

COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS

HIV SURVEILLANCE TRAINING MANUAL

November 2012



Acknowledgements

This training manual was based on a manual used at the Florida Department of Health. Some sections of that document were so useful that only minor changes were made for inclusion in this manual. CSTE acknowledges the contribution of the CSTE workgroup: Marie Antoinette Bernard, Tina Brubaker, Sharon Carter, Melissa English, Douglas Frye, Kelly Gallagher, Joan Greene, Catina James, Bonnie Krampe, Benjamin Laffoon, Martin Ngokion, Luke Shouse, Stephanie Townsell, and Jeff Turner as well as CSTE National Office staff member Lauren Rosenberg. CSTE also acknowledges technical editor Karen Foster for her contributions to the project. The primary author is Michael Campsmith, CSTE consultant.

This publication was supported by Cooperative Agreement Number 5U38HM000414 from CDC. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC.

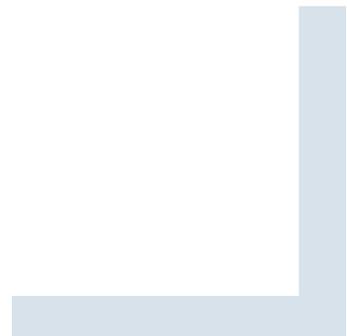
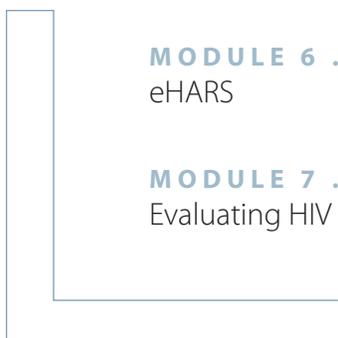


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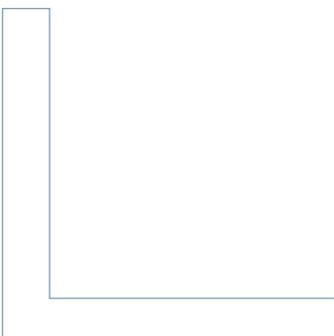


INTRODUCTION

HIV Surveillance Training Manual Objectives

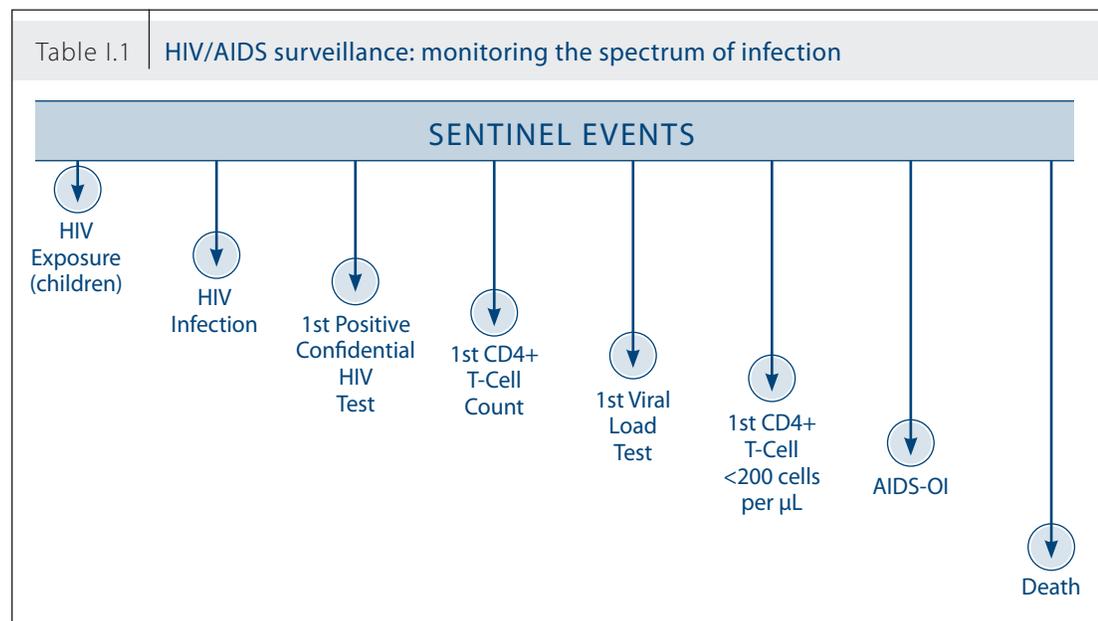
OBJECTIVES:

1. Explain the spectrum of events through the course of HIV infection.
2. Describe the background and purpose of public health surveillance.
3. Outline key events in the timeline of HIV surveillance.
4. Provide information about where to find more in-depth information about topics related to HIV and HIV surveillance.



Introduction

The purpose of an HIV surveillance program is to promote the systematic and ongoing collection, analysis, evaluation, and dissemination of epidemiologic data of the highest possible quality. In turn, public health surveillance data are used to plan, implement, and evaluate HIV programs and interventions. Public health surveillance activities identify HIV-related conditions at various points along the spectrum of HIV disease (Table I.1)—from reporting of HIV infection in otherwise asymptomatic people to periodic clinical evaluations of immune system status (e.g., [CD4 tests](#)) to AIDS diagnosis through low CD4 value/ diagnosis of qualifying opportunistic illnesses to death certificate review for HIV-related mortality.



In the past, surveillance for HIV-related diseases focused on opportunistic infections, cancers, and conditions that are known to occur late in the course of HIV disease. When the condition that became known as [AIDS was first recognized](#) in 1981, the underlying cause of the disease was unknown, and surveillance focused on a group of specific conditions associated with severe immunosuppression (e.g., *Pneumocystis carinii* pneumonia [now known as *Pneumocystis jiroveci* pneumonia], Kaposi sarcoma). In addition, persons with severe manifestations of HIV disease sought medical care and therefore came to the attention of health-care providers who could report cases to local and state health departments. Finally, because all HIV infected people eventually developed severe diseases, AIDS case finding through review of hospital records and AIDS-related deaths provided a relatively complete representation of the demographic and risk groups affected by the epidemic. National surveillance for AIDS began with identification of the initial cases in 1981. However, not until the first HIV-antibody diagnostic tests were licensed in 1985 could public health surveillance be conducted on conditions of HIV infection before a clinical diagnosis of AIDS.

To properly monitor the HIV epidemic, surveillance staff need to collect accurate information about key events from the time HIV infection is first diagnosed in a person until death. This information is collected from many sources and documents, such as health-care providers (adult and pediatric case report forms), laboratories (laboratory reports), and vital records offices (birth and death certificates). Increased use of diagnostic laboratory testing and of electronic reporting have led to an increased number of documents

Introduction

in the HIV surveillance system. Historically, consolidated information from all documents has been used to create a single case record for each HIV-infected person. As technology and the epidemic have evolved, the [Centers for Disease Control and Prevention](#) (CDC) has developed a [document-based data management system](#) to better track information received from HIV surveillance programs and to better monitor HIV disease progression.

Information about the spectrum of HIV disease assists CDC and state and local health departments in better understanding the direction of the epidemic, including populations most affected and in need of prevention and care services. After licensing of HIV diagnostic tests in 1985, many public health programs implemented surveillance for HIV infection (along with continuation of regular AIDS surveillance). However, several jurisdictions had concerns (e.g., confidentiality, stigma, discrimination) about surveillance for HIV infections before an AIDS diagnosis and until recently did not adopt integrated surveillance for the spectrum of HIV disease.

HIV surveillance data are used to monitor trends in the epidemic. Active case finding is conducted by state and local health departments throughout the United States, and uniform reporting methods with timely transmission of data to CDC have enabled CDC to disseminate HIV surveillance data for public health monitoring and planning purposes. Because HIV surveillance is the largest population-based system for monitoring the epidemic nationally, it has become the basis for allocation of federal, state, and local resources for prevention and patient care.

Surveillance for AIDS provides data at the late stage of HIV disease. One disadvantage of examining late-stage disease is that secondary prevention activities, such as referrals for early treatment interventions or partner notification, cannot be facilitated by health departments early in the course of infection when they are most beneficial. For this reason, as of April 2008, public health surveillance programs in all states and territories have expanded their surveillance case finding activities to also include persons in whom HIV infection is diagnosed before development of AIDS.

To ensure maximum efficiency of surveillance activities and optimum quality of resulting data, HIV surveillance program staff need to understand the [concepts of public health surveillance](#). After that understanding, they then need to implement those concepts in a standardized manner. The goal of this training manual is to present the basic concepts of an effective HIV surveillance system in a manner that staff with various levels of experience can use in their activities. Proper application of the principles of public health surveillance will result in a successful HIV surveillance program.

By design this manual presents the basics of HIV surveillance activities. For more in-depth material, the reader is directed to the [references](#) at the end of this introduction.

In addition, this manual is designed to provide a broad overview of HIV surveillance activities and practices. Because local surveillance programs might have developed policies and procedures specific to their own programs, some of the material in this manual might not apply to individual HIV surveillance systems.

Background and Purpose

Infectious disease surveillance was initiated in the United States in the late 1800s as a method of quarantine control to prevent the spread of conditions such as cholera, smallpox, yellow and fever. In 1961, CDC assumed responsibility for the collection and publication of data on [nationally notifiable diseases](#). However, reporting of diseases to CDC by states is *voluntary*; reporting is mandated (i.e., by legislation or regulation) only at the state level. Periodically, the list of nationally notifiable diseases is recommended for revision on the basis of consultation with various public health partners, including the [Council of State and Territorial Epidemiologists \(CSTE\)](#).

HIV surveillance staff should contact their state department of public health or office of general council about specific laws, statutes, and regulations authorizing the collection and reporting of public health information in their jurisdiction.

HIPAA AND PUBLIC HEALTH SURVEILLANCE

The national Health Insurance Portability and Accountability Act (HIPAA) was enacted in 1996. Title II of HIPAA, known as the Administrative Simplification provision, addresses the security and privacy of health data. The standards are intended to improve the efficiency and effectiveness of the nation's health-care system while maintaining strict standards of data protection and confidentiality. HIPAA has a federal [Privacy Regulation](#) (45 CFR § 164.512) to allow access to health records for established public health functions—including HIV surveillance—when the public health authority is authorized by law to collect or receive such information. The Privacy Rule expressly permits disclosures without individual authorization to public health authorities authorized by law to collect or receive the information for the purpose of preventing or controlling disease, injury, or disability, including public health surveillance, investigation, and intervention.

TECHNICAL GUIDANCE FOR HIV SURVEILLANCE PROGRAMS

CDC, in collaboration with CSTE and staff at the state and local levels, has prepared comprehensive material on HIV surveillance practices and recommendations. Much of the material with which new surveillance staff need to be familiar can be found in the various volumes of the [Technical Guidance for HIV Surveillance Programs](#). The *Guidance* is a reference for managing state and local HIV surveillance programs in the United States. The intent of the policies and procedures is to provide the basis for maintaining a national HIV surveillance system by using a standardized framework for collecting complete, timely, and high-quality data. At the federal level, the primary functions of an HIV case surveillance system are 1) to provide accurate epidemiologic data to monitor the incidence and prevalence of HIV infection and HIV-related morbidity and mortality and 2) to use these data trends to assist in public health planning and policy.

CDC is authorized to provide federal funding to states and territories through surveillance cooperative agreements to achieve the goals of the national HIV surveillance program and to assist states in developing their own surveillance programs in accordance with state and local laws and practices. The HIV Incidence and Case Surveillance Branch (HICSB) of the Division of HIV/AIDS Prevention (DHAP), [National Center for HIV/AIDS Viral Hepatitis, STD, and TB Prevention](#), CDC, is responsible for national HIV surveillance. In addition to financial assistance, HICSB provides technical assistance to funded areas to ensure that HIV surveillance systems are comprehensive, timely, accurate, and up-to-date as the HIV epidemic evolves.

DHAP maintains a password-protected website called SharePoint for posting the latest versions of technical guidance volumes, case report forms, and other information for state and local HIV surveillance programs. To request a SharePoint password, or for technical questions about access to the site, send an email to the SharePoint helpdesk at dhapsharepointhelp@cdc.gov. HIV surveillance programs also can contact their CDC epidemiology consultant to discuss updates or changes to surveillance procedures, documents, and technical guidance.

CHANGES TO HIV AND AIDS REPORTING

AIDS reporting began at the national level in 1981 to help monitor the scope and impact of the HIV/AIDS epidemic. After the Food and Drug Administration approved the first HIV-antibody test in 1985, several states expanded their AIDS surveillance systems to include surveillance for HIV infection.

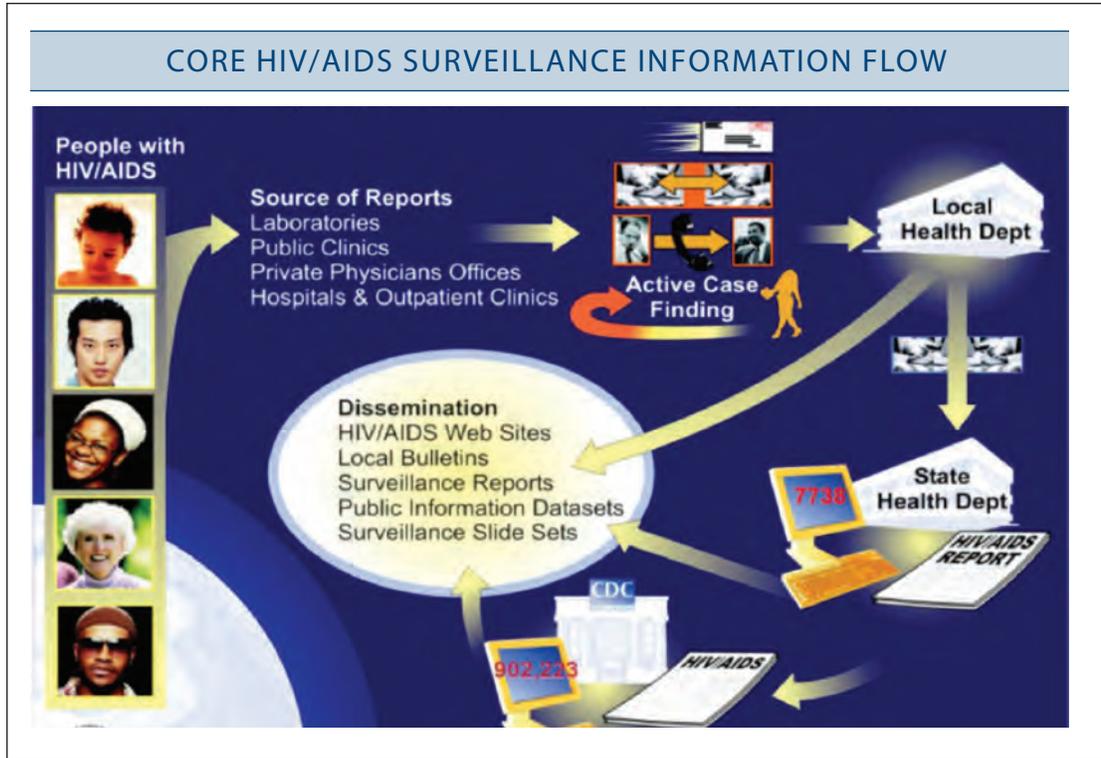
Associated with widespread use of [highly active antiretroviral therapies \(HAART\)](#) that began in the mid-1990s, the progression of HIV infection to AIDS has dramatically slowed among treated persons, and an increasing number of persons with HIV infection are living longer and staying healthier. Although surveillance for late-stage HIV disease remains important because it provides information about populations for whom medical treatment is not accessed or has not succeeded, reliance on AIDS surveillance alone does not adequately describe the effects of HIV disease in the population or current trends in the epidemic. Over time, jurisdictions adopted HIV reporting in various forms (including coded identifiers and name-to-code systems), which complicated comparison of trend data. As of April 2008, all 50 states, the District of Columbia, the Commonwealth of Puerto Rico, and the U.S. Territories conduct integrated public health surveillance for HIV infection, including Stage 3 (AIDS) by using confidential name-based reporting.

An integrated HIV surveillance system, with confidential name-based reporting for the entire spectrum of HIV disease (including Stage 3 [AIDS]), allows for better collection of multiple key events during the case history of a person infected with HIV. In addition, a national, integrated HIV surveillance system is better able to monitor the evolving epidemic and to provide useful data about HIV-infected populations to enhance local, state, and federal efforts to prevent HIV transmission, improve allocation of resources for treatment services, and assist in evaluating the impact of public health interventions.

For HIV surveillance data to be comparable and valuable on a national level, all participating project areas need to collect data with a high level of accuracy and consistency. The purposes of these policies and procedures are to address the importance of maintaining a standardized framework for data collection across all surveillance project areas, to delineate the required components of an effective surveillance system, and to suggest methods and techniques designed to optimize productivity.

PRACTICES AND STANDARDS

CDC and CSTE continue to recommend that all states and territories require reporting of the earliest diagnosis of HIV infection (excluding results of anonymous tests), the earliest diagnosis of HIV infection, Stage 3 (AIDS) in persons of all ages, deaths among persons with HIV infection, and all cases of perinatal HIV exposure. Recommendations represent guidance for best public health practices on the basis of scientific data. Because no single set of policies and procedures can address all of the diversity among, and local needs of, individual state and local surveillance systems, state and local programs should develop their own policies and procedures in accordance with the [Technical Guidance for HIV Surveillance Programs](#), but tailored to their specific situations.



Timeline of surveillance for AIDS and HIV Infection

- 1981** | First report published in CDC's *Morbidity and Mortality Weekly Report (MMWR)* of an immunosuppressive disease condition among gay men in Los Angeles; CDC begins collecting data on cases of unexplained immunosuppression among previously healthy persons.
- 1982** | The term "AIDS" (acquired immune deficiency syndrome) is used for the first time; CDC develops first AIDS case definition (on the basis of presence of disease conditions associated with severe immune deficiency without other known cause).
- 1983** | Researchers identify HIV (human immunodeficiency virus).
- 1985** | The Food and Drug Administration licenses the first HIV-antibody diagnostic blood test; some jurisdictions begin collecting public health surveillance data from persons with a positive HIV test result but without AIDS indicator conditions.
- 1993** | AIDS case definition expanded to include persons with a CD4 count <200 cells/ μ L or $<14\%$ of total lymphocytes ("immunological AIDS"); this expansion creates a large increase in the number of reported AIDS cases in the United States.
- mid 1990s** | First large-scale release of highly active antiretroviral therapies (HAART); for many patients these drugs allow effective suppression of HIV replication and delay advancement of HIV disease.
- 1998** | After steep declines in the number of reported AIDS cases (1994–1997) and deaths resulting from AIDS (1995–1997), these national surveillance indicators show a general leveling off/slow decline through 2009 (latest year of available data)
- 1999** | Revision incorporates HIV infection and AIDS into a single surveillance case definition.
- 2008** | Revised case definition requires laboratory confirmation of HIV infection for inclusion as a case; HIV infection cases are classified on the basis of CD4 count, with AIDS defined as "HIV Infection, Stage 3 (AIDS)."
- 2008** | All 50 states, District of Columbia, and five U.S. territories conduct integrated name-based public health surveillance for HIV infection.

Sources of Material for Training Manual

Material in this manual was adapted primarily from existing published HIV surveillance materials. The manual structure and text were adapted from the “Florida HIV Surveillance Training Manual” developed by the Florida Department of Health.

Centers for Disease Control and Prevention and Council of State and Territorial Epidemiologists. [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](http://www2a.cdc.gov/hicsb/) (<http://www2a.cdc.gov/hicsb/>).

Centers for Disease Control and Prevention and Council of State and Territorial Epidemiologists. [Technical Guidance for HIV Surveillance Programs, Volume II: Data Collection Resources and Reporting](http://www2a.cdc.gov/hicsb/) (<http://www2a.cdc.gov/hicsb/>).

Centers for Disease Control and Prevention and Council of State and Territorial Epidemiologists. [Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs: Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action](http://www.cdc.gov/hiv/resources/guidelines/security_confidentiality_hiv.htm) (http://www.cdc.gov/hiv/resources/guidelines/security_confidentiality_hiv.htm).

