessary changes.

Small group discussion

Get into small groups to discuss these questions.

1. What types of graphs and tables have you used to present your HIV prevalence data in the past?
2. Which types of graphics are most appropriate for presenting the analysis of your results?
3. Design a bar chart based on the data presented in Table 8.1.

Apply what you have learned/case study

Examine the data below to answer the questions below. Remember to title every graph.

**HIV prevalence (%) by district among STI clinic attendees, Menaland 2000–2003**

<table>
<thead>
<tr>
<th>District</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>5.0</td>
<td>2.4</td>
<td>7.2</td>
<td>14.4</td>
</tr>
<tr>
<td>Southern</td>
<td>4.2</td>
<td>2.0</td>
<td>2.3</td>
<td>2.8</td>
</tr>
<tr>
<td>Eastern</td>
<td>6.5</td>
<td>10.4</td>
<td>9.4</td>
<td>5.5</td>
</tr>
<tr>
<td>Western</td>
<td>7.6</td>
<td>6.3</td>
<td>7.6</td>
<td>5.8</td>
</tr>
<tr>
<td>Central</td>
<td>7.1</td>
<td>6.5</td>
<td>5.6</td>
<td>3.2</td>
</tr>
</tbody>
</table>

a. Create a bar chart that shows prevalence by district in 2002.
b. Create a graph to show prevalence trends by year in the Northern District.
c. Create a clustered bar chart to show prevalence by district by year (2000–2003).
d. Using the data in the following table, create a pie chart showing the number of reported cases of syphilis from four STI clinics in the five districts in Menaland in 2002.

**Reported cases of syphilis among men by district, Menaland 2002**

<table>
<thead>
<tr>
<th>District</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>242</td>
</tr>
<tr>
<td>Southern</td>
<td>298</td>
</tr>
<tr>
<td>Eastern</td>
<td>567</td>
</tr>
<tr>
<td>Western</td>
<td>678</td>
</tr>
<tr>
<td>Central</td>
<td>198</td>
</tr>
</tbody>
</table>
Unit 9

Evaluating a public health surveillance system
Overview

What this unit is about

The periodic evaluation of surveillance systems for HIV and STIs is needed in order to maintain:

- a responsive and relevant system of monitoring shifting disease trends
- effective disease control and management interventions.

This unit discusses how to conduct an effective evaluation.

Warm-up questions

1. List three stakeholder groups that should be engaged during the evaluation of the surveillance system.
   a.
   b.
   c.

2. If there is a high probability that cases identified by the surveillance system are actually cases of HIV infection, the system is said to have high:
   a. sensitivity
   b. representativeness
   c. acceptability
   d. positive predictive value
Introduction

What you will learn

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

- list tasks for evaluating a surveillance system
- develop a plan for evaluating your own country’s surveillance system.

Why evaluate?

Once you have set up an HIV/AIDS surveillance system, you want to make sure that it remains effective as the epidemic changes over time. If your system is no longer effective, you will not have the right information to control HIV/AIDS.

Evaluating surveillance systems

Purpose of evaluation

Evaluation provides information to improve services and delivery.

Specific objectives of ongoing surveillance system evaluations may include the following:

- to appraise and prioritize the disease events to be kept under surveillance
- to assess how the system can detect and report these diseases
- to assess the quality of the epidemiological information produced
- to assess how the system can respond to these diseases
- to assess how surveillance results affect disease control and policy
- to identify which elements of the system can be enhanced in order to improve the quality of information.

The elements of a well-focused evaluation are outlined in Figure 9.1.

Evaluation

Documents current state of the surveillance system

- identify strengths and weak points
- recommend improvements
- define training requirements or gaps
- justify resources

possible outcomes

- additional funding
- more/better training
- improved surveillance for better disease control

Figure 9.1 Elements of a well-focused evaluation
Evaluation process

Six evaluation tasks

The evaluation process is organized into a series of discrete tasks that are summarized and then described below. For more detail, refer to the Updated guidelines for evaluating public health surveillance systems, Centers for Disease Control and Prevention, 2001 (http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5013a1.htm).

The six tasks for evaluating a surveillance system are as follows:

1. Engage the stakeholders in the evaluation. Stakeholders are those with an interest in the surveillance activities.
2. Describe the surveillance system to be evaluated.
3. Focus the evaluation design.
4. Gather credible evidence regarding the performance of the surveillance system.
5. Justify and state conclusions and make recommendations.
6. Ensure use of evaluation findings and share lessons learned.

Each of these tasks is described in the following pages.

Task 1: Engage stakeholders

Stakeholders include:

- public health practitioners
- health-care providers
- data providers and users
- representatives of affected communities
- governments at the subnational and national levels
- professional and private non-profit and donor organizations.

Stakeholders may want to define the questions to be addressed by the surveillance system evaluation. They may also want to decide how to use the findings from the evaluation. Therefore, they should be involved in the planning stages of the evaluation.

Examples of ways to engage stakeholders include:

- hold a community meeting to discuss plans for the evaluation
- hold one-on-one meetings with the key people listed above
- invite participants to join the evaluation team.

Task 2: Describe the system

- Describe the public health importance of the health-related event under surveillance. Include indices of frequency, indices of severity, disparities associated with the health-related event, costs, preventability and public interest.
- Describe the purpose and operation of the system. Include objectives, planned uses of data, case definition, where in the organization the system resides and the level of integration with other systems. Draw a flow chart of the system or components of the system.
- Describe the resources used to operate the system, such as funding sources, personnel requirements, travel and supplies.
**Task 3: Focus the design**

To focus the evaluation design:

- determine the specific purpose of the evaluation
- identify stakeholders who will receive findings
- consider what will be done with the information generated from the evaluation
- specify the questions that will be answered by the evaluation
- determine standards for assessing the performance of the system.

**Task 4: Gather evidence**

Gather credible evidence regarding the performance of the surveillance system. Describe the following system attributes:

- Simplicity—is the surveillance system as simple and as easy to operate as possible?
- Flexibility—has the system been able to adapt to new case definitions or operating conditions?
- Data quality—are the data recorded in the surveillance system complete and valid (that is, have they been collected and verified so that they more accurately portray the actual epidemic)?
- Acceptability—are people and organizations willing to participate in the surveillance system? Consider patients, health-care providers and clinics, and district and provincial health departments.
- Sensitivity—what proportion of cases does the surveillance system detect? Can the system detect outbreaks? Can it monitor changes in the number of cases over time?
- Positive predictive value—does the system have a high positive predictive value? That is, is there a high probability that cases identified by the system are actually cases of HIV infection?
- Representativeness—are the prevalence data generated representative of the actual occurrence of cases over time and the distribution in the population by place and person?
- Timeliness—is the system able to provide data in a timely manner?
- Stability—does the system collect, manage and provide data properly without failure? Is the system operational when needed?

**Task 5: State conclusions**

State and justify conclusions and make recommendations:

- justify conclusions through appropriate analysis, synthesis, interpretation and judgment of the gathered evidence
- make recommendations for improvement as modifications to or continuations of the public health surveillance system.

**Task 6: Share lessons learned**

To share evaluation findings and lessons learned:

- develop strategies for communicating the findings from the evaluation
- tailor recommendations to relevant audiences
distribute recommendations for improvements to all partners and sites involved in sentinel surveillance.

**Summary**

You need to evaluate your HIV surveillance system to make sure it remains effective as the epidemic changes over time. The evaluation process includes six tasks: engaging stakeholders, describing the surveillance system, focusing the evaluation design, gathering evidence on the system's performance, stating conclusions and recommendations, and sharing lessons learned.

**Unit 9 exercises**

**Warm-up review**

Take a few minutes to review your answers to this unit’s warm-up questions and make any necessary changes.

**Small group discussion**

Get into small groups to discuss these questions.

1. Has there been a formal evaluation of the HIV seroprevalence surveillance system in your country? If so, which parts of the surveillance system were evaluated?
2. What was the result of the evaluation? What problems were identified?
3. How were the results shared with surveillance staff and clinics?
4. How was the surveillance system modified as a result of the evaluation?

**Apply what you have learned/case study**

Try this case study individually.

The Southern District is in the coastal area of Menaland and has the country’s major port city, Janoubia. A university has been conducting studies of female sex workers in Janoubia for nearly a decade. For the last five years, they have been conducting serial seroprevalence surveys for HIV and syphilis.

You are the district surveillance officer for the Southern District. You are asked by the Ministry to evaluate these special studies to determine if the Ministry should take over sponsorship of the studies and include them in the sentinel surveillance system.

