Introduction to HIV, AIDS and Sexually Transmitted Infection Surveillance

Overview of the HIV/AIDS Epidemic with an Introduction to Public Health Surveillance

Participant Manual

February 2011 Edition 3.0

Acknowledgments

This manual was prepared by the United States Department of Health and Human Services, Centers for Disease Control and Prevention (HHS-CDC), Global AIDS Program (GAP) Surveillance Team in collaboration with:

- The World Health Organization (WHO), Department of HIV/AIDS, Geneva, Switzerland
- the World Health Organization (WHO), Regional Office of the Eastern Mediterranean (EMRO), Division of Communicable Diseases, AIDS and Sexually Transmitted Diseases (ASD) Unit, Cairo, Egypt
- the World Health Organization (WHO), Regional Office of Africa (AFRO)
- the World Health Organization (WHO), Regional Office of South-East Asia (SEARO)
- the University of California at San Francisco (UCSF), Institute for Global Health, AIDS Research Institute through the University Technical Assistance Program (UTAP) with CDC/GAP.

Additional assistance was provided by Tulane University, School of Public Health and Tropical Medicine, New Orleans, USA, through the UTAP with CDC-GAP.

This participant manual is jointly published by HHS-CDC and UCSF.

This manual was funded by the Presidents Emergency Plan for AIDS Relief (PEPFAR) and supported by UNAIDS and the Office of the Global AIDS Coordinator (OGAC) interagency Surveillance and Survey Technical Working Group that consists of:

- United States Census Bureau
- United States Agency for International Development (USAID)
- United States Department of Defense
- United States State Department

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Introduction

How to Study This Module

What you should know before the course

This course is targeted primarily for HIV surveillance officers at the national and sub-national levels. As a participant, you should have a basic medical understanding of HIV/AIDS and public health surveillance before taking the course.

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.

Unit 1 discusses the global HIV/AIDS situation, and then focuses on the HIV/AIDS situation in specific regions. Six Unit 1s are presented in the module, one each for Asia, Caribbean, Eastern Europe and Central Asia, Latin America, North Africa and Middle East, and sub-Saharan Africa. Choose the Unit 1 that is most relevant to your country.

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 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 each unit, the class will discuss the warm-up questions and you can check your work.

As you study this module, you may come across italicised terms and acronyms that are unfamiliar. In Appendix B, you will find a glossary that defines these terms.

Module summary	This module provides an introduction to the HIV/AIDS epidemic and public health.
Appendices	More information is provided in the following appendices:
	Appendix A, References and Further Reading Material Appendix B, Glossary and Acronyms Appendix C, Useful Links Appendix D, Answers to Warm-Up Questions and Case Studies Appendix E, Differences between Public Health and Research Methods

Additions, Corrections, Suggestions

Do you have changes to this module? Is there additional information you would like to see? Please write or email us. We will collect your letters and emails and consider your comments in the next update to this module.

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Notes

Unit 1 The Global HIV/AIDS Situation Focus: Asia

Overview

What this unit is about

This unit discusses the global HIV/AIDS situation and then focuses on the HIV/AIDS situation in Asia. For the purpose of this unit, Asia includes Afghanistan, Bangladesh, Bhutan, Brunei, Cambodia, China, India, Indonesia, Iran, Japan, Korea, Korea DPR, Laos, Malaysia, Maldives, Mongolia, Myanmar, Nepal, Pakistan, Philippines, Singapore, Sri Lanka, Thailand, Timor-Leste, and Vietnam. We consider recent data from Country Reports, WHO, UNAIDS, and other agencies.

Warm-up questions

1. True or false? As of 2009, approximately 33.3 million people were infected with HIV worldwide. Circle your answer below:

True False

2. In Asia, the two main factors driving the epidemic are:

_____ and _____.

3. List risk factors which contribute to the spread of HIV in Asia.

- 4. In which country in the Asia Region has the HIV epidemic begun to decline?
 - a. India
 - b. Myanmar
 - c. Thailand
 - d. Nepal

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 Asia.

Worldwide Epidemic

Acquired immunodeficiency syndrome (AIDS) is unique in human history in its rapid spread and the extent and depth of its effects. Since the first AIDS case was diagnosed in 1981, the world has struggled to cope with the extraordinary dimensions of this disease. Early efforts to mount an effective response were fragmented, piecemeal, and vastly underresourced. Few communities recognised the dangers ahead, and even fewer were able to provide an effective response. As of 2009, 28 years after AIDS was first diagnosed, approximately 33.3 million people (range: 31.4–35.3 million) are living with the *human immunodeficiency virus* (HIV) globally. In 2009, still about 1.8 million people died of AIDSrelated causes, similar to 1.9 million deaths due to AIDS in 2001.¹ The HIV epidemic continues to grow worldwide, destroying people's lives and, in many cases, damaging the fabric of societies.

In 2009, an estimated 2.6 million people became newly infected with HIV. Table 1.1, below, shows some of the HIV statistics worldwide.¹

¹ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010

Success in addressing the epidemic

The sub-Saharan African country of Uganda often has been cited as a 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. Median HIV prevalence at clinics outside major urban areas also has been reduced by 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 often are delaying sexual intercourse or abstaining entirely.

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

- Thailand is one of the 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 140,000 per year in 1991 to about 12,000 per year in 2009.
- There is evidence, however, that HIV is now spreading, largely among the spouses and partners of clients of *sex workers* (SWs) and among marginalised sections of the population, such as *injection drug users* (IDUs).

HIV Prevalence

Prevalence is the proportion of living persons in a population with a particular disease. It excludes those who have died from the disease. *Incidence* is the proportion of people acquiring a disease, such as HIV, in a given time period or in a population at risk for the disease. *Prevalence* is based on a combination of mortality, which lowers *prevalence*, and *incidence*, which increases *prevalence*.

Prevalence of HIV/AIDS in the region

Category	Number worldwide	Asia region	Percentage of global burden in Asia region
Adults and children living with HIV	33.3 million	4.9 million	14.7%
Adults and children newly infected with HIV	2.6 million	331 000	12.7%
Adult and child deaths due to AIDS	1.8 million	269 000	16.4%

Table 1.1 HIV/AIDS epidemic worldwide and in Asia, 2009.²

Note: The estimates for the Asia region provided in the table above include aggregate data from USAID/WHO East Asia and South and South-East Asia regions: Afghanistan, Bangladesh, Bhutan, Brunei, Cambodia, China, India, Indonesia, Iran, Japan, Korea, Korea DPR, Laos, Malaysia, Maldives, Mongolia, Myanmar, Nepal, Pakistan, Philippines, Singapore, Sri Lanka, Thailand, Timor-Leste, and Vietnam.

According to *The Joint United Nations Programme on HIV/AIDS* (UNAIDS) 2010 AIDS Epidemic Update, described in Table 1.1, in 2009 there were 4.9 million adults and children living with HIV in the region. This region represents a majority of the world's population (60%) and as of 2009 was home to 14.7% of the men, women and children living with HIV globally. It therefore has the potential to influence significantly the course and overall effect of the HIV/AIDS pandemic.

Although HIV *prevalence* is relatively low in most Asian countries, Asia has the second highest number of cases in the world after sub-Saharan Africa.

² Data were derived from: UNAIDS 2010 AIDS Epidemic Update.

Prevalence of HIV/AIDS in the region, continued



Figure 1.1. HIV prevalence in adults (aged 15-49 years) in Asia, 2009.³

Discussing prevalence

Study the map in Figure 1.1 above to answer these questions.

- a. Which countries in Asia are most affected by HIV/AIDS?
- b. What does the map show about the prevalence of HIV/AIDS in your country?

³ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010

HIV burden in each country in the region

The 2010 UNAIDS Epidemic Update cites an overall adult HIV prevalence of 0.1% for East Asia and 0.3% for South and South-East Asia. This rate is much lower, relatively, than it is in sub-Saharan Africa, where the overall adult HIV prevalence is 5.0% and as high as 24% in some African countries. Because the population of many Asian nations is very large, even low HIV prevalence means that large numbers of people are living with HIV.

Table 1.2 below shows the HIV disease burden for each country.

Country	Estimated HIV	Estimated number	Estimated number
	prevalence in adults	of PLWHA	of deaths
	(aged 15-49 years)		
	(%)		
East Asia	0.1	770 000	81 000
China	0.1	740 000	
Democratic People's Republic			
of Korea			
Japan	< 0.1	8100	<500
Mongolia	< 0.1	<500	<100
Republic of Korea	< 0.1	9500	<1000
South and South-East Asia	0.3	4 100 000	250 000
Bangladesh	< 0.1	6300	1400
Bhutan	0.2	<1000	
Cambodia	0.5	63 000	1200
India	0.3	2 400 000	120 000
Indonesia	0.2	310 000	
Lao People's Democratic	0.2	8500	<100
Republic			
Malaysia	0.5	100 000	10 000
Maldives	< 0.1	<100	
Myanmar	0.6	240 000	16 000
Nepal	0.4	64 000	4300
Pakistan	0.1	98 000	
Philippines	<0.1	8700	1200
Singapore	0.1	3400	
Sri Lanka	< 0.1	2800	<500
Thailand	1.3	530 000	12 000
Vietnam	0.4	280 000	24 000

Table 1.2. HIV/AIDS burden in Asia, 2009⁴

PLWHA = persons living with HIV/AIDS.

⁴ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010

Examples from the Asia Region

The *prevalence* of HIV among *IDUs* in Vietnam is very high: it was 9% in 1996 and had grown to 34% by 2005 (Ministry of Health Vietnam, 2006 & 2005). In 2005 in certain provinces, such as Hai Phong and Quang Ninh, 57% and 58% of *IDUs* tested positive, respectively (Vietnam Commission for Population, et al, 2006; Ministry of Health Vietnam, 2005). A survey from 2006 done in Ho Chi Minh City reported that 28% of people who had been injecting drugs for less than one year were already infected with HIV (Ministry of Health Vietnam, 2006).

Although the adult HIV *prevalence* in Indonesia in 2006 was only 0.2%, the HIV epidemic in that country is among the fastest-growing in Asia. The epidemic previously had been concentrated among *IDUs* in Bali, Jakarta, and West Java, with only 16 provinces reporting any HIV or AIDS cases in 2000. More recently, the epidemic has spread to the non-injecting sex partners of *IDUs*, *prisoners*, and *SWs* and their clients, with up to 32 provinces reporting HIV or AIDS cases (Ministry of Health Indonesia & Statistics Indonesia, 2007).

As of 2009, the overall Asian epidemic is stable, and no country has a generalized epidemic.⁵ Thailand's rate of new infections has dropped since its peak in the 1990s. However, in countries like Bangladesh, Pakistan and the Philippines where *prevalence* has been comparatively low, prevalence is now increasing.⁶

⁵ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010

⁶ UNAIDS. 2008 Report on the global AIDS epidemic. Geneva: UNAIDS; 2008.

Trends

Surveillance is the systematic collection and analysis of health data for the purpose of disease prevention and control. Because several countries in Asia have very low rates of HIV infection, measuring trends in the general population should be complemented with measuring *surveillance* trends among higher-risk populations. The majority of infections are concentrated among people with risk-taking behaviours, and the growth in the epidemic is seen in rising infection rates in these sub-populations with *high-risk behaviours*, which increase the likelihood that a person will contract HIV infection.

The steepest rises in HIV infections are seen among *IDUs*, as shown in Figure 1.2 below. Female *SWs* also represent a high-risk population. They generally are infected by their clients or boyfriends, and once infected, are likely to pass the infection on to other clients who do not use condoms or who use them incorrectly.





⁷ Monitoring the AIDS Pandemic (MAP). Drug Injection and HIV/AIDS in Asia (2005). Accessed online at http://www.mapnetwork.org/docs/MAP_IDU%20Book%2024Jun05_en.pdf

Trends, continued

Some Asian countries are so large that they contain many simultaneous HIV epidemics that are developing in different populations and at different rates.

- In India, the world's second most populous country, the HIV epidemic is diverse. According to a national *population-based survey* (NFHS-3, 2007), reported adult *prevalence* in six states varied from 0.07% in Uttar Pradesh to 1.13% in Manipur.⁸
- Sentinel surveillance among pregnant women in 2006 in Tamil Nadu, Maharashtra, Karnataka, and Andhra Pradesh show stable or declining prevalence, but high and rising prevalence among SWs, IDUs, and men who have sex with men (MSM).⁹
- Paid sex is a driver of the epidemic throughout the region, but there is evidence that intensive HIV prevention efforts among female *SWs* can be highly effective. In the Indian state of Karnataka, A four-year prevention programme in 18 of the 27 districts almost halved HIV prevalence among young antenatal clinic attendees (from 1.4% to 0.8%) (44).⁹
- In the north-eastern part of India, and other large cities outside of the north-east, high levels of HIV infection have been detected among *IDUs*. In Tamil Nadu in 2006, 24% of drug users were believed to be infected.
- In China, while the five-highest-prevalence provinces account for 53.4% of prevalence, the five provinces with the lowest prevalence account for less than 1% of total infection.

⁸ UNAIDS. 2008 Report on the global AIDS epidemic. Geneva: UNAIDS; 2008.

⁹ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

• Trends, continued



¹⁰ Monitoring AIDS Pandemic (MAP) report, AIDS in Asia: Face the Facts, 2004. Accessed from http://www.mapnetwork.org/docs/MAP_AIDSinAsia2004.pdf

Urban and rural HIV prevalence

Figure 1.4 shows HIV *prevalence* among *ANC* attendees in urban and in rural areas. In several countries in Asia, HIV *prevalence* in rural areas has reached almost the level it has in urban areas.



Figure 1.4. HIV prevalence among ANC attendees¹¹

Myanmar, Thailand, and India, 2004.

Factors that affect HIV prevalence

Various factors may account for the high burden of HIV/AIDS in the region and for the sub-regional variations. The two main factors driving the HIV/AIDS epidemic in Asia are injection drug use and commercial sex. Often, people who have these behaviours are marginalized and put at increased risk due to isolation and *stigmatization*.

Away from their community and their regular sexual partners, migrant and mobile workers, such as truckers and rickshaw pullers, are more likely to become clients of *SWs*. The involvement of girls and women in sex work often results from coercion, or the need for a source of economic survival for themselves and their families, or both.

¹¹ Adapted from UNAIDS/WHO Epidemiology Fact Sheet on HIV and AIDS 2008 Update. Accessed from http://www.who.int/hiv/pub/epidemiology/pubfacts/en/

Other factors that account for the situation in the region may include:

- High *prevalence* of other *STIs*, increasing the risk of acquiring and transmitting HIV
- Lack of care-seeking for *STIs* due to the associated *stigma*
- Illicit drug trafficking
- Poverty
- Cultural taboos preventing open discussion about sex and sex education of youth
- Limited access to or social nonacceptance and nonavailability of condoms
- Low women's status and inability to influence partner's behaviour
- Low literacy rates. Increasing urbanisation, migration, mobilisation and separation of families due to economic effects or other social circumstances

Population mobility

One of the main factors driving the epidemic in Asia is extensive population mobility across national borders.

- Away from their community and their regular sexual partners, men are more likely to engage in commercial sex.
- Because of coercion or the need for a source of income for themselves and their families, girls and women engage in sex work or transactional sexual relationships, in which money or gifts are exchanged for sex.

Summary

By the end of 2009, there were 33.3 million people living with HIV/AIDS worldwide, including an estimated 2 million children. Of these, approximately 4.9 million live in Asia. The Asia region accounts for the second largest number of infections globally. Most HIV infections are concentrated among higher-risk groups such as injection drug users, sex workers, and men who have sex with men.

Unit 1 Exercises

Warm-up

review

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

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. Which provinces and districts are most affected by the HIV/AIDS epidemic in your country?
- 2. What might be the factors contributing to the high rate of HIV in these provinces or districts?
- 3. Which sub-populations are most affected by the HIV/AIDS epidemic in your region?

Apply what you've learned/ case study

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

Serosia is a country in Asia that 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:

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

HIV prevalence (%) by district, Serosia, 1998-2004.

a. In 2004, which district had the highest prevalence?

b. Comment on the HIV infection trends.

Notes

Unit 1 The Global HIV/AIDS Situation Focus: Caribbean

Overview

What this unit is about

This unit discusses the global HIV/AIDS situation and then focuses on the HIV/AIDS situation in the Caribbean Region. For the purpose of this unit this region includes Bahamas, Barbados, Cuba, Dominican Republic, Haiti, Jamaica, and Trinidad and Tobago. We consider recent data from Country Reports, WHO, UNAIDS, and other agencies.

Warm-up questions

1. True or false? As of 2009, approximately 33.3 million people were infected with HIV worldwide. Circle your answer below:

True False

- 2. What region in the Caribbean has been most affected by HIV/AIDS?
- 3. In the Caribbean, unprotected sex between sex workers and clients is a key factor in the spread of HIV.

True False

- 4. The major factor that accounts for the prevalence rates of HIV/AIDS in the Caribbean is:
 - a. Injection drug use
 - b. Women's status and inability to influence partners' behaviour
 - c. Heterosexual transmission
 - d. Blood exposure from unsafe medical practises
 - e. All of the above

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 the Caribbean.

Worldwide Epidemic

Acquired immunodeficiency syndrome (AIDS) is unique in human history in its rapid spread and the extent and depth of its effects. Since the first AIDS case was diagnosed in 1981, the world has struggled to cope with the extraordinary dimensions of this disease. Early efforts to mount an effective response were fragmented, piecemeal, and vastly underresourced. Few communities recognised the dangers ahead, and even fewer were able to provide an effective response. As of 2009, 28 years later, approximately 32 million people have died and 33.3 million people (range: 31.4–35.3 million) globally are living with the *human immunodeficiency virus* (HIV). In 2009, still about 1.8 million people died of AIDS-related causes, similar to 1.9 million deaths due to AIDS in 2001.¹ The HIV epidemic continues to grow worldwide, destroying people's lives and, in many cases, damaging the fabric of societies.

In 2009, an estimated 2.6 million people became newly infected with HIV. Table 1.1, shows some of the HIV statistics worldwide.

¹ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Success in addressing the epidemic

The sub-Saharan African country of Uganda often has been cited as a 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. Median HIV prevalence at clinics outside major urban areas also has been reduced by 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 often are delaying sexual intercourse or abstaining entirely.

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

- Thailand is one of the 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 140,000 per year in 1991 to about 12,000 per year in 2009.
- There is evidence, however, that HIV is now spreading largely among the spouses and partners of clients of *sex workers* (SWs) and among marginalised sections of the population, such as *injection drug users* (IDUs).

HIV Prevalence

Prevalence is the proportion of living persons in a population with a particular disease. It excludes those who have died from the disease. *Incidence* is the proportion of people acquiring a disease (for example, HIV) in a given time period or in a population at risk for the disease. *Prevalence* is based on a combination of mortality, which lowers *prevalence*, and *incidence*, which increases *prevalence*.

Prevalence of HIV/AIDS in the region

Category	Number worldwide	Caribbean region	Percentage of global burden in region
Adults and children living with HIV	33.3 million	240 000	0.7%
Adults and children newly infected with HIV	2.6 million	17 000	0.7%
Adult and child deaths due to AIDS	1.8 million	12 000	0.7%

Table 1.1. HIV/AIDS epidemic worldwide and in the Caribbean, 2009.²

According to *The Joint United Nations Programme on HIV/AIDS* (UNAIDS) 2010 report, described in Table 1.1, in 2009 there were 240,000 (range 229,000–270,000) adults and children living with HIV in the region.

There are substantial differences in the extent and intensity of the epidemic in individual countries in the Caribbean. Most countries in the region show declines or stabilization of HIV *prevalence*, primarily in urban areas; however, changes in semi-urban areas and rural areas have been minimal.

² UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Prevalence of HIV/AIDS in the region, continued

Figure 1.1 HIV prevalence in adults (aged 15-49 years) in the Caribbean, 2009³



Discussing prevalence

Study the map in Figure 1.1 above to answer these questions.

- a. Which countries in the Caribbean are most affected by HIV/AIDS?
- b. What does the map show about the prevalence of HIV/AIDS in your country?

³ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

HIV burden in each country of the Caribbean

The 2010*UNAIDS* Epidemic Update cites an overall adult HIV *prevalence* of 1.0% for the region. This prevalence is much lower relatively than that of sub-Saharan Africa, where the overall adult HIV *prevalence* is 5.2%, but also much higher than that of North Africa and the Middle East, where the overall adult HIV *prevalence* is 0.2%.⁴ In the seven *UNAIDS*-defined countries of the Caribbean, there were an estimated 17,000 new HIV cases and 12,000 deaths in 2009.

Table 1.2 below shows the HIV disease burden for each country.

Country	Estimated HIV prevalence in adults (%)		Estimated number of deaths	
Caribbean	1.0	240 000	12 000	
Bahamas	3.1	6600		
Barbados	1.4	2100		
Cuba	0.1	7100		
Dominican Republic	0.9	57 000	3200	
Haiti	1.9	120 000	7600	
Jamaica	1.7	32 000	2000	
Trinidad and Tobago	1.5	15 000		

Table 1.2. HIV/AIDS burden in the Caribbean, 2009.⁴

PLWHA = persons living with HIV/AIDS.

⁴ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Examples from the region

Although it accounts for a relatively small share of the global epidemic - 0.7% of people living with HIV and 0.7% of new infections in 2009-the Caribbean has been more heavily affected by HIV than any other region outside sub-Saharan Africa. The Caribbean has the second highest level of adult HIV prevalence (1.0%) in the world.⁵

The Bahamas have a high adult *prevalence* of 3.1%, whereas Cuba's adult prevalence in 2009 stood at less than 0.1%. The main mode of transmission in the region seems to be unprotected sex between men and women, particularly paid sex. In Guyana, about 27% of female sex workers are infected. Consequently, many countries focus their prevention efforts on this demographic.⁵

In part due to collaborative efforts to reduce the price of medications, the Caribbean region has made important strides towards increasing access to HIV treatment. As of 2008, treatment coverage for antiretrovirals reached 48% of Caribbean residents in need, whereas in 2004 only 10% who needed treatment were being reached.⁵

Trends

The CAREC surveillance data, 1982-2003,⁶ report are based on quarterly reports or year-end summaries submitted by 19 Caribbean member countries (CMCs). No reports were received from Aruba; combined HIV/AIDS data were received from the Netherlands Antilles. As data for 2004 and 2005 are only available for a small number of countries, this review covers the period from 1982 to 2003.

From 1982 to 2003, a cumulative total of 25,854 AIDS cases were reported to CAREC by 19 of its 21 CMCs. The distribution of cases was: Jamaica 31%; Bahamas 17%; Trinidad and Tobago 20%; Guyana 11%; Barbados 7%; Suriname 7%; St. Vincent and the Grenadines 2%; and Bermuda 2%. The remaining CMCs (except Aruba and the Netherlands Antilles) individually reported less than one percent of the total.

⁵ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

⁶ Caribbean Epidemiology Centre (CAREC) HIV/AIDS Statistics http://www.carec.org/data/aids/hiv-aids.html.

Trends, continued

The first case of AIDS in the CMCs was recorded in Jamaica in 1982, and the general trend since then has been an increasing one, from 669 cases in 1990 to 2638 cases in 2003 (Figure 1.2). Incomplete reports from some relatively large countries, such as Barbados, Belize, and Suriname, were mainly responsible for the decrease in 2000-2002.

The rate at which HIV, and subsequently AIDS, has spread shows a variety of trends in different member countries, the result of a number of factors, including the stage of the epidemic in each country, the primary modes of transmission, the strength of the HIV/AIDS control programme, and the availability of *antiretroviral drugs*. In Jamaica, the trend has been steadily increasing, from one case in 1982 to 70 cases in 1990, to a high of 1070 cases in 2003. Trinidad and Tobago and the Bahamas, which reported higher numbers of cases than Jamaica in 1990-1993, have shown a slower rate of increase, with indications of a plateau in 1996-97 and subsequent declines. Antigua and Barbuda, Dominica, Grenada, and St. Lucia have all reported fewer than 20 cases per year, while Anguilla, Montserrat, the British Virgin Islands, the Cayman Islands, and St. Kitts and Nevis have individually reported fewer than 10 cases per year.





⁷ Caribbean Epidemiology Centre (CAREC) HIV/AIDS Statistics http://www.carec.org/data/aids/hiv-aids.html.

Trends, continued

During the period under review, the HIV/AIDS epidemic in the Caribbean changed from occurring mostly in males, to a male-to-female ratio of 1:1.4 in 2003. In 1985, of 138 total AIDS cases reported by CMCs, 28 (20%) were in females. In the year 1990, of 669 total AIDS cases reported by CMCs, 211 (32%) were in females. As shown in Figure 1.3, in 2003, of 2638 total reported AIDS cases, 1102 (42%) were in females.



Figure 1.3. Reported AIDS cases in the Caribbean region, 1982-2003⁸

 $^{^8}$ AIDS reports from CMCs, accessed from the CAREC Reporting Tool for AIDS at: http://carec.net/index.html on 11th May 2006

Trends, continued

Table 1.3 shows the age distribution of reported AIDS cases for the years 1985, 1990, 1995, 2000, and 2003. The 20- to 49-year-old age group is the most affected, accounting for over 65% of cases annually.

Table 1.3. Reported AIDS cases by age group in 1985, 1990, 1995, 2000,	
and 2003. ⁹	

Age (years)	1985	1990	1995	2000	2003
≤1	8	21	33	32	20
1-4	9	14	36	106	56
5-14	1	6	14	38	34
15-19	3	13	21	29	30
20-24	14	74	128	128	150
25-29	28	110	234	279	290
30-34	27	120	312	309	404
35-39	16	87	256	338	383
40-44	8	57	192	245	321
45-49	1	46	129	220	234
≥ 50	10	64	201	284	366
Unknown	11	57	24	222	350
Total	136	669	1580	2230	2638

Source: AIDS reports from CMCs, accessed from the CAREC Reporting Tool for AIDS at: http://carec.net/index.html on 11th May 2006.

Although the rate of heterosexual transmission of HIV has been steadily increasing over the years in this region and is the major mode of transmission, other routes, such as sexual behaviour among *men who have sex with men* (MSM) and *mother-to-child transmission* (MTCT) also have been consistently responsible for a significant number of AIDS cases. Unlike in some other parts of the world, however, such as North America and Europe, HIV transmission due to intravenous drug use is not responsible for a large number of AIDS cases in the CMCs.

Although there is under-reporting, there is cautious optimism that the AIDS epidemic in some CMCs has reached or is reaching a plateau.

For more detailed AIDS data, please visit CAREC Reporting Tool for AIDS at: http://www.carec.org

⁹ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Factors that affect HIV prevalence

Various factors may account for the regional and the sub-regional variations in *prevalence* of HIV. The Caribbean epidemics occur in the context of high levels of poverty and unemployment, gender and other inequalities, and considerable *stigma*—all of which can aid the spread of HIV, as well as hinder efforts to control the epidemics.