Centers for Disease Control and Prevention. *Introduction to eHARS, the HIV/AIDS Reporting System. User Guide/Student Manual.v3.2.0.0*, 08/2011. (Direct questions about changes to either the eHARS software or the Introduction to eHARS manual to NCHHSTP Informatics Customer Support at 1-877-659-7725 or NCHHSTPInformatics@cdc.gov)

Centers for Disease Control and Prevention. [Revised Surveillance Case Definitions for HIV Infection Among Adults, Adolescents, and Children Aged <18 Months and for HIV infection and AIDS Among Children Aged 18 Months to <13 Years—United States, 2008](http://www.cdc.gov/mmwr/rr/rr10rr08.htm). MMWR 2008;57(No.RR-10)

Teutsch SM, Churchill RE, eds. *Principles and Practice of Public Health Surveillance*. New York, NY: Oxford University Press; 1994

Centers for Disease Control and Prevention. Principles of Epidemiology in Public Health Practice (on-line training course offered through CDC. http://www.cdc.gov/osels/scientific_edu/SS1978/).

Centers for Disease Control and Prevention. HIV publications link: www.cdc.gov/hiv/resources/index.htm

Council of State and Territorial Epidemiologists, HIV-related links: www.cste.org



MODULE ONE

HIV Case Definition and the Human Immune System

OBJECTIVES:

1. Explain the HIV case definition.
2. Explain the mechanism of action of HIV and its effect on the defenses of the human immune system.
3. Provide information about the immune system's components and function.
4. Explain the different types of HIV tests: antibody tests, antigen tests, viral load tests.
5. Demonstrate the clinical manifestations of HIV disease.
6. Explain AIDS-defining conditions and opportunistic infections.
7. Provide sources of information about antiretroviral drugs used in managing HIV disease.

Appendix A: 2008 Surveillance Case Definition for HIV Infection

Appendix B: AIDS-Defining Conditions Diagnosis Criteria

HIV Case Definition

Since the illness that came to be known as AIDS was first reported in 1981, the surveillance case definitions for AIDS and HIV infection have undergone several revisions in response to diagnostic and therapeutic advances. The definitions also have been revised to improve standardization and comparability of surveillance data on all stages of disease. The surveillance case definition is intended for public health surveillance purposes only and not as a guide for clinical diagnosis or treatment. The most current surveillance case definition was implemented in 2008 (*Revised Surveillance Case Definitions for HIV Infection Among Adults, Adolescents, and Children Aged <18 Months and for HIV Infection and AIDS Among Children Aged 18 Months to <13 Years —United States, 2008*)¹ ([Appendix A](#) at the end of this module).

The major change in the revised surveillance case definition is the requirement for laboratory-confirmed evidence of HIV infection in adults and adolescents and in children aged 18 months–12 years. The revised definition also highlights the central role of the CD4 T-lymphocyte (T-cell) counts and percentages (objective measures of immunosuppression) in staging HIV disease.

Cases of HIV infection are now classified according to CD4 count and increase in disease severity from “HIV Infection, Stage 1” to “HIV Infection, Stage 2” to “HIV Infection, Stage 3 (AIDS)”; an unknown disease stage (no CD4 information) is also included. Cases still can be classified as “HIV Infection, Stage 3 (AIDS)” on the basis of diagnosis of a recognized AIDS-defining condition regardless of the CD4 count or percentage; however, AIDS-defining conditions have been less common since the advent of highly active antiretroviral therapy (HAART) during the mid-1990s. HIV disease progression is classified from less severe to more severe; after a case is classified into a surveillance severity state, it cannot be reclassified into a less severe stage. [Table 1.1](#) further describes the stages of HIV infection.

¹Public health case definitions are determined through consultation with CSTE. Members of CSTE propose position statements on topics of interest; those proposals are presented to committees appropriate for the subject matter and drafted. These draft position statements are posted on the CSTE website, then presented for discussion at the CSTE Annual Conference. After appropriate input and revision, the position statements are voted on by the CSTE membership. Information about CSTE position statements is available at www.cste.org.

Table 1.1 Surveillance case definition for HIV infection among adults and adolescents (≥13 years)—United States, 2008

STAGE	LABORATORY EVIDENCE*	CLINICAL EVIDENCE
Stage 1	Laboratory confirmation of HIV infection <i>and</i> CD4+ T-lymphocyte count ≥500 cells/μL <i>or</i> CD4+ T lymphocyte percentage of ≥29%	None required (but no AIDS-defining condition)
Stage 2	Laboratory confirmation of HIV infection <i>and</i> CD4+ T-lymphocyte count 200–499 cells/μL <i>or</i> CD4+ T lymphocyte percentage of 14%–28%	None required (but no AIDS-defining condition)
Stage 3 (AIDS)	Laboratory confirmation of HIV infection <i>and</i> CD4+ T-lymphocyte count <200 cells/μL <i>or</i> CD4+ T lymphocyte percentage of <14% [†]	<i>or</i> Documentation of an AIDS-defining condition (With laboratory confirmation of HIV infection) [†]
Stage unknown [§]	Laboratory confirmation of HIV infection <i>and</i> No information about CD4+ T-lymphocyte count or percentage	<i>and</i> No information about presence of AIDS-defining conditions

*The CD4+ T-lymphocyte percentage is the percentage of total lymphocytes. If the CD4+ T-lymphocyte count and percentage do not correspond to the same HIV infection stage, select the more severe stage.

[†]Documentation of an AIDS-defining condition (Module 1, page 35) supersedes a CD4+ T-lymphocyte count ≥200 cells/μL and CD4+ T-lymphocyte percentage of total lymphocytes of ≥14%. Definitive diagnostic methods for these conditions are available in Appendix C of the 1993 revised HIV classification system and the expanded AIDS case definition ([CDC. 1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults](#), MMWR 1992;41 (No. RR-17).

[§]Although cases with no information about CD4+ T-lymphocyte count or percentage or about AIDS-defining conditions can be classified as stage unknown, every effort should be made to report CD4+ T-lymphocyte count or percentage and AIDS-defining conditions at diagnosis. Additional CD4+ T-lymphocyte counts or percentages and any AIDS-defining conditions identified can be reported as recommended ([Laboratory reporting of clinical test results indicative of HIV infection: new standards for a new era of surveillance and prevention](#) [CSTE Position Statement 04-ID-07]).

Source: CDC. [Revised Surveillance Case Definitions for HIV Infection Among Adults, Adolescents, and Children Aged <18 Months and for HIV Infection and AIDS Among Children Aged 18 Months to <13 Years—United States, 2008](#). MMWR 2008;57 (No. RR-10).

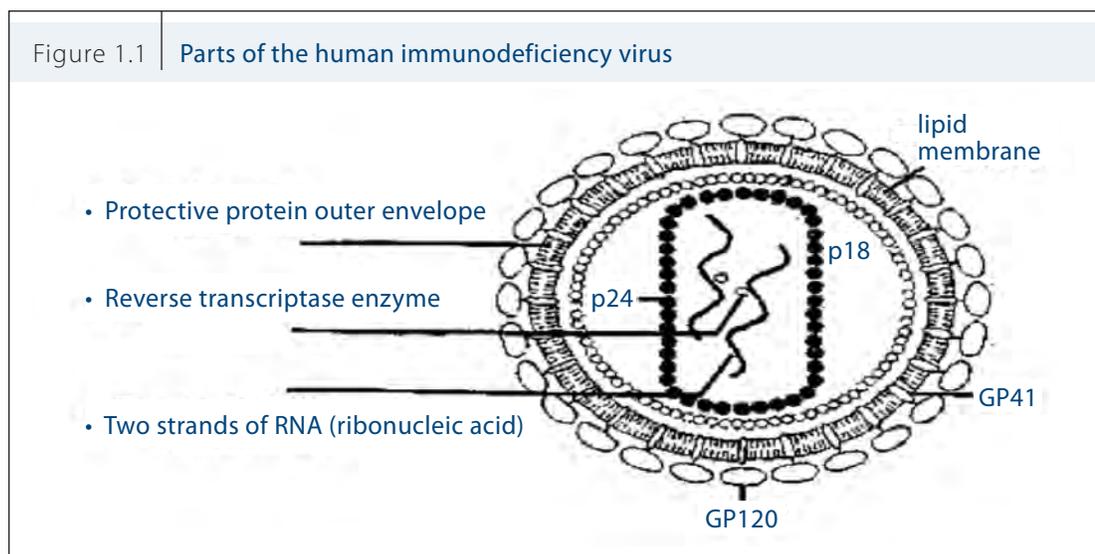
HIV Mechanism of Action



Information in this section is intended for staff new to HIV surveillance or without clinical backgrounds.

HIV is one of a number of retroviruses.² The genetic information of the virus is carried in two single strands of RNA (ribonucleic acid). For the retrovirus to take over a cell and produce more viruses, it must change its RNA to DNA (deoxyribonucleic acid). A unique enzyme, reverse transcriptase, allows the retrovirus to make this conversion.

HIV, comprising three main parts (Figure 1.1), is expert at evading the immune system's defenses. It can enter the body hidden inside the cells of infected body fluids (including blood, semen, and vaginal secretions). Once inside the body, HIV binds specifically to cells bearing a particular surface marker called CD4+ (hereafter referred to as CD4). CD4 cells are part of the human immune system responsible for fighting infections; the cells are also known as T lymphocytes because they mature in the thymus gland. HIV infects and leads to the destruction of cells with CD4 surface markers (found on all CD4 T lymphocytes, some B lymphocytes and about half of all macrophages), as well as cells in the gastrointestinal and central nervous systems. CD4 lymphocytes also are called helper lymphocytes and in the laboratory are measured by a flow cytometer. The level of CD4 lymphocytes is used to divide HIV disease into various stages.



HIV-2 is closely related to HIV-1, the common form of HIV. Most cases of HIV-2 infection occur in West Africa, with relatively few cases reported from the United States. HIV-1 and HIV-2 both damage the immune system and make the body more vulnerable to opportunistic infection (OIs). HIV-2 infection has a longer asymptomatic period and appears to produce a less virulent course of disease.

²Some retroviruses can live in their hosts for years without causing any sign of illness. Retrovirus infections last for life. Outside the body, they are inactivated when exposed to heat, alcohol, most common disinfectants, and usually by desiccation. They have high rates of mutation and tend to evolve quickly into new strains.

Relative concentration of HIV in infected cells with CD4 markers

The highest concentration of HIV in infected cells with CD4 markers occurs in blood and semen. An intermediate concentration of HIV occurs in vaginal secretions, breast milk, tears, and oral fluid. The lowest concentration of HIV in infected cells with CD4 markers occurs in urine, sweat, and feces.

HIV binds to the membrane of the host cell at the site of envelope glycoprotein (gp120) and cytokine receptor sites, then passes through to the glycoprotein (gp41) embedding itself into the CD4 cell membrane (Figure 1.2). The viral coat opens, and the RNA enters the cell. Using the reverse transcriptase enzyme, the RNA makes a DNA copy of itself. This “new” DNA integrates the cell’s DNA, creating a provirus. This process of viral transcription confuses the cell. It becomes no longer a pure cell but part virus, part cell—and therefore the cell acts abnormally. The HIV-infected host cell produces “new” virus particles, which travel back to the cell membrane and bud out to find other cells to infect.

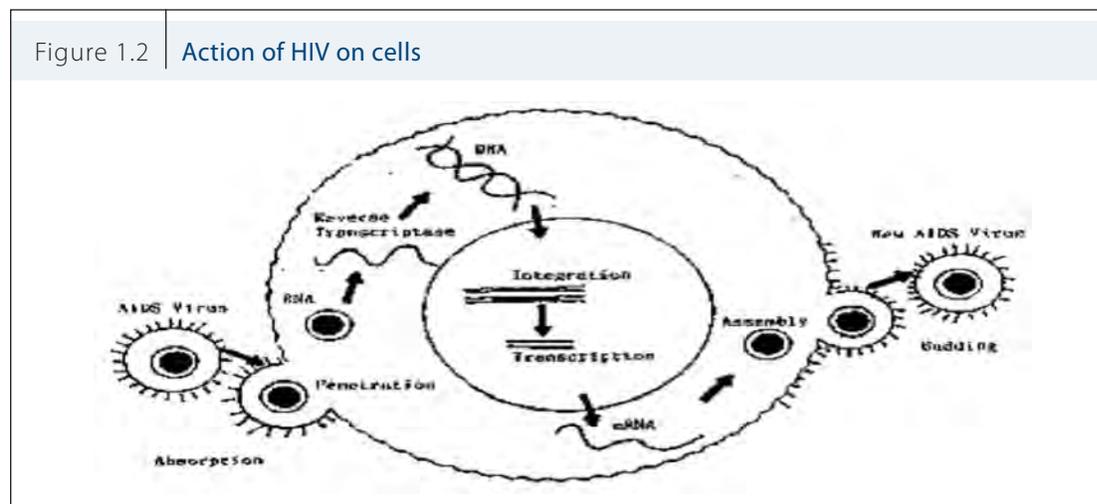
Replication of the virus, which has been calculated at 10 billion copies per day, gradually exceeds the capacity of the lymphatic system to replace CD4 cells, which the virus destroys. Depletion of CD4 helper cells has the greatest impact on the immune system. A CD4 T-lymphocyte count of 800–1500 cells/ μL is considered normal for a person with a healthy immune system. As CD4 counts begin to fall to <500 cells/ μL , the infected person become vulnerable to a variety of OIs.

Immunosuppression is documented when

- Absolute CD4 T-lymphocyte count is <500 cells/ μL ;
- Viral load testing detects HIV in cells;
- The percentage of CD4 cells among total lymphocytes is $<29\%$; or
- The CD4:CD8 cell ratio is <1 .

Many people with HIV infection also develop profound deficiencies in the complete blood count. These include red blood cell deficiencies (causing anemia), white blood cell deficiencies (causing leukopenia), platelet deficiencies (causing thrombocytopenia), and total blood component deficiencies (causing pancytopenia).

HIV-infected persons can be symptomatic from the direct effects of the virus. However, they are most susceptible to illness and death from a host of OIs and cancers that invade and weaken the body ([Appendix B](#)).



The Immune System: Basic Functions and Structure



Information in this section is intended for staff new to HIV surveillance or without clinical backgrounds.

The human immune system is a sophisticated network of organs and cells that protects us from infectious organisms, environmental toxins, and cell mutations. HIV, a retrovirus that has a special affinity for certain types of cells, directly and catastrophically affects the immune system. Once HIV enters the bloodstream, it launches an offensive against the cells responsible for activating the body's defense mechanisms.

Knowledge about the immune system has rapidly increased in recent years, partly because of intense efforts in the fields of cancer and AIDS research. Understanding the impact of HIV infection on a person requires knowledge of basic immunology.

The immune system, a complex network of cells, tissues, and organs, mobilizes the various components of the body's defense system against attack from pathogens (disease-producing organisms). The immune system must be able to

- Distinguish “self” from “nonself” (pathogens)
- Develop a defense against pathogens
- Adapt defenses against specific invading pathogens
- “Remember” a specific response to a particular pathogen

Immune system responses fall into two basic categories: nonspecific defense mechanisms and specific defense mechanisms.

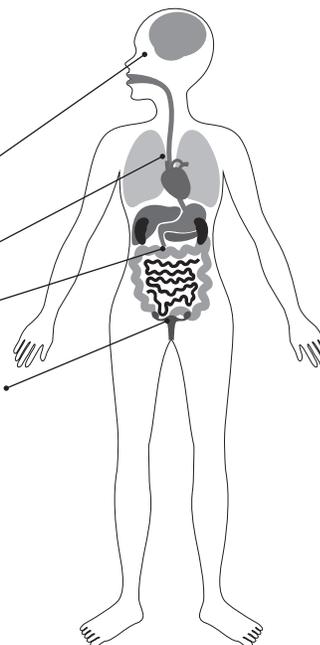
NONSPECIFIC DEFENSE MECHANISMS

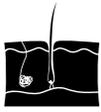
The purpose of the nonspecific defense mechanisms—which comprise a variety of organs and cells throughout the body—is to prevent or hinder microorganisms from entering the body or to destroy microorganisms that do gain entry. The most familiar and obvious of nonspecific defense mechanisms is the external defense system. Another nonspecific defense is phagocytosis (the process by which cells take in and digest antigens [foreign proteins]).

External Nonspecific Defense System

The external defense system consists of four mechanisms:

- Skin and Eyes
- Respiratory tract
- Digestive tract
- Urinary/Reproductive tract





The skin is a first line of defense against pathogens. Although seemingly thin, intact skin is a highly effective barrier. Excretions and secretions—such as sweat—aid in repelling bacteria and fungi.



The small hairs in the lining of the nose similarly filter and prevent larger particles from entering the respiratory tract.



Mucous membranes of the respiratory and digestive tracts trap and remove many foreign particles inhaled or ingested.

The eyes are continually bathed in tears, which wash out large foreign particles and carry away the smaller particles through the tear ducts.



The digestive tract includes strongly acidic stomach fluid that can destroy most microorganisms.

The acidity of the fluids in our urinary and reproductive tracts also provides an effective barrier against some types of bacteria.

Internal Nonspecific Defense System

Phagocytosis

Phagocytes are white blood cells and scavenger cells that are the first “scouts” of the immune system to encounter, engulf, and digest antigens. Monocytes are phagocytes that circulate throughout the bloodstream. Macrophages are phagocytes in the tissues.

Monocytes and macrophages can ingest and destroy a variety of pathogens and cellular debris. A pathogen entering the body activates both. Once an infection is under control, the macrophages and monocytes carry away the particles of the destroyed invaders.

Phagocytes are involved in both the specific and nonspecific immune responses, which often work together to activate the body’s defenses. When nonspecific responses effectively eliminate the pathogen, the specific immune defenses are not activated.

Blood Components

Whole blood consists of the liquid plasma containing the formed elements. The formed elements are

- Erythrocytes (red blood cells)
- Leukocytes (white blood cells)
 - ▶ Granular leukocytes
 - ▷ Neutrophils
 - ▷ Eosinophils
 - ▷ Basophils
 - ▶ Nongranular leukocytes
 - ▷ Lymphocytes
 - ◉ Macrophages
 - ◉ T lymphocytes
 - ◉ B lymphocytes
 - ▷ Monocytes
- Thrombocytes (platelets)

Lymphatic System

The lymphatic system is a network of vessels, lymph nodes, and organs that create, transport, and filter leukocytes. The organs of the lymphatic system are subdivided into two categories:

- **Primary**
 - ▶ Thymus
 - ▶ Bone marrow
- **Secondary**
 - ▶ Tonsils
 - ▶ Lymph nodes
 - ▶ Spleen
 - ▶ Appendix

The primary lymphatic organs produce leukocytes, which fight disease. However, these specialized leukocytes do not begin to defend the body until they reach our secondary organs, where they first contact pathogens.

The thymus is a pyramid-shaped organ located deep beneath the breastbone. It reaches maximum size during early childhood, and then gradually shrinks as we age. The thymus produces specialized cells that play a key role in the body's immune defenses. Bone marrow, the soft material in the hollow interior of the long bones in our arms and legs, is a crucial element of the immune defenses. The immune system begins in the bone marrow before birth, when erythrocytes and leukocytes begin early development. Approximately 99% of blood cells are erythrocytes; <1% are leukocytes.