Now answer the questions below. Look back in the unit for more information if you wish.

a. How would you start your evaluation?
b. On what would you focus in your evaluation?
c. What criteria would you use to assess the performance of the system?
d. What would you recommend?
Final case study
1. You are the HIV seroprevalence officer for the Northern District. Northern District is a large district in Menaland, a country with an HIV epidemic concentrated in sex workers and injecting drug users. To monitor the epidemic in the general population, seroprevalence surveys are conducted annually at ANCs in Northern District. You examine data from the past five years and observe the following:

### Seroprevalence of ANC attendees in Northern District, 2001–2005

<table>
<thead>
<tr>
<th></th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of subjects</td>
<td>1695</td>
<td>1859</td>
<td>1836</td>
<td>1903</td>
<td>1849</td>
</tr>
<tr>
<td>Overall prevalence</td>
<td>0.4%</td>
<td>0.8%</td>
<td>1.3%</td>
<td>1.5%</td>
<td>1.9%</td>
</tr>
<tr>
<td>Prevalence by age (years):</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15–19</td>
<td>0.1%</td>
<td>0.5%</td>
<td>0.6%</td>
<td>0.7%</td>
<td>1.1%</td>
</tr>
<tr>
<td>20–24</td>
<td>0.4%</td>
<td>0.5%</td>
<td>1.4%</td>
<td>1.4%</td>
<td>2.1%</td>
</tr>
<tr>
<td>25–29</td>
<td>0.5%</td>
<td>0.7%</td>
<td>1.4%</td>
<td>1.6%</td>
<td>2.3%</td>
</tr>
<tr>
<td>30–34</td>
<td>0.3%</td>
<td>0.6%</td>
<td>1.1%</td>
<td>1.6%</td>
<td>1.7%</td>
</tr>
<tr>
<td>35–39</td>
<td>0.2%</td>
<td>0.2%</td>
<td>0.7%</td>
<td>1.3%</td>
<td>0.8%</td>
</tr>
<tr>
<td>40–44</td>
<td>0.1%</td>
<td>0.1%</td>
<td>0.3%</td>
<td>0.5%</td>
<td>0.6%</td>
</tr>
</tbody>
</table>

a. Using the above data, create a figure to show HIV prevalence among pregnant women aged 25–29, by year.
b. What trends do you see regarding HIV prevalence in relation to age and year?
c. Based on the above data, how would you characterize the HIV epidemic in the Northern District of Menaland in 2005?
2. Northern District has recently been given funds to begin second-generation HIV surveillance. Until now, HIV surveillance has been limited to HIV case reporting and sentinel seroprevalence surveillance at antenatal and STI clinics.
   a. What components of second-generation HIV surveillance would you implement to strengthen the district’s surveillance system?
   b. What measures would you include?

3. Menaland provides free ART to HIV-infected pregnant women. What ethical issues must you consider when conducting HIV surveillance among pregnant women in a setting where ART is available?

4. Annual seroprevalence surveys have been conducted at five ANCs in the district for the past four years. The survey is conducted between June and September of each year. Evaluation of the seroprevalence surveys is one of your responsibilities. This entails assessing the data for quality and completeness. After the first two months of the current annual survey you examine the database and observe the following:

<table>
<thead>
<tr>
<th>Site</th>
<th>Number of subjects</th>
<th>Age</th>
<th>Date specimen collected</th>
<th>Residence</th>
<th>Parity</th>
<th>Live births</th>
<th>HIV serology</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>158</td>
<td>6%</td>
<td>2%</td>
<td>4%</td>
<td>3%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>2</td>
<td>165</td>
<td>5%</td>
<td>1%</td>
<td>5%</td>
<td>2%</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>3</td>
<td>208</td>
<td>2%</td>
<td>1%</td>
<td>2%</td>
<td>3%</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>4</td>
<td>287</td>
<td>4%</td>
<td>2%</td>
<td>3%</td>
<td>5%</td>
<td>2%</td>
<td>3%</td>
</tr>
<tr>
<td>5</td>
<td>189</td>
<td>5%</td>
<td>3%</td>
<td>5%</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
</tr>
</tbody>
</table>

Percentage of missing data:

<table>
<thead>
<tr>
<th>Site</th>
<th>Age</th>
<th>Date specimen collected</th>
<th>Residence</th>
<th>Parity</th>
<th>Live births</th>
<th>HIV serology</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>6%</td>
<td>2%</td>
<td>4%</td>
<td>3%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>2</td>
<td>5%</td>
<td>1%</td>
<td>5%</td>
<td>2%</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>3</td>
<td>2%</td>
<td>1%</td>
<td>2%</td>
<td>3%</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>4</td>
<td>4%</td>
<td>2%</td>
<td>3%</td>
<td>5%</td>
<td>2%</td>
<td>3%</td>
</tr>
<tr>
<td>5</td>
<td>5%</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
</tr>
</tbody>
</table>

a. What are your thoughts regarding the data in this table? Is there anything of concern?
b. What are some possible explanations for this finding? How would you investigate these? What steps would you take to correct the problem(s)?

you conduct your investigation and find that the HIV serologic results are missing on the hard copies. You then visit the laboratory and meet with the director.
In your discussions, you discover that reagents for HIV testing were not available for a period of time. The laboratory director indicates that there is now an ample supply of HIV reagents and that the survey can be completed without any interruptions.
c. Having identified the problem, how do you address it in the short term, and what are some steps you can take to ensure that such a problem does not recur?
Module summary
Module summary

- About 530,000, or less than 2%, of all HIV-infected persons live in EMR/MENA; however, infection rates are increasing in several countries within the region.
- Overall, adult prevalence of HIV is relatively low in EMR/MENA.
- The majority of the infections in most countries in EMR/MENA are concentrated among populations that engage in high-risk behaviours, such as commercial sex, injecting drug use and men having sex with men. In Djibouti, Somalia and Sudan, however, HIV infection is more widely present in the general population, resembling epidemics in sub-Saharan Africa.
- Two major types of HIV have been recognized: HIV-1 and HIV-2. HIV-1 is the predominant type worldwide.
- The predominant route of HIV transmission in EMR/MENA is through heterosexual intercourse.
- Key risk factors for sexual transmission include:
  - number of sexual partners and high rate of partner change
  - type of sexual contact
  - non-use of condoms
  - untreated genital tract infections.
- An effective surveillance system is necessary for prevention and control of HIV infection. Surveillance involves:
  - the collection of information on demographic and behavioural characteristics of affected populations
  - infection trends.
- Second-generation HIV surveillance systems build upon existing surveillance systems and make the best use of data gathered from different sources.
- There are three epidemic states: low-level, concentrated and generalized. All three types are present in EMR/MENA. Tailor surveillance activities to the type of epidemic.
- Investigators need to be acutely aware of potential harm to individuals and to populations. Make protection of individuals and their data your highest priority.
- Evaluation of the surveillance system is important for ensuring that the surveillance system is effectively meeting the objectives of detecting changes and trends in STI, HIV or AIDS prevalence.
References
References


4) Notes on the HIV and AIDS epidemic: Middle East and North Africa. UNAIDS (December 2006 draft).


Annex 1

Glossary
Glossary

**Acquired immunodeficiency syndrome (AIDS)**  
See Advanced HIV Disease.

**Active surveillance**  
A system in which the organization conducting surveillance initiates procedures to obtain reports. For example, making telephone calls or visits to health facilities to obtain information.

**Adherence**  
The extent to which a patient takes his/her medication according to the prescribed schedule (also referred to as “compliance”).

**Advanced HIV Disease**  
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 Disease is the term now used for AIDS in updated WHO guidelines.

**AIDS**  
Acronym for “Acquired Immunodeficiency Syndrome”.

**AIDS case surveillance**  
The identification and reporting of persons meeting the AIDS case definition to permit public health authorities to track the disease over time. Also known as “AIDS case reporting”.

**AIDS Indicator Survey (AIS)**  
Developed to provide countries with a standardized tool for monitoring nationally-representative HIV/AIDS indicators in the general population.

**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.

**Area map**  
A map used as a graph showing variables by geographic location.

**Bar chart**  
A visual display of the size of the different categories of a variable. Each category or value of the variable is represented by a bar (or column). The y-axis represents frequency. The x-axis represents different classes.
**Behavioural surveillance**  
Surveys of HIV-related behaviour that involve asking a sample of people about their risk behaviours, such as their sexual and drug-injecting behaviour.

**Beneficence**  
Refers to balancing the benefits and risks to individuals. This includes not only physical risk, but also risk of psychological harm and stigmatization.

**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 TB.

**Bridging populations**  
Persons in high-risk groups who interact with people of lower risk in the general population, making it more likely that the HIV epidemic shifts from concentrated to generalized.

**Case definition**  
A set of standard criteria for deciding whether a person has a particular disease or health-related condition, by specifying clinical criteria and limitations on time, place and person.

**Case fatality rate**  
The proportion of patients who become infected or develop a disease that die as a result of that infection or disease.

**Case reporting**  
A surveillance system in which persons who are identified as meeting the case definition are reported to public health authorities.

**Categorical surveillance system**  
A system that deals with reporting a single disease.

**Categorical variable**  
Refers to items that can be grouped into categories, such as marital status or occupation.

**CD4+ cells**  
Cells with CD4 receptors that recognize antigens on the surface of a virus-infected cell and secrete lymphokines that stimulate B cells and killer T cells; helper T cells are infected and killed by the AIDS virus.

**CD4+ cell count**  
A measure of the number of CD4 cells in a millilitre (ml) of blood. The CD4 count is one of the most useful indicators of the health of the immune system and a marker for the progression of HIV/AIDS.