- The primary mode of HIV transmission in the Caribbean is sexual intercourse.
- *Unprotected sex* between *SWs* and clients is a key factor in the spread of HIV.
- Young girls are at high risk of acquiring HIV given the common practice of young girls maintaining relationships with older men, who are more likely to have HIV because of their age.
- Unsafe sex between men contributes to the epidemic in this region, but remains largely hidden. Little research has been conducted in the Caribbean among MSM.
- *Prisoners* are another population group with high levels of HIV infection.
- Unsafe injecting drug use is responsible for a minority of HIV infections, and contributes significantly to the spread of HIV only in Bermuda and Puerto Rico.

Summary

By the end of 2009, there were 33.3 million people living with HIV/AIDS worldwide, including more than 2 million children. Of these, approximately 240,000 live in the Caribbean. Although the Caribbean region accounts for only 0.7% of all infections worldwide, it is the second most HIV-affected region in the world.

Unit 1 Exercises

Warm-up review		few minutes to review your answers to this unit's warm-up ons and make any necessary changes.
Small group discussion		small groups to discuss these questions. Choose a speaker for your who will report back to the class.
	8- ° • P	
	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		

Apply what you've learned/ case study

Try this case study. We'll discuss the answers in class.

Cariba is a Caribbean nation that had its earliest cases of AIDS recognised in 1986. Data below are based on estimates of HIV prevalence by parish.

Parish	1995	1998	2000	2002
St. Mary	.2	0.5	1.0	1.1
Kingstown	0.5	0.7	0.9	1.0
Arima	1.0	2.0	2.7	2.9
St. James	1.1	5.6	2.0	2.8
Yotown	0.4	0.9	1.3	1.2

HIV prevalence (%) by parish, Cariba, 1995-2002.

- a. What parish had the greatest proportion of its population infected with HIV in 1995?
- b. Comment on the HIV infection trends.
- c. In 2002, which parish had the highest prevalence? Is the epidemic increasing or decreasing in this parish?

Notes
Unit 1 The Global HIV/AIDS Situation Focus: Eastern Europe and Central Asia

<u>Overview</u>

What this unit is about

This unit discusses the global HIV/AIDS situation and then focuses on the HIV/AIDS situation in Eastern Europe and Central Asia. For the purpose of this unit this includes the following countries: Armenia, Azerbaijan, Belarus, Bosnia and Herzegovina, Bulgaria, Croatia, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Republic of Moldova, Romania, Russian Federation, Tajikistan, Turkmenistan, Ukraine, and Uzbekistan. We consider recent data from Country Reports, WHO, UNAIDS, and other agencies.

Warm-up Questions

1. True or false? As of 2009, approximately 33.3 million people were infected with HIV worldwide. Circle your answer below:

True False

- 2. In 2009, which two countries accounted for nearly 90% of newly reported HIV diagnoses in the region?
- 3. The HIV epidemics in Eastern Europe and Central Asia are concentrated mainly among which most-at-risk populations?
- 4. Which of the following countries in the region has the highest reported HIV prevalence among adults?
 - a. Russian Federation
 - b. Estonia
 - c. Ukraine
 - d. Republic of Moldova

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 Eastern Europe and Central Asia.

Worldwide Epidemic

Acquired immunodeficiency syndrome (AIDS) is unique in human history in its rapid spread and the extent and depth of its effects. Since the first AIDS case was diagnosed in 1981, the world has struggled to cope with the extraordinary dimensions of this disease. Early efforts to mount an effective response were fragmented, piecemeal, and vastly underresourced. Few communities recognised the dangers ahead, and even fewer were able to provide an effective response. As of 2009, 28 years later, approximately 32 million people have died and 33.3 million people (range: 31.4–35.3 million) globally are living with the hu*man immunodeficiency virus* (HIV).¹ The HIV epidemic continues to grow worldwide, destroying people's lives and, in many cases, damaging the fabric of societies.

In 2009, an estimated 2.6 million people became newly infected with HIV. Table 1.1, shows some of the HIV statistics worldwide.

¹ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Success in addressing the epidemic

The sub-Saharan African country of Uganda often has been cited as a 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. Median HIV prevalence at clinics outside major urban areas also has been reduced by 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 often are delaying sexual intercourse or abstaining entirely.

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

- Thailand is one of the 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 140,000 per year in 1991 to about 12,000 per year in 2009.
- There is evidence, however, that HIV is now spreading largely among the spouses and partners of clients of *sex workers (SWs)* and among marginalised sections of the population, such as *injection drug users* (IDUs).

HIV Prevalence

Prevalence is the proportion of living persons in a population with a particular disease. It excludes those who have died from the disease. *Incidence* is the proportion of people acquiring a disease (for example, HIV) in a given time period or in a population at risk for the disease. *Prevalence* is based on a combination of mortality, which lowers *prevalence*, and *incidence*, which increases *prevalence*.

Prevalence of HIV/AIDS in the region

Table 1.1. HIV/AIDS epidemic worldwide and in Eastern Europe and Central Asia, 2009.²

Category	Number worldwide	Eastern Europe and Central Asia	Percentage of global burden in region
Adults and children living with HIV	33.3 million	1.4 million	4.2%
Adults and children newly infected with HIV	2.6 million	130 000	5.0%
Adult and child deaths due to AIDS	1.8 million	76 000	4.2%

According to *The Joint United Nations Programme on HIV/AIDS* (UNAIDS) 2010 update, described in Table 1.1, in 2009 there were 1.4 million (range 1.3 million–1.6 million) adults and children living with HIV in the region.¹

Although HIV *prevalence* in the region is lower than that observed in sub-Saharan Africa and the Caribbean, recent reports suggest that transmission and HIV *prevalence* is increasing exponentially in certain countries and populations.

Figure 1.1 below shows the adult HIV prevalence in countries of Eastern Europe and Central Asia as of 2009.

² UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Prevalence of HIV/AIDS in the region, continued

Figure 1.1. HIV prevalence in adults (15-49 years) in Eastern Europe and Central Asia, 2009^3



Source: UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Discussing prevalence

Study the map in Figure 1.1 above to answer these questions.

- a. Which countries in Eastern Europe and Central Asia are most affected by HIV/AIDS?
- b. What does the map show about the prevalence of HIV/AIDS in your country?

³ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

HIV burden in each country in the region

The 2010 UNAIDS AIDS Epidemic Update cites an overall adult HIV *prevalence* of 0.8% for the region, which is much lower relatively than in sub-Saharan Africa (5.0%), but higher than the overall adult prevalence of East Asia (0.1%) and Latin America (0.5%).⁴ In the 19 UNAIDS-defined countries of Eastern Europe and Central Asia, there were an estimated 130,000 new HIV cases and 76,000 deaths in 2009.

Table 1.2 below shows the HIV disease burden for each country.

		-	
Country	Estimated HIV prevalence in adults (%)	Estimated number of <i>PLWA</i>	Estimated number of deaths
Eastern Europe and	0.8	1 500 000	76 000
Central Asia			
Armenia	0.1	1400	<500
Azerbaijan	0.1	3600	<200
Belarus	0.3	17 000	1500
Bulgaria	0.1	3800	
Croatia	< 0.1	<1000	<100
Estonia	1.2	9900	<500
Georgia	0.1	3500	<1000
Kazakhstan	0.1	13 000	1900
Kyrgyzstan	0.3	9800	2600
Latvia	0.7	8600	<500
Lithuania	0.1	1200	<200
Republic of Moldova	0.4	12 000	<1000
Romania	0.1	16 000	
Russian Federation	1.0	980 000	
Tajikistan	0.2	9100	1300
Ukraine	1.1	350 000	24 000
Uzbekistan	0.1	28 000	<500

Table 1.2. HIV/AIDS burden in Eastern Europe and Central Asia, 2009.⁴

PLWA = persons living with HIV/AIDS.

⁴ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Examples from the region

Examples from the *UNAIDS* Eastern Europe and Central Asia, AIDS Epidemic Update, Regional Summary (2007)⁵ illustrate the increasing spread of HIV in the region.

The HIV epidemics of Eastern Europe and Central Asia are concentrated mainly among *injection drug users* (IDUs), *sex workers* (SWs), and to a lesser extent *men who have sex with men* (MSM. An estimated 3.7 million people in the region currently inject drugs, and roughly one in four are believed to be HIV-infected.⁶

Russia and Ukraine contribute nearly 90% of newly reported HIV diagnoses in the region.

In Ukraine, the adult HIV *prevalence* (1.1% in 2009) is second only to Estonia (1.2%). The rate of heterosexual transmission has increased. Women now represent 45% of all adults living with HIV in Ukraine, compared with 41% in 2004. Injecting drug use has contributed both directly and indirectly to this increase. Thirty-five percent of women are estimated to have acquired HIV through injecting drug use, and as many as 50% through sexual activity with drug using partners.⁷

Sharing of drug-injecting equipment has contributed to the dramatic increase in HIV cases in Estonia. Nearly free of new HIV cases a decade ago, Estonia now has the highest prevalence of HIV in the region, with at least half of its IDUs infected.⁷

In Kyrgyzstan, which is located on a major drug trafficking route from Afghanistan to Europe and the Russian Federation, the HIV epidemic is largely concentrated among *IDUs*. *Sentinel surveillance* conducted in the cities of Bishkek and Osh found HIV *prevalence* of 0.8% among *IDUs*, 3.5% among *prisoners*, 1.3% among female *SWs*, and 1% among *MSM* in 2006.

⁵ UNAIDS 2007 Eastern Europe and Central Asia AIDS Epidemic Update Regional Summary.

⁶ UNAIDS. 2008 Report on the global AIDS epidemic. Geneva: UNAIDS; 2008.

⁷ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Trends

Although available data show that *prevalence* varies by country and population, the number of newly reported HIV diagnoses is rising throughout much of the region. The following examples illustrate the increasing numbers of new HIV cases in the region.

Figure 1.2. Newly diagnosed HIV infections in Eastern Europe and Central Asia, 1996 - 2003⁸



Because most HIV infections in Eastern Europe and Central Asia are concentrated among individuals participating in *high-risk behaviours*, measuring trends in the general population should be complemented with *surveillance* in high-risk populations. Examining *prevalence* trends among *high-risk groups* may provide useful information on the direction of the epidemics of Eastern Europe and Central Asia.

⁸ HIV/AIDS Surveillance in Europe, EuroHIV mid-year report 2003, No.69 (2) AIDS Foundation East West

Trends, continued

In Russia, the HIV epidemic continues to grow, although not as rapidly as was seen in the late 1990s. Between 2001 and 2003, the annual number of newly registered HIV cases declined from 87 000 in 2001 to 34 000 in 2003, but has since risen to 39 000 in 2006. National HIV *prevalence* among *IDUs* in Russia was consistently 0% between 1991 and 1995, jumping to 0.7% in 1997, peaking at 6.1% in 2001 and decreasing to 3.1% in 2002. A similar trend was seen among *SWs* in Russia in that the national prevalence within this group increased from 0.6% in 1999 to 15.3% in 2000 and decreased to 3.0% in 2002.



Figure 1.3. Registered new HIV cases in Ukraine, 1995-2006.

Source: WHO health for all database and Ukrainian Ministry of Health.

As shown in Figure 1.3 above, annual HIV diagnoses have more than doubled in Ukraine since 2001 and exceeded 8700 in the first six months of 2007, of which 3639 were reported among *IDUs*.

Although much smaller in terms of reported HIV cases than the epidemics in the Ukraine and Estonia, the HIV epidemics in Kyrgyzstan and Tajikistan also are centred largely among *IDUs*. According to the Ministry of Health of Tajikistan, in the Tajik cites of Dushanbe and Khujand, the HIV *prevalence* among *IDUs* increased from 16% in 2005 to 24% in 2006, and increased from 0.7% to 3.7% over the same period among *SWs*.

The HIV *prevalence* among *most-at-risk populations* (MARPs) in Georgia is relatively low (1.3% among female *SWs* and 1.1% among *IDUs*), but with widespread injection drug use and increased cross-border migration

Trends, continued

between Georgia and the high-prevalence countries of Ukraine and Russia, the epidemic will continue to grow in the absence of effective prevention.

Belarus, where the epidemic is also concentrated among urban *IDUs*, is an example of a country in which the HIV epidemic appears to have stabilised, with the annual number of newly reported HIV diagnoses varying only slightly between 2003 and 2007.⁹

Belarus, the Republic of Moldova, the Russian Federation, Ukraine and Uzbekistan 80% of IDUs surveyed reported the use of sterile injection equipment during their last experience.¹⁰

Factors that affect HIV prevalence

Various factors may account for the regional and sub-regional variations in *prevalence* of HIV. In Ukraine and the Russian Federation, major factors driving the epidemic are injection drug use and commercial sex. Often these groups are marginalised and put at increased risk for infection due to isolation and *stigmatisation*.

Away from their communities and their regular sexual partners, migrant and mobile workers, such as truckers, are more likely to become clients of female *SWs*. The involvement of girls and women in sex work often results from coercion or the need to provide economic survival for themselves and their families. Internally displaced persons and refugees, especially from areas with *generalised HIV epidemics*, have increased risks of ongoing transmission among group members 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 *SWs*
- Cultural taboos preventing open discussion about sex 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

⁹ UNAIDS 2007 Eastern Europe and Central Asia AIDS Epidemic Update Regional Summary.

¹⁰ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

- Low literacy rates
- Lack of awareness and access to HIV and *STI* prevention information
- Increasing urbanisation, migration, mobilisation, and separation of families as a result of economic and social circumstances.

Conflict, displacement, and population mobility

A few of the main factors driving the epidemic in some Eastern European and Central Asian countries are drug trafficking, and extensive population mobility across national borders.

- Fall of the Soviet Union
- Employment opportunities in the European Union
- Increase in commercial sex industry
- Away from their community and their regular sexual partners, men are more likely to engage in commercial sex.
- Because of 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.

Summary

By the end of 2009, there were 33.3 million people living with HIV/AIDS worldwide, including more than 2 million children. Of those infected, approximately 1.5 million lived in Eastern Europe and Central Asia. Although the region experiences a much lower adult HIV prevalence than sub-Saharan Africa, 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've learned/ case study

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

Globa, a country in Eastern Europe, had its earliest cases of AIDS recognised in 1984. Data below are based on estimates of HIV prevalence by district. Examine the data and answer the questions that follow.

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

HIV prevalence (%) by district, Globa, 1998-2004.

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

b. Comment on the HIV infection trends.

Notes

Unit 1 The Global HIV/AIDS Situation Focus: Latin America

Overview

What this unit is about

This unit discusses the global HIV/AIDS situation and then focuses on the HIV/AIDS situation in Latin America. For the purpose of this unit this includes the following countries: Argentina, Belize, Bolivia, Brazil, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Guatemala, Guyana, Honduras, Mexico, Nicaragua, Panama, Paraguay, Peru, Suriname, Uruguay, and Venezuela. We consider recent data from Country Reports, WHO, UNAIDS, and other agencies.

Warm-up Questions

1. True or false? As of 2009, approximately 33 million people were infected with HIV worldwide. Circle your answer below:

True False

- 2. Name three factors that might affect prevalence rates in a region.
- 3. The main modes of HIV transmission in this region are among these three groups:
- 4. Which of the following countries in Latin America has the highest reported HIV prevalence among adults?
 - a. Belize
 - b. Brazil
 - c. Suriname
 - d. Honduras

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 Latin America.

Worldwide Epidemic

Acquired immunodeficiency syndrome (AIDS) is unique in human history in its rapid spread and the extent and depth of its effects. Since the first AIDS case was diagnosed in 1981, the world has struggled to cope with the extraordinary dimensions of this disease. Early efforts to mount an effective response were fragmented, piecemeal, and vastly underresourced. Few communities recognised the dangers ahead, and even fewer were able to provide an effective response. As of 2009, 28 years after AIDS was first diagnosed, approximately 33.3 million people (range: 31.4–35.3 million) are living with the *human immunodeficiency virus* (HIV) globally.¹ In 2008, still about 1.8 million people died of AIDSrelated causes, similar to 1.9 million deaths due to AIDS in 2001.¹ The HIV epidemic continues to grow worldwide, destroying people's lives and, in many cases, damaging the fabric of societies.

In 2009, an estimated 2.6 million people became newly infected with HIV.

Table 1.1, shows some of the HIV statistics worldwide.

¹ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Success in addressing the epidemic

The sub-Saharan African country of Uganda often has been cited as a 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. Median HIV prevalence at clinics outside major urban areas also has been reduced by 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 often are delaying sexual intercourse or abstaining entirely.

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

- Thailand is one of the 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 140,000 per year in 1991 to about 12,000 per year in 2009.
- There is evidence, however, that HIV is now spreading largely among the spouses and partners of clients of *sex workers* (SWs) and among marginalised sections of the population, such as *injection drug users* (IDUs).

HIV Prevalence

Prevalence is the proportion of living persons in a population with a particular disease. It excludes those who have died from the disease. *Incidence* is the proportion of people acquiring a disease (for example, HIV) in a given time period or in a population at risk for the disease. *Prevalence* is based on a combination of mortality, which lowers *prevalence*, and *incidence*, which increases *prevalence*.

Prevalence of HIV/AIDS in the region

Category	Number worldwide	Latin America	Percentage of global burden in region
Adults and children living with HIV	33.3 million	1.4 million	4.2%
Adults and children newly infected with HIV	2.6 million	87 000	3.3%
Adult and child deaths due to AIDS	1.8 million	58 000	3.2%

Table 1.1. HIV/AIDS epidemic worldwide and in Latin America, 2009.²

According to *The Joint United Nations Programme on HIV/AIDS* (UNAIDS) 2010 report, described in Table 1.1, in 2009 there were 1.4 million (range 1.2–1.6 million) adults and children living with HIV in the region.

Recent reports regarding adult HIV *prevalence* in Latin America suggest that transmission and prevalence is increasing in certain countries and populations. Soto et al (2007),³ for example, published findings of HIV *prevalence* among *men who have sex with men* (MSM) and female *SWs* in five Central American countries. The *prevalence* of HIV among *MSM* ranged from 7.6% in Nicaragua to 15.3% in El Salvador and among female *SWs*, from 0.2% in Nicaragua and Panama to 9.6% in Honduras.

Figure 1.1 shows the adult HIV prevalence in Latin American countries as of 2009.

² UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

³ Soto RJ et al. (2007). Sentinel surveillance of sexually transmitted infection/HIV and risk behaviours in vulnerable populations in five Central American countries. *Journal of Acquired Immune Deficiency Syndromes*.

Prevalence of HIV/AIDS in the region, continued



Figure 1.1. HIV prevalence in adults (aged 15-49 years) in Latin America, 2009.⁴

Discussing prevalence

Study the map in Figure 1.1 above to answer these questions.

- a. Which countries in Latin America are most affected by HIV/AIDS?
- b. What does the map show about the prevalence of HIV/AIDS in your country?

⁴ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

HIV burden in each country of the region

The 2010 *UNAIDS* AIDS Epidemic Update cites an overall adult HIV *prevalence* of 0.5% for the region, which is relatively much lower than it is in sub-Saharan Africa, where the overall adult HIV prevalence is 5.0% and, lower than in some of the African countries, where it is as high as 24%. Table 1.2 below shows the HIV *disease burden* for each country.

Country	Estimated HIV prevalence in adults (15-49) rate (%)	Estimated number of <i>PLWHA</i>	Estimated number of deaths
Latin America	0.5	1 400 000	87 000
Argentina	0.5	110 000	2900
Belize	2.3	4800	<500
Bolivia	0.2	12 000	<1000
Brazil			
Chile	0.4	40 000	
Colombia	0.5	160 000	1 400
Costa Rica	0.3	9800	<500
Ecuador	0.4	37 000	2200
El Salvador	0.8	34 000	1400
Guatemala	0.8	62 000	2600
Guyana	1.2	5900	<500
Honduras	0.8	39 000	2500
Nicaragua	0.2	6900	<500
Panama	0.9	20 000	1500
Paraguay	0.3	20 000	500
Peru	0.4	75 000	5000
Suriname	1.0	3700	<200
Uruguay	0.6	9900	
Venezuela			

Table 1.2. HIV/AIDS burden in Latin America, 2009.⁵

Examples from

the region

Examples from the November 2010 *UNAIDS* AIDS Epidemic Update, Central and South America Regional Overview illustrate the status of the HIV epidemic in the region.

The UNAIDS 2010 AIDS Epidemic Update stresses that men who have sex with men account for the largest share of infections in Latin America, although a considerable burden is attributed to injecting drug users, sex workers and the clients of sex workers.⁵

⁵ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Examples from the region, continued

Although the epidemic is generally stable in this region, HIV transmission has been increasing in some poverty-stricken and illiterate sections of society. A study found that infection levels were almost three times higher among persons at lower income levels than among those at higher income levels.⁶

Across South America, HIV infection levels are lower for female *SWs* than for *MSM*. HIV prevalence among female *SWs* is found to be 9.6% in Honduras, 4.3% in Guatemala, and 3.2% in El Salvador.⁷

There is high HIV *prevalence* documented among MSM in the region. In 12 of 14 countries, the prevalence of HIV among MSM is estimated at 10% or higher. In many countries social stigma is a factor in the dearth of prevention efforts targeting this population.⁷

Trends

Surveillance is the systematic collection and analysis of health data for the purpose of disease prevention and control. Overall levels of HIV infections in the Latin America Region have changed little since the late 1990s, thus measuring trends in the general population should be complemented with measuring surveillance trends among higher risk populations. The main modes of transmission occurring in this region are primarily through *MSM*, *SWs*, and, to a lesser extent, *IDUs*.⁸

The HIV surveillance systems in Central America are inadequate, limiting the understanding of the HIV epidemic in this sub-region. The available information, however, provides insight into the epidemic as it relates to HIV transmission during *unprotected sex* between men and unsafe paid sex, with migration a key factor in spreading the virus.⁸

Recent HIV *sentinel surveys* have provided more insight into the epidemic in Honduras. Most of the HIV transmission in this country occurs during unsafe paid sex and *unprotected sex* between men; however, a sharp decline in HIV *prevalence* has been observed in three cities in Honduras (Figure 1.2). This decline has been attributed to consistent condom use

⁶ Dourado et al., 2007

⁷ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

⁸ UNAIDS. 2008 Report on the global AIDS epidemic. Geneva: UNAIDS; 2008.

Trends, continued

during the previous 30 days in all three cities (>80% in Tegucigalpa and San Pedro Sula, and 98% in La Ceiba with paying clients).⁹





Injection drug use and use of non-sterile injecting equipment was once a key factor in Argentina's epidemic, but this trend has decreased since the late 1990s. In Uruguay, however, use of non-sterile injecting drug equipment still remains an important factor in the epidemic, accounting for 18% of HIV infections.¹⁰

Women are increasingly becoming infected with HIV in Argentina, Brazil, Peru, and Uruguay. In Uruguay, *unprotected sex*, primarily among heterosexual people, is believed to account for approximately two thirds of newly reported cases.^{Error! Bookmark not defined.} The increase in the number of women becoming infected with HIV is likely due to having acquired the virus from male partners who also have sex with men.

While prevention among MSM lags behind efforts to target *SW* are starting to show success in some countries. Guatemala, El Salvador, Chile (Santiago) report low prevalence and high rates of condom use among SW.⁹

⁹ Secretaria de Salud Honduras, 2007.

¹⁰ UNAIDS. 2008 Report on the global AIDS epidemic. Geneva: UNAIDS; 2008.

Factors that affect HIV prevalence

Various factors may account for regional and sub-regional variations in the *prevalence* of HIV. In some sub-regions, major factors driving the epidemic are commercial sex, injection drug use, and sexual behaviours among *MSM*. Often these groups are marginalised and put at increased risk for infection due to isolation and *stigmatisation*.

Away from their communities and their regular sexual partners, migrant and mobile workers, such as truckers, are more likely to become clients of female *SWs*. The involvement of girls and women in sex work often results from coercion or the need for a source of economic survival for themselves and their families, or both.

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 *SWs*
- Cultural taboos preventing open discussion about sex 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 urbanisation, migration, mobilisation, and separation of families as a result of economic and social circumstances.

Summary

By the end of 2009, there were 33.3 million people living with HIV/AIDS worldwide, including more than 2 million children. Of these, approximately 1.4 million lived in Latin America. Although this region accounts for only 4.2% 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've learned/ case study

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

Nicondama, a country in Latin America, had its earliest cases of AIDS recognised in 1984. Data below are based on estimates of HIV prevalence by district. Study the data and answer the questions that follow.

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

HIV prevalence (%) by district, Nicondama, 1998-2004.

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

b. Comment on the HIV infection trends.

Notes

Unit 1 The Global HIV/AIDS Situation Focus: North Africa and Middle East

<u>Overview</u>

What this unit is about

This unit discusses the global HIV/AIDS situation and then focuses on the HIV/AIDS situation in the North Africa and the Middle East region. For the purpose of this unit this includes the following countries: Algeria, Bahrain, Cyprus, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libyan Arab Jamahiriya, Morocco, Oman, Qatar, Saudi Arabia, Sudan, Syrian Arab Republic, Tunisia, Turkey, United Arab Emirates, and Yemen. We consider recent data from Country Reports, WHO, UNAIDS, and other agencies.

Warm-up questions

1. True or false? As of 2009, approximately 33 million people were infected with HIV worldwide. Circle your answer below:

True False

- 2. In which country in the North Africa and Middle East region 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 the North Africa and Middle East region has the highest reported HIV prevalence among adults?
 - a. Lebanon
 - b. Turkey
 - c. Morocco
 - d. Sudan

Unit 1, Focus: North Africa and Middle East

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 the North Africa and Middle East region.

Worldwide Epidemic

Acquired immunodeficiency syndrome (AIDS) is unique in human history in its rapid spread and the extent and depth of its effects. Since the first AIDS case was diagnosed in 1981, the world has struggled to cope with the extraordinary dimensions of this disease. Early efforts to mount an effective response were fragmented, piecemeal, and vastly underresourced. Few communities recognised the dangers ahead, and even fewer were able to provide an effective response. As of 2009, 27 years after AIDS was first diagnosed, approximately 33.3 million people (range: 31.4–35.3 million) are living with the *human immunodeficiency virus* (HIV) globally.¹ In 2009, still about 1.8 million people died of AIDSrelated causes, similar to 1.9 million deaths due to AIDS in 2001.¹ The HIV epidemic continues to grow worldwide, destroying people's lives and, in many cases, damaging the fabric of societies.

In 2009, an estimated 2.6 million people became newly infected with HIV. Table 1.1, shows some of the HIV statistics worldwide.

¹ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Success in addressing the epidemic

The sub-Saharan African country of Uganda often has been cited as a 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. Median HIV prevalence at clinics outside major urban areas also has been reduced by 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 often are delaying sexual intercourse or abstaining entirely.

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

- Thailand is one of the 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 140 000 per year in 1991 to about 12,000 per year in 2009.
- There is evidence, however, that HIV is now spreading largely among the spouses and partners of clients of *sex workers* (SWs) and among marginalised sections of the population, such as *injection drug users* (IDUs).