Lymphocytes

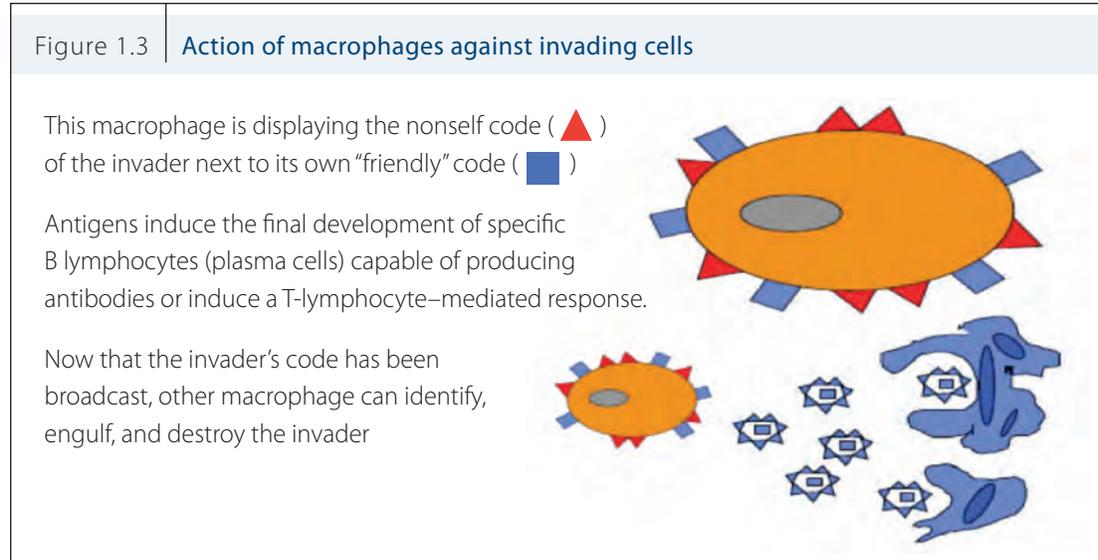
Lymphocytes are a type of leukocyte that can move in and out of the lymphatic and blood systems. They circulate throughout blood and tissues to locate, trap, and destroy antigens. Approximately 25%–30% of total leukocytes are lymphocytes.

Some lymphocytes mature into B lymphocytes (B cells) in the bone marrow; others migrate to the thymus gland. Most T lymphocytes are produced before birth by the thymus. The remaining cells develop during the first 3–5 years of life. By age 5 years, the body's natural immune system is developed. It peaks by our mid-20s and becomes less efficient with age. Three main types of lymphocytes are involved in the immune system's response to antigens:

- **Macrophages** are produced in the bone marrow.
- **T lymphocytes** mature in the thymus.
- **B lymphocytes** mature in the bone marrow.

The secondary lymphatic organs are the information network and the transportation structure for the body's defense forces. A network of vessels that transport lymphatic fluids from tissues connects pea-shaped lymph nodes located throughout the body. In the secondary organs, the primarily unspecialized leukocytes receive their final programming and acquire the specialized functions necessary to defend against pathogens.

After intercepting the invader, the macrophages copy the identifying structural codes of the invading cell and display this code on the surface of their membranes. The macrophages then move about and present themselves to T lymphocytes, stimulating a specific immune response (Figure 1.3).



SPECIFIC IMMUNE MECHANISMS

The specific immune responses involve two complex processes: the cell-mediated and humoral immune responses. They are considered specific because they can identify, remember, and respond to unique patterns of antigens. Each type of lymphocyte and antibody responds only to one specific pattern.

- **Cell-mediated immunity** involves the interaction between antigens and specialized T lymphocytes.
- **Humoral immunity** involves the interaction between antigens and the antibodies produced by B lymphocytes.

Cell-Mediated Immunity

T lymphocytes circulate throughout the body. They secrete their own chemical intensification alarm (chemokines) to directly activate or inactivate other leukocytes.

T lymphocytes perform four basic functions:

- **Helper T lymphocytes** (T4 or CD4 cells) sound a chemical alarm that triggers T and B lymphocytes into action.
- **Killer T lymphocytes** (cytotoxic T lymphocytes) directly kill infected or cancerous cells by puncturing the membranes.
- **Suppressor T lymphocytes** (T8 or CD8 cells) turn off the immune response once the infection is brought under control.
- **Inducer T lymphocytes** induce the maturation of T lymphocytes and other immune system cells.

In healthy persons, approximately 70% of circulating lymphocytes are T lymphocytes. T lymphocytes help provide specific immunity against fungi, viruses, parasites, and a few bacteria. T lymphocytes also play a role in destroying cancer cells and in transplant rejection.

Humoral Immunity

B lymphocytes grow rapidly and manufacture millions of antibodies when alerted by the chemical alarm of T lymphocytes. Often an antigen is carried to a lymph node, where it stimulates some of the B lymphocytes to divide and differentiate into plasma cells that produce antibodies (humoral immunity).

Only a tiny fraction of B lymphocytes will respond to any given antigen. The response time of antibodies to an antigen depends on whether they have been previously exposed to that specific antigen. On first contact with an antigen, the body may take from several hours to days before antibodies respond to the invader. Subsequent exposures usually result in a rapid and effective response because of the B lymphocytes' ability to "remember" that specific antigen.

An antibody (immunoglobulin [Ig]) is a specialized protein capable of chemically combining with the specific antigen (i.e., to the bacteria or virus) that stimulated antibody production. A lock-and-key analogy is often used to describe the relationship: an antibody cannot enter an infected host cell, but it can mark or identify the invading cells as foreign and to guide complement components to kill the invader directly.

An Ig exhibit two fundamental structural differences. Variation in the antigen-combining site, or *variable region*, and outside the antigen combining site, or *constant region*, correlate with the different effector functions mediated by antibodies. Through structural variation, a person's immune system might produce >10 million antibody responses. Igs are divided into five major classes, each distinguished by certain effector functions and structural features (*Kuby, J. 1997. Immunology. W.H. Freeman and Company, New York.*).

- **IgG** comprises about 70% of Ig in the tissues and is the only Ig able to cross the placenta; it is the prime mediator of secondary immune response.
- **IgA** circulates in the bloodstream, killing bacteria.
- **IgM** is concentrated in body fluids, especially the bloodstream; it is the earliest Ig to appear after antigen challenge.
- **IgE** is involved in allergic reactions.
- **IgD** might be involved in the differentiation of B lymphocytes, but little is known about its exact function.

HIV Laboratory Testing Procedures

Three basic types of tests are currently available or under development to test for HIV:

- Antibody tests
- Antigen tests
- Viral load tests

HIV ANTIBODY TESTS

An antibody test indirectly detects the virus by measuring the extent to which the body's immune system has mobilized a response against HIV. The appearance of detectable antibodies to HIV is generally believed to occur 2 weeks to 3 months after the initial infection (and in rare cases up to 6 months after infection).

ELISA

An enzyme-linked immunosorbent assay (ELISA) or enzyme immunoassay (EIA) detects HIV antibodies, which the body starts producing 2–12 weeks after HIV exposure. These tests received FDA approval for screening the U.S. blood supply in 1985 and remain the most widely used diagnostic test for HIV antibody screening. The EIA detects specific serum antibodies (against gp120, gp41, p66, and p24 proteins) that bind to HIV antigens grown in the laboratory. Current HIV antibody tests can detect antibodies as early as 2 weeks after exposure. Current HIV antibody tests are often referred to as second generation (detecting IgG), third generation (detecting IgM and IgG), and fourth generation (detecting both HIV antibody and the p24 antigen, which comes directly from HIV). All positive HIV antibody test results should be

confirmed with a Western blot, a rapid test of a different brand than the initial test, or an HIV viral load test. Some HIV antibody tests will not detect HIV-2 and some less common strains of HIV-1. If HIV-2 infection is suspected, a test suitable to detect HIV-2 should be used for testing.

These tests can use any of three body fluids to detect antibodies to HIV:

- **Blood:** Drawn from a vein, blood is the most common sample used for detecting HIV antibodies. A test that returns a positive result is confirmed with a follow-up test, such as the Western blot, before the client is informed about the results (see Antibody Confirmation Tests, below).
- **Oral fluid:** This test uses oral fluid (not saliva) to detect HIV antibodies in cells found in the mouth along the cheeks and gums. Its [reliability](#) is similar to that of the blood test. The fluid is absorbed by a small device (about half the size of a toothbrush), which is held between the cheek and gums for a few minutes and then sent to a lab for processing. The use of oral fluid for this test does not imply transmission of HIV through oral fluids and saliva. As with all ELISAs, oral tests detect antibodies, not HIV itself. OraSure is the only oral fluid test approved by FDA in the United States. The oral test might have slightly lower [sensitivity](#) than blood-based tests (i.e., oral fluid tests may be less likely to correctly identify HIV when it is actually present; see [Module 4](#) for definition of epidemiologic terms.)
- **Urine:** Some ELISAs use a urine sample to detect HIV antibodies (again, not the virus itself) in urine. Urine tests are somewhat less accurate than blood and oral fluid tests. Positive results must be confirmed with a Western blot.

Results from most ELISAs and confirmatory Western blot tests are usually available within 2–14 days.

Rapid HIV Test

Using technology similar to that of an ELISA, a rapid test produces results in approximately 20 minutes. Rapid tests are available for two types of samples:

- **Blood:** A clinician pricks the client's finger with a small needle and takes a few drops of blood.
- **Oral fluid:** The procedure is similar to the oral fluid test described above.

Rapid tests provide one of two possible outcomes: *negative* (meaning the test does not detect any HIV antibodies) or *preliminary positive*. With a preliminary positive result, the rapid HIV test shows an HIV-positive result, but as with the ELISA, that result must be confirmed with a second test, such as a Western blot or a second rapid test from a different manufacturer. If the result is preliminary positive, the provider will discuss the meaning of the result with the client, including the importance of practicing safe sex and taking other precautions until the confirmation test results are available, and will schedule a time for the client to receive confirmatory results.

Several other rapid HIV tests being used outside the United States are likely to be considered for FDA approval. Many of these tests require a single step; can be performed on whole blood, serum, plasma, oral fluid, or finger-stick blood samples; and provide results within minutes. These tests also have a high sensitivity and specificity. As these tests become available, implementation of strategies might be possible, such as [one recommended by the World Health Organization](#), whereby specific combinations of different rapid tests might immediately confirm reactive rapid HIV test results.

HIV Antibody Confirmation Tests

The ELISA is designed to be highly sensitive, that is, to miss as few HIV infections as possible. The downside of the high sensitivity is that the ELISA can produce a small number of false-positive results, which usually are caused by antibodies to other diseases that the ELISA mistakenly recognizes as antibodies to HIV. For

this reason, positive ELISA and rapid antibody test results should be supplemented with a confirmatory test, such as a Western blot, which is less sensitive but more specific (that is, it has a lower rate of yielding a false-positive results). Sometimes a rapid antibody test is confirmed with a second rapid test from a different manufacturer.

The Western blot is the most common test used to confirm positive results from an ELISA or rapid HIV test. It generally is used only as a confirmatory test because it is difficult to perform and requires highly technical skills. Its advantage, however, is that it is less likely to give a false-positive result because it can more effectively distinguish HIV antibodies from other antibodies. However, the Western blot can yield inconclusive results in some samples.

The *indirect fluorescent antibody* (IFA) test also detects HIV antibodies. As with the Western blot, the IFA is used to confirm the results of an ELISA. However, it is more expensive than a Western blot test and less likely to be conducted as a confirmatory test.

HIV ANTIGEN TESTS

A window period exists from time of HIV exposure/infection to time an antibody test result will be positive. Testing for suspected early infections during the window period can be performed by using FDA-approved fourth-generation HIV antibody or antigen tests, which detect both HIV antibody and the p24 antigen. (Tests for HIV viral load also can detect early infection—see following section). Fourth-generation tests have the advantage of detecting early HIV infection before antibodies develop and before the antibodies indicative of chronic infection are evident.

Detecting early infection enables people to know sooner and more accurately whether they have HIV infection. Early detection also has the indirect benefit of preventing new infections because people who are aware of their HIV-positive status usually take precautions to avoid infecting their intimate partners.

MEASUREMENTS OF HIV VIRAL LOAD

Beginning on the day of infection, the body produces an average of 10 billion new copies of HIV each day and about 2 billion CD4 cells to fight the virus. Tests to measure the amount of HIV in the blood are called viral load, PCR (polymerase chain reaction), or RNA tests. [In the public health community, a test to measure HIV load is called HIV NAAT (nucleic acid amplification testing). The NAAT test is normally conducted to screen for HIV in donated blood]. The viral load test usually is used by clinicians to determine whether antiretroviral medications are suppressing viral replication in HIV-infected persons taking medication. A low level indicates the disease is stable, and an increased level might mean treatment should be changed. Viral load testing also can show whether a new antiviral drug is reducing the amount of virus in the blood.

Unlike HIV antibody tests, viral load tests detect the genetic material (RNA) of the virus rather than antibodies to HIV. HIV load testing is also used to confirm infection in babies born to HIV-infected mothers because antibody testing very early in life does not accurately determine whether the infant is HIV infected.

People concerned that a recent sexual or other exposure has put them at risk for HIV infection or who have symptoms that they suspect could be caused by acute HIV infection should go to a doctor, public health clinic, or an HIV testing site to talk with a clinician. The health-care provider can determine the

risk for HIV on the basis of details of the incident. If the test is available and, in the clinician's opinion, appropriate, a viral load test or fourth-generation HIV test can be performed to assess for very early HIV infection, in addition to an HIV antibody test. These tests to detect HIV in the window period are done on a blood sample drawn from a vein, and results can take from a few days to 2 weeks.

Some laboratories provide pooled viral load testing, a technique allowing blood that is HIV antibody negative to be tested for HIV, thus indicating early infection, without testing each individual sample. However, pooled viral load testing is not widely available.

For several reasons, viral load tests are not the standard even though they can detect HIV much earlier than antibody tests. First, in most cases, antibody tests are sufficient to detect HIV. In addition, viral load tests are expensive and so sensitive that a false-positive result is not unusual. However, the availability of the fourth-generation HIV antibody or antigen test might make simultaneous testing for very early HIV infection and chronic HIV infection much more feasible.

Technologic advances in HIV testing occur rapidly, and HIV surveillance staff are encouraged to keep abreast of advances in the field. Periodic reviews of appropriate websites, such as CDC's [HIV Testing information](#) and the Association of Public Health Laboratories' [2009 update on HIV testing algorithms](#), are recommended to learn of the latest advances in HIV testing technology.

Clinical Manifestations of HIV Disease

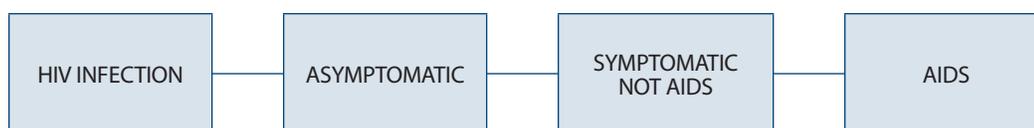


Information in this section is intended for staff new to HIV surveillance or without clinical backgrounds.

CLINICAL PROGRESSION

The CDC classification system presents a clinical view of HIV infection as a continuum of disease. After an initial acute phase of mild flu-like symptoms, most people are asymptomatic for a few months to several years. However, with the advent of intervention therapies, persons living with even advanced HIV disease can live asymptotically for many years.

Traditional Spectrum of Clinical Progression In HIV Infection



As the immune system begins to deteriorate, the early symptoms and signs of HIV infection begin. Prolonged unexplained diarrhea, fever, or sore throat are often among the first symptoms. Persons infected with HIV may initially experience enlarged spleens, seborrheic eczema, folliculitis, and herpes zoster.

The infection can progress to persistent generalized lymphadenopathy in which enlarged, firm, mostly nontender lymph nodes are palpable (>1 cm in diameter) in at least two different sites for at least 3 months without any other explanation. Persistent generalized lymphadenopathy is considered a relatively benign stage of early disease during which a person is HIV symptomatic and without any evidence of OIs or tumors. The number of CD4 cells and the ratio of CD4 to CD8 lymphocytes usually decrease.

The status of an HIV-infected person meets the [HIV Infection, Stage 3 \(AIDS\) case definition](#) when it includes at least one HIV-related OI with no other known underlying cause or the CD4 lymphocyte count is <200/ μ L or the CD4 percentage of total lymphocytes is <14%.

Many clinical manifestations are associated with HIV infection ([Table 1.2](#)). Most do not directly result from HIV infection itself but rather result from the consequence of the virus' impact on the immune system. HIV affects the body in a variety of ways, primarily through OIs, cancers, and wasting syndrome.

OPPORTUNISTIC INFECTIONS

A person with a normal immune system has a natural resistance to microorganisms. Only when the immune system is suppressed do various viruses, fungi, protozoa, and bacteria seize the opportunity to cause infection.

Four major categories of organisms cause infection.



Viruses are microorganisms that reproduce by taking over a host cell. Viruses are structurally simple. Most consist of a core RNA or DNA covered by a protein envelope. An example of a simple virus is adenovirus (which causes the common cold). Influenza is a more complex virus that frequently mutates, thereby hindering the immune system's ability to recognize and respond to future infections. Few antiviral drugs exist. Most have side effects and are toxic. Antibiotics, which work against bacteria, are not helpful against viruses. Common AIDS-defining viral OIs include cytomegalovirus (CMV) disease (other than liver, spleen, or nodes), CMV retinitis (with loss of vision), herpes simplex (chronic ulcers >1 month's duration), and progressive multifocal leukoencephalopathy.



Bacteria are one-celled organisms found throughout the body. Some are beneficial; others cause disease by producing poisons or toxins. Three basic forms of bacteria exist: spherical (coccus), rod-shaped (bacillus), and spiral shaped (spirillum). Common AIDS-defining bacterial OIs include *Mycobacterium avium* or *M. kansasii*, *M. tuberculosis*, other *Mycobacterium* species or unidentified species, and *Salmonella* septicemia, recurrent.



Fungi are plant-like organisms that lack chlorophyll and use organic matter as a source of food. Yeast, mold, and mildew are all capable of producing disease in humans. Fungal infections usually are spread through spores in the atmosphere or soil. Systemic fungal infections are often widely disseminated throughout the body in persons with AIDS. Candidiasis and cryptococcosis are the two fungi most frequently seen in HIV-infected persons. Other common AIDS-defining fungal OIs include coccidioidomycosis, histoplasmosis, and *Pneumocystis jiroveci* pneumonia.



Protozoa belong to the animal kingdom and are microscopic one-celled parasites that depend on living creatures for food. Cryptosporidiosis and toxoplasmosis of the brain are the two most common protozoal infections associated with HIV infection. Other common AIDS-defining protozoal OIs include toxoplasmosis, and PCP.

Other: In addition, the following cancers and conditions are recognized as AIDS indicator diseases: invasive cervical cancer (associated with human papilloma virus), Kaposi sarcoma (associated with a variant of the herpes virus), primary lymphoma of the brain, immunoblastic lymphoma (non-Hodgkin disease), Burkitt lymphoma, HIV encephalopathy (caused by a direct effect of HIV on brain cells), and wasting syndrome attributed to HIV.

Table 1.2 | AIDS-defining conditions

Bacterial infections (multiple or recurrent)*
Candidiasis of bronchi, trachea, or lungs
Candidiasis of esophagus [†]
Cervical cancer, invasive [‡]
Coccidioidomycosis, disseminated or extrapulmonary
Cryptococcosis, extrapulmonary
Cryptosporidiosis, chronic intestinal (>1 month's duration)
Cytomegalovirus disease (other than liver, spleen, or nodes), onset at age >1 month
Cytomegalovirus retinitis (with loss of vision) [†]
Encephalopathy, HIV related
Herpes simplex: chronic ulcers (>1 month's duration) or bronchitis, pneumonitis, or esophagitis (onset at age >1 month)
Histoplasmosis, disseminated or extrapulmonary
Isosporiasis, chronic intestinal (>1 month's duration)
Kaposi sarcoma [†]
Lymphoid interstitial pneumonia or pulmonary lymphoid hyperplasia complex** [†]
Lymphoma, Burkitt (or equivalent term)
Lymphoma, immunoblastic (or equivalent term)
Lymphoma, primary of brain
<i>Mycobacterium avium</i> complex or <i>M. kansasii</i> , disseminated or extrapulmonary [†]
<i>M. tuberculosis</i> of any site, pulmonary, ^{†§} disseminated, [†] or extrapulmonary [†]
<i>Mycobacterium</i> , other species or unidentified species, disseminated [†] or extrapulmonary [†]
<i>Pneumocystis jirovecii</i> pneumonia ^{†§}
Pneumonia, recurrent ^{†‡}
Progressive multifocal leukoencephalopathy
<i>Salmonella</i> septicemia, recurrent
Toxoplasmosis of brain, onset at age >1 month [†]
Wasting syndrome attributed to HIV

*Only among children aged <13 years.

[†]Condition that might be diagnosed presumptively.

[‡]Only among adults and adolescents aged ≥13 years.