**Centers for Disease Control and Prevention (CDC)**  
The US Department for Health and Human Services agency with the mission to promote health and quality of life by preventing and controlling disease, injury and disability.

**Chancroid**  
An acute, sexually transmitted, infectious disease of the genitalia caused by the bacteria *Haemophilus ducreyi*. The infection produces a genital ulcer that may facilitate the transmission of HIV.

**Chlamydia trachomatis**  
The most common sexually transmitted bacterial species of the genus *Chlamydia* that infects the reproductive system. *Chlamydia* infection causes infection of the cervix of women and the urethra of men and is frequently asymptomatic. If left untreated, it can cause sterility in women.

**Clustered bar chart**  
A bar chart in which the columns are presented as clusters of subgroups. Also known as “stacked bar charts”.

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**Cohort studies**  
Cohort studies follow a group of initially uninfected people over time, and test them repeatedly. Cohort studies follow a well-defined group of people who have had a common experience or exposure, who are then followed up for the incidence of new diseases or events, as in a cohort or prospective study tested repeatedly over a long period of time.

**Concentrated epidemic**  
The epidemic state in which HIV has spread to a high level in a defined subpopulation but is not well established in the general population. HIV prevalence is consistently >5% in at least one defined subpopulation and is <1% in pregnant women in urban areas.

**Confidentiality**  
Protecting information that concerns a study participant or patient from release to those who do not need to have the information.

**Continuous variable**  
Items that occur in a numerical order, such as height or age.

**Cotrimoxazole prophylaxis**  
A combination of two anti-infection drugs, sulfamethoxazole and trimethoprim, used to prevent opportunistic infections in patients with HIV.

**Cross-sectional survey**  
A survey that is conducted over a given period of time, such as during a single year, rather than over an extended period of time.

**DALYs**  
See disability-adjusted life years.

**Demographic and Health Survey (DHS)**  
Nationally-representative household surveys that provide data for a wide range of monitoring and impact evaluation indicators in the areas of population, health and nutrition.

**Dichotomous variable**  
A special type of nominal variable that has only two categories, such as male/female.

**Disability-adjusted life years (DALYs)**  
A measure of burden of disease in a population obtained by combining "years of life lost" and "years lived with disability".

**Disease burden**  
The size of a health problem in an area, as measured by cost, mortality, morbidity or other indicators.

**EMR/MENA**  
Acronym for the Eastern Mediterranean Region/Middle East and North Africa created explicitly for use in this module series. This area 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.

**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.

**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.
**Female sex workers**
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.

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

**Gonorrhoea**
An infection caused by *Neisseria gonorrhoeae* bacteria. Although gonorrhoea is considered primarily a sexually transmitted infection, it can also be transmitted to newborns during the birth process.

**Graph**
A diagram that shows a series of one or more points, lines, line segments, curves or areas, representing variations of a variable in comparison with variations of one or more other variables.

**Herpes simplex virus type 2 (HSV-2)**
A virus causing painful sores of the anus or genitals. While this is a sexually transmitted infection, it may be transmitted to a newborn child during birth from an infected mother.

**Highly active antiretroviral therapy (HAART)**
When three or four antiretroviral medications that attack different parts of HIV or stop the virus from entering the blood cells are taken in combination for treatment of HIV.

**High-risk behaviours**
Behaviours that increase the risk that a person will contract a disease.

**High-risk group**
A group in the community with an elevated risk of disease, often because group members engage in some form of risky behaviour.

**Histogram**
A graph that represents a frequency distribution by means of rectangles whose widths represent class intervals and whose areas represent corresponding frequencies.

**HIV**
See human immunodeficiency virus.

**HIV-1**

**HIV-2**
A type of HIV with slight genetic variations from HIV-1. Less easily transmitted than HIV-1.

**HSV-2**
Acronym for Herpes simplex virus type 2. See herpes simplex virus type 2.

**Human immunodeficiency virus (HIV)**
A retrovirus that causes AIDS by infecting T-cells of the immune system.

**IDSR**
See integrated disease surveillance and response.

**IDU**
Acronym for “injecting (injection or intravenous) drug user”.

**Immune system**
The body’s complicated natural defence against disruption caused by invading foreign agents such as microbes or viruses.
Immunodeficient A situation in which a patient’s health is compromised because his/her immune system is insufficient to ward off infections, thus making the person susceptible to certain diseases that they would not ordinarily develop.

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.

Indicators Specific data that are gathered to measure how well a prevention or treatment programme is doing. They define an aspect of behaviour that is key to the spread of HIV. Indicators provide a way to track changes in behaviours over time and provide a way to compare levels of risk behaviours between different population groups.

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.

Injecting drug users Also called “intravenous drug users”, they are persons who use or have used needles or syringes to inject drugs. Injecting drug use is considered a high-risk behaviour.

Integrated disease surveillance (IDS) An approach to surveillance in which communicable diseases are prioritized. Surveillance for all of the high-priority diseases is conducted in an integrated manner and is initiated at the district level. These diseases have a high potential for epidemic spread and can be controlled through public health measures.

Isoniazid prophylaxis Giving isoniazid to individuals with latent Mycobacterium TB infection, in order to prevent the progression to active disease. Prophylaxis with isoniazid significantly reduces the incidence of tuberculosis in adults with HIV and a positive tuberculin skin test result.

Justice The risks and benefits from studies should be distributed fairly and evenly in populations.

Laboratory-based reporting A surveillance system in which the reports of cases come from clinical laboratories.

Latent period A period of unapparent infection following exposure to a pathogen, ending with the onset of symptoms of chronic disease.

Linked anonymous HIV testing In linked anonymous testing, a person agrees to have an HIV test, but the specimen is labelled with a code without a name or identifiers that could reveal the person’s identity. This method is voluntary and requires obtaining informed consent and making the test results available (with appropriate counselling) to the person tested.
Low-level epidemic  The epidemic state in which HIV has not spread to significant levels in any subpopulation, although HIV infection may have existed for many years; HIV prevalence 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 recently been introduced.

Lymphocytes  A type of white blood cell that is involved with fighting infections in the body. The T lymphocyte is the cell that HIV infects and destroys.

Macrophage cells  Tissue cells derived from monocytes that protect the body against infections.

Men who have sex with men (MSM)  Men who have sex with men are one of the highest risk groups in the Americas, Asia, Europe and Oceania. For the purposes of this manual, we also consider male sex workers, transvestites and transgendered persons (hijra) in the MSM category.

Monocyte  A type of white blood cell.

Morbidity  Any departure, subjective or objective, from a state of physiological or psychological well-being.

Mortality rate  A measure of the frequency of occurrence of death in a defined population during a specified interval of time.

Mother-to-child transmission (MTCT)  Transmission of HIV to a child from an HIV-infected woman during pregnancy, delivery or breastfeeding. Also see perinatal transmission.

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”.

Nominal variable  Variables that represent discrete categories without a natural order, such as marital status.

Opportunistic infections  Illnesses caused by various organisms infecting immunodepressed persons that usually do not cause disease in persons with healthy immune systems. Persons with advanced HIV infection (i.e. AIDS) suffer opportunistic illnesses of the lungs, brain, eyes and other organs. These illnesses are referred to as AIDS-defining illnesses or conditions.

Ordinal variable  Variables that have a natural order, such as level of education.

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.

Passive surveillance  A system in which a health-care provider or worker notifies the health authority of any cases of these diseases, as opposed to “active surveillance”.

Mortality rate  A measure of the frequency of occurrence of death in a defined population during a specified interval of time.
### Perinatal transmission
Transmission of an infectious agent, such as HIV, from mother to baby before, during or after the birth process. Also known as “vertical transmission” or “mother-to-child transmission”.

### Pie chart
A circular chart in which the size of each “slice” is proportional to the frequency of each category of a variable. A pie chart compares subclasses or categories to the whole class or category using different coloured slices.

### PLWHIV
Acronym for “people living with HIV”.

### PLWHA
Acronym for “people living with HIV/AIDS”.

### PMTCT
Acronym for “prevention of mother-to-child transmission”.

### Population-based survey
A type of survey that uses a probability sample of a population defined by geographic boundaries, such as villages or provinces.

### Population subgroup
A group within a population that share certain characteristics or behaviours.

### 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”.

### President’s Emergency Plan for AIDS Relief (PEPFAR)
A comprehensive approach to combating HIV/AIDS around the world. PEPFAR employs the most diverse prevention, treatment and care strategy in the world, with an emphasis on transparency and accountability for results. The goals of PEPFAR include support for treatment for 2 million HIV infected people, support for prevention of 7 million new infections, and support for care for 10 million people infected or affected by HIV/AIDS.

### 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.

### Post-exposure prophylaxis
In the case of HIV infection, a course of antiretroviral drugs which is thought to reduce the risk of seroconversion after events with high risk of exposure to HIV.