HIV Prevalence

Prevalence is the proportion of living persons in a population with a particular disease. It excludes those who have died from the disease. *Incidence* is the proportion of people acquiring a disease (for example, HIV) in a given time period or in a population at risk for the disease. *Prevalence* is based on a combination of mortality, which lowers *prevalence*, and *incidence*, which increases *prevalence*.

Prevalence of HIV/AIDS in the region

Category	Number worldwide	North Africa and the Middle East	Percentage of global burden in region
Adults and children living with HIV	33.3 million	460 000	1.4%
Adults and children newly infected with HIV	2.6 million	68 000	2.6%
Adult and child deaths due to AIDS	1.8 million	24 000	1.3%

Table 1.1. HIV/AIDS epidemic worldwide and in the North Africa and Middle East region, 2009.²

According to *The Joint United Nations Programme on HIV/AIDS* (UNAIDS) 2010 report, described in Table 1.1, in 2009 there were 460,000 (range 400,000-440,000) adults and children living with HIV in the region.

This region is home to approximately 10% of the world's population, yet as of 2009, it contained less than 1.5% of men, women, and children living with HIV worldwide. Although HIV *prevalence* is relatively low in the North Africa and Middle East region compared to other parts of the world, recent reports suggest that transmission and *prevalence* is increasing in certain countries and populations.

² UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Prevalence of HIV/AIDS in the region, continued

Figure 1.1 shows HIV *prevalence* in countries of North Africa and the Middle East as of 2009.

Figure 1.1. HIV prevalence in adults (aged 15-49 years) in North Africa and the Middle East, 2009³



Discussing prevalence

Study the map in Figure 1.1 above to answer these questions.

- a. Which countries in North Africa and the Middle East are most affected by HIV/AIDS?
- b. What does the map show about the prevalence of HIV/AIDS in your country?

³ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

HIV burden in each country of the region

The 2009 UNAIDS AIDS Epidemic Update cites an overall adult HIV *prevalence* of 0.24% for the region, which is relatively much lower than in sub-Saharan Africa, where the overall adult HIV *prevalence* is 5.0%, and lower than in some of the African countries, where it is as high as 25%. In the North Africa and Middle East region, there were an estimated 460,000 cases and 24,000 deaths in 2010. Table 1.2 below shows the HIV *disease burden* for each country.

Table 1.2. HIV/AIDS burden in the North Africa and Middle East region, 2009⁴

Country	Estimated HIV prevalence in adults (%)	Estimated number of <i>PLWHA</i>	Estimated number of deaths
North Africa and Middle	0.2	460 000	24 000
East			
Algeria	0.1	18 000	<1000
Djibouti	2.5	14 000	1100
Egypt	< 0.1	11 000	<500
Iran (Isalmic Republic of)	0.2	92 000	6400
Lebanon	0.1	3600	<500
Morocco	0.1	26 000	1200
Oman	0.1	1100	<100
Qatar	< 0.1	<200	<100
Somalia	0.7	34 000	1600
Sudan	1.1	260 000	12 000
Tunisia	< 0.1	2400	<100

PLWHA = persons living with HIV/AIDS.

⁴ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Examples from North Africa and Middle East region

Examples from the *UNAIDS* 2009 AIDS Epidemic Update illustrate the potential for HIV spread in the region, especially where higher risk population groups serve as a bridge to the general population:

- The prevalence of HIV in the region is comparatively low. However, in Djibouti and southern Sudan, *prevalence* levels among pregnant women have risen to above 1%.⁵
- The Islamic Republic of Iran is thought to have the largest IDU population in the region. This coupled with the high rate of Hepatitis C (nearly 80%) in this group suggests a risk for a rapid spread of HIV.
- A study in Sudan found that 'active' *men who have sex with men* (MSM) had an HIV *prevalence* of 8-9%.⁵ Though, as in many regions, sex between men is officially forbidden, *stigmatized*, and under-researched, the limited information available suggests that *unprotected sex* between men is a key risk factor for HIV transmission.
- Paid sex is an understudied area in this region, though numbers suggest that HIV prevalence is low in the SW population. The latest estimates (2006) indicate a 1% infection rate among female SW in Egypt and 2-4% infection in Morocco, Algeria and Yemen.
- HIV surveillance data from the region are very limited; however, available data show that prevalence varies by country and population. Sudan has a generalised HIV epidemic, in which the national sero-prevalence is estimated at 1.1%. Morocco and Algeria both have HIV sero-prevalence rates of 0.1% and more than 18,000 and 26,000 people living with HIV, respectively.⁵

⁵ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Trends

Surveillance is the systematic collection and analysis of health data for the purpose of disease prevention and control. Because several countries in the North Africa and Middle East region have very low rates of HIV infection, measuring trends in the general population should be complemented with measuring trends among higher risk groups. Outside of Sudan, the majority of HIV infections are concentrated among individuals participating in *high-risk behaviours,* such as injection drug use or sex work, and the growth in the epidemic is primarily due to rising rates of infection in these sub-populations.

Factors that affect HIV prevalence

Various factors may account for the regional and sub-regional variations in the *prevalence* of HIV. The situation in parts of Sudan resembles *generalised HIV epidemics* among heterosexual people in Africa. In other sub-regions, major factors are people engaging in commercial sex, injection drug use, and, if male, having sex with men. Often these groups are marginalised and risk infection due to isolation and *stigmatisation*.

Away from their communities and their regular sexual partners, migrant and mobile workers, such as truckers, are more likely to become clients of female *SWs*. The involvement of girls and women in sex work can be from coercion or as a means of economic survival for themselves and their families. *Internally displaced persons* and refugees, especially from areas with *generalised HIV epidemics*, have increased risks of ongoing transmission among themselves and of spreading HIV 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 *SWs*
- Cultural taboos preventing open discussion about sex 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 urbanisation, migration, mobilisation and separation of families as a result of economic and/or social circumstances.

Conflict, displacement, and population mobility

A few of the main factors driving the epidemic in some North Africa and Middle East countries are conflict, displacement, and extensive population mobility across national borders:

- Away from their community and their regular sexual partners, men are more likely to engage in commercial sex.
- Because of 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-thanexpected HIV *prevalence* was seen in displaced populations. There were, for instance, *prevalence* levels of 4% among refugees from Eritrea and Ethiopia and 1.1% among *internally displaced people*.
- In Yemen, migrants entering the country had almost 40% of all test results positive for HIV.

Summary

By the end of 2009, there were 33.3 million people living with HIV/AIDS worldwide, including more than 2 million children. Of these, approximately 460,000 lived in the North Africa and Middle East region. Although this region accounts for only 1.4% 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've learned/ case study

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

Menaland, a country in North Africa, had its earliest cases of AIDS recognised in 1984. Data below are based on estimates of HIV prevalence by district. Study the data and answer the questions that follow.

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

HIV prevalence (%) by district, Menaland, 1998-2004.

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

b. Comment on the HIV infection trends.

Notes

Unit 1 The Global HIV/AIDS Situation Focus: Sub-Saharan Africa

Overview

What this unit is about

This unit discusses the global HIV/AIDS situation and then focuses on the HIV/AIDS situation in sub-Saharan Africa. For the purpose of this unit this includes the following countries: Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Central African Republic, Chad, Comoros, Congo, Côte d'Ivoire, Democratic Republic of Congo, Djibouti, Equatorial Guinea, Eritrea, Ethiopia, Gabon, Gambia, Ghana, Guinea, Guinea-Bissau, Kenya, Lesotho, Liberia, Madagascar, Malawi, Mali, Mauritania, Mauritius, Mozambique, Namibia, Niger, Nigeria, Rwanda, Senegal, Sierra Leone, Somalia, South Africa, Swaziland, Togo, Uganda, United Republic of Tanzania, Zambia, and Zimbabwe. We consider recent data from Country Reports, WHO, UNAIDS, and other agencies.

Warm-up questions

1. True or false? About 33.3 million people are infected with HIV worldwide. Circle your answer below:

True False

- 2. What region of the world has been affected the most by HIV/AIDS, with an infection prevalence of over 20% in some countries?
- 3. What region in Africa has been affected the most by HIV/AIDS?
- 4. Some of the factors that account for the high prevalence of HIV/AIDS in sub-Saharan Africa include:
 - a. Extensive population mobility
 - b. Women's status and inability to influence partner's behaviour
 - c. War and civil disturbance
 - d. Blood exposure from unsafe medical practices
 - e. All of the above.

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 sub-Saharan Africa.

Worldwide Epidemic

Acquired immunodeficiency syndrome (AIDS) is unique in human history in its rapid spread and the extent and depth of its effects. Since the first AIDS case was diagnosed in 1981, the world has struggled to cope with the extraordinary dimensions of this disease. Early efforts to mount an effective response were fragmented, piecemeal, and vastly underresourced. Few communities recognised the dangers ahead, and even fewer were able to provide an effective response. As of 2009, 28 years after AIDS was first diagnosed, approximately 33.3 million people (range: 31.4–35.3 million) are living with the *human immunodeficiency virus* (HIV) globally.¹ In 2009, still about 1.8 million people died of AIDSrelated causes, similar to 1.9 million deaths due to AIDS in 2001.¹ The HIV epidemic continues to grow worldwide, destroying people's lives and, in many cases, damaging the fabric of societies.

In 2009, an estimated 2.6 million people became newly infected with HIV. Table 1.1, shows some of the HIV statistics worldwide.

¹ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

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. Median HIV prevalence at clinics outside major urban areas also has been reduced by 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.

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

- Thailand is one of the 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 140,000 per year in 1991 to about 12,000 per year in 2009.
- There is evidence, however, that HIV is now spreading largely among the spouses and partners of clients of *sex workers* (SWs) and among marginalised sections of the population, such as *injection drug users* (IDUs).

HIV Prevalence

Prevalence is the proportion of living persons in a population with a particular disease. It excludes those who have died from the disease. *Incidence* is the proportion of people acquiring a disease (for example, HIV) in a given time period or in a population at risk for the disease. *Prevalence* is based on a combination of mortality, which lowers *prevalence*, and *incidence*, which increases *prevalence*.

Prevalence of HIV/AIDS in the region

Table 1.1. HIV/AIDS epidemic worldwide and in sub-Saharan Africa, 2009.²

Category	Number worldwide	sub-Saharan Africa	Percentage of global burden in region
Adults and children living with HIV/AIDS	33.3 million	22.5 million	67.6%
Adults and children newly infected with HIV	2.6 million	1.8 million	57.7%
Adult and child deaths due to AIDS	1.8 million	1.3 million	72.2%

According to *The Joint United Nations Programme on HIV/AIDS* (UNAIDS) 2010 report, described in Table 1.1, in 2009 there were 22.5 million (range 20.9 million – 24.2 million) adults and children living with HIV in the region.²

In general, southern Africa is the region most affected by AIDS, with *prevalence* levels ranging from 15% to 25%. In many areas of western Africa, *prevalence* is under 2%. The *prevalence* levels for countries in east and central Africa are between these two rates.

² UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Prevalence of HIV/AIDS in the region, continued

Figure 1.1 shows the adult HIV *prevalence* in countries of sub-Saharan Africa as of 2009.



Figure 1.1. HIV prevalence in adults (15-49) in Africa, 2009³

Study the map in Figure 1.1 above to answer these questions.

- a. Which countries in sub-Saharan Africa are most affected by HIV/AIDS?
- b. What does the map show about the prevalence of HIV/AIDS in your country?

³ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

HIV burden in each country in the region

The 2010 UNAIDS AIDS Global Report cites an overall adult HIV *prevalence* of 5.0% for the region, which is much higher relatively than in other regions, such as Eastern Europe and Central Asia (0.3%), and Latin America (0.5%).⁴ In the 44 UNAIDS-defined countries of sub-Saharan Africa, there were an estimated 1.8 million new HIV cases and 1.3 million deaths in 2009.

Table 1.2 on the next page shows the HIV *disease burden* for each country.

⁴ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

HIV burden in each country in the region, continued

Country	Estimated HIV prevalence in adults (%)	Estimated number of PLWHA	Estimated number of deaths
Sub-Saharan Africa	5.0	22 500 000	1 300 000
Angola	2.0	200 000	11 000
Benin	1.2	60 000	2 700
Botswana	24.8	320 000	5 800
Burkina Faso	1.2	110 000	7 100
Burundi	3.3	180 000	15 000
Cameroon	5.3	610 000	37 000
Central African Republic		130 000	11 000
Chad	3.4	210 000	11 000
Comoros	0.1	<500	<100
	3.4	77 000	6 400
Congo Côte d'Ivoire	3.4	450 000	36 000
	5.4	430 000	30 000
Democratic Republic of			
Congo	5.0	20.000	<1000
Equatorial Guinea	5.0	20 000	<1000
Eritrea	0.8	25 000	1 700
Ethiopia			
Gabon	5.2	46 000	2 400
Gambia	2.0	18 000	<1000
Ghana	1.8	260 000	18 000
Guinea	1.3	79 000	4 700
Guinea-Bissau	2.5	22 000	1 200
Kenya	6.3	1 500 000	
Lesotho	23.6	290 000	14 000
Liberia	1.5	37 000	3 900
Madagascar	0.2	24 000	1 700
Malawi	11.0	920 000	51 000
Mali	1.0	76 000	4 400
Mauritania	0.7	3 600	<1000
Mauritius	1.0	8 800	<500
Mozambique	11.5	1 400 000	74 000
Namibia	13.1	180 000	6700
Niger	0.8	61 000	4300
Nigeria	3.6	3 300 000	220 000
Rwanda	2.9	170 000	4 100
Senegal	0.9	59 000	2 600
Sierra Leone	1.6	49 000	2 800
South Africa	18.1	5 600 000	310 000
Swaziland	17.8	180 000	7 000
Togo	3.2	120 000	7 700
Uganda	6.5	1 200 000	64 000
United Republic of			
Tanzania	5.6	1 400 000	86 000
Zambia	13.5	980 000	45 000
Zimbabwe	14.3	1 200 000	83 000

Table 1.2. HIV/AIDS burden in sub-Saharan Africa, 2007.⁵

⁵ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Examples from the region

Examples from the *UNAIDS* 2009 AIDS Epidemic Update, Regional Summary¹ illustrate the status of the HIV epidemic in the region.

In Côte d'Ivoire, HIV prevalence is twice as high among females (6.4%) compared to males (2.9%). In sub-Saharan Africa as a whole, women account for approximately 60% of estimated HIV infections.⁶

South Africa has the most HIV-infected people worldwide: 5.6 million. However, while national adult HIV prevalence has stabilized, studies have shown that prevalence among young people (aged 15-24) started to decline in 2005, as documented among antenatal clinic attendees (from 25% in 2004-2005 to 21.7% in 2008).

Zimbabwe has been reporting a steady fall in HIV prevalence since the late 1990s; studies have attributed this decline to population-level changes in sexual behaviors. In rural Zimbabwe, consistent condom use has been noted between HIV-positive women and primary partners. However, individuals testing negative reported an overall increase in risky sexual behavior.⁶ Such findings emphasize the need for intensified prevention services to accompany initiatives to promote knowledge of HIV serostatus.

Adult HIV prevalence is below 1% in three West African countries (Cape Verde, Niger, and Senegal) but nearly one in 25 adults (3.9%) in Côte d'Ivoire and 1.9% of the general population in Ghana are living with HIV.

In Burundi, population-based surveys conducted between 2003 and 2008 among 15-24 year olds showed a decline in HIV prevalence in urban areas (4.0% to 3.8%) and in semi-urban areas (6.6% to 4.0%), while HIV prevalence in rural areas increased from 2.2% to 2.9%.

⁶ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Trends

In general, sub-Saharan Africa epidemics seem to be stabilizing; however, especially in southern Africa, there still are high rates of HIV. In 22 sub-Saharan African countries, incidence of HIV fell more than 25% between 2001 and 2009.⁷ In a number of countries, *prevalence* of HIV among adults appears to be decreasing as well.

Almost a third of all new HIV infections and AIDS-related deaths globally in 2009 were found in southern Africa, with national adult HIV *prevalence* at more than 15% in Botswana, Lesotho, South Africa, Swaziland, and Zimbabwe. About 40% of all adult women with HIV live in southern Africa. In Mozambique there has been an increase in HIV *prevalence*. Levels of infection among young people (aged 15-24 years) in recent years suggest that new HIV infections in Mozambique are still increasing.

In Zimbabwe and other countries, there have been slight declines in HIV, and in the rest of the region infection rates are at or near a plateau. Condom use with non-regular partners and the number of men with multiple partners have increased over time in Zimbabwe.

The *incidence* of HIV among children under 15 has shown progress. Thirty-two percent fewer children were newly infected in 2009 vs. 2004, and there were 26% fewer AIDS-related deaths in the later time period.⁷

⁷ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Figure 1.2. PMTCT coverage, ANC coverage and number of HIV+ pregnant women (bubble size)⁸



PMTCT coverage, ANC coverage and number of HIV+ pregnant women (bubble size)

Urban and rural HIV prevalence

Figure 1.3 below shows rural and urban variations in HIV/AIDS prevalence.

⁸ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Figure 1.3. HIV prevalence among young men and women aged 15–49 years, selected national population-based surveys, by location 2001–2002.⁹



Factors that affect HIV prevalence

According to WHO-AFRO, the factors that account for the high prevalence of HIV in sub-Saharan Africa are:

- High *prevalence* of other *sexually transmitted infections* (STIs) increase the risk of acquiring and transmitting HIV
- Limited access to STI management
- Limited access to or social non-acceptance of condoms
- War and civil disturbance
- Cultural/ethnic practices, such as polygamy and wife inheritance
- Women's low status and inability to influence their partner's behaviour
- Low literacy rates
- Increasing urbanisation, migration, mobilisation, and separation of families as a result of poverty and other social circumstances
- Low level of political commitment to the prevention and control of HIV/AIDS
- Exposure to blood from unsafe medical practices and traditional practices.

⁹ World Health Organization, Regional Office for Africa. HIV/AIDS Epidemiological Surveillance for the WHO African Region, 2002. Harare, Zimbabwe: September 2003.

Population mobility

One of the main factors driving the epidemic in southern Africa is extensive population mobility across national borders.

- Away from their community and their regular sexual partners, men are more likely to engage in commercial sex.
- Because of coercion or the need to provide a source of income for themselves and their families, girls and women engage in sex work or transactional sexual relationships in which money or gifts are exchanged for sex.

<u>Summary</u>

By the end of 2009, there were about 33.3 million people living with HIV/AIDS worldwide, including more than 2 million children. Of those infected, approximately 22.5 million live in sub-Saharan Africa. The situation is especially serious in this region, which accounts for 67.7% of HIV infections worldwide.

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 provinces and districts are most affected by the HIV/AIDS epidemic in your country?
- 2. What might be the factors contributing to the high rate of HIV in these provinces or districts?
- 3. Has your province or district been more or less affected than the rest of sub-Saharan Africa?

Apply what you've learned/ case study

Try this case study. We'll discuss the answers in class.

Afrobia is an east African nation that had its earliest cases of AIDS recognised in 1982. Data below are based on estimates of HIV prevalence by province. Examine the data and answer the questions that follow.

HIV prevalence (%) by province, Afrobia, 1995-2002.

Province	1995	1998	2000	2002
Samad	2.3	4.7	10.4	11.2
Risarah	5.0	7.2	9.2	9.1
Yolo	10.5	20.1	27.6	27.8
Inyo	10.3	15.6	20.6	27.9
Plumas	4.0	8.7	12.9	12.2

- a. What province had the greatest proportion of its population infected with HIV in 1995?
- b. Comment on the HIV infection trends.
- c. In 2002, which province had the highest prevalence? Is the epidemic increasing or decreasing in this province?

Unit 2 Impact of the HIV/AIDS Epidemic

<u>Overview</u>

What this unit

is about

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

Warm-up questions

1. True or false? Worldwide, approximately 1.8 million people die each year 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. Globally, what is the burden of HIV/AIDS in terms of disability adjusted life years (DALYs) and deaths?
- 5. List some of the effects stigma has on HIV prevention, care, and support for individuals infected 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

Increase in annual

AIDS deaths

Using UNAIDS' global estimates, there were approximately 1.8 million AIDS-related deaths in 2009¹. This is about a 5% decrease from 2005, partly attributable to the scaling-up of *antiretroviral* treatment services. Because of *stigma* attached to the *human immunodeficiency virus (*HIV) and AIDS, deaths due to HIV may be reported as due to other causes, notably tuberculosis and pneumonia.

Figure 2.1. Estimated adult and child deaths due to AIDS globally, $1990-2007^2$



Source: UNAIDS Epidemic Update, 2007

¹ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

² UNAIDS. 2008 Report on the global AIDS epidemic. Geneva: UNAIDS; 2008.

Increase in annual AIDS deaths, continued

To date, the high *mortality* observed in sub-Saharan Africa and South and South-East Asia has not yet been experienced by countries in other regions, such as those in North Africa and the Middle East and Latin America. Experience from other countries that began with relatively small HIV epidemics, however, suggests that mortality rates may not always remain low.

Life expectancy in the Dominican Republic is estimated to be three years lower than it would have been in the absence of AIDS.³

With the exception of Thailand, every country in Asia has an adult HIV prevalence of less than 1%. However, owing to the region's large population, Asia's comparatively low HIV prevalence translates into a substantial portion of the global HIV burden.¹

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 among people 15-49 years old.¹

¹ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

Projections to 2010

In affected countries, HIV can have a profound effect on life expectancy. Examples from Southeast Asia are illustrative. By 2010, the life expectancy is projected to be two years lower in Thailand and four years lower in Cambodia and Myanmar (Burma).⁴

Figure 2.2. Projected mortality with and without AIDS in selected Asian countries: 2010.



Source: U.S. Census Bureau, International Programs Center, International Data Base and unpublished tables.

⁴ US Bureau of the Census. HIV/AIDS Surveillance Database.

AIDS as a cause of death

In 2004, AIDS was the sixth leading cause of death in the world and the fourth leading cause of death among low-income countries.⁵

In sub-Saharan Africa, AIDS was the leading cause of death among adults between the ages of 15 and 59, whereas in most other regions it was not a leading cause of death.⁵

Figure 2.3. Adult (aged 15-59 years) mortality rates by major cause group and region, 2004^5



Source: World Health Organization. The Global Burden of Disease: 2004 Update.Geneva: 2004

Although HIV/AIDS is not a leading cause of death in many countries, 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 some regions, HIV-associated diseases may contribute significantly to the overall *disease burden*.

⁵ World Health Organization, The Global Burden of Disease: 2004 Update.

DALYs

Globally, HIV/AIDS accounts for 58.5 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." HIV/AIDS was the fifth leading cause of DALYs in 2004⁵ (see Table 2.1). Just as HIV/AIDS is an underappreciated cause of death in some regions, it may also be an underappreciated cause of DALYs lost.

Disease	DALYs (millions)
Lower respiratory tract infections	94.5
Diarrhoeal diseases	72.8
Unipolar depressive disorder	65.5
Ischaemic heart disease	62.6
HIV/AIDS	58.5
Cerebrovascular disease	46.6
Prematurity and low birth weight	44.3
Birth asphyxia and birth trauma	41.7
Road traffic accidents	41.2
Neonatal infections and other	40.4
Tuberculosis	34.2
Malaria	34.0
Chronic obstructive pulmonary disease	30.2
Refractive errors	27.7
Hearing loss, adult onset	27.4
Congenital anomalies	25.3
Alcohol use disorders	23.7
Violence	21.7
Diabetes mellitus	19.7
Self-inflicted injuries	19.6

Table 2.1. Leading caus	ses of disease burden (in	DALYs), all ages, 2004. ⁶
8		

⁶ World Health Organization. The Global Burden of Disease: 2004 Update. Geneva: 2004

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 generally are from the most productive age groups in society: between 15 and 49 years of age. At these ages, people usually are 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 often are left to care for young children.
- There is an increased burden on society to provide orphanages and healthcare 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 in India after HIV infection is detected in a patient. Individuals and families usually cope with the increase in expenditure for care by using savings, borrowing money, and selling and mortgaging assets.

Figure 2.4. Monthly household expenditure after detection of HIV status, Delhi and Manipur, India, 2003.⁷



⁷ ILO, New Delhi, 2003.

Impact on children

Children's education suffers when a family member is infected with HIV. 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 no longer can 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 elevated 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 children of HIVinfected 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.⁸

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, and discrimination and isolation
- Malnutrition and illness.

⁸ UNICEF, 2003

Workforce and Health Services Impact

Effect on the workforce

Employers in several countries will bear a large cost of the *epidemic*. These costs 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. Such losses could be economically significant if HIV continues to spread.

Pressure on health services

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

In Sudan, the cost of caring for an HIV-infected patient with tuberculosis was 50% higher than caring for an HIV-uninfected patient with tuberculosis. As the number of HIV-tuberculosis co-infections increase in the country, this cost difference likely will have a significant impact on tuberculosis 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.

Notwithstanding its comparatively low HIV prevalence, the AIDS epidemic is predicted to force an additional 6 million households in Asia into poverty by 2015 unless national responses are significantly strengthened.¹

Social stigma

AIDS-related *stigma* remains one of the greatest obstacles to the fulfilment of human rights among people living with HIV. *Stigma* also is a major barrier to creating and implementing HIV programming and can result in discrimination. Discrimination of 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 testing for HIV and engaging in protective behaviours and has its roots in attitudes towards *people living with HIV (*PLHA). As an example, a recent survey in Egypt found that only 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.



Figure 2.5. Attitudes toward PLHA, Egypt.⁹

⁹ UNAIDS. Notes on HIV/AIDS Epidemic: Middle East & North Africa, December 2006.

Social stigma, continued

Stigma is not directed only toward PLHA. 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, marginalised people, such as IDUs and *men who have sex with men* (MSM), are often badly served by prevention programmes. In some countries, their needs for care and support 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 a country's development. Even at lower levels, HIV will likely have a substantial impact on healthcare systems and will have a profound effect on the people and their families who are 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.

Describe the impact of HIV and AIDS on the health system in your country.

Is there any evidence of stigma and discrimination against HIV-infected persons in your district? If yes, provide examples. Discuss how stigma can hamper HIV prevention and treatment interventions in your district. What are some ways that stigma and discrimination against HIV-infected persons in your community may be addressed or overcome?

Apply what you've learned/ case study

Try this case study individually.

The five districts in the fictitious country of Melabia have had different experiences with the HIV/AIDS epidemic. Examine the following data:

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

Measures of HIV impact by district, Melabia, 2006.

Now try the questions below.

- a. In which district has the impact of HIV/AIDS been greatest?
- b. Based on the data above, in which district was the proportion of deaths due to HIV/AIDS among working adults the lowest?

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 strains of HIV exist?
- 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
- 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

Warm-up questions, continued

- 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 sexually transmitted infections (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. Tuberculosis (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

12. ______ 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 risk of HIV transmission
- Discuss the natural history of HIV and list the major opportunistic infections that occur among AIDS patients
- Describe the major elements of HIV prevention and control programmes
- Recognise that HIV is treated with antiretroviral drugs and that treatment also involves prevention and treatment of opportunistic infections.