[§]Previously *Pneumocystis carinii* pneumonia (which has been classified as a protozoa but currently is thought to be closer to a fungus).

Source: CDC. [Revised Surveillance Case Definitions for HIV Infection Among Adults, Adolescents, and children Aged <18 Months and for HIV Infection and AIDS Among Children Aged 18 Months to <13 Years—United States, 2008](#). *MMWR* 2008;57(No. RR-10).

HIV Disease Treatment and Drug Therapies

When AIDS and HIV were first recognized in the United States during the early 1980s, no effective medications were available to control the virus itself. Additionally, only a limited number of medications were available for treating the OIs associated with this new severe immune deficiency condition.

Antiretroviral therapy (ART) for the treatment of HIV infection has improved steadily since the advent of potent combination therapy in the mid-1990s. New drugs have been approved that offer new mechanisms of action; improvements in potency and activity, even against multidrug-resistant viruses; dosing convenience; and tolerability.

Because of the constant evolution of treatments for the prevention, prophylaxis, and treatment of HIV and associated OIs, ensuring inclusion of the latest list of available medications is beyond the scope of this manual. However, surveillance staff need to be familiar with the names of current medications used to treat HIV and related OIs because that information is vital for completing information about treatment coverage in surveillance areas.

The treatment guidelines for HIV disease and associated OIs will continue to evolve. Surveillance staff are encouraged to periodically review the literature for updates. Below are some websites with the latest information about treatments for HIV and OIs:

- National Institutes of Health
<http://aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-treatment-guidelines/0/>
- Centers for Disease Control and Prevention
http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5804a1.htm?s_cid=rr5804a1_e
- Community Research Initiative of New England
<http://www.crine.org/>

This website provides a link to a full-color HIV medication chart that displays the names and pictures of current classes of antiretroviral medications.

APPENDIX A:

2008 Surveillance Case Definition for HIV Infection among adults and adolescents



Information in this section is intended for staff new to HIV surveillance or without clinical backgrounds.

The information in Appendix A is specific to adults and adolescents aged ≥ 13 years. For information about surveillance case definitions for children < 13 years of age, see the [2008 Revised Surveillance Case Definition](#).

(The HIV surveillance case definition has been revised several times during the epidemic. State and local HIV surveillance staff are advised to monitor the CSTE [position statement](#) website for information about the most up-to-date HIV case definition.)

HIV Infection Case Definition

A reportable case of HIV infection must meet at least one of the following criteria:

Laboratory Criteria

a) Positive result from an HIV antibody screening test (e.g., reactive enzyme immunoassay) confirmed by a positive result from a supplemental HIV antibody test (e.g., Western blot or indirect immunofluorescence assay).

or

b) Positive result or report of a detectable quantity (i.e., within the established limits of the laboratory test) of any of the following HIV virologic (i.e., nonantibody) tests:

- HIV nucleic acid (DNA or RNA) detection test (e.g., polymerase chain reaction [PCR])
- HIV p24 antigen test, including neutralization assay
- HIV isolation (viral culture)

OR

Other Criterion (for cases that do not meet laboratory criteria)

HIV infection diagnosed by a physician or qualified medical-care provider based on the laboratory criteria and documented in a medical record*. Oral reports of prior laboratory test results are not acceptable.

* An original or copy of the laboratory report is preferred; however, in the rare instance the laboratory report is not available, a description of the laboratory report results by a physician or qualified medical-care provider documented in the medical record is acceptable for surveillance purposes. Every effort should be made to obtain a copy of the laboratory report for documentation in the medical record.

APPENDIX B:

Diagnostic Criteria for AIDS-Defining Conditions



Information in this section is intended for staff new to HIV surveillance or without clinical backgrounds.

In adults and adolescents, a reportable case of AIDS (HIV infection, stage 3) must meet the following criteria:

I. A positive HIV laboratory test (or other criterion) as listed in [Appendix A](#)

AND

II. a) CD4 count <200 cells/ μ L or CD4 T-lymphocyte percentage of <14%

OR

b) One of the following opportunistic illnesses:

(The clinical descriptions on the following pages are adapted from material provided by the New York City Department of Health and Mental Hygiene, HIV Epidemiology and Field Services Program.)

Abbreviations frequently used in Appendix B:

- CT: computed tomography
- HAART: highly active antiretroviral therapy
- MRI: magnetic resonance imaging
- OI: opportunistic infection
- PCR: polymerase chain reaction

Candidiasis of Bronchia, Trachea, or Lungs

DEFINITIVE diagnosis through

Cytologic (histologic) examination of biopsy obtained through bronchoscopy, needle biopsy, open lung biopsy, or autopsy. If the histologic result is positive, it will show clusters of budding yeast or spores and hyphae (i.e., the interwoven thread-like projections that make up the mass of a fungus).

POSSIBLE SIGNS AND SYMPTOMS

Cough
Fever
Fatigue
Shortness of breath

CURRENT TREATMENT OR THERAPIES

Fluconazole (Diflucan)
Ketoconazole (Nizoral) for maintenance therapy
Amphotericin B (Fungizone) systemic treatment

ADDITIONAL INFORMATION

These conditions can be diagnosed definitively only through cytology (histology) from biopsy as indicated above.

CONSULTATION, LABORATORY, SPECIAL REPORTS

Surgical pathology
Microbiology
Autopsy pathology

ICD-9-CM

112.9 Candidiasis of unspecified site

ICD-10-CM

Candidiasis, unspecified

Candidiasis of Esophagus

DEFINITIVE diagnosis through

Gross inspection by endoscopy *OR* autopsy *OR* microscopy (histology or cytology) on a specimen obtained directly from the tissues affected (including scrapings from the mucosal surface) and from a culture.

OR

PRESUMPTIVE diagnosis through

Provider diagnosed. Possible indications of the disease include

1. Recent onset of retrosternal pain on swallowing *AND*
2. Oral candidiasis diagnosed by the gross appearance of white patches or plaques on an erythematous base *OR* by the microscopic appearance of fungal mycelial filaments in an uncultured specimen scraped from the oral mucosa.

RISK FACTORS

Generally seen in patients with CD4 count <100 cells/ μ L

POSSIBLE SIGNS AND SYMPTOMS

Retrosternal pain or discomfort

Dysphagia and/or odynophagia, usually with absence of fever (unless co-infections are present)

Oral thrush: creamy white patches on tongue, palate, or throat

CURRENT TREATMENT OR THERAPIES

Fluconazole (Diflucan)

Itraconazole

Consider intravenous azoles for patients with severe manifestations of disease.

Second-line therapies include voriconazole and amphotericin B (Fungizone).

ADDITIONAL INFORMATION

Definitive diagnosis can be made by gross inspection during endoscopy (esphagoscopy), autopsy, or surgery or through positive histologic report of budding yeast and/or pseudohyphae from biopsy obtained during endoscopy, autopsy, or surgery.

Presumptive diagnosis is based on the presence of oral candidiasis noted on physical examination or characteristic appearance of radiologic contrast study (barium swallow) *AND* the following complaints with swallowing liquids and/or solids of any temperature:

1. Pain during swallowing (bad sore throat, burning in chest or throat, chest pain (tightness or squeezing))
2. Dysphagia (awareness of difficulty in swallowing) with or without pain (food sticking in throat, food not going down)

CONSULTATION, LABORATORY, SPECIAL REPORTS

Operating room or surgery department

Surgical pathology

Autopsy pathology

ICD-9-CM

112.9 Candidiasis of unspecified site

ICD-10-CM

B37.9 Candidiasis, unspecified site

Cervical Cancer, Invasive

DEFINITIVE diagnosis through
Microscopy (histology or cytology)

POSSIBLE SIGNS AND SYMPTOMS

PAP test indicating the presence of class III, IV, or V cells

Presence of a friable mass or ulcer detected during physical examination

CURRENT TREATMENT OR THERAPIES

Combination therapy (can include treatments below)

Radiotherapy

Chemotherapy

Surgery

ADDITIONAL INFORMATION

Can be diagnosed definitively only by histologic identification of the cell type from a biopsy specimen. Invasive cervical cancer includes micro-invasive cervical cancer (stage 1A) and all more advanced stages by using the criteria of the Oncology Committee of the International Federation of Gynecologists and Obstetricians. **Carcinoma in situ (stage 0) is NOT included as invasive cervical cancer.**

CONSULTATION, LABORATORY, SPECIAL REPORTS

Surgical pathology

Autopsy pathology

Radiology

ICD-9-CM

180.1 Cervical carcinoma, invasive

ICD-10-CM

C53 Malignant neoplasm of cervix uteri

ALSO CALLED

Cervical carcinoma

Coccidioidomycosis, Disseminated or Extrapulmonary

DEFINITIVE diagnosis through
Microscopy (histology or cytology)

OR

Culture

OR

Detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

BACKGROUND AND EPIDEMIOLOGY

Coccidioides immitis lives in soil, and the vast majority of cases result from inhalation of soil or dust containing this fungus. Many times, HIV-positive patients have positive serology without clinical disease.

RISK FACTORS

Active disease: CD4 count <250 cells/μL or diagnosis of AIDS

Disseminated disease: Elevated in pregnant women, Filipinos, blacks, and Hispanics

POSSIBLE SIGNS AND SYMPTOMS:

Fever, chills, night sweats (similar presentation to *Pneumocystis jirovecii* pneumonia [PCP])

Malaise

Cough

Weight loss

Chest pain

CURRENT TREATMENT OR THERAPIES

Fluconazole (Diflucan)

Amphotericin B (Fungizone)

Ketoconazole (Nizoral) to prevent relapse

ADDITIONAL INFORMATION

Can be diagnosed through histologic identification of the fungus *Coccidioides immitis* from spinal fluid, biopsy specimen or blood culture **OR** by the presence of coccidioidomycal antigen in the tissue involved or the fluid surrounding the tissue.

CONSULTATION, LABORATORY, SPECIAL REPORTS

Microbiology

Surgical pathology

Clinical immunology

Serology

ICD-9-CM

114 Coccidioidomycosis

ICD-10-CM

B 38 Coccidioidomycosis

Cryptococcosis, Extrapulmonary

DEFINITIVE diagnosis through

Microscopy (histology or cytology)

OR

Culture

OR

Detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

BACKGROUND AND EPIDEMIOLOGY

Cryptococcus is a fungus found worldwide in soil; it is a major OI in sub-Saharan Africa, Thailand, and India. In the pre-HAART era in the United States, cryptococcosis developed in 5%–8% of HIV-positive patients. Its incidence is dramatically lower in the HAART era.

POSSIBLE SIGNS AND SYMPTOMS

Fever

Confusion

Irritability

Neck stiffness

Elevated intracranial pressure (>200 mmHg) common and might be accompanied by evidence of cerebral edema: blurred vision, diplopia (double vision), hearing loss, severe headache, confusion, and papilledema.

Seizures

Loss of appetite

Meningitis

Extreme bizarre behavior

Depression, somnolence

Nausea or vomiting

Blurred vision, photophobia (aversion to light)

Uncontrolled excitement

Impaired memory or focal neurologic deficits

Inappropriate speech and/or dress

CURRENT TREATMENT OR THERAPIES

Amphotericin B (Fungizone)

With or without flucytosine (5-FC), depending on response

Fluconazole (Diflucan) for maintenance therapy

ADDITIONAL INFORMATION

Can be diagnosed definitively through histologic identification of *Cryptococcus neoformans* from spinal fluid, biopsy specimens of tissues, or blood culture **OR** the presence of the cryptococcal antigen in the tissue involved or the fluid surrounding the tissue.

CONSULTATION, LABORATORY, SPECIAL REPORTS

Microbiology
Surgical pathology
Clinical immunology
Serology

ICD-9-CM

117.5 Cryptococcosis
321.0 Cryptococcal meningitis

ICD-10-CM

B45 Cryptococcosis
B45.1 Cryptococcal meningitis

Cryptosporidiosis, Chronic Intestinal (>1 Month Duration)

DEFINITIVE diagnosis through
Microscopy (histology or cytology)

BACKGROUND AND EPIDEMIOLOGY

Cryptosporidium is an intracellular protozoan parasite. In immunocompromised patients (i.e., HIV-infected patients), parasites develop intracellularly throughout the gastrointestinal tract. Infection causes loss of villi, crypt hyperplasia, and reduced brush border enzyme activity (which all affect proper and complete digestion). This pathogen is transmitted by person-to-person contact, often among family members and close contacts, and is infectious even in small doses.

RISK FACTOR

Cryptosporidiosis is the most common cause of diarrhea in severely immunosuppressed persons (i.e. CD4 count <100 cells/ μ L).

POSSIBLE SIGNS AND SYMPTOMS

Profuse and long-term watery diarrhea
Severe abdominal cramps
Bloating
Nausea
Profound weight loss
Dehydration

CURRENT TREATMENT OR THERAPIES

Antiretroviral therapy, with goal of restoring CD4 count to >100 cells/ μ L

ADDITIONAL INFORMATION

The cause of chronic diarrhea can be diagnosed only by a microscopic examination of the stool, duodenal aspirate, or bile smears, which would show the Cryptosporidium cyst when a special modified acid-fast stain is used (i.e., modified Kinyoun)

CONSULTATION, LABORATORY, SPECIAL REPORTS

Microbiology (as for parasites)

Surgical pathology

Autopsy report

ICD-9-CM

007.2 Cryptosporidiosis

ICD-10-CM

A07.2 Cryptosporidiosis

Cytomegalovirus Disease (other than in Liver, Spleen or Nodes), Onset at Age >1 Month

DEFINITIVE diagnosis through

Microscopy (histology or cytology)

OR

Culture

OR

Detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

BACKGROUND AND EPIDEMIOLOGY

Cytomegalovirus (CMV) disease affects up to 40% in untreated AIDS patients. CMV seroprevalence approaches 50%–80%, >90% in sexually active men who have sex with men. Central nervous system disease is seen only in immunosuppressed persons.

RISK FACTOR

CD4 count <50–100 cells/ μ L

POSSIBLE SIGNS AND SYMPTOMS

CMV colitis: diarrhea, abdominal cramps, fever, spasticity of bowel and bladder, and weight loss

CMV pneumonitis: shortness of breath, dry cough, hypoxemia, odynophagia (i.e., pain produced by swallowing), and esophagospasm

CMV encephalitis: headache, confusion, seizures, myelitis, and personality changes

CURRENT TREATMENT OR THERAPIES

Ganciclovir (DHPG, Cytovene)

Foscarnet (Foscavir)

ADDITIONAL INFORMATION

CMV (other than in liver, spleen, or lymph nodes) can be definitively diagnosed only by viral cultures or microscopy or biopsy specimen from the infected tissues because most HIV-positive patients are antigen positive. Tissues that are usually infected are the central nervous system, lungs, and gastrointestinal tract.

CONSULTATION, LABORATORY, SPECIAL REPORTS

Surgical pathology
 Cytology pathology
 Virology/immunology

ICD-9-CM

078.5 Cytomegalic inclusion disease
 369 Vision, low

ICD-10-CM

B25 Cytomegalovirus disease
 H54.7 Unspecified visual loss

Cytomegalovirus Retinitis (With Loss of Vision)

DEFINITIVE diagnosis through
 Microscopy (histology or cytology)

OR

Culture

OR

Detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

OR

PRESUMPTIVE Diagnosis through
 Physician diagnosed. Possible indications of the disease include a characteristic appearance on serial ophthalmoscopic examination (i.e., discrete patches of retinal whitening with distinct borders, spreading in a centrifugal manner, following blood vessels, progressing over several months, frequently associated with retinal vasculitis, hemorrhage, and necrosis). Resolution of active disease leaves retinal scarring and atrophy with retinal pigment epithelial mottling.

BACKGROUND AND EPIDEMIOLOGY

The cytomegalovirus (CMV) is a β -herpes virus that reactivates with advanced HIV disease. Most HIV-positive patients have latent infection (positive CMV IgG). CMV is the most common cause of vision loss in persons with AIDS and the most common ocular disease.

RISK FACTOR

CD4 count <50 cells/ μ L

POSSIBLE SIGNS AND SYMPTOMS

Visual defects or blindness (characteristic appearance of retinal whitening)

CURRENT TREATMENT OR THERAPIES

HAART

Ganciclovir (DHPG) (Cytovene)

Foscarnet (Foscavir)

Valganciclovir for maintenance

ADDITIONAL INFORMATION

Can be diagnosed either definitively or presumptively. Definitive diagnostic method is the same as for CMV disease (viral cultures or microscopy of biopsy specimen from the infected tissues because most HIV-positive patients are antigen positive), with the tissue being from the retina. This is rarely done. The usual method of diagnosis is presumptive because it is not invasive. An ophthalmic examination by an ophthalmologist or other provider skilled in ophthalmology will note the characteristic appearance of discrete patches of retinal whitening with distinct borders.

CONSULTATION, LABORATORY, SPECIAL REPORTS

Surgical pathology or cytology

Virology/immunology

Pathology

Ophthalmologist report

ICD-9-CM

078.5 Cytomegalic inclusion disease

369 Vision, low

ICD-10-CM

B 25 Cytomegalovirus disease

H54.7 Unspecified visual loss

Encephalopathy, HIV Related

DEFINITIVE diagnosis through

- Clinical findings of disabling cognitive or motor dysfunction interfering with occupation or activities of daily living, progressing over weeks to months
- Absence of a concurrent illness or condition other than HIV infection that could explain the findings.
- Methods to rule out such concurrent illnesses and conditions must include cerebrospinal fluid examination **AND**
- Either brain imaging (CT or MRI) **OR** autopsy

BACKGROUND AND EPIDEMIOLOGY

HIV is found in the brain in macrophages and other cells that fight infection. Encephalopathy ensues from neurons injured indirectly when infected cells release noxious substances. The term “HIV-associated neurocognitive dysfunction” (HAND) is now frequently used to refer to neurocognitive dysfunction of any degree of severity.

POSSIBLE SIGNS AND SYMPTOMS

Cognitive: poor concentration, forgetfulness, slowness, inattention

Motor: loss of balance or coordination, clumsiness, leg weakness, ataxia

Behavioral: apathy, reduced spontaneity, social withdrawal, altered personality, senile-like behavior

CURRENT TREATMENT OR THERAPIES

Antiretroviral therapy is mainstay of treatment

Immune reconstitution inflammatory syndrome can occasionally be seen once antiretroviral therapy is started, usually because of progressive multifocal leukoencephalopathy

ADDITIONAL INFORMATION

Can be diagnosed definitively only by a process of elimination. When a disabling cognitive and/or motor dysfunction is present and the spinal fluid examination from a lumbar puncture and CT scan or MRI do not indicate other pathology, HIV encephalopathy is assumed to be the cause.

CONSULTATION, LABORATORY, SPECIAL REPORTS

Neuropathology

Neuroradiology

Psychiatry

Neuropsychology

CT scans

MRI records

ICD-9-CM

348.3 Encephalopathy

049.9 Viral encephalitis

298.9 Dementia

294.9 Dementia, organic

290. Dementia, pre-senile

ICD-10-CM

A85 Viral encephalitis, NEC

ALSO CALLED

HIV dementia

AIDS dementia

Subacute encephalitis due to HIV



Herpes Simplex: Chronic Ulcers (>1 Month Duration) or Bronchitis, Pneumonitis, or Esophagitis (Onset at Age >1 Month)

DEFINITIVE diagnosis through

Microscopy (histology or cytology)

OR

Culture

OR

Detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues

BACKGROUND AND EPIDEMIOLOGY

Pathogens are herpes simplex virus-1 (HSV-1) and 2 (HSV-2)

HSV activates HIV replication and enhances sexual transmission of HIV

POSSIBLE SIGNS AND SYMPTOMS

Open ulcers in oral or anogenital area (classic presentation is grouped vesicles on erythematous base)

Painful blisters can affect eyes or face

Central nervous system (fever, headaches, confusion, and stupor)

Dysphagia, odynophagia (i.e., severe pain on swallowing caused by disorder of the esophagus), esophagospasm

CURRENT TREATMENT OR THERAPIES

Acyclovir (Zovirax)

Valacyclovir

Famciclovir

ADDITIONAL INFORMATION

HSV: chronic ulcer(s) (>1 months' duration) or bronchitis, pneumonitis, or esophagitis can be diagnosed definitively by histology, culture, or detection of antigen from affected biopsy tissue or the fluid surrounding those tissues

CONSULTATION, LABORATORY, SPECIAL REPORTS

Surgical pathology or cytology

Autopsy pathology

Clinical pathology (serology microbiology)

Microbiology

Ob/Gyn report

ICD-9-CM

054-054.9 Herpes simplex (various sites)

ICD-10-CM

B00 Herpes viral (Herpes simplex) infections

Histoplasmosis, Disseminated or Extrapulmonary

DEFINITIVE diagnosis through

Microscopy (histology or cytology)

OR

Culture

OR

Detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues

BACKGROUND AND EPIDEMIOLOGY

In the United States, histoplasmosis is endemic to Ohio and Mississippi River valleys. Also endemic to areas of Central and South America, with small concentrations in eastern United States, southern Europe, Africa, and South and Southeast Asia. Soil-based fungus that thrives in moist, acidic environments, often in high concentrations in caves and old buildings (especially rich in bird and bat droppings).