### Replacement feeding
Feeding infants who are receiving no breast milk with a diet that provides the nutrients infants need until the age at which they can be fully fed on family foods. During the first six months of life, replacement feeding should be with a suitable breast-milk substitute. After six months the suitable breast-milk substitute should be complemented with other foods.

### Representativeness
The degree to which the sample truly reflects the study population i.e. whether it is representative of the study population.

### Risk factor
A variable associated with an increased risk of disease or infection.

### Scale line graph
A graph that represents frequency distributions over time where the y-axis represents frequency and the x-axis represents time.
Second-generation surveillance  Built upon a country's existing data collection system, second-generation HIV surveillance systems are designed to be adapted and modified to meet the specific needs of differing epidemics. This form of surveillance aims to improve the quality and diversity of information sources by developing and implementing standard and rigorous study protocols, using appropriate methods and tools. Second-generation surveillance refers to activities outside of those activities generally considered to be a part of routine case surveillance such as case reporting and sentinel 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.

Sensitivity  The proportion of persons with a disease who are correctly identified by a screening test or case definition as having the disease.

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 agree 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.

Seroprevalence surveillance  Collecting blood samples for the purpose of surveillance. Latent, subclinical infections and carrier states can thus be detected, in addition to clinically overt cases. This is especially important in the case of HIV and other STIs, which often have a long latent period before symptoms are apparent.

Seroprevalence surveys  Surveys that estimate HIV prevalence by testing blood for HIV antibody.

Sex workers (SWs)  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.

Sexual debut  The first time a person has sexual intercourse.
<table>
<thead>
<tr>
<th><strong>Sexual transmission</strong></th>
<th>Transmission of an infectious agent, such as HIV, that occurs predominately through unprotected vaginal or anal intercourse, and less frequently through oral intercourse.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sexually transmitted infection (STI)</strong></td>
<td>Diseases that are spread by the transfer of organisms from person to person during sexual contact.</td>
</tr>
<tr>
<td><strong>Specificity</strong></td>
<td>The proportion of persons without a disease who are correctly identified by a screening test or case definition as not having the disease.</td>
</tr>
<tr>
<td><strong>Stacked bar chart</strong></td>
<td>See clustered bar chart.</td>
</tr>
<tr>
<td><strong>Stakeholders (or stakeholder's group)</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Stigma</strong></td>
<td>A mark of disgrace or shame. For example, in some societies, being infected with HIV causes a person to be stigmatized.</td>
</tr>
<tr>
<td><strong>Surveillance</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Symptomatic</strong></td>
<td>Exhibiting symptoms.</td>
</tr>
<tr>
<td><strong>Symptoms</strong></td>
<td>Any perceptible, subjective change in the body or its functions that indicates disease or phases of disease, as reported by the patient.</td>
</tr>
<tr>
<td><strong>Syphilis</strong></td>
<td>A sexually transmitted disease resulting from infection with the bacterium Treponema pallidum. Syphilis can also be acquired by newborns from their mothers during pregnancy.</td>
</tr>
<tr>
<td><strong>TB</strong></td>
<td>Tuberculosis.</td>
</tr>
<tr>
<td><strong>Transmission</strong></td>
<td>Any mode or mechanism by which an infectious agent is spread through the environment or to another person.</td>
</tr>
<tr>
<td><strong>UAT</strong></td>
<td>See unlinked anonymous testing.</td>
</tr>
<tr>
<td><strong>UNAIDS</strong></td>
<td>Acronym for United Nations Joint Programme on HIV/AIDS.</td>
</tr>
<tr>
<td><strong>UNGASS</strong></td>
<td>Acronym for United Nations General Assembly Special Session on HIV/AIDS.</td>
</tr>
<tr>
<td><strong>Universal case reporting</strong></td>
<td>A surveillance system in which all persons who are identified as meeting the case definition for a particular disease are reported. For example, all persons with AIDS who receive care at any health-care facility are reported. This is in contrast to sentinel reporting in which only selected sentinel sites report all persons who meet the case definition.</td>
</tr>
</tbody>
</table>
Universal precautions

Recommendations issued by CDC to minimize the risk of transmission of bloodborne pathogens, particularly HIV and HBV, by health-care and public safety workers. Barrier precautions are to be used to prevent exposure to blood and certain body fluids of all patients.

Unlinked anonymous testing (UAT)

Testing that occurs when a sample of blood originally collected for other purposes is tested for HIV after being anonymised. The person whose blood is taken does not know that his/her blood will be tested for HIV. All information that could identify the person is removed from the sample so that the results of the test cannot be linked back to them.

VCT

See voluntary counselling and testing.

Vertical surveillance system

See categorical surveillance system.

Vertical transmission

See perinatal transmission

Vesicular

Pertaining to vesicles or blisters.

Viral load

The amount of HIV in the circulating blood. Also known as “viral burden” or “viral dose”.

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.

WHO

World Health Organization.

WHO 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.
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**


**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](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](http://www.childinfo.org)

**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](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](http://www.unaids.org)

**UNAIDS epidemiological information on HIV/AIDS**


**UNAIDS surveillance information on HIV/AIDS**

Available at: [http://www.unaids.org/en/in+focus/topic+areas/surveillance+and+reporting.asp](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](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.ua2001.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://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 is developing 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 scheduled to become available in 2007. The date of release and the URL will be announced by various means, through CDC-GAP and WHO regional offices.

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 programme 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 Regional Office 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 Evaluation 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 and case study.

Answers to the questions within the unit are not included. Unit questions are designed to stimulate small group discussion among participants in the workshop or class.

Unit 1 answers

Warm-up questions

1. True or false? As of 2007, more than 33 million people were infected with HIV worldwide. Circle your answer below:
   
   True.

2. In which three countries in EMR/MENA is there evidence of widespread heterosexual transmission?
   
   Djibouti, Somalia and Sudan.

3. Aside from the countries mentioned in Question 2 above, the three groups in which high prevalence of HIV infection has been found are:
   
   Commercial sex workers, injecting drug users and men who have sex with men.

4. Which of the following countries in EMR/MENA has the highest HIV reported prevalence among adults?
   
   a. Afghanistan
   
   b. Djibouti
   
   c. Morocco
   
   d. Sudan

Case study

Menaland, a country in EMR/MENA, had its earliest cases of AIDS recognized in 1984. Data below are based on estimates of HIV prevalence by district. Study the data and answer the questions that follow.
HIV prevalence (%) by district, Menaland, 1998–2004

<table>
<thead>
<tr>
<th>District</th>
<th>1998</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>2.10</td>
<td>2.30</td>
<td>1.56</td>
<td>1.60</td>
<td>1.18</td>
<td>1.06</td>
<td>1.05</td>
</tr>
<tr>
<td>Southern</td>
<td>2.11</td>
<td>2.43</td>
<td>1.84</td>
<td>1.65</td>
<td>1.64</td>
<td>1.44</td>
<td>1.34</td>
</tr>
<tr>
<td>Eastern</td>
<td>2.19</td>
<td>2.33</td>
<td>2.19</td>
<td>1.67</td>
<td>1.49</td>
<td>1.51</td>
<td>0.99</td>
</tr>
<tr>
<td>Western</td>
<td>1.30</td>
<td>1.24</td>
<td>1.08</td>
<td>1.11</td>
<td>0.91</td>
<td>1.18</td>
<td>0.95</td>
</tr>
<tr>
<td>Central</td>
<td>1.99</td>
<td>2.03</td>
<td>1.58</td>
<td>1.50</td>
<td>1.72</td>
<td>1.06</td>
<td>0.96</td>
</tr>
</tbody>
</table>

a. In 2004, which district had the highest prevalence of HIV?
Southern District.

b. Comment on the HIV infection trends.
A steady decline in HIV prevalence can be observed in all districts.

Unit 2 answers

Warm-up questions

1. True or false? Nearly 100 000 people die every year in EMR/MENA because of AIDS.
   Circle your answer below.
   False

2. What is the impact of HIV/AIDS on children?
   Children are more likely to be kept home, drop out of school, start working to support the family, forgo necessities such as food and clothes, be sent away from home or become the head of the household.

3. What is the economic impact of HIV/AIDS on individuals, families and nations?
   A drop in economic wealth by as much as 40%, a decrease in household income and a drain on health services.

4. What is the burden of HIV/AIDS in terms of DALYs and deaths in EMR/MENA countries?
   In EMR/MENA countries, up to 1.3 million DALYs are lost due to HIV/AIDS. HIV/AIDS is the fifteenth leading cause of DALYs in EMR/MENA.