Biology of HIV

The virus

Extensive research has shown that *human immunodeficiency virus* (HIV) is the virus that causes *acquired immunodeficiency syndrome* (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 protect the body against infection:

- CD4+ *lymphocytes*
- Macrophages.

CD4+ *lymphocytes* are a type of white blood cell that fights infections. The T *lymphocyte* is the cell that HIV infects and destroys. *Macrophages* 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 sub-types worldwide are 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 recognised, *HIV-1* and *HIV-2*. The following table summarises the differences between the two types:

	HIV-1	HIV-2
Geographic distribution	Worldwide.	Primarily confined to West Africa, although cases have been reported in Europe, Asia, and Latin America.
Sub-types	Major group, M, is classified into 10 sub-types; additional highly divergent strains are known as group O.	Five genetic sub-types.
Natural history	More easily transmitted and faster progression to AIDS.	Less easily transmitted than HIV-1 and slower progression to AIDS.

Table 3-1	Characteristics	of HIV-1	and HIV-2
14010 5.1.	Characteristics	011114 1	una 111 v 2.

Differences in distribution

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

- Subtype B predominates in the Americas, Western Europe, and Australia. In eastern South America, there is a large proportion of BF recombinants in addition to subtype B.
- In Eastern Europe, subtypes A, B, and AB recombinants strains dominate.
- In Asia, three different patterns have been observed: (1) subtype C in India, Nepal and Bangladesh; (2) a mixture of B, C, and BC recombinants in China, Bhutan, Myanmar, and east India; and (3) a mixture of subtype B and CRF01_AE in Thailand, Laos, Cambodia, Vietnam, Malaysia, and Indonesia.
- The greatest diversity of subtypes is seen in Africa. Subtype C dominates southern and eastern Africa, except for pockets of subtypes A and D in Kenya, Rwanda, and Uganda. West and central Africa mainly have CRF02_AG, with several other recombinants circulating at low levels. The most complex epidemic is in central Africa, where rare subtypes and a wide variety of recombinant forms circulate without any predominant strain.
- There is very little data on the HIV-1 subtypes circulating in northern Africa, the Middle East, and Central Asia.

¹ Kahn, Patricia. Do clades matter for HIV vaccines? IAVI Report 7(2) May-August 2003.

Differences in distribution, continued

Figure 3.1 below shows the most common HIV-1 subtypes and recombinants in different parts of the world.

Figure 3.1 Global Distribution of HIV-1 Subtypes and Recombinants²



² Kahn, Patricia. Do clades matter for HIV vaccines? IAVI Report 7(2) May-August 2003.

HIV Transmission and Natural History

How HIV is transmitted

All strains of HIV are transmitted in the same ways:

- The predominant route of HIV transmission is through heterosexual intercourse. There are areas, however, where the HIV epidemic has emerged among *injection drug users* (IDUs) and *men who have sex with men* (MSM).
- HIV is also transmitted through blood, blood products and donated organs or semen. Blood-borne, or *parenteral*, transmission occurs primarily through the use of inadequately sterilised 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 figures below from Iran and Indonesia.



Figure 3.2. Modes of HIV transmission, Iran, 2007³.

³ WHO, 2007
How HIV is transmitted, continued



Figure 3.3. Modes of HIV transmission, Indonesia 2005⁴

Discussing the figures

Looking at Figure 3.2 and Figure 3.3, answer the following questions:

- a. What is the most common mode of transmission in Iran? In Indonesia?
- b. What does perinatal mean?

⁴ National AIDS Programme, Ministry of Health, Indonesia.

How HIV is transmitted, continued

The distribution of modes of transmission includes the following:

- In Swaziland, as in much of sub-Saharan Africa, the primary mode of HIV transmission is heterosexual sexual transmission and accounts for 94% of incident infections.⁵
- In Brazil, heterosexual transmission, sex between men and injecting drug use continue to be almost equally responsible for the burden of HIV infection.²
- In the Russian Federation, 57% of newly diagnosed cases of HIV infection in 2008 were associated with injection drug use. Between 38.5% and 50.3% of injecting drug users in Ukraine are believed to be living with HIV.⁵
- In Honduras, HIV transmission occurs mainly during unsafe paid sex and *unprotected sex* between men.⁶
- The primary mode of transmission in the Caribbean is sexual intercourse, primarily heterosexual, with *unprotected sex* between *sex workers* (SWs) and clients playing a key role in the spread of HIV. Unsafe injection drug use is only a significant factor in the HIV epidemics of Bermuda and Puerto Rico.⁶
- In Mauritius, exposure to non-sterile drug-injecting equipment is the main risk factor for HIV infection. In the first six months of 2004, approximately 75% of HIV infections diagnosed were among IDUs.²
- Among men who have sex with men in El Salvador, condom use during the last episode of sexual intercourse rose significantly between 2004 and 2007, from 70.5% to 82.1%.⁵
- Research from 2008 shows that untreated sexual transmission infections may be facilitating the spread of HIV among men who have sex with men. In Peru, newly infected HIV-infected men who have sex with men were four times more likely than their uninfected peers to have syphilis or herpes simplex virus type 2.⁵

⁵ UNAIDS. 2010 Report on the global AIDS epidemic. Geneva: UNAIDS; 2010.

⁶ UNAIDS. 2008 Report on the global AIDS epidemic. Geneva: UNAIDS; 2008.

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:

- 1. 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.
- The greater the number of partners an individual has, the greater the likelihood of having intercourse with someone with HIV infection.
- 2. A variety of biological factors appear to increase the risk of becoming infected. These include the following:
- The infected patient's *viral load*, which is the amount of virus present in blood, semen, cervicovaginal fluids and amniotic fluid
- Type of intercourse anal intercourse is riskier than vaginal intercourse, and vaginal intercourse is substantially riskier than oral intercourse
- The coexistence of *sexually transmitted infections* (STIs) inflammatory, such as *gonorrhoea* or *chlamydia*, or ulcerative, such as *syphilis*, *chancroid* or *herpes simplex virus type 2*
- Failure to use prevention methods, such as condoms.

Role of STIs

In the rapid transmission of HIV during an epidemic's growth phase in a country, *STIs* are of particular importance. There is ample evidence that viral *STIs*, such as *HSV-2* and acute bacterial *STIs*, are co-factors 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, due to an immature cervix.

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 control programmes could lead to a decline in HIV *incidence*. Several 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.

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, especially in countries with *low-level* and *concentrated* epidemics.

Role of male circumcision

Male circumcision consistently has been shown to decrease the risk of HIV acquisition for men. In three randomised 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, the WHO has recommended circumcision for uncircumcised adolescent and adult men living in areas with high transmission of HIV. In regions where HIV transmission is relatively low and the majority of men are already circumcised, the impact of this intervention probably will not be substantial.

Natural history

AIDS is the late stage of HIV infection and is characterised by a severely weakened *immune system* that no longer can ward off life-threatening infections and cancers. The risk for AIDS is related to the length of time a person has had HIV infection. Almost all HIV-infected individuals eventually will develop AIDS.

A review of *cohort* studies in developing countries found that the median interval from HIV infection to death is 11 years (UNAIDS/WHO 2007) in the absence of any treatment interventions. *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. This treatment has been associated with changes in the types of *opportunistic infections* that appear with AIDS. In Brazil, for example, 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* (HAART) was introduced.

Preventing Transmission of HIV/AIDS

Preventing transmission

The best long-term solution for controlling the HIV/AIDS epidemic is a low-cost, highly effective vaccine, but one is not available and is not foreseen 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 injection equipment with an infected person
- Decreasing the risk for transmission, if exposed.

Prevent sexual

transmission

The most basic approach to preventing sexual transmission, other than *abstinence*, is to:

- Delay age of *sexual debut* (first time a person has sexual intercourse)
- Decrease the number of sexual partners
- Consistently use male or female condoms
- Undergo voluntary counselling and testing (VCT) to know one's HIV status
- Treat *STIs*
- Perform male circumcision in high-*incidence* countries

In a *VCT* programme, both counselling and testing services are provided to individuals and communities, allowing persons who are tested to obtain emotional and medical support before and after their HIV tests.

Prevent bloodborne transmission

Blood-borne, or *parenteral*, transmission of HIV may account for a significant number of new HIV transmissions in some countries. It typically occurs in *IDUs* through re-use and sharing of injection equipment without sterilisation.

HIV can be transmitted in medical settings through transfusion, re-use of needles and surgical equipment without sterilisation, and needle-stick injuries to healthcare workers.

Prevent blood-borne transmission, continued

Parenteral transmission can be prevented by sterilising or not reusing needles, screening blood and blood products for HIV prior to administration, sterilisation of surgical instruments and *universal precautions* for healthcare workers.

Prevent injection drug use associated transmission

In some parts of the world, 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 efficiency, HIV prevalence can rise rapidly among *IDUs* who share needles. Data show that, in many settings, sharing needles and syringes is very common.

- In Iran, surveys done in 2001 and 2004 found an increase in *sero-prevalence* among *IDUs* from 15% in 2003 to 23% in 2004, although the studies were done in somewhat different *IDU* populations. At the same time, another study found that between 30% and 100% of *IDUs* in five districts in Tehran routinely shared needles and syringes.
- In Pakistan, the HIV *prevalence* among *IDUs* varies by city: 26% in Karachi, 2.5% in Lahore, 12% in Sargodha, 0.5% in Rawalpindi, 1% in Sialkot, and 9.5% in Faisalabad (UNAIDS 2006).
- In the Ukraine, the number of *IDUs* newly diagnosed with HIV infection increased from 3964 in 2001 to 7127 in 2006, and in the first half of 2007, 3639 new cases of HIV infection were reported among *IDUs*. Exceptionally high HIV *prevalence* has been found among *IDUs*, ranging from 10% in Lugansk to 13% in Kiev, to 89% in Krivoi Rog. (UNAIDS 2007)
- In contrast to the epidemics in the rest of the Caribbean region, injection drug use is the largest contributing factor to HIV transmission in Bermuda and Puerto Rico.

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

Prevent injection drug use associated transmission, continued

Although HIV prevention services for *IDUs* remain controversial politically, there are now good examples from Iran and the Netherlands to suggest that these programmes can be effective. If injectors are to avoid contracting or passing on HIV, they must have easy access to clean needles.

Clean needles or condoms are the two things that can most immediately interrupt HIV transmission among *IDUs*.

Method of transmission	Method of prevention
Transfusion	 Sterilising or not re-using needles Screening blood and blood products for HIV prior to administration Selection of volunteer blood donors at low risk for HIV
Re-use of needles and surgical instruments without sterilisation	Sterilisation of surgical instrumentsSterilising or not re-using needles
Needle-stick injuries to healthcare workers	 Universal precautions for healthcare workers (for example, use of gloves and eyewear, proper disposal of needles) Post-exposure prophylaxis

Table 3.2. Prevention of blood-borne and injection drug use associated transmission of HIV.

Prevent mother-to-child transmission

Perinatal HIV transmission may contribute to increasing trends in HIV infection. Multiple interventions are now available to prevent *mother-to-child transmission*. These include:

- Beginning the infected mother on *HAART*
- Performing a Caesarean section to deliver the HIV-exposed baby
- Giving the mother and baby short courses of *antiretroviral* drugs around the time of labour and delivery
- Avoiding breastfeeding where possible, which is called *replacement feeding*.

Prevent mother-to-child transmission, continued

Although breastmilk substitutes can be used to avoid the risk for transmission through infected breastmilk, significant health risks are associated with this practice, including:

- Malnutrition
- Exposure to other infections.

WHO/UNICEF/UNAIDS have developed several documents that address HIV and breastfeeding. A summary of their recommendations⁷ follows:

- When *replacement feeding* is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-positive mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life.
- All HIV-infected mothers should receive counselling about the risks and benefits of various infant-feeding options. Whatever a mother decides, she should be supported in her choice.
- When HIV-infected mothers choose not to breastfeed from their child's birth or to stop breastfeeding later, they should be provided with specific guidance and support for at least the first two years of the child's life to ensure adequate *replacement feeding*.
- Breastfeeding should be discontinued as soon as is feasible. This is known as "early weaning," and it should take into account local circumstances, nutritional considerations, the individual woman's situation, and the risks associated with *replacement feeding*.
- Mixed feeding, in which a combination of breastfeeding and replacement feeding is practiced, places the infant at increased risk for HIV infection.

HIV/AIDS Treatment

Antiretroviral drugs

Antiretroviral drugs are used to treat HIV infection. In the past, the high cost of these drugs made them infrequently used in resource-limited settings. The new Global Fund to Fight AIDS, Tuberculosis and Malaria and other organisations are now making funds available for *antiretroviral*

⁷ UNAIDS, Prevention of HIV transmission from mother to child: Strategic options. 1999.

Antiretroviral drugs, continued

and other therapies. There are three classes of first-line *antiretroviral* drugs:

- Nucleoside reverse-transcriptase inhibitors
- Non-nucleoside reverse-transcriptase inhibitors
- Protease inhibitors.

The regimens that will most likely be used in resource-limited settings include a combination of three antiretroviral drugs, according to the WHO guidelines publication "The Use of Antiretroviral Therapy: A Simplified Approach for Resource-Constrained Countries." Several countries have adapted this publication for use as their own national guidelines.

If available, tests for the level of CD4+ cells and plasma viral load can be used to make judgments about when to begin therapy. Treatment is started when patients develop clinical symptoms from their *immunodeficiency* or reach a CD4+ cell count of less than 200 cells per mm³. ART may be considered for persons with a CD4 count of less than 350 cells per mm³. Treatment options and types of medication will change over time.

Preventing and treating opportunistic infections

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

- Anti-tuberculosis drugs extend the lives of patients with HIV and TB.
- *Cotrimoxazole and isoniazid prophylaxis* has been used successfully to prevent the onset of *opportunistic infections* in HIV patients.
- Vaccines are available for some potential *opportunistic infections*, such as pneumococcal disease.

Summary

HIV is a virus that can be transmitted sexually, parenterally, or perinatally. For each type of transmission there are precautions for prevention, including condom use, needle sterilisation, and short-course antiretroviral treatment during pregnancy. Treatment includes antiretroviral drugs and the prevention and treatment of opportunistic infections.

Notes

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 sub-type 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've learned/ case study

Work on this case study independently.

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

	2000	2001	2002
Gonorrhoea*	5.0	12.8	23.5
Syphilis*	2.1	4.5	16.4
Reported cases of urethritis from STI clinic	2 987	3 452	6 784
HIV incidence (estimated)	2%	4.3%	5.0%

Incidence of various STIs over time, Western District.

* Cases per 1,000 population 15-49 years old

- a. Do you think that sexually transmitted infections (STIs) may be playing an important role in the spread of HIV infection? Why or why not?
- b. Given the HIV incidence in the Western District, what do you think will happen with tuberculosis rates in the next several 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 being 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

3.

- 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.

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

Warm-up questions, continued

- 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 be ongoing, with sufficient accuracy and completeness for analysis and dissemination of data. It should lead to effective prevention and control.

Types of activities included in HIV surveillance are:

- HIV case reporting
- HIV sero-prevalence 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 *crosssectional surveys*, which are conducted at a given point in time, such as during a specific year rather than over time, are not considered surveillance activities.

Information

loops

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

- Healthcare 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 *surveillance* of *human immunodeficiency virus* (HIV) and *acquired immunodeficiency syndrome* (AIDS) *surveillance*, or *surveillance* of a different disease, is conducted in your country.

Information loops, continued

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. Antenatal clinic (ANC) hands out forms to midwives.
- 2. ANC technician draws blood and sends it for testing.

Collation:

1. 2.

Analysis/Interpretation:

1. 2.

Dissemination/Utilisation:

1. 2.

Surveillance terms

Information from *surveillance* is used to make decisions about the best ways to prevent and control the disease. The term "*surveillance*" implies information used to perform an action. Let's 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 healthcare 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 — the number of persons who newly develop a disease or condition within a specified time period. *Incidence* is expressed as a rate with the time period in the denominator.

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 organisation conducting *surveillance* initiates procedures to obtain reports. Example: making telephone calls or visits to health facilities to obtain information.

Relation between disease and case definition

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

	True		
Case definition	Present	Absent	Total
Definition met	а	b	a+b
Definition not met	С	d	c+d
Total	a+c	b+d	N

Table 4.1. Relation between disease and case definition.

Sensitivity — Referring to Table 4.1 above, the ability of a case definition to predict the presence of 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 — The proportion of persons who have true disease, verified by meeting a case definition and having a positive laboratory test (a/(a+b)).

Negative predictive value—The proportion of persons who do not have true disease, verified by not meeting a case definition and having a negative laboratory test (d/(c+d)).

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

Determine the *specificity* of this case definition:

a = 10, b = 10, c = 30 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:

- <u>Duplication of effort</u>. Vertical or categorical surveillance systems were established to report a single disease as a part of specific disease intervention programmes, resulting in duplication of effort and resources. Different programmes approached the same agency for similar surveillance activities. This duplication of effort results in inefficient use of resources.
- <u>Delay in reporting</u>. Health workers failed to report on time the first cases of epidemic-prone diseases that fit standard case definitions. This delay in reporting the earliest suspected cases significantly slows identification of outbreaks and impedes the effectiveness of response.
- <u>Inadequate data collection, analysis, use, and dissemination of data</u>. Collection, analysis, utilisation, and dissemination of surveillance data at the sub-national 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.
- <u>Lack of integrated training</u>. Little attention has been given to seeking opportunities to combine *surveillance* training activities to increase efficiency. As a result, each programme organises programme-specific training courses (including surveillance) for the same health personnel, especially at sub-national and health facility levels.
- <u>Lack of evaluation</u>. 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 is inadequate. Neither national nor inter-country 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.
- <u>Lack of supervision</u>. Supervisory support, completeness, and timeliness of reporting are generally inadequate.

Integrated Disease Surveillance

IDSR strategy

defined

The *Integrated Disease Surveillance and Response* (IDSR) 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 *World Health Organization* as an approach to strengthen communicable disease *surveillance*. Integration involves combining all functions and resources of surveillance and administering them together, so that the problems listed on the previous page are solved. In an integrated system:

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
- Mobilising 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.

The *WHO* encourages the adoption of the *IDSR* strategy, which has been endorsed by all Member States. Toward this goal, a strategic document has been prepared for implementation of *IDSR* in Member States. Activities using this approach are underway in the African, Eastern Mediterranean, European, and South-East Asian regions.

IDSR goals

The *IDSR* 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

IDSR goals, continued

- 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
- emphasise community participation in detection and response to public health problems
- Strengthen the involvement of laboratory personnel in epidemiologic *surveillance*.

Priority diseases

The high 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

<u>Other priority communicable diseases</u>: *Examples:* Tuberculosis, HIV and 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.

<u>Unit 4 Exercises</u>

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've learned/ case study

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

Background:

Until 2006, Melabia 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 adults and paediatric HIV disease and new HIV surveillance case definitions.

The WHO is sponsoring a pilot project in Melabia 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.

Apply what you've learned/case study, continued

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.

2006 WHO case definition				
1994 case	Present	Absent	Total	
definition				
Definition met	65	4	69	
Definition not met	6	25	31	
Total	71	29	100	

- 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

Wha is ab

What this unit is about	- -				
	The	e two core elements of HIV/AIDS surveillance include:			
	•	ase reporting of HIV and/or advanced HIV disease requiring eatment IV sero-prevalence surveys in selected clinic populations, such as tenatal clinic attendees and patients with sexually transmitted fections, and in selected high-risk populations such as injection drug ers and sex workers.			
	very	ese two elements provide basic information on the distribution of HIV, y basic data on trends in the epidemic and data that can be used to luate 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 sero-prevalence surveillance is more likely to under-report 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 reportingb. Sentinel surveillance			

Warm-up questions, continued

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 sero-prevalence 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.

Purpose of HIV Surveillance

The primary objective of epidemiologic *surveillance* is to detect trends in *incidence* and *prevalence* of a disease over time. *Human immunodeficiency virus* (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 sub-groups* (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 prioritising prevention and care programmes
 - Monitoring and evaluating prevention and care programmes
 - Resource allocation and programme planning
 - Mobilisation of political commitment.
- To educate the public about HIV
- To guide scientific research
- To make estimates and projections for new and total HIV infections, *acquired immunodeficiency syndrome* (AIDS) cases, AIDS deaths, HIV infected pregnancies and births, number of orphans and other strategic information, such as *antiretroviral treatment* (ART) need, survival on ART, and so on.

One standardised package for making these sorts of projections 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.

More information on Spectrum can be found at: http://www.unaids.org/en/KnowledgeCentre/HIVData/Epidemiology/epi_ software2007.asp

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 HIV cases that have not progressed to AIDS) are also reported.
- In contrast, HIV sero-prevalence surveillance seeks to estimate the prevalence of HIV infection in selected populations, such as antenatal clinic (ANC) attendees, patients with sexually transmitted infections (STIs) and blood donors, by conducting sero-prevalence surveys in these populations on an ongoing basis. Sero-prevalence surveys estimate HIV prevalence by testing blood for HIV antibody.

WHO has begun to emphasise HIV case reporting, especially in countries with lower levels of HIV infection, and reporting of cases of *advanced HIV* disease—that is, persons who should be receiving *ART*.

- HIV *case reporting* involves routinely reporting all cases of HIV infection of all four clinical stages. This reporting allows us to accurately monitor the HIV epidemic, assess how the epidemic is changing, and create programs for HIV prevention and care that work for people and their communities.
- Advanced HIV case reporting involves routine reporting of all cases of advanced HIV disease. 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 <5 years old are based on CD4 percentage (≤11 months, 25%; 12-35 months, 20%; 36–59 months, 15%). Keep in mind that this includes AIDS case reporting (Clinical Stage 4). *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.

Core elements, continued

Table 5.1. WHO clinical staging of HIV/AIDS for adults and adolescents with confirmed HIV infection, Stages 3 and 4 only, 2007.^{1,2}

Clinical stage 3

Clinical stage 3
Unexplained* severe weight loss (>10% of presumed or measured body weight)**
Unexplained chronic diarrhoea for longer than one month
Unexplained persistent fever (intermittent or constant for longer than one month)
Persistent oral candidiasis
Oral hairy leukoplakia
Pulmonary tuberculosis
Lymph node <i>tuberculosis (TB)</i>
Severe bacterial infections (for example, pneumonia, empyema, pyomyositis, bone or joint
infection, meningitis, bacteraemia)
Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis
Unexplained anaemia ($\langle 8g/dL \rangle$, neutropenia ($\langle 0.5 \times 10^9/L \rangle$) and/or chronic
thrombocytopenia ($< 50 \times 10^9$ /L ³)
Clinical stage 4
HIV wasting syndrome
Pneumocystis pneumonia
Recurrent severe bacterial pneumonia
Chronic herpes simplex infection (orolabial, genital or anorectal of more than one month's
duration or visceral at any site)
Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs)
Extrapulmonary tuberculosis
Kaposi's sarcoma
Cytomegalovirus infection (retinitis or infection of other organs)
Central nervous system toxoplasmosis
HIV encephalopathy
Extrapulmonary cryptococcosis including meningitis
Disseminated non-tuberculous mycobacteria infection
Progressive multifocal leukoencephalopathy
Chronic cryptosporidiosis
Chronic isosporiasis
Disseminated mycosis (extrapulmonary histoplasmosis or coccidiomycosis)
Recurrent septicaemia (including non-typhoidal Salmonella)
Lymphoma (cerebral or B cell non-Hodgkin)
Invasive cervical carcinoma
Atypical disseminated leishmaniasis
Symptomatic HIV-associated nephropathy or HIV-associated cardiomyopathy
* Unexplained refers to cases in which the condition is not explained by other conditions.
**Assessment of body weight in pregnant woman must consider the expected weight gain
of pregnancy
or preshancy

¹ WHO, Case Definitions of HIV for Surveillance and Revised Clinical Staging and Immunological Classification of HIV-Related Disease in Adults and Children, 2007.

² Monitoring the AIDS Pandemic (MAP). Drug Injection and HIV/AIDS in Asia (2005). Accessed online at http://www.mapnetwork.org/docs/MAP_IDU%20Book%2024Jun05_en.pdf

Core elements, continued

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.

Figure 5.1. Options for HIV case reporting.



Core elements, continued

HIV case *surveillance* and HIV *sero-prevalence 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 sero-prevalence surveillance.

HIV Case Surveillance	HIV Sero-Prevalence Surveillance			
Advantages				
 Provides information on relative importance of HIV <i>transmission</i> categories <i>Case surveillance</i> for <i>advanced HIV disease</i> measures clinical <i>disease burden</i> (the size of the health problem in the area) and corresponds roughly to the size of the population that should be on <i>antiretroviral therapy</i>. Provides information on people accessing care 	 High <i>specificity</i> of case definition HIV has a very short <i>latent period</i> Under-reporting not a problem Better measures of <i>prevalence</i> and trends in HIV infection in population groups 			
Disad	vantages			
 Advanced HIV infection has a long latent period Under-reporting of both HIV and advanced HIV infection may be severe Does not necessarily indicate levels of HIV infection in people who have not tested for HIV 	 Provides no information on morbidity Less information on the relative importance of HIV transmission categories 			

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 injection drug use and heterosexual transmission, which 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 ART:

- Advanced *case surveillance* alone may severely under-represent 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 *sero-prevalence 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*.

- <u>Incidence</u> is the rate at which new HIV infections occur in a population in a given period of time. Because it is a rate, its unit of measurement always has time in the denominator.
- <u>Prevalence</u> measures the level of HIV infection in a population. It is
 measured as a unitless proportion, such as the percent 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 organising case reporting systems for HIV and STIs, *universal case reporting* and *sentinel surveillance*. Both approaches are recommended under the *Integrated Disease Surveillance and Response* (IDSR) strategy. Table 5.3, below, describes each system and its advantages.

Table 5.3. Overview of two common surveillance systems.

	Description	Advantages
Universal case reporting	A minimum amount of data is collected from all the health facilities in the country where cases are seen	Provides data that can be generalised to the entire population of a nation
Sentinel surveillance	More complete data are obtained from all patients seen at a small number of facilities, which are known to be diligent and motivated to report cases	Provides detailed, high-quality data about a more specific population by using a smaller, more reliable system

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 *sexually transmitted infections* (STIs).

<u>Summary</u>

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 sub-groups 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 sero-prevalence surveillance is being conducted in your country?

Apply what you've learned/ case study

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

In the Northern District of Melabia, the Ministry of Health has conducted a long-term cohort study of 1 000 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.

HIV infection status	1998	1999	2000	2001	2002
New HIV infections	10	25	50	80	114
Total HIV infections	10	35	85	165	279
Population at risk (non-infected)	1 000	990	965	915	835
Total population (infected and non- infected)	1 000	1 000	1 000	1 000	1 000

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 other sources, such as behavioural surveillance, HIV case reporting, death registration and STI surveillance. Additional data are added to HIV sero-prevalence 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 sub-populations 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.