RISK FACTORS

CD4 count <150 cells/ μ L

POSSIBLE SIGNS AND SYMPTOMS

No symptoms or mild pulmonary symptoms in most patients

Cough

Fever

Nausea and vomiting

Chills and sweating

Diarrhea

Weight loss

Swollen lymph nodes

CURRENT TREATMENT OR THERAPIES

Amphotericin B (Fungizone)

Itraconazole

ADDITIONAL INFORMATION

Can be diagnosed definitively by histologic identification of *Histoplasma capsulatum* from biopsied tissue of gastrointestinal tract, blood, bone marrow, and/or lymph nodes. This fungal disease is often found in the lung but does not indicate AIDS. If it is found outside the lungs in a patient who is HIV positive, it constitutes AIDS.

CONSULTATION, LABORATORY, SPECIAL REPORTS

Microbiology

Surgical pathology or cytology

Autopsy pathology

ICD-9-CM

115 Histoplasmosis

ICD-10-CM

B39 Histoplasmosis

Isosporiasis, Chronic Intestinal (>1 Month Duration)

DEFINITIVE diagnosis through
Microscopy (histology or cytology)

BACKGROUND AND EPIDEMIOLOGY

Isosporiasis is an uncommon diarrheal illness caused by the protozoan *Isospora belli*. Humans are the only known hosts for this organism, which has no known animal reservoir. Isosporiasis is distributed worldwide but is more common in tropical and subtropical climates. Infection results from ingestion of oocysts in contaminated food or water.

POSSIBLE SIGNS AND SYMPTOMS

Chronic, profound diarrhea (>1 month's duration)
Abdominal cramps
Nausea
Vomiting
Weight loss

CURRENT TREATMENT OR THERAPIES

Trimethoprim/sulfamethoxazole (Septra or Bactrim)
Pyrimethamine-sulfadiazine (Fansidar)
Hydration and nutritional support until infection is controlled

ADDITIONAL INFORMATION

Isosporiasis, chronic diarrhea (>1 month duration), can be diagnosed definitively only by histologic identification of *Isospora belli* from a specially prepared stool specimen

CONSULTATION, LABORATORY, SPECIAL REPORTS

Surgical pathology
Microbiology (as for parasites)

ICD-9-CM

007.2 Isosporiasis

ICD-10-CM

A07.3 Isosporiasis

Kaposi Sarcoma

DEFINITIVE diagnosis through
Microscopy (histology or cytology)

OR

PRESUMPTIVE diagnosis through
Provider diagnosed. Possible indications of the disease include a characteristic gross appearance of an erythematous or violaceous plaque-like lesion on skin or mucous membrane

(Presumptive diagnosis of Kaposi sarcoma should not be made by clinicians who have seen few cases of it.)

BACKGROUND AND EPIDEMIOLOGY

Associated with human herpesvirus-8 (a γ -herpes virus)

POSSIBLE SIGNS AND SYMPTOMS

Night sweats

Weight loss

Red-purple nodular skin or mucous membrane lesions, usually painless

Cough, bronchospasm, dyspnea

Visceral lesions

CURRENT TREATMENT OR THERAPIES

Antiretroviral therapy

Chemotherapy (particularly if viscera are involved)

(Note: Prognosis of this OI appears to be correlated with overall immune status)

ADDITIONAL INFORMATION

Can be diagnosed definitively by tissue biopsy or presumptively by gross inspection of the patient by a clinical specialist in oncology, dermatology, or infectious diseases.

CONSULTATION, LABORATORY, SPECIAL REPORTS

Autopsy pathology

Tissue biopsy

ICD-9-CM

173 Other malignant neoplasm of skin

173.9 Skin, site unspecified

176.0-176.9 Kaposi's sarcoma

ICD-10-CM

C46. Kaposi's sarcoma

ALSO CALLED

KS

Lymphoma, Burkitt (or Equivalent Term)

DEFINITIVE diagnosis through
Microscopy (histology or cytology)

BACKGROUND AND EPIDEMIOLOGY

Burkitt lymphoma is a malignancy (cancer) of the lymphatic system

POSSIBLE SIGNS AND SYMPTOMS

Fatigue

Fever

Night sweats

Weight loss

Other symptoms relate primarily to the specific site of obstruction by tumor masses

CURRENT TREATMENT OR THERAPIES

Combination chemotherapy

ADDITIONAL INFORMATION

Can be diagnosed definitively only by histologic identification of the cell type from a biopsy specimen (biopsy of enlarged nodes, bone marrow, liver, and other organs)

CONSULTATION, LABORATORY, SPECIAL REPORTS

Surgical pathology

Autopsy pathology

ICD-9-CM

200.2 Burkitt's tumor or lymphoma

ICD-10-CM

C83.7 Burkitt's lymphoma

ALSO CALLED

Burkitt tumor

Lymphoma, Immunoblastic (or Equivalent Term)

DEFINITIVE diagnosis through
Microscopy (histology or cytology)

BACKGROUND AND EPIDEMIOLOGY

Strong association with Epstein-Barr virus and casual association with human herpesvirus-8

POSSIBLE SIGNS AND SYMPTOMS

Night sweats

Weight loss

Fatigue

Fever

Other symptoms related primarily to the specific site of obstruction by tumor masses

CURRENT TREATMENT OR THERAPIES

Combination chemotherapy

Effective chemotherapy regimens include R-CHOP (rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone) and R-EPOCH (rituximab, etoposide, vincristine, cyclophosphamide, doxorubicin given by continuous infusion with prednisone).

Glanulocyte colony-stimulating facto is often given during chemotherapy to lower incidence of neutropenia

ADDITIONAL INFORMATION

Can be diagnosed definitively only by histologic identification of the cell type from a biopsy specimen (from enlarged nodes, bone marrow, liver, and other organs)

CONSULTATION, LABORATORY, SPECIAL REPORTS

Surgical pathology

Autopsy pathology

ICD-9-CM

200.0 Reticulosarcoma

200.8 Sarcoma, immunoblastic

ICD-10-CM

C85.9 Non-Hodgkin's lymphoma

ALSO CALLED

Non-Hodgkin lymphoma

B-cell immunologic phenotype

Immunoblastic sarcoma

Large-cell lymphoma

Diffuse histiocytic lymphoma

Lymphoma, Primary, of Brain

DEFINITIVE diagnosis through
Microscopy (histology or cytology)

BACKGROUND AND EPIDEMIOLOGY

Epstein-Barr virus is present in almost 100% of cases of HIV-associated primary brain lymphoma. Primary lymphoma of the brain is a late manifestation of HIV disease and has become very rare since the advent of antiretroviral therapy..

RISK FACTORS

Usually associated with CD4 count <50 cells/ μ L

POSSIBLE SIGNS AND SYMPTOMS

Headache

Confusion

Seizures

Focal motor and/or sensory deficits

CURRENT TREATMENT OR THERAPIES

Radiation, although prognosis is extremely poor

ADDITIONAL INFORMATION

Can be diagnosed definitively only by histologic identification of cell type from biopsy specimen. The disease was rare before AIDS epidemic. The symptoms and indications on CT scan resemble toxoplasmosis. Diagnostic methods include lumbar puncture and culture of cerebrospinal fluid (to eliminate other diseases), CT scan, brain biopsy, or autopsy

CONSULTATION, LABORATORY, SPECIAL REPORTS

Surgical pathology

Autopsy pathology

ICD-9-CM

202.8 Primary lymphoma of the brain

ICD-10-CM

No specific code; could use C85.7 Other specified types of non-Hodgkin's lymphoma

ALSO CALLED

Microgliomatosis

Reticulum cell sarcoma

Mycobacterium Avium Complex or Mycobacterium Kansaii, Disseminated or Extrapulmonary

DEFINITIVE diagnosis through

Culture (single blood culture 90% sensitive, >1 blood culture increases sensitivity)

OR

PRESUMPTIVE diagnosis through

Provider diagnosed. Possible indications of the disease include microscopy of a specimen from stool OR normally sterile body fluids OR tissue from a site other than lungs, skin, or cervical or hilar lymph nodes, showing acid-fast bacilli of a species not identified by culture.

POSSIBLE SIGNS AND SYMPTOMS

- Fever
- Night sweats
- Weakness
- Anemia or other cytopenia
- Wasting
- Swollen lymph glands
- Diarrhea
- Abdominal pain

RISK FACTORS

Seen almost exclusively in HIV-positive patients with CD4 count <50 cells/μL

CURRENT TREATMENT OR THERAPIES

Primary prophylaxis: azithromycin or clarithromycin
Active disease: clarithromycin + ethambutol (with the possible addition of isoniazid or rifabutin in cases of advanced immunosuppression or poor treatment response)

ADDITIONAL INFORMATION

M. avium or *M. kansasii* disseminated or extrapulmonary (at site other than or in addition to the lungs, skin, or cervical or hilar lymph nodes) can be diagnosed definitively by culture identification of bacilli from tissue specimen or fluids; or presumptively by microscopic acid-fast stain identification of bacilli from tissue specimen or fluids. Usually seen in blood culture or bone marrow (as granulomas).

CONSULTATION, LABORATORY, SPECIAL REPORTS

Microbiology

ICD-9-CM

031.8 Other specified mycobacterial diseases

ICD-10-CM

A31.2 Disseminated Mycobacterium *avium-intracellulare* complex (DMAC)

Mycobacterium Tuberculosis of any Site

(a) (Pulmonary)

DEFINITIVE diagnosis through
Positive laboratory culture of appropriate organism

OR

PRESUMPTIVE diagnosis through
Provider diagnosed. When bacteriologic confirmation is not available, other reports can be considered verified cases of pulmonary tuberculosis if the CDC criteria are used. The criteria in use as of April 10, 2009, are available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5804a1.htm>

POSSIBLE SIGNS AND SYMPTOMS

Malaise

Cough (>2 weeks' duration), hemoptysis (bloody expectorate)

Chronic fever, weight loss, night sweat

Anergy

Dyspnea, chest pain

Abnormality (i.e., upper lobe infiltrate) on chest radiograph

CURRENT TREATMENT OR THERAPIES

Isoniazid + rifampin + ethambutol + pyrazinamide

Use rifabutin in place of rifampin in patients on protease inhibitors or non-nucleoside reverse transcriptase inhibitors

ADDITIONAL INFORMATION

Can be diagnosed definitively by culture identification of bacilli from tissue specimen or fluids. The presumptive diagnosis for pulmonary tuberculosis is based on CDC criteria. A case can be laboratory confirmed, or in the absence of laboratory confirmation, a case may meet the clinical case definition.

1. Laboratory criteria include

- a. Isolation of *M. tuberculosis* from a clinical specimen OR
- b. Demonstration of *M. tuberculosis* from a clinical specimen by DNA probe or mycolic acid pattern on high-pressure liquid chromatography OR
- c. Demonstration of acid-fast bacilli in clinical specimen when a culture has not been or cannot be obtained

2. Clinical case criteria include

- a. A positive tuberculin skin test, which could include
 - 1) Tuberculin skin test OR
 - 2) Quantiferon tuberculosis gold test
- b. Other signs and symptoms compatible with tuberculosis, such as abnormal, unstable (worsening or improving) findings on chest radiograph or clinical evidence of current disease
- c. Treatment with two or more antituberculosis medications
- d. Completed diagnostic evaluation

CONSULTATION, LABORATORY, SPECIAL REPORTS

Microbiology

Radiology

ICD-9-CM

011-011.9 Pulmonary tuberculosis

ICD-10-CM

A15.0 Tuberculosis of lung

ALSO CALLED

TB

Mycobacterium Tuberculosis of any Site

(b) Disseminated or Extrapulmonary

DEFINITIVE diagnosis through

Positive laboratory culture of appropriate organism

OR

PRESUMPTIVE diagnosis through

Provider diagnosed. Possible indications of the disease include microscopy of a specimen from stool OR normally sterile body fluids OR tissue from a site other than lungs, skin, or cervical or hilar lymph nodes, showing acid-fast bacilli of a species not identified by culture.

POSSIBLE SIGNS AND SYMPTOMS

Brain abscess (meningitis)
 Systemic wasting
 Arthritis
 Swollen lymph nodes
 Cutaneous and soft tissue lesions
 Chronic fever, weight loss, night sweat
 Anergy
 Enteritis
 Ascites
 Cough

CURRENT TREATMENT OR THERAPIES

Isoniazid + rifampin + ethambutol + pyrazinamide
 Respiratory isolation for cough >2 weeks' duration + abnormal findings on chest radiograph
 Respiratory isolation if sputum smear is positive for acid-fast bacilli

ADDITIONAL INFORMATION

M. tuberculosis, extrapulmonary or disseminated, can occur with or without lung involvement. *M. tuberculosis* can infect any organ in the body, including lymph nodes, gastrointestinal tract, bone/joints, and central nervous system. Chronic febrile wasting is the most common clinical manifestation. *M. tuberculosis*, extrapulmonary or disseminated, can be diagnosed definitively by culture identification of bacilli from tissue specimen or fluids or presumptively by microscopic Gram stain identification of bacilli from tissue specimen or fluids, usually seen in blood cultures, bone marrow, or urine (caseating granulomas).

CONSULTATION, LABORATORY, SPECIAL REPORTS

Microbiology

ICD-9-CM
010-018 Tuberculosis

ICD-10-CM
A17–A19 Tuberculosis

ALSO CALLED
MTB

***Mycobacterium*, Other Species or Unidentified Species, Disseminated or Extrapulmonary**

DEFINITIVE diagnosis through
Positive laboratory culture of appropriate organism

OR

PRESUMPTIVE diagnosis through
Provider diagnosed. Possible indications of the disease include microscopy of a specimen from stool **OR** normally sterile body fluids **OR** tissue from a site other than lungs, skin, or cervical or hilar lymph nodes, showing acid-fast bacilli of a species not identified by culture.

POSSIBLE SIGNS AND SYMPTOMS

Fever
Night sweats
Weakness
Anemia or other cytopenia
Wasting
Swollen lymph nodes
Diarrhea
Abdominal pain

CURRENT TREATMENT OR THERAPIES

Isoniazid + rifampin + ethambutol + pyrazinamide

ADDITIONAL INFORMATION

Mycobacterium, extrapulmonary or disseminated (at a site other than or in addition to lungs, skin, or cervical or hilar lymph nodes), can be diagnosed definitively by culture identification of bacilli from tissue specimen or fluids or presumptively by microscopic Gram stain identification of bacilli from tissue specimen or fluids, usually seen in blood cultures or bone marrow (as granulomas).

CONSULTATION, LABORATORY, SPECIAL REPORTS

Microbiology

ICD-9-CM

031.8 Other mycobacterial diseases

031.9 Unspecified diseases due to mycobacteria

ICD-10-CM

031.9 Other mycobacterial infections

Pneumocystis Jirovecii Pneumonia

DEFINITIVE diagnosis through

Positive laboratory culture of appropriate organism

OR

PRESUMPTIVE diagnosis through

Provider diagnosed. Possible indications of the disease include

1. A history of dyspnea on exertion OR nonproductive cough of recent onset (within the past 3 months) AND
2. Chest radiographic evidence of diffuse bilateral interstitial infiltrates OR gallium scan evidence of diffuse bilateral pulmonary disease AND
3. Arterial blood gas analysis showing an arterial pO₂ of <70 mmHg or low respiratory diffusing capacity (<80% of predicted value) OR an alveolar-arterial oxygen tension gradient of >35 mmHg AND
4. No evidence of a bacterial pneumonia

BACKGROUND AND EPIDEMIOLOGY

This term has changed from the previous nomenclature of *Pneumocystis carinii* pneumonia; however, the abbreviation PCP is still used to designate *Pneumocystis pneumonia*. *P. carinii* now refers only to the pneumocystis that infects rodents, whereas *P. jirovecii* refers to the distinct species that infects humans. *Pneumocystis* sp. spreads by the airborne route. Disease probably occurs by new acquisition of infection and by reactivation of latent infection.

RISK FACTORS

CD4 count <200 cells/μL, CD4 T-lymphocyte percentage <14%

Previous episodes of PCP

Oral thrush

Recurrent bacterial pneumonia

Unintentional weight loss

H_{high} plasma HIV RNA

POSSIBLE SIGNS AND SYMPTOMS

Fever (present in most cases, probably the most common presenting symptom)

Anemia

Dyspnea

Fatigue

Leukopenia, thrombocytopenia

Hypoxemia, hypercarbia

Nonproductive cough

CURRENT TREATMENT OR THERAPIES

Intravenous or oral trimethoprim/sulfamethoxazole (Septra or Bactrim)

Corticosteroid treatment may be added in certain circumstances

HAART

Diaminodiphenylsulfone (Dapsone)

ADDITIONAL INFORMATION

Definitive diagnosis: cytologic evidence of *P. jirovecii* on silver stain

Presumptive diagnosis: The physician would inquire/examine the patient for

1. A history of shortness of breath OR a nonproductive cough (Note: A productive cough is more likely a sign of a bacterial or fungal infection)
2. Chest radiograph showing bilateral interstitial infiltrates. Gallium scan evidence
3. Measurable decrease in the level of oxygen in the blood: pO₂ <70 mmHg on arterial blood gas

CONSULTATION, LABORATORY, SPECIAL REPORTS

Surgical pathology or cytology

ICD-9-CM

136.3 Pneumocystosis

ICD-10-CM

B59 Pneumocystosis

ALSO CALLED

PCP

Pneumonia, Recurrent

DEFINITIVE diagnosis through

Recurrent (>1 episode in a 1-year period), acute (new radiographic evidence not present earlier) pneumonia diagnosed by

1. Culture (or other organism-specific diagnostic method) obtained from a clinically reliable specimen of a pathogen that typically causes pneumonia (other than *Pneumocystis jirvocii* or *Mycobacterium tuberculosis* **AND**
2. Radiologic evidence of pneumonia; cases that do not have laboratory confirmation of causative organism for one of the episodes of pneumonia will be considered presumptively diagnosed

OR

PRESUMPTIVE diagnosis through

Provider diagnosed. Possible indications of the disease include recurrent (>1 episode in a 1-year period, acute (new radiographic evidence not present earlier). Pneumonia diagnosed on clinical or radiologic evidence by patient's provider.

POSSIBLE SIGNS AND SYMPTOMS

Fever
 Productive cough
 Dyspnea
 Chest pain
 Chills
 Headache

CURRENT TREATMENT OR THERAPIES

Depends on infecting agent
 Penicillin G, tetracycline, erythromycin, cephalexin, clindamycin, ampicillin, amantadine, rifampin

ADDITIONAL INFORMATION

For both definitive and presumptive diagnoses, documentation of HIV infection is not required for the first episode as long as HIV infection is documented for the second episode of pneumonia that occurs within a 12-month period.

CONSULTATION, LABORATORY, SPECIAL REPORTS

Microbiology
 Radiology

ICD-9-CM

480 Viral pneumonia
 481 Pneumococcal pneumonia
 482 Other bacterial pneumonia
 483 Pneumonia due to other specific organism

ICD-10-CM

J15 Bacterial pneumonia, NEC

Progressive Multifocal Leukoencephalopathy

DEFINITIVE diagnosis through
Microscopy (histology or cytology)

BACKGROUND AND EPIDEMIOLOGY

Caused by the JC virus (named using the initials of a patient with progressive multifocal leukoencephalopathy [PML]). The JC virus is present in >70% of humans and is typically asymptomatic, although it can reactivate and cause PML in immunosuppressed (i.e. HIV-positive) host.