5. List some of the effects stigma has on HIV prevention, care and support for individuals with HIV and their families.
   Some of the effects of stigma include: discrimination in the workplace and in health-care settings, exclusion from social functions, and denial of benefits, privileges and services. Stigma is a barrier to protective behaviours and testing, and often results in the needs of marginalized populations being systematically ignored.
Case study

The five districts in Menaland have had different experiences with the HIV/AIDS epidemic. Examine the following data:

**Measures of HIV impact by district, Menaland, 2006**

<table>
<thead>
<tr>
<th>District</th>
<th>Proportion of deaths in adults due to HIV (estimated)</th>
<th>Life expectancy at birth</th>
<th>Proportion of deaths among working adults due to HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern</td>
<td>1.3%</td>
<td>65.6 years</td>
<td>1.5%</td>
</tr>
<tr>
<td>Southern</td>
<td>1.7%</td>
<td>67.3 years</td>
<td>1.3%</td>
</tr>
<tr>
<td>Eastern</td>
<td>2.7%</td>
<td>55.1 years</td>
<td>4.8%</td>
</tr>
<tr>
<td>Western</td>
<td>2.5%</td>
<td>58.9 years</td>
<td>3.5%</td>
</tr>
<tr>
<td>Central</td>
<td>1.5%</td>
<td>55.9 years</td>
<td>2.1%</td>
</tr>
</tbody>
</table>

a. In which district has the impact of HIV/AIDS been greatest?
   *The impact of HIV/AIDS has been greatest in the Eastern District.*

b. Based on the data above, which district would you expect to have the greatest impact of HIV/AIDS by the year 2012?
   *Given the high proportion of deaths among working adults due to HIV/AIDS combined with the high proportion of deaths among the general population in the Eastern District, a reasonable suspicion would be that by 2012 the impact indicators would be worse in the Eastern District.*

**Unit 3 answers**

**Warm-up questions**

1. Which body cells does HIV primarily infect?
   a. respiratory cells
   b. skin cells
   c. red blood cells
   d. white blood cells
   *HIV infects white blood cells, which are involved with protecting the body against infection as part of the immune system. These include lymphocytes and macrophage cells.*

2. How many major strains of HIV exist?
   *Two: HIV-1 and HIV-2.*

3. Which of the following is NOT a method of HIV transmission?
   a. sexual intercourse
   b. *casual physical contact*
   c. blood transfusion
   d. mother to foetus
   *HIV transmission is transmitted through body fluids, not through casual physical contact.*
4. What type of infectious agent is HIV?
   a. bacterium
   b. virus
   c. prion
   d. none of the above

   *HIV stands for human immunodeficiency virus.*

5. True or false? HIV infection and the onset of AIDS occur simultaneously.
   False. *AIDS is characterized by the clinical appearance of symptoms. It can occur years after the initial HIV infection.*

6. Which of the following is associated with increased risk of sexual transmission of HIV?
   a. failure to use a male or female condom
   b. a greater number of sexual partners
   c. a higher viral load in an infected partner
   d. all of the above

   *Failure to use a condom allows the virus to pass more easily from an infected to an uninfected person. The more sexual partners an individual has, the more likely the risk of one of them being infected with HIV. A greater amount of virus in the bodily fluids increases the chances that the virus will be transmitted to the uninfected partner.*

7. List the three main types of antiretroviral drugs used to treat HIV infection.
   *The three main types of antiretroviral drugs are nucleoside reverse transcriptase inhibitors, non-nucleoside reverse transcriptase inhibitors and protease inhibitors.*

8. True or false? The presence of existing STIs increases the risk of acquiring HIV during sexual intercourse.
   True. *The inflammation and ulceration caused by existing STIs makes it easier for HIV to enter the body.*

9. Which of the following opportunistic infections commonly occurs in AIDS patients?
   a. herpes zoster
   b. cryptococcosis
   c. TB
   d. all of the above

   *AIDS patients have weaker immune systems, making it easier for the patients to acquire these opportunistic infections.*

10. True or false? A vaccine for the prevention of HIV infection is currently available.
    False. *While vaccines are being researched and may be available many years in the future, currently there is no HIV vaccine.*
11. True or false? Some STIs, such as *Chlamydia*, are biologically more easily acquired by young women, making them more susceptible to HIV infection.

*True. Because of their more fragile vaginal walls, young women are more likely to be infected.*

12. *Prophylaxis* is the term used to describe the treatment to prevent or suppress infection.

*This helps to prevent opportunistic infections from developing in patients with HIV infection.*

Case study

The Western District in Menaland has experienced rapid expansion of the HIV epidemic. Examine the data and answer the questions below.

**Incidence of various STIs over time, Western District**

<table>
<thead>
<tr>
<th>STI</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gonorrhoea(\text*)</td>
<td>5.0</td>
<td>12.8</td>
<td>23.5</td>
</tr>
<tr>
<td>Syphilis(\text*)</td>
<td>2.1</td>
<td>4.5</td>
<td>16.4</td>
</tr>
<tr>
<td>Reported cases of urethritis from STI clinic</td>
<td>2987</td>
<td>3452</td>
<td>6784</td>
</tr>
<tr>
<td>HIV incidence (estimated)</td>
<td>2%</td>
<td>4.3%</td>
<td>5.0%</td>
</tr>
</tbody>
</table>

\(\text*\) Cases per 1000 population 15–49 years old

a. Do you think that STIs may be playing an important role in the spread of HIV infection? Why?

*Yes, STIs are likely to be playing a major role in the spread of sexually transmitted HIV in this district. It is likely that STIs are important in HIV transmission because: rates of STIs are high and increasing; and prevalence of HIV is relatively low and incidence is rising.*

b. Would an STI prevention programme be an important part of the district’s HIV control efforts?

*Yes, an enhanced STI control programme may be critical to decreasing HIV incidence.*

c. Given the HIV incidence in the Western District, what do you think will happen with TB rates in the next several years and why?

*TB rates will likely increase as the HIV epidemic spreads. TB is the most important opportunistic infection in EMR/MENA. TB cases will involve both the appearance of active TB among persons already infected with TB and transmission of TB from HIV-infected persons to both those with and without HIV infection.*
Unit 4 answers

Warm-up questions

1. Which of the following terms indicates the number or proportion of persons in a population who have a disease at a given point in time?
   a. sensitivity  
   b. prevalence  
   c. negative predictive value  
   d. none of the above  
   Sensitivity and negative predictive value are terms used to describe a case definition, while prevalence is a measure of disease burden in a given population.

2. True or false? One-time cross-sectional surveys are valid methods of HIV/AIDS surveillance.  
   False. Surveillance systems involve ongoing collection and analysis of data, not a one-time survey.

3. Match the following terms with their definitions:
   - **c. sentinel surveillance**: c. surveillance system in which reports are obtained only from certain selected facilities and populations.
   - **a. laboratory-based reporting**: a. surveillance system in which the reports of cases come from clinical laboratories as opposed to health-care practitioners or hospitals.
   - **b. case definition**: b. clinical and laboratory characteristics that a patient must have to be counted as a case for surveillance purposes.

4. Which of the following terms indicates the number of persons who newly develop a disease within a specified time period?
   a. specificity  
   b. positive predictive value  
   c. incidence  
   d. none of the above  
   Specificity and positive predictive value are terms used to describe a case definition, while incidence is the rate at which disease burden is increasing in a particular population.
Case study

Background:
Until 2006, Menaland reported AIDS using the 1994 WHO AIDS case definition, so only patients with AIDS were reported.
In 2006, WHO expanded AIDS case reporting to include all clinical stages of HIV. Also in 2006, WHO developed new clinical staging of adult and paediatric HIV disease and new HIV surveillance case definitions.
The WHO is sponsoring a pilot project in Menaland to examine the sensitivity, specificity and positive predictive value of the 1994 case definition using the newer 2006 case definition for advanced HIV disease as a “gold standard”.
One hundred patients were evaluated using the 1994 AIDS case definition and the 2006 case definition for advanced HIV infection.
Examine the comparison data in the following table:

### Number of patients who meet the 2006 WHO case definition for advanced HIV disease and the 1994 WHO AIDS case definition

<table>
<thead>
<tr>
<th>1994 case definition</th>
<th>2006 WHO case definition</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Present</td>
<td>Absent</td>
<td>Total</td>
<td></td>
</tr>
<tr>
<td>Definition met</td>
<td>65</td>
<td>4</td>
<td>69</td>
<td></td>
</tr>
<tr>
<td>Definition not met</td>
<td>6</td>
<td>25</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>71</td>
<td>29</td>
<td>100</td>
<td></td>
</tr>
</tbody>
</table>

a. If the 2006 WHO case definition is defined as the “gold standard”, what are the sensitivity and specificity of the 1994 AIDS case definition to detect advanced HIV disease?

Sensitivity = 65/71 (92%), specificity = 25/29 (86%).

b. What is the positive predictive value of the 1994 AIDS case definition in patients similar to those in this study?

PPV = 65/69 (94%).

c. What proportion of the patients in this study actually have advanced HIV disease, as defined by the 2006 WHO case definition?

You cannot tell from these data. Case definitions are for epidemiological, not clinical, purposes. However, at least 71% of patients (as defined by the 2006 WHO case definition) have advanced HIV disease. The true proportion is likely to be higher.
Unit 5 answers

Warm-up questions

1. True or false? HIV/AIDS surveillance can be used to identify groups or geographic areas for targeted interventions.
   True. By providing an assessment of the distribution and prevalence of the disease, surveillance can help to identify the areas and populations that might benefit the most from interventions.