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 epidemic of human *immunodeficiency virus* (HIV) and *acquired immunodeficiency syndrome* (AIDS) is spreading and becoming more complex. *Surveillance* efforts must become more sophisticated if they are to be effective. Recognising this, the *World Health Organization* (WHO) and the *United Nations Joint Programme on HIV/AIDS* (UNAIDS) 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 sero-prevalence surveillance
- Death registration
- Sexually transmitted infection (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 *sero-prevalence surveillance* alone. It also provides a better understanding of the effectiveness of control and prevention measures. Figure 6.1, on the next page, summarises the components of *second-generation surveillance*.

Second-Generation HIV Surveillance, continued



Figure 6.1. The components of second-generation surveillance.*

*Monitoring and evaluation is ongoing

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 sub-populations 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 *socio-demographic indicators*. These form a relatively standard set of data elements that allow for comparison across time and among geographic areas.

Table 6.1. Major indicators used in second-generation HIV surveillance.

Biological indicators

- HIV prevalence
- *STI incidence* and *prevalence*
- TB *incidence* and *prevalence*
- Number of adult cases of HIV infection and *advanced HIV* disease
- Number of paediatric cases of HIV infection and *advanced HIV disease*
- Prevalence and trends of *mother-to-child transmission*

Behavioural indicators

- 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
- Reported number of clients in the last week by sex workers (SWs)

Sociodemographic indicators

- Age
- Sex
- Socioeconomic and educational status (may include occupation)
- Residency or migration status
- Parity (for antenatal sites)
- Marital status

Behavioural indicators

In addition to *surveillance* for cases of HIV, *advanced HIV* and *HIV seroprevalence surveys*, a number of other data are collected and examined in *second-generation surveillance*. Behavioural surveillance is an example of these additional data. Behavioural surveys can be done both in smaller populations, such as most at-risk populations, and in the general population. When surveying the general population at a national level, one of two survey methods designed by Measure Evaluation (<u>www.unc.edu/measure</u>) is often used. These are the *AIDS Indicator Survey* (AIS) and the *Demographic and Health Survey* (DHS).

The *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* (UNGASS) 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. The *AIS* takes about nine months to complete. It has been carried out in Cote D'Ivoire, Guyana, Tanzania, Uganda, Vietnam and Kenya. Additionally, Sudan is in the process of planning a *household survey* modeled on the *AIS* conducted in other countries.

Behavioural indicators, continued

The *DHSs* 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. The *DHSs* occur at fairly broad intervals, typically every five years; they take 18 to 20 months from start to finish. The *DHSs* 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 the following:

- Asia: Bangladesh, Cambodia, India, Indonesia, Nepal, Pakistan, Philippines, Sri Lanka, Thailand, and Vietnam.
- **Caribbean**: Dominican Republic, Haiti and Trinidad and Tobago.
- Eastern Mediterranean: Egypt, Jordan, Morocco, Sudan and Yemen.
- Eastern Europe/Central Asia: Armenia, Azerbaijan, Kazakhstan, Kyrgyz Republic, Moldova, Turkey, Turkmenistan, Ukraine and Uzbekistan
- Latin America: Guatemala, Bolivia, Brazil, Colombia, Ecuador, El Salvador, Honduras, Mexico, Nicaragua, Paraguay and Peru
- Sub-Saharan Africa: Most countries.

Data collection methods

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

- Expanded *biological surveillance* for HIV (primarily *sero-prevalence* surveys in defined and general populations)
- Serial *behavioural surveys* in defined and general population
- Other sources of information.

An overview of data collection methods is shown in Table 6.2

Data collection methods, continued

Table 6.2. Data collection methods for second-generation	
HIV surveillance.	

Basic components	Additional components
 Sentinel HIV sero-prevalence surveillance in defined sub- populations (such as antenatal clinic (ANC) attendees, STI clinic patients, SWs) Serial cross-sectional behavioural surveys in high-risk sub- populations Regular HIV screening of donated blood Case surveillance for advanced HIV disease 	 Regular screening of occupational cohorts or other sub-populations (for example, factory workers, military recruits) HIV screening of specimens taken in general population surveys HIV screening of specimens taken in special population surveys Serial cross-sectional <i>behavioural surveys</i> in general populations Data from other programmes, such as <i>voluntary counselling and testing</i> Death registration and mortality <i>surveillance</i> <i>STI surveillance</i> Data from HIV care and treatment programmes

UNGASS indicators

The UNGASS 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 (Table 6.3), which are called the UNGASS indicators. Sub-sets 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 care and treatment (8 of 25).

UNGASS indicators, continued

The UNGASS indicators are divided into four categories: national indicators, national programme indicators (such as blood safety, antiretroviral therapy (ART) coverage, prevention of mother-to-child transmission, co-management 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.²

	National Indicators
1.	Domestic and international AIDS spending by categories and financing sources.
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).
3.	Percentage of donated blood units screened for HIV in a quality assured manner.
4.	Percentage of adults and children with advanced HIV infection receiving <i>ART</i> .
5.	Percentage of HIV-positive pregnant women who received <i>ART</i> to reduce the risk of <i>mother-to-child transmission</i> .
6.	Percentage of estimated HIV-positive <i>incident</i> TB cases that received treatment for TB and HIV.
7.	Percentage of women and men aged 15-49 years who received an HIV test in the last 12 months and who know their results (<i>UNGASS indicators</i> , 2008).
8.	Percentage of <i>most-at-risk populations</i> that have received an HIV test in the last 12 months and who know their results.
9.	Percentage of <i>most-at-risk populations</i> reached with HIV prevention programmes.
10.	Percentage of orphaned and vulnerable children aged 0-17 years whose households received free basic external support in caring for the child.
11.	Percentage of schools that provided life skills-based HIV education in the last academic year.

Table 6.3. UNGASS indicators, continued

Knowledge and Behaviour
12. Current school attendance among orphans and among non-orphans aged
10-14 years.
13. Percentage of young women and men aged 15-24 years who both
correctly identify ways of preventing the sexual transmission of HIV and
who reject major misconceptions about HIV transmission.
14. Percentage of <i>most-at-risk populations</i> who both correctly identify
ways of preventing the sexual transmission of HIV and who reject
major misconceptions about HIV transmission.
15. Percentage of young women and men aged 15-24 years who have had
sexual intercourse before the age of 15 years.
16. Percentage of women and men aged 15-49 years who have had sexual
intercourse with more than one partner in the last 12 months.
17. Percentage of women and men aged 15-49 years who had more than one
sexual partner in the past 12 months and reporting the use of a condom
during their last sexual intercourse.
18. Percentage of female and male <i>SWs</i> reporting the use of a
condom with their most recent client.
19. Percentage of men reporting the use of a condom the last time they had
anal sex with a male partner.
20. Percentage of <i>IDUs</i> reporting the use of a condom the
last time they had sexual intercourse.
21. Percentage of <i>IDUs</i> reporting the use of sterile injecting
equipment the last time they injected.
Impact
22. Percentage of young women and men aged 15-24 years who are HIV
infected.
23. Percentage of <i>most-at-risk populations</i> who are HIV-infected.
24. Percentage of adults and children with HIV known to be on treatment
12 months after initiation of ART.
25. Percentage of infants born to HIV-infected mothers who are infected.
Source: UNAIDS 2007

Source: UNAIDS, 2007

How the data are used

The *prevalence* of STIs sometimes can be used as a proxy for *risk* behaviour, 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 below shows national-level data on the total reported cases of HIV and other *STIs* from 1987-2005 in the fictitious country of Globa.

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



Low, Concentrated and Generalised 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 *generalised*. 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.

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 sub-population.
- Recorded infection is largely confined to individuals with higher *risk* behaviour, such as SWs, IDUs, and men who have sex with men (MSM).
- 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* include those in the following countries: Afghanistan, Algeria, Croatia, Cuba, Egypt, Iraq, Lebanon, Philippines, Sri Lanka, Syria, Tunisia, and Yemen.

Low-level epidemic, continued

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

Table 6.4. Surveillance approaches to	low-level	epidemics.
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Concentrated epidemic

Characteristics of *concentrated epidemics* include the following:

- HIV has spread rapidly in a defined sub-population, but is not wellestablished in the general population.
- This epidemic state suggests active networks of risk within the subpopulation.
- 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* include those in the following countries: Cambodia, China, India, Iran, Libya, Myanmar, Pakistan, the Russian Federation and Thailand.

Main questions	Basic second- generation HIV surveillance activities	Additional second- generation HIV surveillance activities
How much HIV infection is there?	 HIV sero-prevalence surveillance in groups with risk behaviour Annual sentinel sero- prevalence surveillance in pregnant women in urban/high-exposure areas Analysis of available blood donor screening data 	 Wider geographical coverage and increased frequency of HIV <i>sero-prevalence</i> <i>surveillance</i> in identified groups with <i>risk behaviour</i> HIV <i>surveillance</i> in <i>bridging</i> <i>populations</i> (such as clients of <i>SWs</i>) and pregnant women
What are the main <i>risk behaviours</i> and how do they change over time?	 Repeated risk behaviour surveys in groups with risk behaviour Repeated risk behaviour surveys in bridging populations Analysis of STI data in groups with risk behaviour and bridging populations 	 Wider geographical coverage and increased frequency of repeated <i>behavioural surveys</i> in groups with <i>risk behaviour</i> and <i>bridging populations</i> Surveys of health-seeking behaviour for <i>STIs</i>
Who else might be affected and to what extent?	 Repeated <i>risk behaviour</i> surveys in the general population in urban/high- exposure areas HIV <i>case reporting</i> 	 Repeated <i>risk behaviour</i> surveys in the general population in all areas HIV <i>case reporting</i>

Table 6.5. Surveillance approaches to concentrated epidemics.

Generalised epidemic

Characteristics of generalised epidemics include the following:

- HIV is firmly established in the general population
- Although sub-populations 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 sub-populations at higher risk for infection.
- HIV *prevalence* is consistently over 1% in pregnant women.

Examples of countries with generalised epidemics include the following: Haiti, Papua New Guinea, South Africa, Sudan, and Uganda,.

Main questions	Core HIV surveillance activities	Expanded (second- generation) HIV surveillance activities
What are the trends in HIV infection?	 Annual <i>sentinel sero-prevalence</i> <i>surveillance</i> in pregnant women in urban and rural areas Increase sample size in high- volume sites to enable analysis by age groups HIV disease <i>case reporting</i> 	 HIV sentinel sero- prevalence surveillance in pregnant women in a larger number of sentinel sites HIV sero-prevalence surveillance in groups considered at high risk Population-based prevalence studies to validate surveillance data
Is behaviour changing? Do recorded changes help explain trends in HIV infection?	 Repeated <i>behavioural surveys</i> in groups considered at high risk for HIV infection Analysis of <i>STI surveillance</i> data in groups considered at high risk for HIV infection Repeated <i>risk behaviour</i> surveys in the general population with a focus on young people Analysis of <i>STI surveillance</i> data in the general population 	 Larger coverage of behavioural surveys by expanding populations and age groups
What is the impact of HIV?	 Vital registration data <i>Surveillance</i> of TB and other HIV/AIDS-related illnesses 	 Other death data (census and studies) Studies of access to care

Table 6.6. Surveillance approaches to generalised epidemics.

Low, Concentrated and Generalised Epidemics, continued

Figure 6.3 depicts HIV prevalence among pregnant women in the Dominican Republic, 1991-2005.

Figure 6.3. HIV prevalence among pregnant women in the Dominican Republic, 1991-2005¹



Discussing the figure

Looking at Figure 6.3, answer the following questions:

- a. Did the *prevalence* of HIV among pregnant women in La Romana, Dominican Republic increase or decrease between 2002 and 2005?
- b. In which cities is the HIV *prevalence* among pregnant women consistently over 1%?

¹ 2007 AIDS Epidemic Update, UNAIDS

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 *voluntary counselling and testing (VCT)*
- Treatment programmes, including:
 - Prevention of mother-to-child transmission (PMTCT) programmes
 - o clinical monitoring of ART 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 *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 sero-prevalence 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 sub-populations 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: lowlevel, concentrated or generalised.

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, generalised)? 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've learned/ case study

Try this case study individually.

The fictitious country of Globa 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, Sadcity, where HIV incidence and STI rates are reported to be increasing in SWs.

- a. How would you suggest investing these funds?
- b. What is your goal, and what benefits do you expect from an investment in surveillance?

Notes

Unit 7

Ethical Considerations in HIV Surveillance

<u>Overview</u>

What this unit is about

Persons 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.

True False

- 2. The principle of beneficence refers to minimising risk to individuals in the areas of:
 - a. Physical risk
 - b. Psychological harm
 - c. Stigmatisation
 - 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 marginalised groups should be widely publicised to prevent further spread of the disease.

True False

Warm-up questions, continued

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

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 and general populations
- Use correctly 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 and general populations.

Addressing Ethical Issues

What are

the issues?

People infected with *human immunodeficiency virus* (HIV) and groups with increased risk for HIV and *acquired immunodeficiency syndrome* (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 populations*, 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.

Three ethical principles, continued

- 2. *Beneficence* refers to balancing the benefits and risks to individuals. This includes not only physical risk, but also risk of psychological harm and stigmatisation.
- 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.

Surveillance ethics terms

When you plan HIV *sero-prevalence 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 assuring 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 informed 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
 - \circ 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.

Surveillance ethics terms, continued

Linked anonymous 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 bio-behavioural surveillance studies such as *AIS* or *DHS*+. As in *UAT*, in *linked anonymous testing* the HIV test results of individuals should not be identifiable, 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 surveil/ance activity is reporting cases of HIV and/or AIDS. Nations may consider implementing or modifying their *surveillance* HIV/AIDS 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 characterisation 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 *sero-prevalence studies*, to provide the most accurate epidemiological picture that is achievable given the available resources?

Balancing Risks and Benefits

Fear of stigmatisation

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 (SWs)
- Injection drug users (IDUs)
- Prisoners
- Mobile populations
- *Men who have sex with men (MSM).*

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

- 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, such as 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 injection 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 marginalised. 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 populations, many successful *surveillance* efforts centre on clinics and educational programs designed to meet the needs of people most vulnerable to HIV and its impact.

These clinics provide services to the high-risk population. In doing so, they provide a *sentinel site* where *sero-prevalence 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 publicise information about marginalised groups' HIV infection 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 programs more difficult and encouraging the spread of the virus. Table 7.1 describes some of the potential harms caused by HIV *surveillance*.

Low-level and concentrated epidemic considerations, continued

Type of Harm	Result
Physical	Public attackSpousal/partner abuseDomestic violence
Legal	 Arrest Prosecution, (especially with high-risk populations)
Social	 Disruption of family Workplace discrimination Loss of employment Isolation
	Loss of healthcare servicesRefusal of care by healthcare workers

Table 7.1. Potential harms caused by HIV surveillance.

Generalised epidemic considerations

In surveillance of *generalised epidemics*, there is less focus on highest-risk populations, such as sex workers. In countries where monitoring is done primarily through *anonymous unlinked sero-prevalence surveillance* activities, threats to *confidentiality* are typically low.

Given the stigmatised 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 *voluntary counselling and testing* (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 those data from public release.

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

Benefits

Participating in *surveillance* holds benefits to society as a whole, especially to populations highly affected by HIV/AIDS and to HIVinfected 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 to public awareness of and sympathy for *burden of disease* in the population
- Reducing *stigma* and effecting social change, especially around HIV infection
- Providing special services for certain *high-risk populations*, such as STI clinics specifically for MSM or SWs
- Providing 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 *SWs* under a certain age
- Require reporting of individuals with HIV infection
- Minimise 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 minimise 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 *antenatal clinics* (ANCs), 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 *generalised epidemics*. *UAT* has been deemed ethical if:

- No interaction takes place with the survey participant solely for the purpose of the surveys
- 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.

Ethics and UAT, continued

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 the *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 minimised.

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 care and treatment.

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, and so on.)
- 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, 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 when an adolescent can participate in research, including biological testing, involving sexual behaviours, with his or her parents' consent. Familiarise 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 healthcare.

As a special case, in *respondent-driven sampling*, modest incentives are provided to participants to recruit additional members of the high-risk population 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 populations?

Apply what you've learned/ case study

Try this case study individually.

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

You are weighing two choices:

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

Notes

Unit 8

Presenting Data in Charts, Graphs and Tables

<u>Overview</u>

What this unit	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	 List two demographic variables by which surveillance data can be analysed. True or false? Compiling all the data into one comprehensive chart or
	 graph is more effective than including many simpler diagrams. True False Which of the following can be extracted from public health
	surveillance data?a. Changes over timeb. Changes by geographic distributionc. Differences according to subject's sexd. All of the above

Warm-up questions, continued

4. Match the type of chart/graph with its example:



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 epidemiologic and programmatic issues.
Types of variables

There are two general types of variables: 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 10 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 policymakers 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.

General rules for tables, charts and graphs, continued

- 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

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 Globa, 1997-2006.

Rules

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

- *Y-axis* should be shorter than *X-axis*.
- Start the *Y*-axis with 0.
- Determine the range of values needed.
- Select an interval size.

<u>Charts</u>

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, Globa, 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 sub-groups. 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 sub-groups by year, as in Figure 8.3.

Figure 8.3. HIV prevalence levels among injection drug users (IDUs) at four clinic sites, Globa, 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 sub-groups 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 five- 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 four-year-old age group, which is only a one-year interval.





Pie chart

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

Figure 8.5. Projected annual expenditure requirements for HIV/AIDS care and support by 2005, by region.



Source: Schwartlander B et al. (2001) Resource needs for HIV/AIDS, Science

Area map

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

Figure 8.6. State of the HIV epidemic countries of North Africa and the Middle East, 2006.



<u>Tables</u>

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).

Region	Adults and adolescents ≥ 15 years	Children <15 years	Total
1	14 800	2	14 802
2	4 000	200	4 200
3	9 970	30	10 000
4	9 850	150	10 000
5	14 600	400	15 000
6	4 650	350	5 000
7	9 400	100	9 500
8	3 800	2 200	6 000
9	9 000	6 000	15000
10	5 450	50	5 500
Total	85 520	9 482	95 002

Table 8.1. Adults and children living with HIV/AIDS by region in Country Y, Year X.

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 sub-divisions 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, and so on. 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've learned/ case study

Examine the data below to answer questions 1-3. Remember to title every graph.

HIV prevalence (%) by district among sexually transmitted infection (STI) clinic attendees, Melabia 2000-2003.

District	2000	2001	2002	2003
Northern	5.0	2.4	7.2	14.4
Southern	4.2	2.0	2.3	2.8
Eastern	6.5	10.4	9.4	5.5
Western	7.6	6.3	7.6	5.8
Central	7.1	6.5	5.6	3.2

- 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).

Apply what you've learned/case study, continued

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 Melabia in 2002.

Reported cases of syphilis among men by district, Melabia 2002.

District	Cases		
Northern	242		
Southern	298		
Eastern	567		
Western	678		
Central	198		

Unit 9

Evaluating a Public Health Surveillance System

Overview

What this unit

is about

The periodic evaluation of surveillance systems for HIV and sexually transmitted infections 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 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 prioritise 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 epidemiologic 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.

See Figure 9.1, on the next page.

Purpose of evaluation, continued

Figure 9.1. Elements of a well-focused evaluation.



Evaluation Process

Six evaluation

tasks

The evaluation process is organised into a series of discrete tasks that are summarised 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), available at 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. 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
- Healthcare providers
- Data providers and users
- Representatives of affected communities
- Governments at the sub-national and national levels
- Professional and private non-profit and donor organisations.

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 organisation the system resides, 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 organisations willing to participate in the *surveillance* system? Consider patients, healthcare 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.
- Recommendations for improvements should be distributed to all partners and sites involved in *sentinel surveillance*.

<u>Summary</u>

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 sero-prevalence 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've learned/ case study

Try this case study individually.

The Southern District is in the coastal area of Globa and has the country's major port city, Port Marina. A university has been conducting studies of female sex workers in Port Marina for nearly a decade. For the last five years, they have been conducting serial sero-prevalence 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.

Apply what you've learned/case study, continued

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 sero-prevalence* officer for the Northern District. Northern District is a large district in Globa, a country with an HIV epidemic concentrated in *sex workers* (SWs) and *injection drug users* (IDUs). To monitor the epidemic in the general population, *sero-prevalence surveys* are conducted annually at *antenatal clinics* (ANCs) in Northern District. You examine data from the past five years and observe the following:

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

- 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 characterise the HIV epidemic in the Northern District of Globa 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 sero-prevalence surveillance* at *ANCs* 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. Globa provides free *antiretroviral therapy* (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?

Final Case Study, continued

4. Annual *sero-prevalence 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 *sero-prevalence 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:

	Site 1	Site 2	Site 3	Site 4	Site 5
Number of subjects	158	165	208	287	189
Percent missing data:					
Age	6%	5%	2%	4%	5%
Date specimen collected	2%	1%	1%	2%	3%
Residence	4%	5%	2%	3%	5%
Parity	3%	2%	1%	2%	3%
Live births	1%	2%	2%	1%	3%
HIV serology	1%	1%	0%	20%	1%

- 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

- By the end of 2009, there were 33.3 million people living with HIV/AIDS worldwide, including an estimated 2 million children.
- *Prevalence* is the proportion of living persons in a population with a particular disease. Globally, HIV *prevalence* was estimated to be 0.8% among adults aged 15-49 in 2009, however HIV *prevalence* varies widely by region and population.
- Two major types of HIV have been recognised: *HIV-1* and *HIV-2*. HIV-1 is the predominant type worldwide.
- The predominant route of HIV transmission is through sexual intercourse. HIV is also transmitted through blood, blood products and donated organs or semen. HIV may also be transmitted from an infected mother to her foetus or infant during pregnancy, delivery or when breastfeeding.
- 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.
- In some regions, the majority of HIV infections are concentrated among populations that engage in *high-risk behaviours*, such as commercial sex, injection drug use and, if male, having sex with men,

Module Summary, continued

- 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 *generalised*. 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.
- Data from surveillance are analysed to show trends over time and geographic area . It is important to display data clearly in graphs, tables, and figures for:
 - \circ Data analysis
 - Interpretation
 - Effective communication of complex issues
- Evaluation of the *surveillance* system is important for ensuring that it is effectively meeting the objectives of detecting changes and trends in *STI*, HIV or AIDS *prevalence*.

Appendix A, References and Further Reading

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Notes

Appendix B, Glossary and Acronyms

ACASI: Acronym for 'audio computerised assisted survey instruments.'

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

Acquired immunodeficiency syndrome (AIDS): See Advanced HIV infection.

Active infection: An infection that is currently producing symptoms (disease) or in which the organism that causes disease is reproducing.

Active surveillance: A system in which the organisation conducting surveillance initiates procedures to obtain reports. Example: making telephone calls or visits to health facilities to obtain information.

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

Advanced HIV disease reporting: The systematic and standardized ongoing reporting of persons diagnosed with advanced HIV disease (clinical stage 3 or 4 and/or CD4 counts \leq 350.

Advanced HIV infection: (*also* Advanced HIV disease) The late stage of HIV infection that includes development of one or more opportunistic illnesses (illnesses that occur because of low levels of CD4 lymphocytes, or immunodeficiency). Advanced HIV infection (disease) is the term now used for AIDS in updated WHO Guidelines.

Actiologic case reporting: A surveillance system in which a laboratory test has confirmed the presence of the pathogen.

Aetiological: Refers to the causes of disease. Also known as 'aetiologic.'

Agent: A factor, such as a micro-organism, chemical substance, or form of radiation, whose presence is essential for the occurrence of a disease.

Aggregate case reporting: A single form summarises all of the patients who were diagnosed with the condition at certain sites in a given time period.

AIDS: Acronym for 'Acquired Immunodeficiency Syndrome.'

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

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

AIDS-defining illness: Any of a series of health conditions that are considered, in isolation, or in combination with others, to be indicative of the development of AIDS. These conditions result from low levels of CD4 lymphocytes which are destroyed by HIV.

AIDS Indicator Survey (AIS): A standardized tool to obtain indicators for effective monitoring of national HIV/AIDS programs. The protocols will help us provide, in a timely fashion and at a reasonable cost, the information required for meeting HIV/AIDS program reporting requirements.

Algorithm: Step-by-step procedure for decision-making; a recipe for achieving a specific goal.

Aliquot: A portion of a sample; for example, an aliquot of a 100 millilitre sample of blood might be a 5 millilitre portion of that sample.

Alliances: Partnerships created to assist with formative assessment. These partnerships differ based on the type of most-at-risk group being sampled, but usually include gatekeepers, governmental or non-governmental organisations, influential members of the target group, advocates, and physicians and others who provide health care to the target group.

Anonymous: Having no known name or identity. Removing all personally identifying information from a sample that will be tested for HIV, for example, in order to protect the patient's identity.

Anti-microbial resistance: The ability of an organism to avoid destruction or deactivation typically caused by drugs or chemicals designed to do so.

Antibiotic medicines: Drugs that kill or inhibit the growth of bacteria.

Antibodies: Molecules in the blood or secretory fluids that tag, destroy, or neutralise bacteria, viruses, or other harmful toxins.

Antimicrobial agents: An agent that kills or inhibits microbial growth. 'See Antibiotic medicines.'

Antiretroviral drugs: Drugs used to fight infections caused by retroviruses, such as Advanced HIV Disease.

Antiretroviral drug resistance: Resistance to one or more antiretroviral drugs. Antiretroviral drug resistance is one of the more common reasons for therapeutic failure in the treatment of HIV.

Antiretroviral therapy (ART): Treatment with drugs that inhibit the ability of HIV to multiply in the body.

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

Artefact: An inaccurate observation, effect or result caused by experimental error.

Asymptomatic: Without symptoms.

At-risk groups: Groups of people that are at increased risk for passing HIV on to others or for being infected by others.

B-lymphocytes: Also known as 'B-cells.' Blood cells of the immune system involved in the production of antibodies. In persons living with AIDS, the functional ability of both the B and the T lymphocytes is damaged, with the T lymphocytes being the principal site of infection by HIV.

Bacterial vaginosis: A chronic inflammation of the vagina caused by the bacterium *Gardnerella vaginalis*.

Bangui: The initial WHO AIDS surveillance case definition, developed to provide case definition of AIDS for use in countries where testing for HIV antibodies was not available.

Bar chart: A visual display of the size of the different categories of a variable. Each category or value of the variable is represented by a bar (or column). The Y-axis represents frequency. The X-axis represents different classes.

BED assay: A simple enzyme immunoassay (EIA) that can be used for detecting recent HIV-1 infection (within the last 160 days). It uses a branched peptide that includes sequences from HIV sub-types B, E and D, and allows detection of HIV-specific antibodies among various sub-types.

BED capture-EIA test: This test detects an antibody to a small HIV protein, gp41. It was first tested in HIV types B, E and D, hence its name BED.

Behavioural surveillance: Surveys of HIV-related behaviour that involve asking a sample of people about their risk behaviours, such as their sexual and drug-injecting behaviour.

Beneficence: To promote the interest of the patient or participant. To balance the benefits and risks to people involved in surveys. These risks include physical harm, such as violence and psychological harm, such as social stigmatisation.