POSSIBLE SIGNS AND SYMPTOMS

Memory loss
Loss of motor control
Seizures
Mood changes
Vision impairment

CURRENT TREATMENT OR THERAPIES

Most effective treatment is antiretroviral therapy
Interferon- α showed delay in progression and increased survival

ADDITIONAL INFORMATION

PML can be diagnosed definitively only by histologic identification of JC virus on culture from brain tissue biopsy. This is seldom done because the test itself can result in significant morbidity or even death.

CONSULTATION, LABORATORY, SPECIAL REPORTS

Surgical pathology
Autopsy pathology
Clinical pathology (serology microbiology)
Microbiology

ICD-9-CM

046.3 Leukoencephalopathy,
Multifocal (progressive)

ICD-10-CM

A81.2 Progressive Multifocal leukoencephalopathy

ALSO CALLED

PML

Salmonella Septicemia, Recurrent

DEFINITIVE diagnosis through
Microscopy (histology or cytology)

BACKGROUND AND EPIDEMIOLOGY

The three most common causes of bacterial diarrhea among patients with HIV-1 infection in developed countries are *Salmonella*, *Campylobacter*, and *Shigella* species. As with non-HIV-associated salmonellosis, the probable source for *Salmonella* infection is ingestion of contaminated food, particularly undercooked poultry and eggs.

POSSIBLE SIGNS AND SYMPTOMS

Fever
Chills
Abdominal pain
Abdominal cramps and bloating
Nausea
Diarrhea
Weight loss

CURRENT TREATMENT OR THERAPIES

Ciprofloxacin is treatment of choice
Ampicillin
Trimethoprim/sulfamethoxazole (Septra or Bactrim)
Cephalosporins
Immunoglobulin therapy is recommended for children.

ADDITIONAL INFORMATION

Can be diagnosed definitively only with blood cultures that show *Salmonella* bacteria on cytology

CONSULTATION, LABORATORY, SPECIAL REPORTS

Microbiology

ICD-9-CM

003.1 *Salmonella* septicemia

ICD-10-CM

A41.9 Sepsis, unspecified septicemia, NOS

Toxoplasmosis of the Brain, Onset at Age >1 Month

DEFINITIVE diagnosis through
Microscopy (histology or cytology)

OR

PRESUMPTIVE diagnosis through

Provider diagnosed. Possible indications of the disease include

1. Recent onset of a focal neurologic abnormality consistent with intracranial disease **OR** a reduced level of consciousness **AND**
2. Brain imaging evidence of a lesion having a mass effect (on CT scan or nuclear MRI) **OR** the radiographic appearance of which is enhanced by injection of contrast medium **AND**
3. Serum antibody to *Toxoplasma gondii* **OR** successful response to therapy for toxoplasmosis

BACKGROUND AND EPIDEMIOLOGY

Toxoplasma gondii is an obligate intracellular protozoan. Environmental exposure in cat feces or undercooked meat can lead to human infection.

POSSIBLE SIGNS AND SYMPTOMS

Fever

Confusion, lethargy

Headaches

Visual disturbances

Seizures, aphasia, ataxia, dysmetria

Personality and behavior changes, delusions

Cognitive disorders, disorientation

CURRENT TREATMENT OR THERAPIES

Pyrimethamine and sulfadiazine (Fansidar)

Clindamycin (Cleocin) and pyrimethamine

Folinic acid (Leucovorin)

Azithromycin, trimetrexate, recombinant γ -interferon, recombinant α -interferon, and recombinant interleukin-2 are experimental

ADDITIONAL INFORMATION

Toxoplasmosis can be diagnosed definitively by histologic identification of *T. gondii* from cerebrospinal fluid and presumptively with brain imaging (CT scan or MRI) evidence of mass effect (which frequently appears as ring lesions) plus serum antibody to *Toxoplasma* or response to toxoplasmosis therapy.

CONSULTATION, LABORATORY, SPECIAL REPORTS

Surgical pathology
Autopsy pathology
Cytology
CT scan
MRI records

ICD-9-CM

130 Toxoplasmosis

ICD-10-CM

B 58.2 Toxoplasmosis

Wasting Syndrome Due to HIV

DEFINITIVE diagnosis through

Findings of profound involuntary weight loss (>10% of baseline body weight).

AND

Chronic diarrhea (at least two loose stools per day for >30 days) **OR** chronic weakness and documented fever (for >30 days, intermittent or constant) BACKGROUND AND EPIDEMIOLOGY

AND

Absence of a concurrent illness or condition other than HIV infection that could explain the findings (e.g., cancer, tuberculosis, cryptosporidiosis, or other specific enteritis)

BACKGROUND AND EPIDEMIOLOGY

Wasting is much less common in the HAART era, not to be confused with lipoatrophy, which is often seen in patients on successful antiretroviral therapy. Wasting is a diagnosis of exclusion. Other OIs, depression, and substance abuse must be ruled out.

POSSIBLE SIGNS AND SYMPTOMS

Considerable weight loss
Weakness and fever
Diarrhea
Abdominal pain
Cachectic muscle wasting

CURRENT TREATMENT OR THERAPIES

High-protein nutritional supplements
HAART

ADDITIONAL INFORMATION

Before a patient's weight loss can be considered to be wasting, three requirements must be fulfilled:

1. Patient must have a positive test for HIV infection, as reflected by laboratory documentation or medical record notes.
2. Patient must have a documented fever and chronic weakness for >30 days (intermittent or constant) or chronic diarrhea for >30 days (at least two loose stools per day). The fever/weakness or diarrhea requirements should be written in the medical record and can be established by the observations of health-care workers or through patient self-reports acceptable to examining provider.
3. The medical records do not contain positive laboratory results or a provider's statement indicating the presence of other conditions that could have caused the same group of symptoms, such as cancer, tuberculosis, cryptosporidiosis, cryptococcosis, histoplasmosis, isosporiasis, or cytomegalovirus colitis.

After these three criteria have been satisfied, wasting can be considered. The loss of weight must be 10% of baseline body weight, involuntary, and not resulting from depression or desired weight loss or lack of appetite attributable to medication. Baseline weight is defined as the patient's usual weight before illness onset. Baseline weight can be established by actual weights recorded by health-care workers or through patient statements acceptable to the examining provider and recorded in medical records. Wasting involves the loss of protein muscle mass. Terms such as cachectic, emaciated, and bitemporal wasting found in medical records often support a diagnosis of HIV wasting syndrome.

CONSULTATION, LABORATORY, SPECIAL REPORTS

General medical records

ICD-9-CM

Abnormal loss of weight

ICD-10-CM

R63.4 Abnormal weight loss

ALSO CALLED

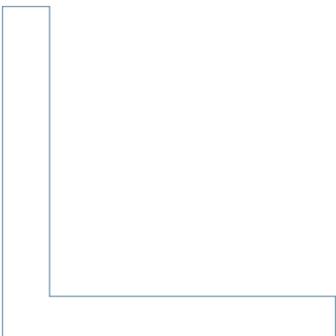
Slim disease or emaciation due to HIV

MODULE TWO

HIV Case Report
Forms

OBJECTIVES:

1. Provide information about completing the Adult HIV Confidential Case Report Form
2. Provide information about completing the Pediatric HIV Confidential Case Report Form



This section highlights the recording of HIV case report information. New HIV case report forms for adult and pediatric HIV surveillance were implemented in late 2011 for use by all state and local surveillance programs. Although the basic elements of the forms are similar to those of previous versions, the forms were changed to conform to the Centers for Disease Control and Prevention's (CDC's) Enhanced HIV/AIDS Reporting System (eHARS) data management system. All staff should familiarize themselves with the new forms before using them.

COMPLETION OF FORMS

The standardized forms are designed to collect confidential case report information (including HIV infection, Stage 3 [AIDS]) and used to update information relevant to the reported case. This information might include updates on identified risk, CD4 counts and percentages, additional opportunistic infections and/or the date of death.

HIV surveillance programs have two specific forms for reporting HIV information:

- Adult HIV Confidential Case Report form (ACRF; CDC 50.42A, revised 6/2011), for persons >13 years of age at diagnosis)
- Pediatric HIV Confidential Case Report form (PCRF; CDC 50.42B, revised 6/20/11), (for persons <13 years of age at diagnosis)

Data obtained through the case reporting process are electronically transferred by the State Health Office to CDC. To protect patient confidentiality, identifying information is not sent to CDC, and the remaining information is encrypted. Only electronic information is forwarded to CDC.

GENERAL INSTRUCTIONS

- Print or write legibly.
- Complete all applicable blanks accurately.
- Certain data elements are **“REQUIRED”** for a record to be included as a case in eHARS. Other data elements are considered as **“Recommended”** or **“Optional”**; regardless, staff should make every effort to complete all fields in the case report form.
- Place updates for previously reported cases on a new case report form. Include identifying information about updates (i.e., name and alternate name/alias; date of birth; race; sex; county of residence; and state patient number, if known).

CDC considers certain cases to be priority for reporting and follow-up. Immediately contact your state cases of public health importance (COPHI) coordinator if you identify or receive a report for the following:

- An HIV case for a health-care worker or person in a health-care setting
- HIV-2 infection
- Cases attributed to organ or tissue transplant or to artificial insemination
- Transmission from transfusion after March 1985
- Transmission from suspected child abuse
- Transmission from a nursing mother
- Unusual modes of transmission

Additional information about completion of adult and pediatric case report forms is available in [Technical Guidance for HIV Surveillance Programs, Volume II, Data Collection, Resources, and Reporting](#).

Adult HIV Confidential Case Report Form (ACRF)

PURPOSE OF ACRF

The ACRF is designed to collect information that promotes understanding of HIV infection and AIDS morbidity and mortality among U.S. residents >13 years of age at diagnosis. *This form reflects data that should be collected; this guidance applies to this data collection even if surveillance sites use a different form or medium for HIV case surveillance.*

THE ACRF IN THE CONTEXT OF DOCUMENT-BASED SURVEILLANCE

Unlike case-based data management, document-based data management allows all documents to be stored and retained electronically in their original formats. Instead of completing one form for a given reported case, fill out the applicable part of the form for each data source contributing to that HIV case.

PATIENTS FOR WHOM THE ACRF IS INDICATED

- Each person with an HIV (not AIDS) diagnosis
- Each person with an AIDS diagnosis
- Each person with previously reported HIV infection whose condition progresses to Stage 3 (AIDS) or each person with HIV who dies

EXPLANATION OF VARIABLE DESIGNATORS

- **Required:** Variables that are required to meet the HIV case definition, to identify and track cases, and to conduct meaningful statistical analysis
- **Recommended:** Information useful for analysis but not essential for core surveillance
- **Optional:** Information that should be ascertained if readily available

DISPOSITION OF FORM

- The completed form is for state or local health agency use and is not to be sent to CDC with patient identifiers. Some of the Pacific Territory sites send forms to CDC for data entry; those forms do not contain patient identifying information.
- Data obtained from these forms are entered into standardized computer software (eHARS) provided by CDC, and then transferred without identifiers through an electronic secure data network. This transmission is the only way in which CDC receives electronic surveillance data.

The ACRF provided by CDC is divided into 14 sections:

- Patient Identification
- Health Department Use Only
- Facility Providing Information
- Patient Demographics
- Residence at Diagnosis
- Provider Information
- Facility of Diagnosis

- Patient History
- Laboratory Data
- Clinical Status
- Treatment/Services Referrals
- HIV Testing & Antiretroviral Use
- Comments
- Local/Optional Fields

INSTRUCTIONS FOR ACRF COMPLETION

Most of the fields on the ACRF are self-explanatory. Fields of greater importance for inclusion as a case in eHARS, or those requiring greater explanation, are described in detail in the Technical Guidance.

Complete instructions for all variables in the ACRF are available in Section I of the *Technical Guidance for HIV Surveillance Programs, Volume II: Data Collection Resources and Reporting* (<http://www2a.cdc.gov/hicsb/>).

The Comments and Local/Optional Fields sections can be used for explaining and expanding on data collected on the ACRF. These sections also can be used to record information not requested on the form. For example, surveillance staff can document investigative progress toward ascertaining risk factor information. Surveillance programs also can choose to collect data elements of local interest. Those can be included in a Local/Optional Fields section.

Information in the Comments and Local/Optional Fields sections is for state/local health department use only and are not transmitted to CDC.



ADULT HIV CONFIDENTIAL CASE REPORT FORM

Page 1

Patient Identification				
*Patient Name	*First Name	*Middle Name	*Last Name	Last Name Soundex
*Alternate Name Type (ex Alias, Married)		*First Name	*Middle Name	*Last Name
Address Type <input type="checkbox"/> Residential <input type="checkbox"/> Bad Address <input type="checkbox"/> Correctional Facility <input type="checkbox"/> Foster Home <input type="checkbox"/> Homeless <input type="checkbox"/> Postal <input type="checkbox"/> Shelter <input type="checkbox"/> Temporary		*Current Street Address		*Phone () _____
City	County	State/Country	*ZIP Code	
*Medical Record Number		*Other ID Type: _____ Number: _____		

U.S. Department of Health & Human Services

Adult HIV Confidential Case Report Form
(Patients ≥13 Years of Age at Time of Diagnosis) * Information NOT transmitted to CDC

Centers for Disease Control and Prevention

Form approved OMB no 0920-0573 Exp. 01/31/2013

Health Department Use Only	
Date Received at Health Department ____/____/____	eHARS Document UID _____ State Number _____
Reporting Health Dept - City / County _____ City/County Number _____	
Document Source _____	Surveillance Method <input type="checkbox"/> Active <input type="checkbox"/> Passive <input type="checkbox"/> Follow up <input type="checkbox"/> Reabstraction <input type="checkbox"/> Unknown
Did this report initiate a new case investigation? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	
Report Medium <input type="checkbox"/> 1-Field Visit <input type="checkbox"/> 2-Mailed <input type="checkbox"/> 3-Faxed <input type="checkbox"/> 4-Phone <input type="checkbox"/> 5-Electronic Transfer <input type="checkbox"/> 6-CD/Disk	

Facility Providing Information (record all dates as mm/dd/yyyy)				
Facility Name _____				*Phone () _____
*Street Address _____				
City	County	State/Country	Zip Code	
Facility Type <i>Inpatient:</i> <input type="checkbox"/> Hospital <input type="checkbox"/> <i>Outpatient:</i> <input type="checkbox"/> Private Physician's Office <input type="checkbox"/> <i>Screening, Diagnostic, Referral Agency:</i> <input type="checkbox"/> CTS <input type="checkbox"/> STD Clinic <input type="checkbox"/> <i>Other Facility:</i> <input type="checkbox"/> Emergency Room <input type="checkbox"/> Adult HIV Clinic <input type="checkbox"/> Laboratory <input type="checkbox"/> Corrections <input type="checkbox"/> Unknown <input type="checkbox"/> Other, specify _____ <input type="checkbox"/> Other, specify _____ <input type="checkbox"/> Other, specify _____				
Date Form Completed ____/____/____		*Person Completing Form _____		*Phone () _____

Patient Demographics (record all dates as mm/dd/yyyy)	
Sex assigned at Birth <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Unknown	Country of Birth <input type="checkbox"/> US <input type="checkbox"/> Other/ US Dependency (please specify) _____
Date of Birth ____/____/____ Alias Date of Birth ____/____/____	
Vital Status <input type="checkbox"/> 1- Alive <input type="checkbox"/> 2- Dead	Date of Death ____/____/____ State of Death _____
Current Gender Identity <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Transgender Male-to-Female (MTF) <input type="checkbox"/> Transgender Female-to-Male (FTM) <input type="checkbox"/> Unknown <input type="checkbox"/> Additional gender identity (specify) _____	
Ethnicity <input type="checkbox"/> Hispanic/Latino <input type="checkbox"/> Not Hispanic/Latino <input type="checkbox"/> Unknown *Expanded Ethnicity _____	
Race (check all that apply) <input type="checkbox"/> American Indian/Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Black/African American <input type="checkbox"/> Native Hawaiian/Pacific Islander <input type="checkbox"/> White <input type="checkbox"/> Unknown *Expanded Race _____	

Residence at Diagnosis (add additional addresses in Comments)			
Address Type (Check all that apply to address below) <input type="checkbox"/> Residence at HIV diagnosis <input type="checkbox"/> Residence at AIDS diagnosis <input type="checkbox"/> Check if <u>SAME as Current Address</u>			
*Street Address _____			
City	County	State/Country	*ZIP Code

This report to the Centers for Disease Control and Prevention (CDC) is authorized by law (Sections 304 and 306 of the Public Health Service Act, 42 USC 242b and 242k). Response in this case is voluntary for federal government purposes, but may be mandatory under state and local statutes. Your cooperation is necessary for the understanding and control of HIV/AIDS. Information in CDC's HIV/AIDS surveillance system that would permit identification of any individual on whom a record is maintained, is collected with a guarantee that it will be held in confidence, will be used only for the purposes stated in the assurance on file at the local health department, and will not otherwise be disclosed or released without the consent of the individual in accordance with Section 308(d) of the Public Health Service Act (42 USC 242m).