2. True or false? HIV seroprevalence surveillance is more likely to underreport the status of an epidemic than HIV case reporting is.
   False. Because HIV case reporting is based on clinical symptoms, and since HIV has a long latent period, HIV case reporting can lead to an underreporting of the true number of infected people.

3. _______________ provides detailed, high-quality data about a more specific population by using a smaller, more reliable system.
   a. Universal AIDS case reporting
   b. Sentinel surveillance

   Unlike universal case reporting, sentinel surveillance allows for a more complete data set to be obtained from a smaller number of sites that are known to be more reliable at reporting cases.

4. True or false? Prevalence and incidence data can be directly compared.
   False. While prevalence measures the number or proportion of people in a given population with a particular disease or condition, incidence measures the rate at which new cases are occurring. While they cannot be compared, they help to provide a more complete picture of the epidemic. For example, while prevalence might be low at the beginning of an epidemic, incidence might be high because of a rapid rate of transmission.

5. Which of the following is not a direct objective of HIV surveillance?
   a. providing an accurate assessment of the distribution of disease by person, place and time
   b. distributing antiretroviral medications to patients with advanced HIV disease
   c. providing information to evaluate the effectiveness of prevention efforts
   d. providing data for prevention programme management
   e. None of the above

   Surveillance focuses on gathering and analysing data to learn more about the HIV/AIDS epidemic. Providing treatment in a more effective way might be one of the uses of the data, but it is not a component of surveillance itself.

6. Name two sentinel populations that can be sampled for HIV sentinel surveillance activities.
   Potential sentinel populations include antenatal clinic attendees, STI patients, blood donors, etc.
7. Incidence is the rate at which new HIV infections occur in a population in a given period of time, while prevalence is a unitless proportion that measures the level of HIV infection in a population. 

Incidence measures the rate of new infections, while prevalence measures the number or proportion of people in a population who are infected with HIV.

8. Which of the following is/are core elements of an HIV surveillance system?
   a. case reporting of advanced HIV disease
   b. HIV seroprevalence surveys in selected populations
   c. both a and b
   d. neither a nor b

Used together, these two elements of surveillance help to give a more complete picture of the epidemic. While HIV surveillance can describe the current levels and trends, advanced HIV disease reporting gives a picture of clinical disease burden and important methods of HIV transmission.

**Case study**

In the Northern District of Menaland, the Ministry of Health has conducted a long-term cohort study of 1000 residents who were originally uninfected with HIV in 1997. The goal is to measure the incidence and prevalence of HIV infection.

Examine the data in the table below:

**HIV infections in Northern District Cohort Study, 1998–2002**

<table>
<thead>
<tr>
<th>HIV infection status</th>
<th>1998</th>
<th>1999</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
</tr>
</thead>
<tbody>
<tr>
<td>New HIV infections</td>
<td>10</td>
<td>25</td>
<td>50</td>
<td>80</td>
<td>114</td>
</tr>
<tr>
<td>Total HIV infections</td>
<td>10</td>
<td>35</td>
<td>85</td>
<td>165</td>
<td>279</td>
</tr>
<tr>
<td>Population at risk (non-infected)</td>
<td>1000</td>
<td>990</td>
<td>965</td>
<td>915</td>
<td>835</td>
</tr>
<tr>
<td>Total population (infected and non-infected)</td>
<td>1000</td>
<td>1000</td>
<td>1000</td>
<td>1000</td>
<td>1000</td>
</tr>
</tbody>
</table>

a. What is the prevalence of HIV infection in 2002?
   \[
   \frac{279}{1000} = 27.9\%.
   \]

b. What is the incidence of HIV infection in 2002?
   \[
   \frac{114}{915} = 12.5\% \text{ or } 12.5 \text{ per } 100 \text{ person-years}
   \]

c. In which year was the incidence the highest?
   2002.
Unit 6 answers

Warm-up questions

1. Which of the following is the goal of second-generation HIV surveillance?
   a. better understanding of behaviours driving the epidemic
   b. surveillance more focused on subpopulations at highest risk for infection
   c. surveillance of the children of patients who acquired HIV in the first wave of infections
   d. a and b
   e. none of the above
   
   Second-generation surveillance is designed to collect and integrate data from a variety of sources, including behavioural surveys, sentinel surveillance, STI surveillance, etc.

2. The types of elements included in second-generation surveillance vary according to the type of epidemic. List the three types of HIV/AIDS epidemics.
   The three possible types of epidemic are low-level, concentrated and generalized.

3. True or false? Second-generation surveillance is flexible and can change with the needs and state of the epidemic in a particular country.
   True. Second-generation surveillance has many components that can be selected for use in a country, depending on its particular circumstances.

4. Which of the following is not yet a regular element of second-generation HIV surveillance?
   a. screening of donated blood
   b. behavioural surveillance
   c. surveillance for coexisting opportunistic infections
   d. HIV case reporting
   
   As access to care improves, surveillance for opportunistic infections will become more important, but it is not yet a regular component of second-generation surveillance.

Case study

Ormeland has a concentrated HIV epidemic, but has yet to move beyond HIV case reporting, research projects and an occasional HIV prevalence survey.

There is limited funding from the World Bank to expand surveillance activities in the capitol city, Orme, where HIV incidence and STI rates are reported to be increasing in sex workers.

a. How would you suggest investing these funds?
   There is no single correct answer. Given the limited nature of surveillance activities in Orme, improving second-generation HIV surveillance in this district should be made a priority. Components of second-generation surveillance that could be implemented include HIV and STI seroprevalence surveillance in defined and general populations and behavioural surveillance to assess sexual and drug-injecting behaviours.

b. What is your goal, and what benefits do you expect from an investment in surveillance?
The goal of an improved second-generation surveillance programme is to provide sufficient data to guide the prevention and treatment programmes.

Since Orme has a concentrated epidemic, surveys of most-at-risk populations (MARPs) should be instituted and conducted every two years. These data could then be used to estimate the spread of HIV in Orme in MARPs and to evaluate the impact of prevention programmes designed to limit transmission among MARPs.

In addition, given the prominent role that STIs appear to play in the epidemiology of HIV in Orme, improving surveillance of STIs may also be an important investment. STI surveillance is also good because STI incidence can serve as a surrogate to monitor HIV risk behaviours.

### Unit 7 answers

#### Warm-up questions

1. True or false? Because of the urgent need to treat and prevent HIV/AIDS, issues such as confidentiality and informed consent do not need to be addressed.

   False. Because of the stigma associated with HIV and related behaviours, infected individuals are vulnerable to social, physical and legal harms. They need to have their privacy protected through measures such as confidentiality and informed consent.

2. The principle of beneficence refers to minimizing risk to individuals in the areas of:

   a. physical risk
   b. psychological harm
   c. stigmatization
   d. all of the above.

   Beneficence refers to balancing the benefits and risks to individuals. This includes not only physical dangers, but also psychological harm and stigmatization.

3. True or false? Providing large monetary or in-kind incentives is an ethical way to ensure that more participants agree to give informed consent.

   False. With excessive incentives, individuals may decide to participate for purely economic reasons. This might create bias, since the sample might then include a larger number of people with high infection rates who are in greater need of money or health care.

4. True or false? In low-level epidemics, information about HIV infection in high-risk or marginalized groups should be widely publicized to prevent further spread of the disease.

   False. Early on during a low-level epidemic, the general public may react to information about HIV infection in high-risk groups by calling for restrictive and prohibitive measures, driving these groups further underground. Be careful when designing public awareness programmes during this stage.

5. The process by which potential threats to confidentiality are discussed with subjects before they decide to participate is known as informed consent. Giving subjects full information about the study and the potential risks and benefits helps them to make a more informed decision about whether to participate.
6. List three potential risks to participants in a behavioural surveillance study.

Potential risks include disclosure leading to isolation, loss of employment, prosecution, etc.

7. List two types of programmes or services that can be developed as a result of surveillance activities.

Potential services include STI clinics, voluntary testing and counselling centres, HIV prevention programmes, public awareness campaigns, etc.

8. Fill in the blank with one of the choices below. If _____________ about HIV infection is violated, subjects may suffer discrimination and stigmatization. They may even be subject to criminal charges.

a. privacy  
b. informed consent  
c. confidentiality  
d. beneficence

Confidentiality involves protecting the personal information of study participants, including their infection status. If this is violated, they may suffer physical, social or legal harms, because of stigma associated with HIV.

9. True or false? In unlinked anonymous testing, informed consent is obtained. Some information identifying the sample with the patient remains.

False. Informed consent does not need to be obtained because the survey is anonymous i.e. no personal identifying information of the patient remains on the sample.

Case study

You are the health officer in charge of HIV surveillance for the Northern District in Menaland. You have been asked to design and implement a special HIV seroprevalence survey among male patients with acute urethritis attending the STI clinic at the provincial referral hospital.

You are weighing two options:

1. The first would entail a self-administered questionnaire and an additional blood test for HIV and syphilis.

2. The second would entail a blinded survey of all patients who have blood drawn for syphilis serologies. Approximately 50% of patients who present with acute urethritis have serum samples drawn for syphilis; syphilis serologies are done at the clinician’s discretion, and there is no standard protocol for when to order these serologies.

a. For which option would you need informed patient consent?