Bias: A systematic error in the sample selection and the collection or interpretation of data.

Biological surveillance: Surveillance that involves regular and repeated cross-sectional surveys, but collects biological samples that are tested for HIV and other related illnesses, such as sexually transmitted diseases and tuberculosis.

Bivariate analysis: One of the main types of behavioural surveillance analysis that is performed to determine whether one variable is related to the distribution of another. For example, there might be an association between a respondent's age (the explanatory variable) and their use of condoms (the outcome variable). Variables are associated if the value of one tells you something about the value of another. Statistical tests in bivariate analysis determine whether any observed difference reflects a true difference, or may be due to chance.

Body fluids: Any fluid produced by the human body, such as blood, urine, saliva, sputum, tears, semen, mother's milk, or vaginal secretions. Fluids that commonly transmit HIV are blood, semen, pre-ejaculate, vaginal fluids, and breast milk.

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

BSS: Acronym for 'behavioural surveillance survey.'

Candida albicans: The fungal causative agent of vulvovaginitis in women and inflammation of the penis and foreskin in men.

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

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

Carrier: A person or animal without apparent disease who harbours a specific infectious agent and is capable of transmitting the agent to others.

Case: An individual in the population or sample with a particular disease of interest.

Case-based reporting: each person diagnosed with the disease is reported separately, as opposed to aggregate case reporting in which data from patients with the disease are combined.

Case-control study: A type of observational analytic study. Enrolment into the study is based on presence ('case') or absence ('control') of disease. Characteristics such as previous exposure are then compared between cases and controls. The purpose of case

control studies is to identify factors that are associated with, or explain the occurrence of the specific disease or condition being studied.

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

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

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

CASI: Acronym for 'computerised assisted survey instruments.'

Catchment population: A geographic area that is to be examined or surveyed. Can refer to the population served by a given clinic.

Categorical surveillance system: System that deals with reporting a single disease.

Categorical variable: Items that can be grouped into categories, such as marital status or occupation.

Cause of disease: A factor (characteristic, behaviour, etc.) that directly influences the occurrence of disease. A reduction of the factor in the population should lead to a reduction in the occurrence of disease.

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

CD4 receptors: Markers found on the surface of some body cells, including T-cells. These receptors are targets of HIV, and thus CD4+ cells are attacked by the virus.

Census sampling: Every unit, or case, is measured for the entire population. A de facto census allocates persons according to their location at the time of enumeration. A de jure census assigns persons according to their usual place of residence at the time of enumeration (Last).

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

Chain referral sample: Any sampling method wherein participants refer other potential participants for inclusion in the sample. There are several types of chain referral sampling

methods, most of which are non-probability samples. Examples of chain referrals include RDS, network sampling, random walk and snowball sampling.

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

Characteristic: A definable or measurable feature of a process, product, or variable.

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

Clinic-based surveys: Surveys that use samples that have been selected in clinical facilities, such as STI or drug treatment clinics. The most common type of the clinic-based surveys that are done using biological markers, such as HIV infection, is clinic-based sentinel sero-surveillance.

Cluster: Any aggregate of the population of interest (for example, departments, villages, health facilities).

Cluster sampling: The population of interest is broken into groups or clusters and a sample of clusters is randomly selected (Levy & Lemeshow).

Clustered bar chart: A bar chart in which the columns are presented as clusters of subgroups. Also known as 'stacked bar chart.'

Code: A unique identification for a specimen. It may or may not be linked to any personal identifying information.

Cohort analysis: Analysis that involves following groups of subjects over time.

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

Community advisory board: Members of the community who offer input into study design and local procedures. CAB members include community activists and/or professionals associated with HIV/AIDS prevention and services delivery. Some CAB members are trial participants.

Community-based surveys: Surveys that use samples that have been selected from nonclinical settings. They often include most-at-risk populations, such as sex workers or truck drivers, who are not included in clinic-based surveys. As with clinic-based surveys, the most common type of community-based survey is called 'repeated cross-sectional community-based sentinel sero-surveillance.'

Community sites: Locations in the community, such as households or brothels.

Completeness of data elements: The extent to which the information requested in the case report form is provided.

Completeness of reporting: One of several attributes of a surveillance system. The term refers to the proportion of cases that were reported. Completeness of reporting is also referred to as the sensitivity of the surveillance system and is determined by using an alternative (and thorough) method of identifying cases of the disease and then dividing the number of cases reported by the total number of cases identified. Completeness is often reported as a percentage.

Compulsory testing: Testing that is required of all individuals in a population to be surveyed. For example, requiring HIV tests to be done on all members of a prison population.

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

Confidence interval: The compound interval with a given probability, for example, 95% that the true value of a variable such as mean, proportion, or rate is contained within the limits. Also known as 'confidence limits.'

Confidence limits: See 'confidence interval.'

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

Consecutive sampling: This sampling method consists of sampling every patient who meets the inclusion criteria until the required sample size is obtained or the survey period is over. While this method is not strictly a probability sample, it is easier to use and offers less occasion for sampling bias.

Contact: Exposure to a source of an infection, or a person so exposed.

Contagious: The characteristic of an organism or person that renders it capable of being transmitted from one person to another by contact or close proximity.

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

Convenience sampling: The selection of entities from a population based on accessibility and availability. Available participants may be people on the street, patients in a hospital or employees in an agency. This type of sampling does not generally represent the population of interest and is best used in the exploratory stage of research.

Core data elements: Information about a patient that must be collected during a survey.

Cotrimoxazole preventative therapy (CPT): Administering cotrimoxazole prophylaxis to prevent opportunistic infections among HIV- infected patients.

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

Coupon: Used in RDS studies to provide incentives to participants. Coupons in RDS can be used both to track participation for reimbursements and to link the recruiters to the recruits. Other methods may use coupons to encourage participation, much like the advertisements placed in popular clubs or bars. Some coupons may have two parts that can be easily separated. One part of the coupon serves as the referral coupon, which the recruiter uses to recruit a peer into the study. The other part of the coupon serves as the payment coupon. It is kept by the recruiter and he or she will use it to claim an incentive for having recruited a peer into the study. Both parts of the coupon have the unique identification number of the recruitee printed on them. The dual system eliminates the need to collect names for incentive collection.

Coupon rejecters: People who are offered a coupon by a recruiter, but decline to take it.

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

Cruising area: Cruising areas are public space, such as parks, public restrooms, bath houses, dance clubs and railway stations where MSM meet, congregate and arrange and/or engage in sexual activity.

Cryolabel: Labels designed to adhere during freezer storage.

Cryovial: A vial that is designed to be stored in a freezer.

CSW: Acronym for 'commercial sex worker.'

DALYs: See 'disability-adjusted life years.'

Database: A computer programme that stores the variables for each patient in the survey sample or surveillance system.

Data dictionary: Electronic files that describe the basic organisation of a project or database. They contain all of the rules that guide data entry.

Data entry: The process of entering paper records into a computer database

Data entry screens: The forms on the computer screen into which a data entry clerk enters the data.

Data synthesis: See 'triangulation.'

Definitive diagnosis: A diagnosis based on laboratory or other tests specifically designed for diagnosis and considered authoritative.

Demographic Health Survey: National household surveys that provide data for a wide range of monitoring and impact evaluation on topics including HIV prevalence and attitudes and beliefs about HIV/AIDS.

Demographic information: The 'person' characteristics of epidemiology (usually collected with "place" and "time") – age, sex, race and occupation – used to characterise the populations at risk.

Denominator: The population (or population experience, as in person-years, etc.) at risk in the calculation of a proportion or rate. The denominator is the lower portion of a fraction used to calculate a rate or ratio.

Dependent variable: In a statistical analysis, the outcome variable(s) or the variable(s) whose values are a function of other variable(s).

Descriptive statistics: Used to describe the basic features of the data, they provide simple summaries about the sample and the measures.

DHS: Acronym for 'demographic and health surveys.'

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

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

Direct transmission: The immediate transfer of an agent from a reservoir to a susceptible host by direct contact or droplet spread.

Disaggregated data: Data which is divided up according to different variables, to provide a more detailed analysis.

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

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

Disease registry: The file of data that contains reported diseases.

Disease reporting: The process by which notifiable diseases are reported to the health authority.

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

Distribution: The frequency and pattern of health-related characteristics and events in a population. In statistics, the observed or theoretical frequency of values of a variable.

Double-entered: Entered twice, to avoid mistakes by identifying and correcting discrepancies.

Double Y-scale: On a graph, two Y-axes, one on the vertical left for data with large values and one on the vertical right for data with smaller values.

Dysuria: Painful, frequent or difficult urination.

EIA: See 'enzyme-linked immunoassay.'

ELISA: See 'enzyme-linked immunosorbent assay.'

Emic: Refers to accounts, descriptions, and analyses expressed in terms of the concepts and categories regarded as meaningful and appropriate by the members of the population of interest.

Endemic disease: The constant presence of a disease or infectious agent within a given geographic area or population group; may also refer to the usual prevalence of a given disease within such area or group.

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

Enzyme immunoassay (EIA): A type of test that identifies antibodies to an organism such as HIV. EIAs rely on a primary antigen-antibody interaction and can use whole viral lysate of HIV or one or more antigens from the virus.

Enzyme-linked immunosorbent assay (ELISA): A type of enzyme immunoassay (EIA) to determine the presence of antibodies to an infectious agent such as HIV in the blood or oral fluids.

Epidemic: The occurrence of a disease (or other health-related event) at a greater than expected level of increase to a baseline. For example, the high prevalence of HIV found in many parts of the world today, including sub-Saharan Africa, Latin America and South and Southeast Asia.

Epidemic state: The prevalence the epidemic has reached in a country or region. Can be low-level, concentrated, or generalized within a sub-population or within the general population.

Epidemiology: The study of the distribution and determinants of the frequency of healthrelated states or events in specified populations, and the application of this study to the control of health problems.

Epi Info[™]: Freely distributed epidemiological software available on the CDC website (<u>www.cdc.gov/epiinfo</u>).

Equilibrium: In RDS, the point in the recruitment process where a variable is not expected to change by more than 2% with each successive wave.

Ethnographic assessments: Ethnographic assessments are written analyses of the cultural practices, beliefs and behaviours of a particular culture, network or sub-group.

Ethnographic mapping: Collecting information on the geographic location, temporal movement of and interactions among members of the study population.

Etic: Refers to accounts, descriptions and analyses expressed in terms of the concepts and categories regarded as meaningful and appropriate by the community of scientific observers.

Exclusion criteria: Characteristics of patients who should be excluded from the sample, but who would otherwise be eligible.

Experimental study: A study in which the investigator specifies the exposure category for each individual (clinical trial) or community (community trial), then follows the individuals or community to detect the effects of the exposure.

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

Factor: An intrinsic factor (age, race, sex, behaviours, etc.) which influences an individual's exposure, susceptibility, or response to a causative agent

False negatives: Test results that are negative when the patient actually has the disease that is being tested for.
False positives: Test results that are positive when the patient does not actually have the disease that is being tested for.

Female sex workers: Females who engage in sex work, or the exchange of sex for money, which includes many practises and occurs in a variety of settings. These may include 'direct' or 'formal' sex workers, who are sometimes included in registries and often found in brothels, and 'indirect' or 'casual' sex workers, who do not engage in sex work full time and are unlikely to be included in registries.

Filter paper: Porous paper on which samples can be placed.

Focus groups: A group setting in which people are asked by a facilitator about their views about a topic. Participants are free to talk with other group members as well as the facilitator. Focus groups allow interviewers to study people in a more natural setting than they can in a one-to-one interview.

Formative assessment (or research): Research conducted before the study begins. Researchers use qualitative methods, such as focus groups, in-depth interviews, mapping or observations of the target population and the individuals who work with them to ensure that the research team sufficiently understands the community.

GAP: Acronym for the CDC's 'Global AIDS Program.'

Gatekeepers: Persons who can provide access to a high-risk population. Examples are a brothel owner who can provide access to female sex workers, or a prison warden who can provide access to prisoners.

General population surveillance: Surveillance that measures HIV risk behaviours in a sample of people selected to represent the people living in a region or nation. The surveillance can be restricted to certain ages (for example, young people aged 15-24) or genders.

Generalisability: The results from the sample are the same as the results we would have obtained had we tested every person in the study population (that is, the results from the sample are generalisable to the study population).

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

Genital discharge syndrome: This syndrome includes infections due to *N. gonorrhoea*, and *C. trachomatis*.

Genital ulcer syndrome: Genital lesions due to *T. pallidum*, *H. ducreyi*, HSV, *C. trachomatis* or *C. granulomatis*.

Geographical Information System (GIS): System of hardware, software.

Gigolo: Male sex workers who identify as straight. They tend to have foreign clients and engage in male-male sexual activity.

Glycoprotein (HIV): Proteins on the surface of the HIV virus that bind to CD4 receptors on target cells.and procedures designed for integrated storing, management, manipulation, analysing, modelling and display of spatially referenced data for solving planningand management problems.

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

Gram-negative: Bacteria that do not absorb the stain during the process of Gram staining.

Gram-positive: Bacteria that do absorb the stain during the process of Gram staining.

Gram stain: A laboratory method of staining microscopic slides of organisms in order to identify and classify the various types of bacteria. Bacteria are classified as either Gramnegative (does not absorb the stain) or Gram-positive (absorbs the stain).

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

Grey literature: Material that is not published in easily accessible journals or databases. Besides programme evaluations, government surveillance reports and programme planning documents mentioned earlier, it includes the abstracts of research presented at conferences, and unpublished theses and dissertations.

Haemophilus ducreyi: The causative agent of chancroid. See 'chancroid.'

Health indicator: A measure that reflects, or indicates, the state of health of persons in a defined population; for example, the infant mortality rate.

Health information system: A combination of health statistics from various sources, used to derive information about health status, healthcare, provision and use of services, and impact on health.

Health-seeking behaviour: The actions individuals or populations take to care for their health, for example, attending a clinic or district hospital when they feel ill.

Hard-to-reach populations (HTRP): Groups of people linked by behaviours, socioeconomic situations or societal structures, who for various reasons (e.g. law, stigma) refrain from involvement in the legal economy and other aspects of the majority social

institutions. Includes but is not limited to: IDUs, MSM, CSW and undocumented migrants.

Hepatitis B virus (HBV): The causative agent of hepatitis B. The virus is transmitted by sexual contact, the use of contaminated needles and instruments and by contaminated serum in blood transfusion. The infection may be severe and result in prolonged illness, destruction of liver cells, cirrhosis or death.

Hepatitis C virus (HCV): The causative agent of hepatitis C. This virus is transmitted largely by the use of contaminated needles and instruments and by blood transfusions. The disease progresses to chronic hepatitis in up to 50% of the patients acutely infected.

Herpes simplex virus 1 (HSV-1): A virus that causes cold sores or fever blisters on the mouth or around the eyes, and can be transmitted to the genital region.

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

Herpes viruses: A group of viruses that includes herpes simplex type 1 (HSV-1), herpes simplex type 2 (HSV-2), cytomegalovirus (CMV), Epstein-Barr virus (EBV), varicella zoster virus (VZV), human herpes virus type 6 (HHV-6), and HHV-8, a herpes virus associated with Kaposi's sarcoma.

Highly active antiretroviral therapy (HAART): The use of at least three ARV drugs in combination to suppress viral replication and progression of HIV disease by reducing the viral load to undetectable levels.

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

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

High-risk group surveillance: Surveillance that measures HIV risk behaviours in groups whose behaviours, occupations or lifestyles could expose them to higher risk of acquiring and transmitting HIV than the rest of the population. These groups are often important in establishing, accelerating or sustaining the HIV epidemic.

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

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

HIV: See 'Human Immunodeficiency Virus.'

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

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

HIV case reporting: the systematic, standardized, ongoing collection of reports of persons diagnosed with HIV infection (clinical stages 1-4) and/or advanced HIV disease (clinical stages 3 and 4).

HIV clinical stages: In these modules, a classification by WHO of HIV disease on the basis of clinical manifestations that can be recognized and treated by clinicians in diverse settings, including resource-constrained settings. In order of severity, starting with the lowest, the stages are:

Stage 1: Often asymptomatic or with swollen glands

- Stage 2: Symptoms, including moderate weight loss and respiratory infections
- Stage 3: More severe symptoms, including extreme weight loss and severe bacterial infections. Called advanced HIV disease.
- Stage 4: End-stage HIV infection (AIDS), with manifestations such as wasting syndrome, tuberculosis, lymphoma. Called advanced HIV disease.

HIV-negative: Showing no evidence of infection with HIV (for example, absence of antibodies against HIV) in a blood or tissue test.

HIV-positive: Showing indications of infection with HIV (for example, presence of antibodies against HIV) based on a test of blood or tissue.

HIV sub-types: Distinct lineages of HIV that contain genetic differences.

HIV viral suppression: Lowering the level of HIV RNA in plasma, below the threshold of detection.

Homophily: In RDS, a measure of the tendency of people to connect to other people like themselves.

HSV-2: see herpes simplex virus 2.

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

Human papilloma virus (HPV): A causative agent of genital warts.

IDSR: See 'Integrated disease surveillance and response.'

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

Immune response: The activity of the immune system against foreign substances such as infectious agents including bacteria and viruses.

Immune system: The body's complicated natural defence against disruption caused by invading foreign agents (for example, microbes or viruses).

Immunodeficient: A situation in which a patient's health is compromised because his/her immune system is insufficient to ward off infections, thus making the person susceptible to certain diseases that they would not ordinarily develop.

Immunology: The science of the system of the body that fights infections.

Impact evaluation: An evaluation of a programme that determines what the impact of the programme is, as opposed to 'process evaluation.'

Impact indicators: A standardised set of indicators developed by UNAIDS to help monitor HIV prevalence in particular populations.

Incentive: A reward or reimbursement given to participants in a study. In RDS surveys, there are typically two levels of incentive: primary incentive and secondary incentive. A participant receives the primary incentive for enrolling in the study and completing an interview. The same participant receives secondary incentive(s) for recruiting his or her peers into the study. Incentives are not absolutely necessary in every situation and should be determined during formative research.

Incidence: A measure of the frequency with which an event, such as a new case of illness, occurs in a population over a period of time. The denominator is the population at risk; the numerator is the number of new cases occurring during a given time period.

Inclusion criteria: Characteristics required in study participants, in order to be considered for the sample.

Incubation period: A period of sub-clinical or unapparent pathologic changes following exposure, ending with the development of the infection.

Independent variable: An exposure, risk factor, or other characteristic being observed or measured that is hypothesised to influence the outcome (that is, the dependent variable).

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

Indicator mutations: Genotypic mutations that best predict resistance to a specific antiretroviral agent.

Indirect transmission: The transmission of an agent carried from a reservoir to a susceptible host by suspended air particles or by animate (vector) or inanimate (vehicle) intermediaries.

Infectiousness: The ability of an organism to cause infection.

Infectivity: The proportion of persons exposed to a causative agent who become infected by an infectious disease.

Information bias: Error that results from people who have a disease being misclassified as not having the disease.

Informed consent: The permission granted by a patient or a participant in a research study after he or she has received comprehensive information about a research study or medical procedure. Informed consent protects the person's freedom of choice and respects his or her autonomy with regard to decisions affecting his or her body and health.

In-group affiliation: In RDS, what homophily measures (group similarity based on ethnicity, age, socio-economic status and so forth).

Injection drug users (IDUs): Also called 'intravenous drug users,' they are persons who use or have used needles or syringes to inject drugs. Injection drug use is considered a high-risk behaviour.

Institutional review board (IRB): The <u>committee</u> designated to approve, monitor, and review <u>biomedical</u> and <u>behavioral research</u> involving <u>humans</u> with the aim of protecting the rights and welfare of research participants. Also known as ethics committee.

Institutional sampling: Individuals in an institution, such as prison, are sampled.

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

Internal validity: The absence of substantial differences between groups at baseline; the absence of substantial difference of attrition rates between groups at follow-up.

Internally displaced persons (IDPs): IDPs are persons who have left their homes due to civil unrest or natural disasters, but have stayed in their homeland and have not sought sanctuary in another country.

Interval width: The range of certainty as to the true value of the calculated outcome value. For example, in the case of a 95% confidence interval, there is 95% certainty that the true outcome lies between the upper and lower bound of the interval. Statistically, this interval is equal to two standard deviations on either side of the calculated outcome value.

Interviewer error: Problems stemming from the actions and behaviours of the person doing the interview.

Intradermally: Injected into the layers of the skin.

Intramuscularly: Injected into a muscle.

Intravenously: Injected into a vein.

Involuntary migrants: Involuntary migrants include persons who have migrated away or have been displaced from their home countries due to an established or well-founded fear of persecution, or have been moved as a result of deception or coercion.

Isolates: A population of bacteria or other cells that has been isolated and cultured.

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

Key informants: Members of the target group, who can often become informal assistants.

Kick-off meeting: A meeting you host for community members who may in turn become seeds for the RDS survey. The purpose of the meeting is to educate seeds on study goals and process, inform seeds of their importance to the success of the study and encourage the seeds to be enthusiastic.

Klebsiella granulomatis: The bacterial causative agent of granuloma inguinale or donovanosis.

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

Laryngeal TB: Tuberculosis involving the larynx, producing ulceration of the vocal cords and elsewhere on the mucosa, and commonly attended by hoarseness, cough, pain on swallowing, and hemoptysis.

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

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

Linked anonymous HIV testing: In linked anonymous testing, a person agrees to have an HIV test, but the specimen is labelled with a code without a name or identifiers that could reveal the person's identity. This method is voluntary and requires obtaining informed consent and making the test results available (with appropriate counselling) to the person tested.

Linked confidential HIV testing: In linked confidential testing, a person agrees to have an HIV test with the assurance that the test result will be kept confidential and only selected health-care providers may be informed. This method is voluntary and requires obtaining informed consent and discussing the test results with the person. Linked confidential testing also allows for the collection of more detailed demographic and riskbehaviour information.

Linking: Refers to whether a tested individual's names or identifying information is associated with his or her HIV test results.

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

Log scale: In a graph, when the data covers a large range of values, they are presented on a logarithmic scale. This type of scale reduces data to a smaller range so that it is easier to work with.

Longitudinal surveillance: Surveillance over time during which patients' status can be updated. *Longitudinal databases* allow the update of patients records over time with, for example, start dates for care, disease progression, new information.

Low-level HIV epidemic: The epidemic state in which HIV has never spread to significant levels in any sub-population, although HIV infection may have existed for many years. HIV prevalence has not consistently exceeded 5% in any defined sub-population. This state suggests that networks of risk are rather diffuse or that the virus has only been recently introduced.

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

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

Male sex workers: Males who engage in sex work, or the exchange of sex for money, which includes many practises and occurs in a variety of settings.

Mandatory testing: Testing that is required of a patient if he or she is to obtain certain services; for example, mandatory HIV testing of individuals who request marriage certificates.

Margin of error: An estimation of the extent to which a survey's reported percentages would vary if the same survey were taken multiple times.

Markov process: A mathematical theory that provides a probabilistic description of the state of a system at any future time. The Markov process is especially relevant to RDS because of the nature of the recruitment process, whereby a chain of peers recruiting peers is monitored through a coupon mechanism.

Marriage pressure: Family pressure on sons to marry to provide stability for parents and the continuation of the family name as well as to avoid the stigma of a person being MSM.

MARP: Acronym for most-at-risk population, a group within the community with an elevated risk of disease, often because group members engage in some form of high-risk behaviour.

Masking: Describes the behaviour of reclusive respondents, people who do not want to be found.

Mean: The measure of central location commonly called the average. It is calculated by adding together all the individual values in a group of measurements and dividing by the number of values in the group.

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

Microbe: A micro-organism, such as a bacteria or virus.

Microbicide: A chemical or other agent that destroys microbes.

MICS: See 'Multiple Indicator Cluster Survey.'

Migrants: see 'mobile populations'

Mobile populations: Refers collectively to groups of people who move from one place to another (migrants). They may move temporarily, seasonally, or permanently and for either voluntary or involuntary reasons.

Monitoring: Evaluating a programme's performance over time.

Monitoring and Evaluation (M&E): Collecting and analysing accurate and reliable information that can be used to improve programme performance and planning.

Monocyte: A type of white blood cell.

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

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

Mortality rate, infant: A ratio expressing the number of deaths among children under one year of age reported during a given time period divided by the number of births reported during the same time period.

MSC: See 'multi-stage cluster sampling.'

MSM: Acronym for 'men who have sex with men.'

MSW: Acronym for 'male sex worker.'

MTCT: Acronym for 'mother-to-child transmission.' See 'perinatal transmission.'

Multi-stage cluster sampling (MSC): Two- or more- stage sampling. Final units from selected clusters may be randomly selected.

- Simple two-stage cluster sampling
- Probability proportional to size sampling (PPS) is used when all clusters do not have the equal probability of being selected in the sample. PPS is a class of unequal probability sampling in which the probability of a unit being sampled is proportional to the level of some known variable (Levy & Lemeshow).

Multivariate analysis: One of the main types of analysis conducted in behavioural surveillance that is performed to look at the influence of at least two variables on another variable. since relationships between variables are often complex and interwoven. Multivariate techniques can pinpoint the individual effects of several explanatory variables on an outcome variable, which may be related to each other.

Natural history of disease: The temporal course of disease.

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

Negative controls: Specimens known to be negative and used to ensure that a laboratory reagent is working properly prior to testing specimens from patients.

Negative predictive value: In HIV testing, the probability that a person with a negative test result is not infected. Also known as 'predictive value negative.'

Neisseria gonnorrhoeae: The causative agent of gonorrhoea.

Network: This sampling method may be used for groups whose members are socially linked. Ego-centred network sampling is based on random, representative or any other form of quota sampling (Schensul). Full relational network sampling begins with identification of individuals (see 'seeds') who act as entry points to the network.

NGO: Acronym for 'non-governmental organisation.'

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

Non-probability sampling: The sampling units are selected through a non-randomised process; therefore, the probability of selecting any sampling unit is not known.

Non-random mixing: The tendency of people to associate preferentially with others who are like themselves.

Non-vesicular genital ulcer disease: An STI syndrome characterised by ulcers and the absence of vesicles.

Notifiable disease: A disease for which law or regulation requires reporting to the health authority.

Numerator: The upper portion of a fraction. In a rate, the numerator is usually the number of people infected.

Operational definitions of target populations: Definitions that are operationally useful for sampling and fieldwork purposes. For example, a definition that clearly identifies what constitutes a sex worker, in terms of duration of selling sex, form of payment, type of venue where they work, etc.

Operations manual: A document that describes every step to be taken during the implementation of a survey or study. Ideally, it provides standard operational procedures for every foreseeable occurrence.

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

Opt-in: A patient or participant agrees to be tested.

Opt-out: A patient or participant refuses to be tested.

Optical density: The intensity of colour as measured by a machine in an EIA HIV antibody test, indicating whether the patient's sample is HIV-positive.