CDC 50.42A Rev. 6/2011 (Page 1 of 4)
—ADULT HIV CONFIDENTIAL CASE REPORT—

ADULT HIV CONFIDENTIAL CASE REPORT FORM

Page 2

STATE/LOCAL USE ONLY	– Patient identifier information is not transmitted to CDC! –
Physician's Name: (Last, First, M.I.) _____ Phone No: () _____ Medical Record No. _____	
Hospital/Facility: _____ Person Completing Form: _____ Phone No: () _____	
Facility of Diagnosis (add additional facilities in Comments)	
Diagnosis Type <input type="checkbox"/> HIV <input type="checkbox"/> AIDS (check all that apply to facility below) <input type="checkbox"/> Check if <u>SAME</u> as Facility Providing Information	
Facility Name _____ *Phone () _____	
*Street Address _____	
City _____	County _____
State/Country _____	Zip Code _____
Facility Type <i>Inpatient:</i> <input type="checkbox"/> Hospital <input type="checkbox"/> Other, specify _____ <i>Outpatient:</i> <input type="checkbox"/> Private Physician's Office <input type="checkbox"/> Adult HIV Clinic <input type="checkbox"/> Other, specify _____ <i>Screening, Diagnostic, Referral Agency:</i> <input type="checkbox"/> CTS <input type="checkbox"/> STD Clinic <input type="checkbox"/> Other, specify _____ <i>Other Facility:</i> <input type="checkbox"/> Emergency Room <input type="checkbox"/> Laboratory <input type="checkbox"/> Corrections <input type="checkbox"/> Unknown <input type="checkbox"/> Other, specify _____	
*Provider Name _____	*Provider Phone () _____
*Specialty _____	
Patient History (respond to all questions) (record all dates as mm/dd/yyyy) <input type="checkbox"/> Pediatric risk (please enter in Comments)	
After 1977 and before the earliest known diagnosis of HIV infection, this patient had:	
Sex with male	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Sex with female	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Injected non-prescription drugs	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Received clotting factor for hemophilia/ coagulation disorder	Specify clotting factor: _____ Date received (mm/dd/yyyy): ____/____/____ <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
HETEROSEXUAL relations with any of the following:	
HETEROSEXUAL contact with intravenous/injection drug user	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
HETEROSEXUAL contact with bisexual male	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
HETEROSEXUAL contact with person with hemophilia / coagulation disorder with documented HIV infection	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
HETEROSEXUAL contact with transfusion recipient with documented HIV infection	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
HETEROSEXUAL contact with transplant recipient with documented HIV infection	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
HETEROSEXUAL contact with person with AIDS or documented HIV Infection, risk not specified	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Received transfusion of blood/blood components (other than clotting factor) (document reason in Comments section)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
First date received ____/____/____ Last date received ____/____/____	
Received transplant of tissue/organs or artificial insemination	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Worked in a healthcare or clinical laboratory setting	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
If occupational exposure is being investigated or considered as primary mode of exposure, specify occupation and setting.	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Other documented risk (please include detail in Comments section)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Public reporting burden of this collection of information is estimated to average 20 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC, Project Clearance Officer, 1600 Clifton Road, MS D-74, Atlanta, GA 30333, ATTN: (PRA) (0920-0573). Do not send the completed form to this address.	
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ADULT HIV CONFIDENTIAL CASE REPORT FORM

Page 3

Laboratory Data (record additional tests in Comments section)

HIV Antibody Tests (Non-type differentiating) [HIV-1 vs. HIV-2]

TEST 1: HIV-1 EIA HIV-1/2 EIA HIV-1/2 Ag/Ab HIV-1 WB HIV-1 IFA HIV-2 EIA HIV-2 WB Other: Specify Test: _____

RESULT: Positive/Reactive Negative/Nonreactive Indeterminate **RAPID TEST (check if rapid):** **Collection Date:** ____/____/____

TEST 2: HIV-1 EIA HIV-1/2 EIA HIV-1/2 Ag/Ab HIV-1 WB HIV-1 IFA HIV-2 EIA HIV-2 WB Other: Specify Test: _____

RESULT: Positive/Reactive Negative/Nonreactive Indeterminate **RAPID TEST (check if rapid):** **Collection Date:** ____/____/____

HIV Antibody Tests (Type differentiating) [HIV-1 vs. HIV-2]

TEST: HIV-1/2 Differentiating (e.g., Multispot)

RESULT: HIV-1 HIV-2 Both (undifferentiated) Neither (negative) **Collection Date:** ____/____/____

HIV Detection Tests (Qualitative)

TEST 1: HIV-1 RNA/DNA NAAT (Qual) HIV-1 P24 Antigen HIV-1 Culture HIV-2 RNA/DNA NAAT (Qual) HIV-2 Culture

RESULT: Positive/Reactive Negative/Nonreactive Indeterminate **Collection Date:** ____/____/____

TEST 2: HIV-1 RNA/DNA NAAT (Qual) HIV-1 P24 Antigen HIV-1 Culture HIV-2 RNA/DNA NAAT (Qual) HIV-2 Culture

RESULT: Positive/Reactive Negative/Nonreactive Indeterminate **Collection Date:** ____/____/____

HIV Detection Tests (Quantitative viral load) Note: Include earliest test after diagnosis

TEST 1: HIV-1 RNA/DNA NAAT (Quantitative viral load)

RESULT: Detectable Undetectable **Copies/mL:** _____ **Log:** _____ **Collection Date:** ____/____/____

TEST 2: HIV-1 RNA/DNA NAAT (Quantitative viral load)

RESULT: Detectable Undetectable **Copies/mL:** _____ **Log:** _____ **Collection Date:** ____/____/____

Immunologic Tests (CD4 count and percentage)

CD4 at or closest to current diagnostic status: CD4 count: _____ cells/ μ L **CD4 percentage:** ____% **Collection Date:** ____/____/____

First CD4 result <200 cells/ μ L or <14%: CD4 count: _____ cells/ μ L **CD4 percentage:** ____% **Collection Date:** ____/____/____

Documentation of Tests

Date of last documented negative HIV test: ____/____/____

If HIV laboratory tests were not documented, is HIV diagnosis documented by a physician?
 Yes No Unknown

Specify type of test: _____

If YES, provide date of documentation by physician: ____/____/____

Clinical (select D for Definitive or P for Presumptive where applicable) (record all dates as mm/dd/yyyy)

	D	P	Date		D	P	Date		D	P	Date
Candidiasis, bronchi, trachea, or lungs				Herpes simplex: chronic ulcers (>1 mo. duration), bronchitis, pneumonitis, or esophagitis				M. tuberculosis, pulmonary*			
Candidiasis, esophageal				Histoplasmosis, disseminated or extrapulmonary				M. tuberculosis, disseminated or extrapulmonary*			
Carcinoma, invasive cervical				Isosporiasis, chronic intestinal (>1 mo. duration)				Mycobacterium, of other/undefined species, disseminated or extrapulmonary			
Coccidioidomycosis, disseminated or extrapulmonary				Kaposi's sarcoma				Pneumocystis pneumonia			
Cryptococcosis, extrapulmonary				Lymphoma, Burkitt's (or equivalent)				Pneumonia, recurrent, in 12 mo. period			
Cryptosporidiosis, chronic intestinal (>1 mo. duration)				Lymphoma, immunoblastic (or equivalent)				Progressive multifocal leukoencephalopathy			
Cytomegalovirus disease (other than in liver, spleen, or nodes)				Lymphoma, primary in brain				Salmonella septicemia, recurrent			
Cytomegalovirus retinitis (with loss of vision)				Mycobacterium avium complex or M. kansasii, disseminated or extrapulmonary				Toxoplasmosis of brain, onset at >1 mo. of age			
HIV encephalopathy								Wasting syndrome due to HIV			

*If TB selected above, indicate RVCT Case Number: _____

Pediatric HIV Confidential Case Report Form (PCRf)

Instructions for completing the PCRf are the same as for completing the ACRf. The PCRf contains additional data elements related to maternal and child risk and treatment.

PURPOSE OF THE PCRf

The PCRf is designed to collect information that promotes understanding of HIV morbidity and mortality among persons <13 years of age at diagnosis. *This form reflects data that should be collected; these guidelines apply to this data collection even if surveillance sites use a different form or medium for HIV case surveillance.*

THE PCRf IN THE CONTEXT OF DOCUMENT-BASED SURVEILLANCE

Unlike case-based data management, document-based data management enables all documents to be stored and retained electronically in their original formats. Instead of completing one form for a given reported case, fill out the applicable part of the form for each data source contributing to that case.

PATIENTS FOR WHOM THE PCRf IS INDICATED

- Each child whose illness meets the pediatric HIV case definition (including Stage 3 [AIDS]).
- In areas with confidential perinatal exposure HIV reporting, all children born to HIV-infected mothers, including children whose infection status has not yet been determined, seroreverters, and children exposed but determined not to be infected with HIV; inclusion of such patients is for public health surveillance purposes only.

A federal assurance of confidentiality applies to information about children exposed perinatally with or without consequent infection.

EXPLANATION OF VARIABLE DESIGNATORS

- **Required:** Variables that are required to meet the case definition of HIV, to identify and track cases, and to conduct meaningful statistical analysis
- **Recommended:** Information useful for analysis but not essential for core surveillance
- **Optional:** Information that should be ascertained if readily available

DISPOSITION OF PCRf

- The completed form is for state or local health agency use and is not to be sent to CDC with patient identifiers. Some of the Pacific Territory sites send forms to CDC for data entry; those forms do not contain patient identifying information.
- Data obtained from these forms are entered into standardized computer software (eHARS) provided by CDC, and then transferred without identifiers to CDC electronically through a secure data network.

The PCRf provided by CDC is divided into 14 sections:

- Patient Identification
- Health Department Use Only
- Facility Providing Information
- Patient Demographics
- Residence at Diagnosis
- Provider Information
- Facility of Diagnosis
- Patient History
- Laboratory Data
- Clinical
- Birth History (for Perinatal Cases Only)
- Services Referrals
- Comments
- Local/Optional Fields

INSTRUCTIONS FOR PCRf COMPLETION

Most fields on the PCRf are self-explanatory. Those of greater importance for inclusion as a case in eHARS, or those requiring greater explanation, are described in detail in the Technical Guidance.

Complete instructions for all the variables in the PCRf are available in Section I of the *Technical Guidance for HIV Surveillance Programs, Volume II: Data Collection Resources and Reporting* (<http://www2a.cdc.gov/hicsb/>).

The Comments and Local/Optional Fields sections can be used for explaining and expanding on data collected on the PCRf. These sections also can be used to record information not requested on the form. For example, surveillance staff can document investigative progress toward ascertainment of risk factor information. Surveillance programs also might choose to collect data elements of local interest. Those can be included in a Local/Optional Fields section.

The information in the Comments and Local/Optional Fields sections are for state/local health department use only and are not transmitted to CDC.



PEDIATRIC HIV CONFIDENTIAL CASE REPORT FORM

Page 1

Patient Identification				
*Patient Name	*First Name	*Middle Name	*Last Name	Last Name Soundex
*Alternate Name Type (ex Birth, Call Me)	*First Name	*Middle Name	*Last Name	
Address Type <input type="checkbox"/> Residential <input type="checkbox"/> Bad Address <input type="checkbox"/> Correctional Facility <input type="checkbox"/> Foster Home <input type="checkbox"/> Homeless <input type="checkbox"/> Postal <input type="checkbox"/> Shelter <input type="checkbox"/> Temporary		*Current Street Address		*Phone () _____
City	County	State/Country	*ZIP Code	
*Medical Record Number		*Other ID Type:	Number:	

Pediatric HIV Confidential Case Report Form
(Patients <13 Years of Age at Time of Diagnosis) * Information NOT transmitted to CDC

U.S. Department of Health & Human Services Centers for Disease Control and Prevention

Form approved OMB no 0920-0573 Exp. 01/31/2013

Health Department Use Only	
Date Received at Health Department	eHARS Document UID
State Number	
Reporting Health Dept - City / County	City/County Number
Document Source	Surveillance Method <input type="checkbox"/> Active <input type="checkbox"/> Passive <input type="checkbox"/> Follow up <input type="checkbox"/> Reabstraction <input type="checkbox"/> Unknown
Did this report initiate a new case investigation? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	Report Medium <input type="checkbox"/> 1-Field Visit <input type="checkbox"/> 2-Mailed <input type="checkbox"/> 3-Faxed <input type="checkbox"/> 4-Phone <input type="checkbox"/> 5-Electronic Transfer <input type="checkbox"/> 6-CD/Disk

Facility Providing Information (record all dates as mm/dd/yyyy)			
Facility Name			*Phone () _____
*Street Address			
City	County	State/Country	Zip Code
Facility Type <input type="checkbox"/> Inpatient: <input type="checkbox"/> Hospital <input type="checkbox"/> Other, specify _____	Outpatient: <input type="checkbox"/> Private Physician's Office <input type="checkbox"/> Pediatric Clinic <input type="checkbox"/> Pediatric HIV Clinic <input type="checkbox"/> Other, specify _____		Other Facility: <input type="checkbox"/> Emergency Room <input type="checkbox"/> Laboratory <input type="checkbox"/> Unknown <input type="checkbox"/> Other, specify _____
Date Form Completed	*Person Completing Form	*Phone () _____	

Patient Demographics (record all dates as mm/dd/yyyy)			
Diagnostic Status at Report <input type="checkbox"/> 3-Perinatal HIV Exposure <input type="checkbox"/> 4-Pediatric HIV <input type="checkbox"/> 5-Pediatric AIDS <input type="checkbox"/> 6-Pediatric Seroreverter		Sex assigned at Birth <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Unknown	Country of Birth <input type="checkbox"/> US <input type="checkbox"/> Other/ US Dependency (please specify)
Date of Birth		Alias Date of Birth	
Vital Status <input type="checkbox"/> 1-Alive <input type="checkbox"/> 2-Dead	Date of Death	State of Death	
Date of Last Medical Evaluation		Date of Initial Evaluation for HIV	
Ethnicity <input type="checkbox"/> Hispanic/Latino <input type="checkbox"/> Not Hispanic/Latino <input type="checkbox"/> Unknown			*Expanded Ethnicity
Race (check all that apply) <input type="checkbox"/> American Indian/Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Black/African American <input type="checkbox"/> Native Hawaiian/Pacific Islander <input type="checkbox"/> White <input type="checkbox"/> Unknown			*Expanded Race

Residence at Diagnosis (add additional addresses in Comments)					
Address Type (Check all that apply to address below) <input type="checkbox"/> Residence at HIV diagnosis <input type="checkbox"/> Residence at AIDS diagnosis <input type="checkbox"/> Residence at Perinatal Exposure <input type="checkbox"/> Residence at Pediatric Seroreverter <input type="checkbox"/> Check if SAME as Current Address					
* Street Address					
City	County	State/Country	*ZIP Code		

This report to the Centers for Disease Control and Prevention (CDC) is authorized by law (Sections 304 and 306 of the Public Health Service Act, 42 USC 242b and 242k). Response in this case is voluntary for federal government purposes, but may be mandatory under state and local statutes. Your cooperation is necessary for the understanding and control of HIV/AIDS. Information in CDC's HIV/AIDS surveillance system that would permit identification of any individual on whom a record is maintained, is collected with a guarantee that it will be held in confidence, will be used only for the purposes stated in the assurance on file at the local health department, and will not otherwise be disclosed or released without the consent of the individual in accordance with Section 308(d) of the Public Health Service Act (42 USC 242m).

CDC 50.42B Rev. 6/2011 (Page 1 of 4) —PEDIATRIC HIV CONFIDENTIAL CASE REPORT—

PEDIATRIC HIV CONFIDENTIAL CASE REPORT FORM

Page 2

STATE/LOCAL USE ONLY	– Patient identifier information is not transmitted to CDC! –
Physician's Name: (Last, First, M.I.) _____ Phone No: () _____ Medical Record No. _____	
Hospital/Facility: _____ Person Completing Form: _____ Phone No: () _____	
Facility of Diagnosis (add additional facilities in Comments)	
Diagnosis Type <input type="checkbox"/> HIV <input type="checkbox"/> AIDS <input type="checkbox"/> Perinatal Exposure (check all that apply to facility below) <input type="checkbox"/> Check if <u>SAME</u> as Facility Providing Information	
Facility Name _____	*Phone () _____
*Street Address _____	
City _____	County _____
State/Country _____	Zip Code _____
Facility Type <u>Inpatient</u> : <input type="checkbox"/> Hospital <input type="checkbox"/> Other, specify _____ <u>Outpatient</u> : <input type="checkbox"/> Private Physician's Office <input type="checkbox"/> Pediatric Clinic <input type="checkbox"/> Pediatric HIV Clinic <input type="checkbox"/> Other, specify _____ <u>Other Facility</u> : <input type="checkbox"/> Emergency Room <input type="checkbox"/> Laboratory <input type="checkbox"/> Unknown <input type="checkbox"/> Other, specify _____	
*Provider Name _____	*Provider Phone () _____
*Specialty _____	
Patient History (respond to all questions) (record all dates as mm/dd/yyyy)	
Child's biological mother's HIV infection status (select one): <input type="checkbox"/> 1-Refused HIV testing <input type="checkbox"/> 2-Known to be uninfected after this child's birth <input type="checkbox"/> 3-Known HIV+ before pregnancy <input type="checkbox"/> 4-Known HIV+ during pregnancy <input type="checkbox"/> 5-Known HIV+ sometime before birth <input type="checkbox"/> 6-Known HIV+ at delivery <input type="checkbox"/> 7-Known HIV+ after child's birth <input type="checkbox"/> 8-HIV+, time of diagnosis unknown <input type="checkbox"/> 9-HIV status unknown	
Date of mother's first positive HIV confirmatory test: ____/____/____	Was the biological mother counseled about HIV testing during this pregnancy, labor, or delivery? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
After 1977 and before the earliest known diagnosis of HIV infection, this child's biological mother had:	
Perinatally acquired HIV Infection	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Injected non-prescription drugs	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Biological Mother had HETEROSEXUAL relations with any of the following:	
HETEROSEXUAL contact with intravenous/injection drug user	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
HETEROSEXUAL contact with bisexual male	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
HETEROSEXUAL contact with person with hemophilia / coagulation disorder with documented HIV infection	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
HETEROSEXUAL contact with transfusion recipient with documented HIV infection	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
HETEROSEXUAL contact with transplant recipient with documented HIV infection	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
HETEROSEXUAL contact with person with AIDS or documented HIV Infection, risk not specified	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Received transfusion of blood/blood components (other than clotting factor) (document reason in Comments section)	
First date received ____/____/____ Last date received ____/____/____	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Received transplant of tissue/organs or artificial insemination	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Before the diagnosis of HIV infection, this child had:	
Injected non-prescription drugs	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Received clotting factor for hemophilia/ coagulation disorder	Specify clotting factor: _____ Date received (mm/ dd/yyyy): ____/____/____ <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Received transfusion of blood/blood components (other than clotting factor) (document reason in Comments section)	
First date received ____/____/____ Last date received ____/____/____	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Received transplant of tissue/organs	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Sexual contact with male	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Sexual contact with female	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
Other Documented Risk (please include detail in Comments section)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown
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PEDIATRIC HIV CONFIDENTIAL CASE REPORT FORM

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Laboratory Data (record additional tests in Comments section)

HIV Antibody Tests (Non-type differentiating) [HIV-1 vs. HIV-2]

TEST 1: HIV-1 EIA HIV-1/2 EIA HIV-1/2 Ag/Ab HIV-1 WB HIV-1 IFA HIV-2 EIA HIV-2 WB Other: Specify Test: _____

RESULT: Positive/Reactive Negative/Nonreactive Indeterminate **RAPID TEST (check if rapid):** **Collection Date:** ___/___/___

TEST 2: HIV-1 EIA HIV-1/2 EIA HIV-1/2 Ag/Ab HIV-1 WB HIV-1 IFA HIV-2 EIA HIV-2 WB Other: Specify Test: _____

RESULT: Positive/Reactive Negative/Nonreactive Indeterminate **RAPID TEST (check if rapid):** **Collection Date:** ___/___/___

HIV Antibody Tests (Type differentiating) [HIV-1 vs. HIV-2]

TEST: HIV-1/2 Differentiating (e.g., Multispot)

RESULT: HIV-1 HIV-2 Both (undifferentiated) Neither (negative) **Collection Date:** ___/___/___

HIV Detection Tests (Qualitative)

TEST 1: HIV-1 RNA/DNA NAAT (Qual) HIV-1 P24 Antigen HIV-1 Culture HIV-2 RNA/DNA NAAT (Qual) HIV-2 Culture

RESULT: Positive/Reactive Negative/Nonreactive Indeterminate **Collection Date:** ___/___/___

TEST 2: HIV-1 RNA/DNA NAAT (Qual) HIV-1 P24 Antigen HIV-1 Culture HIV-2 RNA/DNA NAAT (Qual) HIV-2 Culture

RESULT: Positive/Reactive Negative/Nonreactive Indeterminate **Collection Date:** ___/___/___

HIV Detection Tests (Quantitative viral load) Note: Include earliest test after diagnosis

TEST 1: HIV-1 RNA/DNA NAAT (Quantitative viral load)

RESULT: Detectable Undetectable **Copies/mL:** _____ **Log:** _____ **Collection Date:** ___/___/___

TEST 2: HIV-1 RNA/DNA NAAT (Quantitative viral load)

RESULT: Detectable Undetectable **Copies/mL:** _____ **Log:** _____ **Collection Date:** ___/___/___

Immunologic Tests (CD4 count and percentage)

CD4 at or closest to current diagnostic status: CD4 count: _____ cells/μL CD4 percentage: _____% **Collection Date:** ___/___/___

First CD4 result <200 cells/μL or <14%: CD4 count: _____ cells/μL CD4 percentage: _____% **Collection Date:** ___/___/___

Documentation of Tests

If laboratory tests were not documented, HIV-Infected Yes No Unknown **Date of Documentation:** ___/___/___

is patient confirmed by a physician as: Not HIV-Infected Yes No Unknown **Date of Documentation:** ___/___/___

Clinical (select D for Definitive or P for Presumptive where applicable) (record all dates as mm/dd/yyyy)

	D	P	Date		D	P	Date
Bacterial infection, multiple or recurrent (including Salmonella septicemia)				Kaposi's sarcoma			
Candidiasis, bronchi, trachea, or lungs				Lymphoid interstitial pneumonia and/or pulmonary lymphoid hyperplasia			
Candidiasis, esophageal				Lymphoma, Burkitt's (or equivalent)			
Coccidioidomycosis, disseminated or extrapulmonary				Lymphoma, immunoblastic (or equivalent)			
Cryptococcosis, extrapulmonary				Lymphoma, primary in brain			
Cryptosporidiosis, chronic intestinal (>1 mo. duration)				Mycobacterium avium complex or M. kansasii, disseminated or extrapulmonary			
Cytomegalovirus disease (other than in liver, spleen, or nodes)				M. tuberculosis, disseminated or extrapulmonary [†]			
Cytomegalovirus retinitis (with loss of vision)				Mycobacterium, of other/unidentified species, disseminated or extrapulmonary			
HIV encephalopathy				Pneumocystis pneumonia			
Herpes simplex: chronic ulcers (>1 mo. duration), bronchitis, pneumonitis, or esophagitis				Progressive multifocal leukoencephalopathy			
Histoplasmosis, disseminated or extrapulmonary				Toxoplasmosis of brain, onset at >1 mo. of age			
Isosporiasis, chronic intestinal (>1 mo. duration)				Wasting syndrome due to HIV			