You would need informed patient consent for option 1 because this involves procedures that would not be routinely conducted (interview and separate blood draw). If you wanted to administer a questionnaire to patients in option 2 and link it to their HIV results, you would need an informed consent for this, as well.
b. How likely are the two options to yield an accurate estimate of the prevalence of HIV infection in this patient population?

*It would depend on the participation rate. If you could get most patients to participate in option 1, that would be preferable. Because syphilis serologies, which are the basis for HIV testing in option 2, are only drawn for 50% of the patients and are drawn at the discretion of the clinician, they are unlikely to represent a true random sample of the clinic population.*

c. In which option would patient confidentiality be better protected?

*Option 2 because the patients’ names would not be linked to their HIV results. On the other hand, patients found to be HIV-infected in option 2 would not necessarily have the opportunity to seek care for HIV.*

d. If you were to offer an incentive (such as reimbursement for transportation) to participants in option 1, would this be considered ethical?

*Incentives must be modest in order to be ethical. Reimbursing participants for out-of-pocket expenses for getting to the study site is a reasonable incentive. Buying them a cow or chickens is not.*

### Unit 8 answers

#### Warm-up questions

1. List two demographic variables by which surveillance data can be analysed.

   *Data can be analysed using variables such as age, sex, marital status, etc.*

2. True or false? Compiling all the data into one comprehensive chart or graph is more effective than including many simpler diagrams.

   *False. Do not include too much data in one graphic, since it makes it confusing and difficult to interpret. Creating multiple simple graphics is more effective.*

3. Which of the following can be extracted from public health surveillance data:

   a. changes over time
   b. changes by geographic distribution
   c. differences according to subject’s sex
   d. all of the above.

   *If data are analysed properly, they can be used to examine all of the above issues.*
4. Match the type of chart/graph with its example:

1. Scale line graph
   answer: d

![Scale line graph image]

2. Area map
   answer: c

![Area map image]

3. Pie chart
   answer: a

![Pie chart image]

4. Histogram
   answer: b

![Histogram image]
**Case study**

Examine the data below to answer the questions below. Remember to title every graph.

**HIV prevalence (%) by district among STI clinic attendees, Menaland 2000–2003**

<table>
<thead>
<tr>
<th>District</th>
<th>2000</th>
<th>2001</th>
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<td>5.0</td>
<td>2.4</td>
<td>7.2</td>
<td>14.4</td>
</tr>
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<td>2.0</td>
<td>2.3</td>
<td>2.8</td>
</tr>
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<td>7.6</td>
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<td>6.5</td>
<td>5.6</td>
<td>3.2</td>
</tr>
</tbody>
</table>

a. Create a bar chart that shows prevalence by district in 2002.

**HIV prevalence by district, Menaland 2002.**

b. Create a graph to show prevalence trends by year in the Northern District.

**HIV prevalence by year, Northern District, Menaland**
c. Create a clustered bar chart to show prevalence by district by year (2000–2003).

**HIV prevalence by district and year, Menaland**

<table>
<thead>
<tr>
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<td>708</td>
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<tr>
<td>2003</td>
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<td>36%</td>
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<td>18%</td>
<td>32%</td>
<td>27%</td>
<td>9%</td>
</tr>
</tbody>
</table>


d. Using the data in the following table, create a pie chart showing the number of reported cases of syphilis from four STI clinics in the five districts in Menaland in 2002
Unit 9 answers

Warm-up questions

1. List three stakeholder groups that should be engaged during the evaluation of the surveillance system.
   
   Potential stakeholder groups include public health practitioners, health-care providers, government officials, representatives of affected communities, non-profit and donor organizations, etc.

2. If there is a high probability that cases identified by the surveillance system are actually cases of HIV infection, the system is said to have high:
   
   a. sensitivity
   b. representativeness
   c. acceptability
   d. positive predictive value.

   If a system has a high positive predictive value, then cases that are identified are more likely to be actual cases instead of false positives. This system is better than one that has a low positive predictive value.

Case study

The Southern District is in the coastal area of Menaland and has the country’s major port city, Janoubia. A university has been conducting studies of female sex workers in Janoubia for nearly a decade. For the last five years, they have been conducting serial seroprevalence surveys for HIV and syphilis.

You are the district surveillance officer for the Southern District. You are asked by the Ministry to evaluate these special studies to determine if the Ministry should take over sponsorship of the studies and include them in the sentinel surveillance system.

a. How would you start your evaluation?

   Get stakeholders involved by meeting:
   
   ● representatives of the provincial health department
   ● community-based organizations working with HIV prevention among female sex workers
   ● representatives of the university who have been conducting the surveys.

   You may want to invite one or two of them to become a part of the evaluation team. Before designing your evaluation, you would gather details about the surveys—the particulars of data collection, the costs (personnel, other) etc.

b. On what would you focus in your evaluation?

   It would be important to understand the acceptance of the university among the local population and how they are perceived in the community. Also, gather information about the process of data collection. Ask questions such as:

   ● Who collects the data?
   ● What type of training did they receive?
   ● Where do they get participants?
   ● Where are blood samples analysed?
Introduction to HIV/AIDS and sexually transmitted infection surveillance

● What is the quality of the laboratory results?
● If blood samples are sent away for analysis, is there a long time-lag between data collection and announcing results?
● If the Ministry of Health is to take over the sponsorship of the studies, would the personnel need to be changed?
● Who would do the work?
● Is the expertise/capacity there? If not, how would it be built?
● What would the cost of this be?
● Where are the data analysed?
● What have the data been used for?

c. What criteria would you use to assess the performance of the system?

The cost of the system would be an important factor to evaluate. The acceptability of the surveillance system would also be key:
● Do individuals agree to complete the surveys?
● How representative are those that complete the surveys of the general population?
● Are others missing? How valid is the data that is collected?
● How would the data be used?

d. What would you recommend?

It would depend on the results of the evaluation. If the university is widely accepted in the community and is eager to assist the Ministry in a smooth and cost-effective transition it may be worth considering, but the data would need to be valid and of good predictive value to be a worthwhile investment.
Final case study

1. You are the HIV seroprevalence officer for the Northern District. Northern District is a large district in Menaland, a country with an HIV epidemic concentrated in sex workers and injecting drug users. To monitor the epidemic in the general population, seroprevalence surveys are conducted annually atANCs in Northern District. You examine data from the past five years and observe the following:

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of subjects</th>
<th>Overall prevalence</th>
<th>Prevalence by age (years):</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001</td>
<td>1695</td>
<td>0.4%</td>
<td>15–19: 0.1%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>20–24: 0.4%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>25–29: 0.5%</td>
</tr>
<tr>
<td>2002</td>
<td>1859</td>
<td>0.8%</td>
<td>30–34: 0.3%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>35–39: 0.2%</td>
</tr>
<tr>
<td>2003</td>
<td>1836</td>
<td>1.3%</td>
<td>40–44: 0.1%</td>
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<td>1.5%</td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>1849</td>
<td>1.9%</td>
<td></td>
</tr>
</tbody>
</table>

a. Using the above data, create a figure to show HIV prevalence among pregnant women aged 25–29, by year.

HIV prevalence among ANC attendees ages 25 to 29 years, Northern District, 2001–2005

b. What trends do you see regarding HIV prevalence in relation to age and year?
HIV prevalence increased among ANC clinic attendees of all age groups between 2001 and 2005 from an overall HIV prevalence of 0.4% in 2001 to 1.9% in 2005. In general, HIV prevalence was highest among pregnant women aged 25 to 29 years and lowest among pregnant women aged 15 to 19 years and 40 to 44 years.

c. Based on the above data, how would you characterize the HIV epidemic in the Northern District of Menaland in 2005?
As the prevalence of HIV among pregnant women in the Northern District is consistently greater than 1%, the Northern District has a generalized HIV epidemic.
2. Northern District has recently been given funds to begin second-generation HIV surveillance. Until now, HIV surveillance has been limited to HIV case reporting and sentinel seroprevalence surveillance at antenatal and STI clinics.

   a. What components of second-generation HIV surveillance would you implement to strengthen the district’s surveillance system?

   When possible, components of second generation surveillance that would strengthen the district’s surveillance system would include:

   ● behavioural surveillance, which involves asking a sample of people about their sexual behaviour and, sometimes, their drug-injecting behaviour
   ● improving and using HIV case reporting
   ● improving and using death registries
   ● STI surveillance.

   b. What measures would you include?

   Biological measures could include: HIV prevalence, STI incidence and prevalence, TB prevalence, the number of adult AIDS cases and the number of paediatric AIDS cases. Behavioural indicators could include: sex with a non-regular partner in last 12 months, condom use at last sex with a non-regular partner, age at first sex, use of unclean injecting equipment reported by drug injectors and reported number of clients in the last week by sex workers.

   Sociodemographic indicators could include: age, gender, socioeconomic and educational status, geographic residency (urban vs. rural) or migration status, marital status and parity (for antenatal sites).