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

Over-sampling: A sample may obtain more members of a particular sub-group than their representation in the target population warrants. In some cases, over-sampling is carried on purpose to learn more about a small sub-group, such as female injection drug users in communities that are predominantly male.

p24 antigen: A protein that appears in the serum of infected individuals approximately one week before HIV antibodies appear, or about 14 days after actual infection. In very large sero-surveys, persons who tested negative for HIV antibody can be retested for p24 antigen.

Pandemic: An epidemic occurring over a very wide geographic area (several countries or continents) and usually affecting a large proportion of the population. HIV is an example of a pandemic.

Parameter: The summary numerical description of variables about the target population.

Parenteral transmission: Transmission of an infectious agent through blood. Parenteral transmission of HIV can occur from the sharing of injection drug equipment, from transfusions with infected blood or blood products, or from needle stick injuries.

Participant observation: A qualitative research method in which direct observation is carried out over a period of time, and which is understood and accepted by the group being observed.

Participation bias: Error in results from a study that is due to differences in characteristics between those who participate in a survey and those who do not. For example, persons who already know they are HIV-infected may find testing unnecessary; those who suspect they are HIV-infected may decline testing in order to avoid stigma.

Partner concurrency: Having extensive sexual network connections to many persons at the same time, which increases the spread of HIV and STIs.

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

Pathogen: A biological agent that causes disease or illness to its host (for example, bacteria or virus).

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

Perinatal transmission: Transmission of an infectious agent, such as HIV, from mother to baby before, during, or after the birth process. Also known as 'vertical transmission' or 'mother-to-child transmission.'

Period prevalence: The amount a particular disease that is present in a population over a specified period of time.

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

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

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

PMTCT: Acronym for 'prevention of mother-to-child transmission.'

Point estimate: The amount of a particular disease present in a population.

Point prevalence: Refers to prevalence at a single point in time. Also known as 'point incidence.'

Population: The total number of inhabitants of a given area or country. In sampling, the population may refer to the unit from which the sample is drawn, not necessarily the total population of people.

Population-based sero-survey: A type of sero-survey that uses a probability sample of a population defined by geographic boundaries, such as villages or provinces, in order to obtain a direct measure of HIV prevalence in a general population.

Population sub-group: A group within a population that share certain characteristics or behaviours.

Positive controls: Specimens known to be positive, as used in proficiency testing.

Positive predictive value: The probability that a person with a positive test result is infected; in surveillance this refers to the proportion of cases reported by a surveillance system or classified by a case definition which are true cases. Also known as 'predictive value positive.'

PPS: See 'Probability proportional to size sampling.'

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

Presumptive clinical diagnosis: Diagnosis made solely on the basis of symptoms, without the use of specific diagnostic tests.

Pre-surveillance assessment: Describes a set of activities that occur prior to beginning formal HIV and behavioural surveillance in *high-risk* groups. These activities include developing detailed plans and reviewing and collecting information that will help in planning and designing surveillance activities.

Prevalence: The proportion of persons in a given population with a disease or condition at a given point in time; a specific group infected. Prevalence is a direct measurement of the burden of disease in a population.

Prevalence assessment: Surveys that determine prevalence of a disease in a population.

Prevalence monitoring: Monitoring prevalence repeatedly over time to track trends.

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

Primary units: A sampling frame of larger unit. When it is difficult or impossible to make a list/sampling frame of each individual in the target population, we can develop a sampling frame of some larger unit; that is, clusters or primary sampling units. We then sample in stages by first sampling clusters and then sampling people within the clusters.

Priorities for Local AIDS Control Efforts (PLACE): A new, rapid assessment tool used to identify high transmission areas, which formalises the collection of information on high transmission areas. PLACE uses key informants to identify sites where people meet new sex partners, then interviews people at the site in order to characterise the site in each area and map sites, and, finally, interviews individuals socialising at the site to describe the characteristics of the people at the site.

Priority communicable disease: These are diseases that have the potential for epidemic spread and can be controlled through public health action. They are the diseases included in the Integrated Disease Surveillance form.

Prisoner: Any person involuntarily confined or detained in a penal institution, including persons detained pending arraignment, trial, or sentencing.

Probability proportional to size sampling: A class of unequal probability sampling in which the probability of a unit being sampled is proportional to the level of some known variable (Levy & Lemeshow).

Probability sampling: A sampling scheme that ensures that each entity in a population has a known, non-zero chance of being selected.

Process evaluation: An evaluation of a programme that determines how well the programme is functioning, as opposed to 'impact evaluation.'

Proficiency panel: A set of samples designed to judge the accuracy and precision of a laboratory. A necessary component of laboratory quality assurance. In the context of HIV testing this may be a group that contains approximately six HIV-negative and HIV-positive (weak to strong) specimens representative of the HIV strains circulating in a country and of the different stages of HIV infection. The panel should be sent to participating laboratories once or twice each year for quality assurance testing.

Proficiency testing: The act of sending a proficiency panel to a laboratory, designed to test the accuracy and precision of that laboratory.

Prophylaxis: Treatment to prevent or suppress infection, often given before a person's exposure to the pathogen. For example, the treatment given to mother's during childbirth in order to prevent infection of the newborn child.

Proportion: The relationship of a part to the whole, in which the numerator is included in the denominator; often depicted as a percent by multiplying by 100.

Prospective case reporting: To watch a group of cases for outcomes, such as the development and progress of HIV disease, over time and to relate this to other factors such as suspected risk or protection factors.

Prostitués homosexuels: Homosexual prostitutes. Male sex workers who identify as homosexual or gay.

Protocol: The detailed plan for conducting a research study or other activities in which specific steps are required, including surveillance activities.

Purposive sampling: A non-random sampling method that involves choosing respondents with certain characteristics.

Qualitative research: Research that focuses on the characteristics or quality of things, rather than the quantity. The sample included qualitative research is usually much less used than that included in quantitative research.

Quality assurance: The dynamic and ongoing process of monitoring a system for reproducibility and reliability of results that permits corrective action when established criteria are not met.

Quality control: A laboratory's internal processes for running specimens to ensure that the test equipment and reagents function properly.

Quantitative research: Research that focuses on quantity of things, rather than the quality. Quantitative research has powerful tools for the analysis of numbers, but researchers know that the things counted are often qualitative categories or definitions.

Questionnaire faults: Problems with the way questions are phrased, set out and ordered, which lead to misunderstandings of the questions.

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

Random sample: A sample derived by selecting individuals such that each individual has the same probability of selection.

Random walk: A variation of link-tracing sampling procedure in which the respondent is asked to give the names of other members of a hidden population. From that list, one is selected randomly, located and added to the sample. The process is repeated for a desired number of waves. (S.K. Thompson et al.)

Range: The difference between the largest and smallest values in a distribution.

Rapid assessment and response (RAR): A method that is used to assess the nature and extent of a public health problem and to suggest ways to address the problem. RAR is not designed as a surveillance tool, but as a way to assess a situation quickly, and bring in resources to address it.

Rapid HIV test: An HIV antibody test that is simple, does not require any reagents or equipment other than what is contained in the kit and provides results in less than 20 minutes.

Rapid plasma reagin test (RPR): A common serologic test for syphilis. Specifically, a non-treponemal test for anticardiolipin antibodies.

Rate: An expression of the frequency with which an event occurs in a defined population.

Ratio: The quantitative relationship between two or more things; the value obtained by dividing one quantity by another.

RDS: See 'Respondent driven sampling.'

RDSAT: Acronym for respondent driven sampling analysis tool (a freeware software package for analysing RDS data).

Reference laboratory: A laboratory that functions as a recognised centre of expertise and standardisation of diagnostic techniques.

Referral coupon: Used by the recruiter to recruit a peer into the study.

Refugees: By legal definition, refugees are persons who are outside their country of nationality and who are unable or unwilling to return to that country. They cannot return due to a well-founded fear of persecution because of race, religion, political opinion or membership in an ethnic or social group.

Relative risk: A comparison of the risk of some health-related event such as disease or death in two groups. For example, an HIV-uninfected individual who has sexual intercourse with an HIV-infected person once a year may have a 5% chance of infection. But if the uninfected individual uses a condom every time, the relative risk when compared to condom non-use is 15%.

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

Representative sample: A sample whose characteristics correspond to those of the original population or reference population.

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

Resistance: The ability of an organism, such as HIV, to overcome the inhibitory effect of a drug.

Resource assessment: A component of RAR, a systematic examination of the response (funds, people, buildings, knowledge) that is either available or required to solve the problem.

Respondent driven sampling (RDS): A sampling technique that does not require a sampling frame. It is an adaptation of a non-probability sampling method (snowball sampling) and is based on the assumption that members of the sub-population themselves can most efficiently identify and encourage the participation in surveillance of other sub-group members. RDS starts with initial contacts or 'seeds' who are surveyed and then become recruiters. Each of these recruiters is given coupons to use to invite up to three eligible people that he/she knows in the high-risk group to be interviewed. The new recruits bring their coupon to a central place where they are interviewed. The recruits then become recruiters. This occurs for five to six waves. Both the recruits and the recruiters are given incentives to encourage participation.

Retrospective case reporting: To look backwards and examine exposures to disease, for example, HIV infection, and suspected risk or protection factors in relation to an outcome (infection) that is established at the start of the reporting.

Retrovirus: A type of RNA virus that produces reverse transcriptase which converts RNA into DNA. HIV is an example of a retrovirus.

Reverse-transcription: The process by which HIV's genetic material (RNA) is transformed into DNA, which allows it to fuse with the host's genetic material (DNA).

RIBA: Acronym for recombinant immunoblot assay, also known as Western blot. Immunoblot assays confirm anti-HCV reactivity. Serum is incubated on nitrocellulose strips on which four recombinant viral proteins are blotted. Color changes indicate that antibodies are adhering to the proteins. A positive result is if two or more proteins react and form bands. An indeterminate result is if only one positive band is detected.

Risk: The probability that an event will occur; for example, that an individual will become ill within a stated period of time.

Risk factor: An aspect of personal behaviour or lifestyle; an environmental exposure; an inborn, inherited, or demographic characteristic. Associated with an increased occurrence of disease or other health-related event or condition. For example, injection drug use is a risk factor for acquiring HIV.

RPR: See 'Rapid Plasma Reagin test.'

Safety protocol: A study document that describes how to deal with field incidents or adverse events.

Sample: A selected subset of a population. There are specific types of samples used in surveillance and epidemiology such as convenience, systematic, population-based and random.

Sample size: The number of subjects to be used in a given study.

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

Sampling bias: Also called selection bias. This refers to errors in sampling that decrease accuracy and lead to incorrect estimates. We also use the term 'biased samples' to mean that errors were made in choosing the people in the sample.

Sampling element: Individual member of the population whose characteristics are to be measured. See 'Sampling unit.'

Sampling error: The part of the total estimation error of a parameter caused by the random nature of sampling.

Sampling interval: The standard distance between elements selected in the sample population.

Sampling scheme: Procedure for choosing individuals to be included in a sample.

Sampling units: Refers to individual members of the population whose characteristics are to be measured. See 'Sampling element.'

Sampling variation: Difference between the estimate you measure in a sample and the true value of the variable in the study population.

Scale line graph: A graph that represents frequency distributions over time where the Y-axis represents frequency and the X-axis represents time

Second-generation surveillance: Built upon a country's existing data collection system, second-generation HIV surveillance systems are designed to be adapted and modified to meet the specific needs of differing epidemics. This form of surveillance aims to improve the quality and diversity of information sources by developing and implementing standard and rigorous study protocols, using appropriate methods and tools. Second generation surveillance refers to activities outside of those activities generally considered to be a part of routine case surveillance such as case reporting and sentinel sero-surveys and uses additional sources of data to gain additional understanding of the epidemic. It includes biological surveillance of HIV and other STIs, as well as systematic surveillance of the behaviours that spreads them.

Secondary incentive: The incentive a participant gets for recruiting his or her peers into the study.

Seeds: Non-randomly selected (by the investigators) members of the target population who will initiate the RDS recruitment process by recruiting members of his or her peer group. From each seed, a recruitment chain is expected to grow.

Selection bias: A systematic error in the process respondent selection for a study or survey.

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

Sentinel case reporting: Reporting cases of a disease from sentinel sites.

Sentinel populations: Populations that are subject to sentinel surveillance activities. They may not necessarily be representative of the general population, but rather they might be the first affected by HIV. Examples include sexually transmitted infection patients or truck drivers.

Sentinel sites: Sites at which sentinel surveillance activities take place, including clinics attended by individuals who may or may not be representative of the general population but are likely to represent groups initially infected or at higher risk for infection than the general population.

Sentinel surveillance: A surveillance system in which a pre-arranged sample of reporting sources at 'watch post' or 'sentinel' sites agrees to report all cases of one or more notifiable conditions. Often designed to provide an early indication of changes in the level of disease. Depending on the nature of the population surveyed, these data may be representative of the general population, or they may simply give more detailed information about the populations tested.

Sero-conversion: The development of antibodies to a particular microbe. When people develop antibodies to HIV, they 'sero-convert' from HIV-negative to HIV-positive.

Sero-incidence surveillance: Collecting blood samples for measuring newly acquired HIV infection for the purposes of surveillance.

Serologic test: A blood test that determines the presence of antibodies to particles such as viruses. For example, a blood test that detects the presence of antibodies to HIV.

Sero-prevalence: The proportion of a population that is infected, as determined by testing blood for the appropriate antibody. For example, the proportion of a population that is infected with HIV, as determined by testing for HIV antibodies in blood samples.

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

Sero-status: Refers to the presence/absence of antibodies in the blood. For example, the presence or absence of HIV.

Sero-surveillance: Collecting blood samples for the purpose of surveillance. Latent, 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.

Sexual transmission: Transmission of an infectious agent, such as HIV, that occurs predominately through unprotected vaginal or anal intercourse, and less frequently through oral intercourse.

Sexually transmitted diseases: Symptomatic. Caused by organisms that are spread by sexual contact from person to person.

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

Sex workers (SWs): Persons who engage in sex work, or the exchange of sex for money, which includes many practises and occurs in a variety of settings. These may include 'direct' or 'formal' sex workers, who are sometimes included in registries and often found in brothels, and '**indirect**' or '**casual**' sex workers, who do not engage in sex work full time and are unlikely to be included in registries. The term 'sex worker' can be used to refer to female, male and transgendered sex workers.

Simple random sampling (SRS): Sampling where everyone has an equal chance of being randomly selected (a non-zero probability) and we know what that chance is.

Skewed: A distribution that is asymmetrical and does not follow a normal (bell-shaped) distribution.

Snowball sampling: Relies on informants to identify other relevant study participants in a chain referral pattern. Informants (seeds) who meet inclusion criteria are identified. This sampling design is based on chain referral and relies on the seed(s) to identify other relevant subjects for study inclusion. Those other subjects may identify other relevant subjects for inclusion. Snowball sampling is useful for studying populations that are difficult to identify or access. Representativeness is limited.

Social influence: Mild peer pressure from the recruiter who will receive a secondary incentive for recruiting his/her peers.

Social network: Members of a peer group who know each other.

Socio-metric stars: Seeds who are not only willing to recruit their peers, but are well-regarded by their peers and have a lot of them. Such seeds are more likely to influence others to be recruited into the study.

Specificity: The proportion of persons without disease who are correctly identified by a screening test or case definition as not having disease.

SRS: See simple random sampling.

Stacked bar chart: See 'clustered bar chart.'

Stakeholders (or stakeholder's group): Those with an interest in the results of surveillance activities. Includes public health practitioners, healthcare providers, data providers and users, representatives of affected communities; governments at the district, province and national levels; members of professional and private non-profit and donor organisations.

Standard error: Estimate of precision in probability sampling that can be used to construct a range of values within which the true population measure is likely to fall. We usually want to be 95% sure that the true population measure lies in our range.

Standardised Testing Algorithm for Recent HIV Sero-conversion (STARHS): A calculation for measuring new infection that uses a single blood test. STARHS uses the

results of two EIA tests, one highly sensitive and another modified to be less sensitive. The less sensitive EIA test is called the 'detuned' assay.

Statistics: A branch of applied mathematics concerned with the collection and interpretation of quantitative data and the use of probability theory to estimate population parameters.

Steering method: In RDS, using additional methods to recruit a special sub-population of interest; for example, providing an extra coupon to be used only to recruit female IDUs.

STI: See 'sexually transmitted infection.'

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

Strata: A sub-group in stratified sampling.

Strategic information (SI): Refers to any data collected by surveillance or monitoring and evaluation of a programme or system. Includes, but is not limited to, process indicators, output indicators and surveillance data.

Stratification: The classification of a survey population into sub-groups or strata on the basis of selected characteristics.

Stratified and constant incentives: In a study of SWs, a constant incentive level was considered too low to attract the more hidden SWs who earned a higher income. The research team considered using a stratified incentive process. The SWs received an incentive based on the type of sex work they did. For instance, a street-based SW received a \$5.00 incentive, while a call-girl-type SW received a \$10.00 incentive

Stratified sampling: Stratified sampling is generally used to obtain a representative sample when the population is heterogeneous, or dissimilar, where certain homogeneous, or similar, sub-populations can be isolated (strata). A stratified sample is obtained by taking samples from each stratum or sub-group of a population.

Street children: Children who live and/or work on the streets, including orphaned, homeless, runaway, or neglected children who live chiefly in the streets without adequate protection, supervision, or direction from responsible adults.

Subcutaneously: Below the skin, as in an injection.

Sub-population: See 'population sub-group.'

Sufficient cause: A causal factor or collection of factors whose presence is always followed by the occurrence of the effect (of disease).

Surveillance: The systematic collection, analysis, interpretation, and dissemination of health data on an ongoing basis, to gain knowledge of the pattern of disease occurrence and potential in a community, in order to control and prevent disease in the community.

Surveillance sites: The places from which case reports are obtained. This includes sites at which universal reporting and sentinel reporting are done. These may be healthcare facilities or other locations at which sero-surveys are conducted.

Survey population: The target population modified to take into account practical considerations (for example, all commercial sex workers in a city over the age of 15, excluding those who are based at home, as they cannot be accessed).

Survey protocol: A manual that describes all the steps and tasks involved in a sero-survey.

Survival sex: To barter sex for the necessities of living, such as food, shelter, goods, money. Engaged in by vulnerable populations, for example, by displaced women, street children, and transgendered people who are marginalised and discriminated against.

Susceptible: Vulnerable or predisposed to a disease.

Symptomatic: Exhibiting symptoms.

Symptoms: Any perceptible, subjective change in the body or its functions that indicates disease or phases of disease, as reported by the patient.

Syndrome: A group of symptoms as reported by the patient and signs as detected in an examination that together are characteristic of a specific condition.

Syndromic case reporting: A surveillance system in which a diagnosis of the infection is made through the presence of symptoms using a standard case definition. Frequently used for surveillance of sexually transmitted infections in countries in which access to laboratory testing may be limited.

Syndromic prevalence: The prevalence of a particular syndrome, or set of symptoms, in a given population. Usually calculated when testing equipment is not available to verify the presence of particular pathogen in a laboratory.

Syphilis: A sexually transmitted disease resulting from infection with the bacterium *Treponema pallidum*. Syphilis can also be acquired by newborns from their mothers during pregnancy.

Systematic sampling: A sampling method that consists of randomly selecting the initial patient who meets the inclusion criteria and then selecting every 'nth' (for example, third or fifth) eligible patient thereafter until the predetermined sample size is reached or the survey period is over.

Systemic: Concerning or affecting the body as a whole.

Table: A set of data arranged in rows and columns.

Target population: The group that meets a survey's measurement objective (for example, all commercial sex workers in a city).

Targeted sampling: Targeted sampling uses pre-existing indicator data (qualitative and quantitative) to construct a sampling frame from which recruitment sites are then randomly selected. Qualitative indicator data includes ethnographic data and key informant interviews. Types of quantitative indicator data include cases of HIV/AIDS and STIs, admissions to drug treatment and population characteristics from census data. There are several limitations: 1) indicator data may not be useful in characterising the target population; 2) sampling may be biased and difficult to replicate; 3) geographic areas may not be sampled in proportion to the number of members in the population of interest; 4) the population of interest may not be sampled in proportion to the intensity of risk behaviour and 5) the probability of selecting a member of the population of interest may not be known.

TB: Acronym for tuberculosis.

Testing (HIV) strategy: The use of an appropriate HIV test or combination of HIV tests. The choice of testing strategy used is based on the objective of the test, the sensitivity and specificity of the test, and HIV prevalence in the population being tested.

T-helper lymphocyte: Also known as 'T-cell.' Immune cells that seek and attack invading organisms. HIV enters T-cells through their CD4 receptor proteins, making T-cells virtual HIV-factories.

Time-location sampling (TLS): Similar to conventional cluster sampling, but gets around the problem of clusters that are not stable (that is, clusters where the number and type of people vary by, for example, time of day). Time-location sampling allows the same site to be included in the sample frame more than once (for example, at different times of the day or different days of the week).

Timeliness of reporting: One of several attributes of a surveillance system. Timeliness may be defined as the time period between the diagnosis of the disease and the receipt of a case report form at the health district.

Transactional sex: Distinct from other forms of commercial sex. Includes the receipt of gifts or services in exchange for sex.

Transgendered persons: Persons who identify with or express a gender and/or sex different from their biologic sex.

Transition probability: The likelihood that a person will change from one state to another, for example becoming HIV positive.

Transmission: Any mode or mechanism by which an infectious agent is spread through the environment or to another person.

Trend: A long-term movement or change in frequency, usually upwards or downwards.

Treponema pallidum: The bacterial causative agent of syphilis.

Triangulation: The process of examining several different sets of data, which are measuring different things to come up with a better understanding of how and where an epidemic is spreading. For example, the use of antenatal clinic data, census data, and registered deaths in order to create a more complete picture of the AIDS burden in a country.

Trichomonas vaginalis: A sexually transmitted protozoan parasite that causes the vaginal infection, **trichomoniasis**, characterised by itching, burning and vaginal discharge. Reinfection is common if sexual partners are not treated simultaneously.

True negatives: Test results that are negative when the patient actually does not have the disease that is being tested for.

True positives: Test results that are positive when the patient actually has the disease that is being tested for.

Tuberculosis: An airborne, often fatal bacterial infection caused by *Mycobacterium tuberculosis*. It causes damage to the lungs and other parts of the body. Infection is more likely in people with weak immune systems.

UAT: See 'unlinked anonymous testing.'

UNAIDS: Acronym for The Joint United Nations Programme on HIV/AIDS.

UNGASS: Acronym for United Nations General Assembly Special Session on HIV/AIDS.

Univariate analysis: The most basic, yet often the most important, type of behavioural surveillance analysis, because it shows the distribution of each variable. Most of the indicators defined for behavioural surveillance purposes are calculated through univariate analysis. They would include variables like the proportion of young men who have had sex with more than one partner during a given time period. When trends are analysed, statistical techniques are used to calculate how likely it is that changes in the proportions could have occurred by chance, or whether observed changes are likely to reflect real changes.

Universal case reporting: A surveillance system in which all persons who are identified as meeting the case definition for a particular disease are reported. For example, all persons with AIDS who receive care at any healthcare facility are reported. This is in contrast to sentinel reporting in which only selected sentinel sites report all persons who meet the case definition.

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

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

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

Unprotected sex: Having sex without using a condom as protection against HIV and other sexually transmitted infections.

Urethritis: Inflammation of the urethra.

Vaccine: When injected into an individual, a vaccine protects against subsequent infection by a particular organism or results in a less severe illness should infection occur. Currently there is no vaccine for HIV.

Validity: The validity of a measure is the extent to which it actually measures what it is suppose to measure: the truth.

Values: Magnitude of measurements (statistics).

Variable: Any characteristic or attribute that can be measured.

VCT: See 'voluntary counselling and testing.'

VDRL: See 'Venereal Disease Research Laboratory test.'

Venue-based: Locations in the community, such as bars, tea houses, and street corners.

Venue-based sampling: Recruit respondents in places and at times where they would reasonably be expected to gather. The venues act as screeners in identifying potential respondents. Venue-based sampling requires comprehensive formative research.

Venereal Disease Research Laboratory test (VDRL): A common serologic test for syphilis. Specifically, a non-treponemal test for anticardiolipin antibodies.

Vertical surveillance system: See 'categorical surveillance system.'

Vertical transmission: See 'perinatal transmission.'

Vesicular: Pertaining to vesicles or blisters.

Viral load: The amount of HIV in the circulating blood. Also known as 'viral burden' or 'viral dose.'

Viral load test: Test that measures the quantity of HIV in the blood.

Virulence: The relative capacity of an organism to overcome the body's immune defenses.

Virus: Micro-organisms that typically contain a protein coat surrounding nucleic acid (RNA or DNA) that are capable of growth only within living cells.

Vital records: Certificates of birth, death, marriage and divorce that are required by law.

Voluntary counselling and testing (VCT): A programme that provides both counselling and testing services to communities, allowing persons who are tested to obtain emotional and medical support before and after their HIV tests.

Voluntary migrants: People who temporarily work or travel away from their homes.

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

Vulnerable population: A group whose members are discriminated against and who face stigma, making them vulnerable to negative consequences of surveillance, including social and physical harm.

Western blot: A type of HIV test, Western blot uses an electroblotting method in which proteins are transferred from a gel to a thin, rigid support and detected by binding of labeled antibody to HIV.

WHO: Acronym for the 'World Health Organization.'

Width: See 'interval width.'

X-axis: The horizontal line of a graph, usually found at the bottom.

Y-axis: The vertical line of a graph, usually found at the left but sometimes also at the right.

Years of potential life lost: A measure of the impact of premature mortality on a population, calculated as the sum of the differences between some predetermined minimum or desired life span and the age of death for individuals who died earlier than that predetermined age.

YLL: See 'years of potential life lost.'