3. Menaland provides free ART to HIV-infected pregnant women. What ethical issues must you consider when conducting HIV surveillance among pregnant women in a setting where ART is available?

   Because ART is available in Menaland, conducting HIV surveillance through anonymous unlinked seroprevalence surveillance presents ethical issues. If anonymous unlinked surveillance surveys are used, women must have access to voluntary HIV counselling and testing with referrals for care for HIV-infected women. Case reporting and surveys conducted in conjunction with VCT would diagnose individuals with HIV infection and give them their results, so that if needed, they could begin ART. They must present the same ethical concerns as anonymous unlinked surveys.

4. Annual seroprevalence surveys have been conducted at five ANCs in the district for the past four years. The survey is conducted between June and September of each year. Evaluation of the seroprevalence surveys is one of your responsibilities. This entails assessing the data for quality and completeness. After the first two months of the current annual survey you examine the database and observe the following:
Annex 3  Answers to warm-up questions and case studies

<table>
<thead>
<tr>
<th></th>
<th>Site 1</th>
<th>Site 2</th>
<th>Site 3</th>
<th>Site 4</th>
<th>Site 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of subjects</td>
<td>158</td>
<td>165</td>
<td>208</td>
<td>287</td>
<td>189</td>
</tr>
<tr>
<td><strong>Percentage of missing data:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>6%</td>
<td>5%</td>
<td>2%</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>Date specimen collected</td>
<td>2%</td>
<td>1%</td>
<td>1%</td>
<td>2%</td>
<td>3%</td>
</tr>
<tr>
<td>Residence</td>
<td>4%</td>
<td>5%</td>
<td>2%</td>
<td>3%</td>
<td>5%</td>
</tr>
<tr>
<td>Parity</td>
<td>3%</td>
<td>2%</td>
<td>1%</td>
<td>2%</td>
<td>3%</td>
</tr>
<tr>
<td>Live births</td>
<td>1%</td>
<td>2%</td>
<td>2%</td>
<td>1%</td>
<td>3%</td>
</tr>
<tr>
<td>HIV serology</td>
<td>1%</td>
<td>1%</td>
<td>0%</td>
<td>20%</td>
<td>1%</td>
</tr>
</tbody>
</table>

a. What are your thoughts regarding the data in this table? Is there anything of concern?

*20% of HIV serologic results are missing from site 4.*

b. What are some possible explanations for this finding? How would you investigate these? What steps would you take to correct the problem(s)?

There are many possible explanations, including:

- A problem with data entry. This could be investigated by examining the hard copies of the data.
- A laboratory error: testing was not done.
- A laboratory error: testing was done but not recorded.

You conduct your investigation and find that the HIV serologic results are missing on the hard copies. You then visit the laboratory and meet with the director.

In your discussions, you discover that reagents for HIV testing were not available for a period of time. The laboratory director indicates that there is now an ample supply of HIV reagents and that the survey can be completed without any interruptions.

c. Having identified the problem, how do you address it in the short term, and what are some steps you can take to ensure that such a problem does not recur?

- Additional training might be needed. At a minimum, the seroprevalence coordinator should meet first with the laboratory director and then with laboratory staff to review the protocol.
- In addition, since one lapse in protocol was found, the coordinator should keep a close watch on the data from this site and should make frequent visits there to assess adherence to protocol, answer questions and stress the importance of seroprevalence surveys.
- Improving communication between the seroprevalence coordinator and the laboratory director regarding the adequacy of supplies should also be discussed.
Annex 4

Differences between public health and research models
Differences between public health and research methods

Research or non-research classification

Public health surveillance and programme evaluation are usually not considered to be research and do not have the same requirements for informed consent as research with human subjects. There are, however, some areas where public health surveillance and programme evaluation overlap with research. In general, when knowledge acquired from surveillance activities can be applied generally or does not result in public health action, the activity is considered research. Specific criteria, suggested by the U.S. Centers for Disease Control and Prevention (CDC), for classifying a study as not being research are listed below, and specific guidance is shown in Table A4.1. Determining whether a surveillance system is research or not research is important because it determines whether research protections, such as institutional review board approval and informed consent are needed.

The CDC criteria for classifying a public health activity as non-research include when the:

- intent of a study is to identify and control a health problem or improve a public health programme or service
- intended benefits of the project are primarily or exclusively for the participants or the participants’ community
- data collected are needed to assess and/or improve the programme or service, the health of the participants or the participants’ community
- knowledge that is generated does not extend beyond the scope of the activity
- project activities are not experimental.

Surveillance systems may be either research or non-research. Surveillance systems are likely to be non-research when:

- they involve the regular, ongoing collection and analysis of health-related data conducted to monitor the frequency of occurrence and distribution of disease or a health condition in the population
- data generated by these systems are used to manage public health programmes
- they have in place the ability to invoke public health mechanisms to prevent or control disease or injury in response to an event.

Thus, the primary intent of these surveillance systems is to prevent or control disease...
### Table A4.1 Guidance for classifying public health activities as research and to protect human subjects

<table>
<thead>
<tr>
<th>Research</th>
<th>Practice (non-research)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition</strong></td>
<td>Systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge.</td>
</tr>
<tr>
<td><strong>Primary intent</strong></td>
<td>To generate new or generalizable knowledge (information that can be applied in other settings)</td>
</tr>
<tr>
<td><strong>Methodology</strong></td>
<td>- Scientific principles and methods used</td>
</tr>
<tr>
<td></td>
<td>- Hypothesis testing/generating</td>
</tr>
<tr>
<td></td>
<td>- Knowledge is generalizable</td>
</tr>
<tr>
<td><strong>Examples</strong></td>
<td><strong>Surveillance projects</strong></td>
</tr>
<tr>
<td></td>
<td>- Scope of data is broad</td>
</tr>
<tr>
<td></td>
<td>- Analytical analyses</td>
</tr>
<tr>
<td></td>
<td>- Hypothesis testing</td>
</tr>
<tr>
<td></td>
<td>- Subsequent studies using cases</td>
</tr>
<tr>
<td></td>
<td><strong>Emergency response</strong></td>
</tr>
<tr>
<td></td>
<td>- Samples stored for future use</td>
</tr>
<tr>
<td></td>
<td>- Additional analyses performed beyond immediate problem</td>
</tr>
<tr>
<td></td>
<td>- Investigational drugs tested</td>
</tr>
<tr>
<td></td>
<td><strong>Programme evaluation</strong></td>
</tr>
<tr>
<td></td>
<td>- Test an intervention</td>
</tr>
<tr>
<td></td>
<td>- Systematic comparison of standard and nonstandard interventions</td>
</tr>
</tbody>
</table>

or injury in a defined population by producing information about the population from whom the data were collected.

Activities that would be classified as non-research include:

- AIDS case reporting systems
- regular ANC seroprevalence surveillance surveys
- regular behavioural surveys
- many surveys of high-risk groups that collect simple demographic, biological and behavioural data on an ongoing basis for the purposes of guiding HIV prevention and control efforts.

Surveillance systems are likely, however, to be classified as research when:

- they involve the collection and analysis of health-related data conducted either to generate knowledge that is applicable to other populations and settings than the ones from which the data were collected or to contribute to new knowledge about the health condition.
- the information gained from the data collection system may or may not be used to invoke public health mechanisms to prevent or control disease, but this is not a primary intent of the project.

Thus, the primary intent of these surveillance systems is to generate generalizable knowledge. Characteristics of surveillance systems that most likely fit into this category are:

- when they are longitudinal data collection systems (for example, follow-up surveys and registries) that allow for hypothesis testing
- when the scope of the data is broad and includes more information than occurrence of a health-related problem
- when analytic analyses can be conducted
- when cases may be identified to be included in subsequent studies.

**Institutional review boards**

If a study is classified as research, it does not mean that ethical standards can be ignored in that study. If it has been determined that a study is a research project rather than surveillance, review and approval by a local or national ethics committee or institutional review board is necessary. Most donor agencies and countries have additional requirements regarding review and approval. External review by these committees provides extra protection for study subjects and investigators and is helpful in anticipating problems and suggesting solutions.

In special circumstances, institutional review boards will include on their committee special advocates for the risk populations that will be participating in research. For example, when conducting surveillance or special studies among prisoners, a prisoner advocate should be included in the institutional review board and participate in all discussion regarding the study protocol. When this sort of review is needed, the study protocol should be submitted as soon as possible, since the review may take several weeks.
WHO ethical guidelines

WHO has commissioned a set of ethical guidelines specifically directed at second-generation surveillance, available at www.who.int/hiv/pub/epidemiology/en/sgs_ethical.pdf. These guidelines provide an overview of literature in the field of medical ethics, the ethics of epidemiological research and the ethics of surveillance. Other issues addressed relate to:

- data collection in behavioural surveillance
- seroprevalence surveillance, with an emphasis on consent
- data use and dissemination, with an emphasis on the obligation to disseminate data
- the right to access test results.

The guidelines also take into account the ethical implications of the data collection by type of epidemic: low-level, concentrated and generalized.
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.