Notes

Appendix C, Useful Links

Organisational Sites

The Global Fund to Fight AIDS, Tuberculosis and Malaria

The Global Fund was created to finance a dramatic turnaround in the fight against AIDS, tuberculosis, and malaria. These three diseases kill more than six million people a year. This massive scaling-up of resources is already supporting aggressive interventions against all three.

www.theglobalfund.org

World Bank, The Global HIV/AIDS Program

The Global HIV/AIDS Program was created in 2002 to support the World Bank's efforts to address the HIV/AIDS pandemic from a cross-sectoral perspective. The programme offers global learning and knowledge sharing on approaches and best practices to addressing HIV/AIDS.

www1.worldbank.org/hiv_aids/globalprogram.asp

World Health Organization (WHO)

The World Health Organization is the United Nations specialised agency for health. WHO's objective, as set out in its Constitution, is the attainment by all peoples of the highest possible level of health. WHO is governed by 192 Member States through the World Health Assembly. The Health Assembly is composed of representatives from WHO's Member States.

www.who.int

WHO: Department of HIV/AIDS

The HIV/AIDS Department coordinates a strategic, organisation-wide response to the HIV/AIDS epidemic and enables WHO to provide enhanced technical support in HIV/AIDS to countries and regional offices. www.who.int/hiv/en

WHO: Regional Office for Eastern Mediterranean Region (EMRO)

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, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syrian Arab Republic, Tunisia, United Arab Emirates and Yemen.

www.emro.who.int

UNAIDS (Joint United Nations Programme on HIV/AIDS)

As the main advocate for global action on HIV/AIDS, UNAIDS leads, strengthens and supports an expanded response aimed at preventing the transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS and alleviating the impact of the epidemic.

www.unaids.org

United Nations General Assembly Special Session (UNGASS)

This site is dedicated to tracking compliance with the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), which in 2001 concluded with a declaration of commitment signed by 189 member states to take actions to reduce the spread and impact of HIV/AIDS. As part of this effort, UNAIDS reports on progress toward achieving this goal every two years. To measure progress, UNAIDS developed a set of 25 indicators called the UNGASS indicators.

http://www.ua2010.org/index.php/en/UNGASS

Epidemiological information on HIV/AIDS from UNAIDS

www.unaids.org/en/resources/epidemiology.asp

Surveillance information on HIV/AIDS from UNAIDS

www.unaids.org/en/in+focus/topic+areas/surveillance+and+reporting.asp

United Nations Children's Fund (UNICEF)

UNICEF is one of the United Nations' key agencies in the fight against HIV/AIDS, mobilising financial resources and helping persuade governments to put HIV/AIDS at the top of their agendas and to treat the epidemic as a national emergency. UNICEF is working in 160 countries around the world to combat the epidemic. www.unicef.org/aids

Family Health International (FHI)

Family Health International has pioneered ways to curtail the spread of HIV/AIDS. Many of the HIV prevention "best practices" in use today have emerged from FHI's work in more than 60 countries.

www.fhi.org/en/HIVAIDS

The Body

An AIDS and HIV Information Resource based in New York City, NY, USA. Provides Information on various questions related to HIV/AIDS www.thebody.com

HIV InSite

HIV InSite is developed by the Center for HIV Information (CHI) at the University of California, San Francisco (UCSF). HIV InSite's mission is to be a source for comprehensive, in-depth HIV/AIDS information and knowledge. <u>hivinsite.ucsf.edu</u>

Cochrane HIV/AIDS Group

An affiliate of the International AIDS Society and the UCSF AIDS Research Institute, the Cochrane Collaborative Review Group on HIV Infection and AIDS is an international network of health-care professionals, researchers and consumers working to prepare, maintain and disseminate systematic reviews on the prevention and treatment of HIV infection and AIDS.

www.igh.org/Cochrane

US Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH) Sites

Centers for Disease Control and Prevention (CDC)

CDC serves as the national focus for developing and applying disease prevention and control, environmental health, and health promotion and education activities designed to improve the health of the people of the United States. www.cdc.gov

Global AIDS Program (CDC)

The Global AIDS Program (GAP) exists to help prevent HIV infection, improve care and support and build capacity to address the global HIV/AIDS pandemic. www.cdc.gov/nchstp/od/gap

Division of HIV/AIDS Prevention (CDC)

The mission of the Division of HIV/AIDS Prevention is to prevent HIV infection and reduce the incidence of HIV-related illness and death, in collaboration with community, state, national and international partners.

www.cdc.gov/hiv/dhap.htm

Division of AIDS, STD, and TB Laboratory Research (CDC)

The Division of AIDS, STD, and TB Laboratory Research (DASTLR) was established to centralise CDC's laboratory studies on human immunodeficiency virus (HIV), other retroviruses, other sexually transmitted diseases (STDs), hematologic disorders, and mycobacteria, including Mycobacterium tuberculosis. www.cdc.gov/ncidod/dastlr

National Center for HIV, STD, and TB Prevention (CDC)

Umbrella organisation at the CDC for the divisions listed above. www.cdc.gov/nchstp/od/nchstp.html

National Institutes of Health (NIH)

National Institutes of Health is the Federal focal point for medical research in the United States. The NIH, comprising 27 separate institutes and centres, is one of eight health agencies of the Public Health Service, which, in turn, is part of the U.S. Department of Health and Human Services. Simply described, the goal of NIH research is to acquire new knowledge to help prevent, detect, diagnose and treat disease and disability. www.nih.gov

National Library of Medicine (NLM)

NLM provides a wide variety of resources related to the biomedical and health sciences. The Web site has information on how to access the various NLM databases, including how to establish an account for free access to its HIV/AIDS databases. www.nlm.nih.gov

National Institute of Allergy and Infectious Diseases (NIAID)

News releases from the NIH's primary AIDS research institute, plus AIDS reagent programme catalogue and other information. www.niaid.nih.gov

National Institute on Drug Abuse (NIDA)

NIDA's mission is to lead the nation in bringing the power of science to bear on drug abuse and addiction. This charge has two critical components: The first is the strategic support and conduct of research across a broad range of disciplines. The second is ensuring the rapid and effective dissemination and use of the results of that research to significantly improve drug abuse and addiction prevention, treatment, and policy. www.nida.nih.gov

Division of AIDS and Health and Behavior Research of the National Institute of Mental Health

The Division of AIDS and Health and Behavior Research (DAHBR) supports research and research training to: develop and disseminate behavioural interventions that prevent HIV/AIDS transmission, clarify the pathophysiology and alleviate the neuropsychiatric consequences of HIV/AIDS infection and use a public health model to reduce the burden of mental illness

www.nimh.nih.gov/dahbr/dahbr.cfm

National Institute for Child Health & Human Development (NICHD)

NICHD is part of the National Institutes of Health, the biomedical research arm of the US Department of Health and Human Services. The mission of the NICHD is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from the reproductive process, and that all children have the chance to fulfil their potential for a healthy and productive life, free of disease or disability. www.nichd.nih.gov

Fogarty International Center

The Fogarty International Center promotes and supports scientific research and training internationally to reduce disparities in global health. www.fic.nih.gov

NIH Office of AIDS Research (OAR)

NIH's OAR is located within the Office of the Director of NIH and is responsible for the scientific, budgetary, legislative and policy elements of the NIH AIDS research programme.

www.nih.gov/od/oar

Other U.S. Government Sites

United States Agency for International Development

USAID is an independent federal government agency that receives overall foreign policy guidance from the Secretary of State. The agency works to support long-term and equitable economic growth and to advance U.S. foreign policy objectives by supporting: economic growth, agricultural and trade, global health, democracy, conflict prevention and humanitarian assistance.

www.usaid.gov

Development Experience Clearinghouse

The Development Experience Clearinghouse (DEC) is the largest online resource for USAID-funded, international development documentation, including fact sheets on HIV/AIDS in the Eastern Mediterranean and North Africa. www.dec.org

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

The International Programs Center, part of the Population Division of the U.S. Bureau of the Census, conducts demographic and socio-economic studies and strengthens statistical development around the world through technical assistance, training, and software products. The IPS maintains an HIV/AIDS Surveillance database, the Monitoring the AIDS Pandemic (MAP) Network, and a series of HIV/AIDS country profiles. http://www.census.gov/ipc/www

Veterans Health Administration: Public Health Strategic Health Care Group, AIDS Information Center

Provides a variety of educational links related to HIV/AIDS care, treatment, policy and research. Detailed information is also provided on blood exposure and needle stick safety in healthcare settings as well as treatment guidelines and recommendations. <u>vhaaidsinfo.cio.med.va.gov/aidsinfo/TOC.htm</u>

Appendix C: Useful Links

Notes

Appendix D, 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: Asia Answers

Warm up questions

- 1. True or false? As of 2009 approximately 33.3 million people were infected with HIV worldwide. *True*.
- 2. In Asia, the two main factors driving the epidemic are *commercial sex*, and *injecting drug use*.
- 3. List risk factors which contribute to the spread of HIV in Asia. *Risk factors which contribute to the spread of HIV in Asia include the high prevalence of STIs, organised commercial sex, illicit drug trafficking, poverty, low literacy and taboos to discuss sex, migration, and the low status of women.*
- 4. In which country in the Asia Region has the HIV epidemic has begun to decline?
 - a. India
 - b. Myanmar
 - c. Thailand
 - d. Nepal

Thailand has been widely hailed for success in its response to AIDS; however, Thailand's epidemic is far from over.
Unit 1: Asia Answers

Case study

Serosia is a country in Asia that 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, Serosia, 1998-2004.

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

- a. In 2004, which district had the highest prevalence? *Southern District*
- b. Comment on the HIV infection trends. *A steady decline in HIV prevalence was observed in all districts.*

Appendix D, 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: Caribbean Answers

Warm-up questions

- 1. True or false? As of 2009, approximately 33.3 million people were infected with HIV worldwide. *True*.
- What region in the Caribbean has been most affected by HIV/AIDS?
 Bermuda has the highest prevalence of HIV in the Caribbean region
- 3. In the Caribbean, unprotected sex between sex workers and clients is a key factor in the spread of HIV. *True*.
- 4. The major factor that accounts for the prevalence rates of HIV/AIDS in the Caribbean is:
 - a. Injection drug use
 - b. Women's status and inability to influence partners' behaviour
 - c. Heterosexual transmission
 - d. Blood exposure from unsafe medical practises
 - e. All of the above

In the Caribbean, the primary mode of sexual transmission has changed from being predominantly homosexual to being a mosaic of homosexual/bisexual and heterosexual epidemics. Heterosexual transmission accounts for the majority of HIV/AIDS cases in the Caribbean. Injecting drug use is responsible for a minority of HIV infections and only contributes significantly to the spread of HIV in Bermuda.

Unit 1:Caribbean Answers

Case study

Cariba is a Caribbean nation that had its earliest cases of AIDS recognised in 1986. Data below are based on estimates of HIV prevalence by parish.

Parish	1995	1998	2000	2002
St. Mary	.2	0.5	1.0	1.1
Kingstown	0.5	0.7	0.9	0.8
Arima	1.0	2.0	2.7	2.9
St. James	0.1	0.7	2.8	3.8
Yotown	0.4	0.9	1.3	1.2

HIV prevalence (%) by parish, Cariba, 1995-2002.

- a. What parish had the greatest proportion of its population infected with HIV in 1995? *Arima*.
- b. Comment on the HIV infection trends. Prominent recent trends are continued slow growth in St. Mary and Arima, levelling off or a decrease in Kingstown and Yotown, and rapid growth in St. James.
- c. In 2002, which parish had the highest prevalence? Is the epidemic increasing or decreasing in this parish? *St. James. The epidemic is increasing rapidly.*

Appendix D, 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: Eastern Europe and Central Asia Answers

Warm-up

- questions
- 1. True or false? As of 2009, approximately 33.3 million people were infected with HIV worldwide. Circle your answer below: *True*.
- 2. In 2009, which two countries accounted for nearly 90% of newly reported HIV diagnoses in the region? *Russia and Ukraine*.
- 3. The HIV epidemics in Eastern Europe and Central Asia are concentrated mainly among which most-at-risk populations?

HIV epidemics of Eastern Europe and Central Asia are concentrated mainly among injection drug users, sex workers, and, to a lesser extent, men who have sex with men.

- 4. Which of the following countries in the region has the highest reported HIV prevalence among adults?
 - e. Russian Federation
 - f. Estonia
 - g. Ukraine
 - h. Republic of Moldova

In 2009, the reported HIV prevalence among adults in Estonia was 1.2%.

Unit 1: Eastern Europe and Central Asia Answers

Case study

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

Globa, a country in Eastern Europe, had its earliest cases of AIDS recognised in 1984. Data below are based on estimates of HIV prevalence by district. Examine the data and answer the questions that follow.

District	1998	1999	2000	2001	2002	2003	2004
Northern	2.10	2.30	1.56	1.60	1.18	1.06	1.05
Southern	2.11	2.43	1.84	1.65	1.64	1.44	1.34
Eastern	2.19	2.33	2.19	1.67	1.49	1.51	0.99
Western	1.30	1.24	1.08	1.11	0.91	1.18	1.25
Central	1.99	2.03	1.58	1.50	1.72	1.06	0.96

HIV prevalence (%) by district, Globa, 1998-2004.

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

In 2004, Southern District had the highest prevalence of HIV.

b. Comment on the HIV infection trends.

Prominent recent trends are slow decrease in prevalence in Northern, Southern, Eastern, and Central districts and levelling off in Western District.

Appendix D, 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: Latin America Answers

Warm-up

questions

- 1. True or false? As of 2009, approximately 33.3 million people were infected with HIV worldwide. *True*.
- 2. Name three factors that might affect prevalence rates in a region.
 - High prevalence of other 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 SWs
 - 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 urbanisation, migration, mobilisation, and separation of families as a result of economic and social circumstances.
- 3. The main modes of HIV transmission in this region are among these three groups: *Men who have sex with men, sex workers, and (to a lesser extent) injection drug users.*
- 4. Which of the following countries in Latin America has the highest reported HIV prevalence among adults?
 - a) Nicaragua
 - b) Guyana
 - c) Chile
 - d) Honduras

Unit 1: Latin America Answers

Case study

Nicondama, a country in Latin America, had its earliest cases of AIDS recognised 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, Nicondama, 1998-2004.

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

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 was observed in all districts.*

Appendix D, 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: North Africa and Middle East Answers

Warm-up

questions

- 1. True or false? As of 2009, approximately 33.3 million people were infected with HIV worldwide. *True*.
- 2. In which country in the North Africa and Middle East region is there evidence of widespread heterosexual transmission? *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: *Female sex workers, injection drug users, men who have sex with men*
- 4. Which of the following countries in the North Africa and Middle East region has the highest reported HIV prevalence among adults?
 - a. Lebanon
 - b. Turkey
 - c. Morocco
 - d. Sudan

Unit 1: North Africa and Middle East Answers

Case study

Menaland, a country in North Africa, had its earliest cases of AIDS recognised 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.

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

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 was observed in all districts.

Appendix D, 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: Sub-Saharan Africa Answers

Warm-up questions

- 1. True or false? About 33.3 million people are infected with HIV worldwide. *True*.
- What region of the world has been affected the most by HIV/AIDS, with an infection prevalence of over 20% in some countries? Sub-Saharan Africa.
- 3. What region in Africa has been affected the most by HIV/AIDS? *Southern Africa.*
- 4. Some of the factors that account for the high prevalence of HIV/AIDS in sub-Saharan Africa include:
 - a. Extensive population mobility
 - b. Women's status and inability to influence partner's behaviour
 - c. War and civil disturbance
 - d. Blood exposure from unsafe medical practices
 - *e. All of the above.*

Unit 1: Sub-Saharan Africa Answers

Case study

Afrobia is an east African nation that had its earliest cases of AIDS recognised in 1982. Data below are based on estimates of HIV prevalence by province. Examine the data and answer the questions that follow.

HIV prevalence (%) by province, Afrobia, 1995-2002.

Province	1995	1998	2000	2002
Samad	2.3	4.7	10.4	11.2
Risarah	5.0	7.2	9.2	9.1
Yolo	10.5	20.1	27.6	27.8
Inyo	10.3	15.6	20.6	27.9
Plumas	4.0	8.7	12.9	12.2

- a. What province had the greatest proportion of its population infected with HIV in 1995? *Yolo Province.*
- b. Comment on the HIV infection trends. *A steady increase in HIV prevalence was observed in all provinces.*
- c. In 2002, which province had the highest prevalence? Is the epidemic increasing or decreasing in this province? *Inyo Province. Prevalence is increasing in this province.*

Unit 2 Answers

Warm-up questions

- 1. True or false? Worldwide, approximately 1.8 million people die each year because of AIDS. Circle your answer below. *True*.
- 2. What is the impact of HIV/AIDS on children? Children more likely to be kept home, drop out of school, start working to support family, forgo necessities such as food and clothes, be sent away from home, or become the head of household.
- 3. What is the economic impact of HIV/AIDS on individuals, families and nations? Drop in economic wealth by as much as 40%, decrease in household income, drain on health services.
- 4. Globally, what is the burden of HIV/AIDS in terms of disability adjusted life years (DALYs) and deaths? *Globally, up to 58.5 million DALYs are lost due to HIV/AIDS. In 2004, HIV/AIDS was the fifth leading cause of DALYs worldwide. AIDS was the sixth leading cause of death in the world in 2004.*
- 5. List some of the effects stigma has on HIV prevention, care and support for individuals infected with HIV and their families. *Some of the effects of stigma include: discrimination in the workplace and in healthcare settings, exclusion from social functions, denial of benefits, privileges and services. Stigma is a barrier to protective behaviours and testing and often results in the needs of marginalised populations being systematically ignored.*

Case study

The five districts in the fictitious country of Melabia have had different experiences with the HIV/AIDS epidemic. Examine the following data:

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

Measures of HIV impact by district, Melabia, 2006.

- 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, in which district was the proportion of deaths due to HIV/AIDS among working adults the lowest? *In the Southern 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 macrophages.

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

Warm-up questions, continued

- 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 characterised by 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 sexually transmitted infections (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.*

Warm-up questions, continued

- 9. Which of the following opportunistic infections commonly occurs in AIDS patients?
 - a. Herpes zoster
 - b. Cryptococcosis
 - c. Tuberculosis (TB)
 - *d. All of the above*

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

- 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 Melabia has experienced rapid expansion of the HIV epidemic. Examine the data and answer the questions below:

	2000	2001	2002
Gonorrhoea*	5.0	12.8	23.5
Syphilis*	2.1	4.5	16.4
Reported cases	2 987	3 452	6 784
of urethritis			
from STI clinic			
HIV incidence	2%	4.3%	5.0%
(estimated)			

Incidence of various STIs over time, Western District.

* Cases per 1,000 population 15–49 years old

- a. Do you think that sexually transmitted infections (STIs) may be playing an important role in the spread of HIV infection? Why or why not? *Yes, STIs likely are playing a major role in the spread of sexually transmitted HIV in this district. It's likely that STIs are important in HIV transmission because:*
 - *Rates of STIs are high and increasing*
 - Prevalence of HIV is relatively low and incidence is rising.
- b. Given the HIV incidence in the Western District, what do you think will happen with tuberculosis rates in the next several years and why? *Tuberculosis (TB) rates will likely increase as the HIV epidemic spreads. TB is one of the most important opportunistic infections associated with advanced HIV and AIDS. TB cases will involve both the appearance of active tuberculosis 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

- 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.*

Warm-up questions, continued

3. Match the following terms with their definitions:

_ <i>c</i> _ Sentinel surveillance	c. Surveillance system in which reports are obtained only from certain selected facilities and populations
<u>a</u> Laboratory-based reporting	a. Surveillance system in which the reports of cases come from clinical laboratories as opposed to healthcare practitioners or hospitals
<u><u>b</u> Case definition</u>	b. Clinical and laboratory characteristics that a patient must have to be counted a 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, Melabia 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, the WHO developed new clinical staging of adults and paediatric HIV disease and new HIV surveillance case definitions.

The WHO is sponsoring a pilot project in Melabia 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.

	2006 WHO	2006 WHO case definition				
1994 case	Present	Absent	Total			
definition						
Definition met	65	4	69			
Definition not met	6	25	31			
Total	71	29	100			

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 can not tell from these data. Case definitions are for epidemiologic, 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 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 sero-prevalence surveillance is more likely to under-report 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 under-reporting 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.

Warm-up questions, continued

- 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 <u>rate</u> of new infections, while prevalence measures the <u>number</u> or <u>proportion</u> 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 sero-prevalence 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 Melabia, the Ministry of Health has conducted a long-term cohort study of 1 000 residents who were originally uninfected with HIV in 1997. The goal is to measure the incidence and prevalence of HIV infection.

	1998	1999	2000	2001	2002
New HIV infections	10	25	50	80	114
Total HIV infections	10	35	85	165	279
Population at risk (non-infected)	1 000	990	965	915	835
Total population (infected and non- infected)	1 000	1 000	1 000	1 000	1 000

HIV infections in Northern District Cohort Study, 1998-2002.

a. What is the prevalence of HIV infection in 2002? $279/1\ 000 = 27.9\%$

- b. What is the incidence of HIV infection in 2002? 114/915=12.5% or 12.5 per 100 person-years
- c. In which year was the incidence the highest? 2002

<u>Unit 6 Answers</u>

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 sub-populations 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 generalised.*
- 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

The fictitious country of Globa 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, Sadcity, where HIV incidence and STI rates are reported to be increasing in SWs.

a. How would you suggest investing these funds?

There is no single correct answer. Given the limited nature of surveillance activities in Globa, improving second-generation HIV surveillance in the capitol city 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 Sadcity 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 Sadcity 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 Sadcity, 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 minimising risk to individuals in the areas of:
 - a. Physical risk
 - b. Psychological harm
 - c. Stigmatisation
 - *d.* All of the above.

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

- 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 healthcare.*
- 4. True or false? In low-level epidemics, information about HIV infection in high-risk or marginalised groups should be widely publicised to prevent further spread of the disease. False. Early 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.

Warm-up questions, continued

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 stigmatisation. 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 <u>anonymous</u>. That is, 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 Melabia. You have been asked to design and implement a special HIV sero-prevalence survey among male patients with acute urethritis attending the STI clinic at the provincial referral hospital.

You are weighing two choices:

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







Case study

Examine the data below to answer questions 1-3. Remember to title every graph.

HIV prevalence (%) by districtamong sexually transmitted infection (STI) clinic attendees, Melabia, 2000-2003.

District	2000	2001	2002	2003
Northern	5.0	2.4	7.2	14.4
Southern	4.2	2.0	2.3	2.8
Eastern	6.5	10.4	9.4	5.5
Western	7.6	6.3	7.6	5.8
Central	7.1	6.5	5.6	3.2

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



HIV prevalence by district, Melabia, 2002.

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

HIV prevalence by year, Northern District, 2000-2003.



c. Create a clustered bar chart to show prevalence by district by year (2000-2003).

HIV prevalence by district and year, Melabia, 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 Melabia in 2002.

District	Cases
Northern	242
Southern	298
Eastern	567
Western	678
Central	198

Reported cases of syphilis among	ŗ
men by district, Melabia, 2002.	



Reported cases of syphilis among males by district, Melabia, 2002.

Unit 9 Answers

Warm-up questions

- List three stakeholder groups that should be engaged during the evaluation of the surveillance system. Potential stakeholder groups include public health practitioners, healthcare providers, government officials, representatives of affected communities, non-profit and donor organisations, 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 Globa and has the country's major port city, Port Marina. A university has been conducting studies of female sex workers in Port Marina for nearly a decade. For the last five years, they have been conducting serial sero-prevalence 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—that is, the particulars of data collection, the costs (personnel, other).

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?
- What is the quality of the lab results?
- If blood samples are sent away for analysis, is there a long lag time 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

 You are the HIV sero-prevalence officer for the Northern District. Northern District is a large district in Globa, a country with an HIV epidemic concentrated in sex workers and injection drug users. To monitor the epidemic in the general population, sero-prevalence surveys are conducted annually at antenatal clinics in Northern District. You examine data from the past five years and observe the following:

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

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?

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 ages 25 to 29 years and lowest among pregnant women ages 15 to 19 years and 40 to 44 years.

Final Case Study, continued

- c. Based on the above data, how would you characterise the HIV epidemic in the Northern District of Globa in 2005? *As the prevalence of HIV among pregnant women in the Northern District is consistently greater than 1%, the Northern District has a generalised HIV epidemic.*
- 2. Northern District has recently been given funds to begin secondgeneration HIV surveillance. Until now, HIV surveillance has been limited to HIV case reporting and sentinel sero-prevalence 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
 - Sexually transmitted infection (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 resisdency (urban vs. rural) or migrantion status, marital status and parity (for antenatal sites).
- 3. Globa provides free antiretroviral therapy (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 Globa, conducting HIV surveillance through anonymous unlinked sero-prevalence 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

Final Case Study, continued

conjunction with voluntary counselling and testing 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 sero-prevalence surveys have been conducted at five antenatal clinics in the district for the past four years. The survey is conducted between June and September of each year. Evaluation of the sero-prevalence 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:

	Site 1	Site 2	Site 3	Site 4	Site 5
Number of subjects	158	165	208	287	189
Percent missing data:					
Age	6%	5%	2%	4%	5%
Date specimen collected	2%	1%	1%	2%	3%
Residence	4%	5%	2%	3%	5%
Parity	3%	2%	1%	2%	3%
Live births	1%	2%	2%	1%	3%
HIV serology	1%	1%	0%	20%	1%

- 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. A problem with data entry. This could be investigated by examining the hard copies of the data.
- b. Laboratory error: testing was not done.
- c. 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.

Final Case Study, continued

- 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 session might be needed. At a minimum, the sero-prevalence 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 sero-prevalence surveys.
 - Improving communication between the sero-prevalence coordinator and the laboratory director regarding the adequacy of supplies should also be discussed.

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

Appendix E, Differences between Public Health and Research <u>Methods</u>

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, for classifying a study as not being research are listed below, and specific guidance is shown in Table E.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:

- 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.
- These systems have in place the ability to invoke public health mechanisms to prevent or control disease or injury in response to an event.

Research or non-research classification, continued

• Thus, the primary intent of these surveillance systems is to prevent or control disease 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 antenatal clinic (ANC) sero-prevalence surveillance surveys
- Regular behavioural surveys
- Many surveys of high-risk populations 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 generalisable knowledge. Characteristics of surveillance systems that most likely fit into this category are:

- Longitudinal data collection systems (for example, follow-up surveys and registries) that allow for hypothesis testing
- The scope of the data is broad and includes more information than occurrence of a health-related problem
- Analytic analyses can be conducted
- 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 the extra protection for study subjects and investigators and is helpful in anticipating problems and suggesting solutions.

Institutional review boards, continued

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

The World Health Organization 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
- Sero-prevalence 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 the epidemic: low-level, concentrated and generalised.

WHO ethical guidelines, continued

Table E-1. Guidance for classifying public health activities as research and to protect human subjects.^{*}

	Research	Practice (non-research)
Definition	"systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalisable knowledge."	May use scientific methods to identify and control a health problem with benefits for the study participants or their communities.
Primary Intent	To generate new or generalisable knowledge (information that can be applied in other settings).	To benefit study participants or the communities from which they come.
Methodology	 Scientific principles and methods used Hypothesis testing/generating Knowledge is generalisable 	 Scientific principles and methods may be used Hypothesis testing/generating Knowledge may be generalisable
Examples		
Surveillance Projects	 Scope of data is broad Analytical analyses Hypothesis testing Subsequent studies using cases 	 Regular, ongoing collection and analyses to measure occurrence of health problem (disease registry) Scope of data is health condition or disease, demographics, and known risk factors Invokes public health mechanisms to prevent or control disease or injury
Emergency Response	 Samples stored for future use Additional analyses performed beyond immediate problem Investigational drugs tested 	 Solves an immediate health problem No testing of methods or interventions
Programme Evaluation	 Test an intervention Systematic comparison of standard and non-standard interventions 	 Assess success of established intervention Evaluation information used for feedback into programme (management)

^{*} U.S. Centers for Disease Control and Prevention. Guidelines for Defining Public Health Research and Public Health Non-Research, revised June, 1999, URL: http://www.cdc.gov/od/ads/opspoll1.htm. Accessed 10 December 2003. CFR refers to U.S Code of Federal Regulations.