Has this child been diagnosed with pulmonary tuberculosis? Yes No Unknown **If Yes, initial diagnosis:** Definitive Presumptive Unknown **Date:** _____ **[†]If TB selected above, indicate RVCT Case Number:** _____

Public reporting burden of this collection of information is estimated to average 20 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC, Project Clearance Officer, 1600 Clifton Road, MS D-74, Atlanta, GA 30333, ATTN: (PRA) (0920-0573). **Do not send the completed form to this address.**

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PEDIATRIC HIV CONFIDENTIAL CASE REPORT FORM

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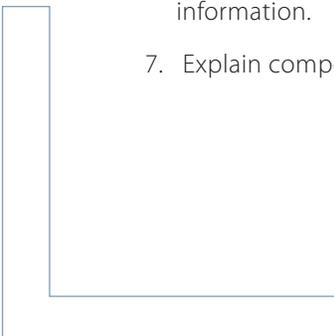
Birth History (for Perinatal Cases only)			
Birth History Available <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Residence at Birth <input type="checkbox"/> Check if SAME as Current Address	
* Street Address		City	
County	State/Country	*Zip Code	
Hospital of Birth			
<input type="checkbox"/> Check if SAME as Facility Providing Information			
Facility Name		*Phone ()	Zip Code
*Street Address	City	County	State/Country
Birth History			
Birth Weight _ lbs _ oz _ grams	Type <input type="checkbox"/> 1-Single <input type="checkbox"/> 2-Twin <input type="checkbox"/> 3->2 <input type="checkbox"/> 9-Unknown	Delivery <input type="checkbox"/> 1-Vaginal <input type="checkbox"/> 2-Elective Cesarean <input type="checkbox"/> 3-Non-Elective Cesarean <input type="checkbox"/> 4-Cesarean, unknown type <input type="checkbox"/> 9-Unknown	
Birth Defects <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	If yes, please specify:		
Neonatal Status <input type="checkbox"/> 1-Full-term <input type="checkbox"/> 2-Premature <input type="checkbox"/> Unknown	Neonatal Status Weeks: _____ (99-Unknown)		
Prenatal Care – Month of Pregnancy Prenatal Care began (00-None, 99-Unknown)	Prenatal Care - Total number of prenatal care visits: _____ (00-None, 99-Unknown)		
Did mother receive zidovudine (ZDV,AZT) during pregnancy: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Refused <input type="checkbox"/> Unknown	If yes, what week of pregnancy was zidovudine (ZDV, AZT) started: _____ (99-Unknown)		
Did mother receive zidovudine (ZDV,AZT) during labor/delivery: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Refused <input type="checkbox"/> Unknown	Did mother receive zidovudine (ZDV,AZT) prior to this pregnancy: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		
Did mother receive any other Anti-retroviral medication during pregnancy? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	If yes, please specify:		
Did mother receive any other Anti-retroviral medication during labor/delivery? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown	If yes, please specify:		
Maternal Information			
Maternal DOB	Maternal Soundex	Maternal Stateno	Maternal Country of Birth
*Other Maternal ID – List Type:		Number:	
Services Referrals (record all dates as mm/dd/yyyy)			
This child received or is receiving:			
Neonatal zidovudine (ZDV,AZT) for HIV prevention: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Date: ____/____/____	
Other neonatal anti-retroviral medication for HIV prevention: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Date: ____/____/____	
If Yes, please specify: 1) _____ 2) _____ 3) _____ 4) _____ 5) _____			
Anti-retroviral therapy for HIV treatment: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Date: ____/____/____	
PCP Prophylaxis: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Date: ____/____/____	
Was this child breastfed? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown			
This child's primary caretaker is: <input type="checkbox"/> 1- Biological Parent <input type="checkbox"/> 2- Other Relative <input type="checkbox"/> 3- Foster/Adoptive parent, relative <input type="checkbox"/> 4- Foster/Adoptive parent, unrelated <input type="checkbox"/> 7- Social Service Agency <input type="checkbox"/> 8- Other (please specify in comments) <input type="checkbox"/> 9- Unknown			
*Comments			
*Local / Optional Fields			

MODULE THREE

Managing Collection
of Surveillance Data

OBJECTIVES:

1. Explain how collection of HIV surveillance data is managed.
2. Explain differences between the terms *passive surveillance* and *active surveillance*.
3. Explain how to establish an active HIV surveillance system.
4. Identify major reporting sources of HIV surveillance data.
5. Explain components of the medical world and how they relate to HIV surveillance.
6. Demonstrate why and how medical records should be reviewed for HIV surveillance information.
7. Explain components of the medical examination and medical record.



Managing Data Collection

The information in this section will help surveillance staff build and manage an HIV data collection system. Surveillance staff should design the system to fit the needs and staffing of their particular area; however, consultation with staff in the HIV Incidence and Case Surveillance Branch at CDC is suggested to ensure the system meets surveillance standards.

DISTRIBUTION OF FORMS

The Adult HIV Confidential Case Report Form (ACRF; CDC50.42A) is used for reporting HIV infection in persons ≥ 13 years of age. The Pediatric HIV Confidential Case Report Form (PCRf; CDC50.42B) is used for reporting HIV infection in persons <13 years of age. HIV surveillance staff can download the reporting forms directly from the CDC secure surveillance website. Photocopies of case report forms are acceptable. Surveillance staff should establish a system to ensure that forms are readily available to reporting sources in their areas.

In some states, local HIV surveillance staff complete all the case report forms through medical chart abstraction and record review. In other states, surveillance staff and county health department staff supply case forms to physicians, hospitals, and clinics. In addition, surveillance staff teach reporting sources to properly complete the case report form, which provides an opportunity to build a reporting system. Training can be conducted at hospital staff meetings or at infection control meetings.

ENHANCED HIV/AIDS REPORTING SYSTEM

The [Enhanced HIV/AIDS Reporting System \(eHARS\)](#) is a data collection software developed by CDC. All HIV surveillance areas use this system to collect and maintain HIV case report information electronically, along with the hard copy. Case reports are downloaded onto the central eHARS registry at the state surveillance program. The data are reviewed for completeness and accuracy and then electronically encrypted and transmitted, without personal identifiers, to CDC for inclusion in the national HIV surveillance registry.

FACILITY/PROVIDER FILE

The purpose of a facility/provider file is to track information about facilities/providers that treat or diagnose HIV infection. The following information is required.

- Name of facility
- Address
- Phone number
- Contact person
- Fax number
- Email, if available, for nonconfidential communication
- Office manager's name
- Copy of permission to follow up for HIV
- Laboratories used for HIV testing
- Availability of CD4 test results
- Medical doctor's name(s)
- Availability of electronic reporting (Note: **All** information taken from a facility in electronic form **must be encrypted**)

HIV CASE FILE

Once cases are entered into eHARS, surveillance staff should forward the case report form and pertinent notes to the state HIV surveillance program with the eHARS transfer. For security reasons, hard copy case reports should not be kept at the local level, except for

- Non-eHARS users
- Transplant and transfusion cases
- Cases with an unusual transmission
- Cases under special investigation
- Pediatric cases

ACTIVITY RECORD

A system should be developed to account for activities, such as training sessions and surveillance visits to hospitals, clinics, and physicians' offices. This system will assist staff with filling out the required biannual progress report and evaluating work priorities. A system can be as simple as a monthly calendar or as complex as a computer program to record staff activities.

TICKLER FILES

Tickler or pending files are kept as reminders of actions or reviews that must be completed, for example

- Phone calls
- Field visits
- Follow-up permission requests

Labeling folders with color-coded flags or by date might prove useful.

TELEPHONE USE

Using the telephone to gather information is a proven method for expediting case reporting. Surveillance staff often need to phone physicians, nurses, hospital record department staff, and staff in other agencies to request additional case reporting information.

Before placing a call to a reporting source, prepare by

- Securing a confidential location in which to conduct the call
- Identifying the information you want to obtain through the call
- Developing an opening statement
- Anticipating problem areas
- Writing down questions

Remember to

- Properly identify yourself
- Know the identity of the other person
- Inform the other person that you intend to discuss confidential information in case he/she needs to relocate to a confidential area
- Conduct all conversations involving HIV infection securely and confidentially
- Use terminology appropriate for discussing HIV surveillance issues (i.e., proper medical terminology and not slang)

- During or immediately after the call, document all information obtained, including the name of the person spoken with during the call

Passive Versus Active Surveillance

Among the several types of surveillance are **passive** and **active** surveillance. Passive surveillance is initiated by the provider, while active surveillance is initiated by the health department.

In a passive surveillance system, physicians, laboratories and hospitals are required to send case reports to local health departments where the results are processed. The “direct costs” (personnel and financial resources for the state surveillance program) of a passive surveillance system are relatively low. Although a passive system uses fewer resources than does an active system, it usually results in underreporting and a lack of timeliness and completeness of reporting.

In an active surveillance system, health department staff solicit case reports from likely sources. Active surveillance involves identifying reporting sources and establishing communication with personnel, facilities, and laboratories that provide services to HIV-infected persons. Active case finding is necessary for timely and complete reporting of HIV surveillance information.

Active surveillance

- Provides greater reliability in monitoring HIV diagnoses and trends in morbidity and mortality
- Identifies emerging transmission categories
- Guides laboratory studies and epidemiologic investigations
- Provides data that can be used to project health-care costs

Active surveillance requires frequent communication between surveillance staff and reporting sources through face-to-face meetings, telephone contact, and/or correspondence to stimulate and encourage reporting of HIV cases. Communication also can include periodic medical record reviews, quarterly requests for data, and review of hospital discharge summaries and death certificates.

Surveillance systems usually comprise both active and passive components. The organization of a surveillance system and the level of effort expended by state and local health departments depend on multiple factors. These include

- Extent of the problem
- Cooperation of physicians and other health-care professionals
- Resources available to devote to surveillance
- State laws covering reporting requirements, which also influence the effectiveness of the surveillance system and the design of an active program

Certain indicators show HIV surveillance staff when active surveillance is needed. Such indicators include

- **Excessive delay in reporting.** Ideally, 80% of HIV cases should be reported within 6 months after diagnosis. Generating frequency reports in eHARS by “dxmoyr” and “arptdate” by month for a 6–12-month period enables surveillance staff to measure this indicator.
- **A decrease over time in the number of cases reported by a particular source or facility of diagnosis.** Reporting trends among providers (hosp-dx field in eHARS) should be generated from eHARS on a regular basis. A review of these trends, as well as informal discussions with laboratories, health-care providers, and community-based organizations, helps to determine what level of active surveillance needs to be targeted toward reporting or potential reporting sites.

- **Routine, systematic review of death certificates available through vital statistics offices at the county health department can reveal cases not previously reported.**

Active surveillance activities should be prioritized to maximize the case yield for the expenditure of staff time. Providers who report relatively few cases should be visited less often and encouraged to complete the reports themselves. Providers should have validation studies to evaluate case reporting activities at least once or twice a year, depending on morbidity. Such validation studies include review of a sample of case reports by health department staff and reabstraction of critical surveillance elements (e.g., age, sex, race, transmission risk) to confirm accuracy of surveillance information. Additional information on evaluation is available in [Module 7—Evaluating HIV Surveillance Programs](#).

Surveillance programs differ in regard to use of passive and active surveillance for collecting public health information about cases of HIV disease. Surveillance staff must evaluate their systems critically and, where indicated by such factors as resource availability and completeness and timeliness of reporting, make concerted efforts to convince providers to complete case report forms themselves and submit completed forms to the health department. Success of such an effort gives surveillance staff more time for surveillance activities with major reporting providers.

Establishing an Active HIV Reporting Network

Surveillance staff should routinely promote HIV surveillance to ensure that physicians, laboratorians, and other health-care workers are aware of state reporting laws, the importance of surveillance, and the multiple uses of surveillance data. Many techniques have been used successfully to introduce community agencies to, and familiarize them with, HIV surveillance staff and surveillance goals, including

- Routinely publishing newsletters with statistical data and abbreviated, user-friendly reporting forms
- Sending annual “Dear Doctor” letters
- Participating in local and regional meetings or seminars
- Participating on expert advisory panels or task forces
- Providing technical assistance to local community planning groups
- Teaching medical and public health students
- Presenting surveillance data to medical societies and infection control practitioner organizations

Some surveillance programs have produced pamphlets that encourage infected persons to ask their providers to complete case reports on them. These pamphlets outline the importance of surveillance to understanding the epidemic, emphasize established and reliable confidentiality procedures, and explain the relation between accurate case counts and funding for HIV preventive and patient-care services in their communities.

Your first step in establishing an active HIV surveillance system is to identify, contact, and involve medical and community groups that have contact with HIV-positive persons or interest in the HIV epidemic. Provide HIV surveillance information packets when meeting with new reporting sources. These packets should include

- Reporting law(s)
- State and local HIV statistics (including Stage 3 [AIDS])
- Case reporting forms
- Local resources for clients
- Local surveillance contact information

Contacting community-based organizations and medical groups who are involved with the HIV community is an effective way to share information, stimulate reporting, maximize cooperation, and involve the medical and academic communities with the surveillance initiative. State HIV surveillance personnel are available to help local staff establish, develop, and implement an active surveillance system.

Identifying Major Reporting Sources of HIV and AIDS

SOURCES OF HIV CASE INFORMATION

Useful sources of HIV case information in acute-care institutions include

- Infection control practitioners
- Medical records staff
- Charge nurses
- Social workers
- Discharge planners
- Billing office staff
- Virology or immunology laboratory staff
- Computer information systems staff
- Pediatric clinic staff

Because many hospitals perform CD4 laboratory tests or maintain a log of CD4 test results from reference laboratories, an active surveillance system should include all hospitals in the HIV surveillance catchment area. Surveillance staff should meet with the hospital laboratory director to request CD4 results that are reportable under state public health laws and regulations. All states require reporting of CD4 results <200 cells/ μ L or 14% and positive tests used to diagnose HIV. Check with your surveillance program to learn what level of CD4 result is reportable in your state.

Surveillance staff also should be familiar with the medical laboratories in their areas that conduct tests used to diagnose HIV. Periodic laboratory visits are useful to establish and maintain HIV case reporting procedures.

Reporting requirement periods can differ for various reporting sources. For example, laboratories might be required to report test results within a shorter period, and physicians might be allowed more time in which to report new diagnoses. Surveillance staff need to be aware of potential differences in reporting periods and decide on an appropriate period for initiating surveillance activities. It may be prudent when receiving a laboratory report of a new HIV diagnosis to contact the health-care provider who ordered the test to discuss the new case and determine whether the provider has initiated a surveillance case report on the patient with newly diagnosed infection.

All surveillance staff need to develop an information exchange with their reporting sources. The local health department director or his/her designee might need to assist initial liaison with hospital officials and should be asked to intervene when necessary to facilitate the reporting process. This opportunity also can be used to educate hospital officials about the need for complete case report information, including information about HIV transmission risks. Once the reporting process is established, site-specific data analysis and reports should be routinely generated to inform individual providers who report HIV cases.

MATCHING DISEASE CONTROL REGISTRIES

If a person is reported to be co-infected with HIV and tuberculosis (TB), the TB program might evaluate the case before it is entered into eHARS (the Enhanced HIV/AIDS Reporting System). Alternatively, cases might be entered into eHARS before evaluation by the TB program. If an evaluation shows that HIV cases are not verified cases of TB, the report of TB should be removed from the HIV surveillance registry.

Verified TB cases are assigned a Report of Verified Case of Tuberculosis (RVCT) number by the state TB program. The RVCT number, a unique identifier for each TB case, is used in reporting TB cases to CDC. An RVCT number is not required for entering a TB report into eHARS; however, eHARS issues a warning when TB is entered without this number. If the RVCT number is not available at initial data entry, the eHARS record should be updated when the RVCT number becomes available. The RVCT number facilitates communication between the HIV and TB surveillance programs and ensures that cases are accurately reported to both systems.

CDC encourages all HIV surveillance programs to match eHARS to the TB registry at least once yearly. Matching is a good way to assess completeness of reporting of TB/HIV co-morbidity to both surveillance programs. However, registry matches should not be relied on to identify co-morbidity. HIV surveillance should include active case finding for TB/HIV co-infected persons through routine surveillance methods. Timely identification of HIV infection in TB patients is recommended through patient clinical management and testing. Similarly, matches with the STD program's Management Information System (STD*MIS) number can be used to identify missing HIV cases and possibly provide risk information.

Components of the Medical World that Relate to HIV Surveillance



Information in this section is intended for staff new to HIV surveillance or without clinical backgrounds.

All professions tend to develop their own language, methods, and conventions over time. The medical profession has maintained time-honored forms and language while incorporating new words, techniques, and concepts at an increasingly rapid rate.

MEDICAL TERMINOLOGY

Definitions of commonly used medical abbreviations and symbols are located in [online medical dictionaries](#), as are medical prefixes and suffixes. Abbreviations can change meaning according to context. For example, MR can mean mental retardation or muscle relaxant; LS can stand for left side or liver and spleen. Names and indications for all classes of medications (prescription and over-the-counter) can be found in the [Physicians' Desk Reference](#).

PHYSICIAN OFFICE ORGANIZATION

The primary sources of medical information are the physician attending or treating the patient and the patient medical record. Most physicians are affiliated with one or more hospitals, either as full-time staff members or as attending physicians with staff privileges; such affiliation means they can hospitalize their patients in these institutions.

The general setup of a physician's office directly influences the quality of the record keeping and the ease with which information from these records can be obtained. The setup varies considerably by the size and nature of the practice. Some physicians personally handle requests for medical information from health department officials, lawyers, and insurance companies, but in many offices, surveillance staff's initial contact is with the office nurse or the office manager.

MEDICAL DISCIPLINES

Primary-Care Physician

The primary-care physician is the medical doctor who has the usual care of the patient and who provides medical care at a basic level, usually in an outpatient setting. The primary-care physician usually has charge of the maintenance medical care of a person or family over time and thus has formed a medical relationship with that person or family. When you ask a person, "Who is your doctor?" the answer usually is the name of the primary-care physician. The primary-care physician is often a general practitioner but could be a family practitioner, an internist, or another specialist.

Because the office of the primary-care physician is the medical home base for the patient, it should be a good source of consolidated medical records. However, often the primary-care physician is the doctor who refers a patient to a specialist or surgeon; in that instance, the primary-care physician's records on the patient will contain reports of the results of treatment provided by the specialist.

Attending Physician

The attending physician is the medical doctor who follows the patient in the hospital and tracks treatment by hospital staff. The attending physician could be the patient's primary-care physician, the admitting doctor, or a doctor on the hospital medical staff. As with the primary-care physician, the attending physician should be a good source of information about the patient.

Admitting Physician

The admitting physician is the doctor who authorizes hospitalization of the patient. The admitting physician also might be the attending or the primary-care physician.

Consulting Physician

The consulting physician has special knowledge, training, or experience in a medical area or specialty. A primary care physician might refer a patient to a consulting physician for further evaluation regarding diagnosis or treatment. Referrals for consultation can take place in both outpatient and hospital settings. The consulting physician prepares a consultation report that is sent to the referring physician and becomes a permanent part of the patient's medical records.

Advanced Registered Nurse Practitioners

The advanced registered nurse practitioner (ARNP) is a registered nurse who has received advanced education and clinical training in a health-care specialty. ARNPs perform physical examinations, diagnosis, and treatment of acute and chronic illness; provide health maintenance care; order and interpret laboratory studies; and prescribe medications. ARNPs practice in collaboration with a supervisory physician.

Physician Assistant

The physician assistant (PA) is a health-care professional licensed to practice medicine with physician supervision. PAs commonly perform the history and physical exam, order and interpret laboratory studies, diagnose and treat illnesses, prescribe medications, and counsel patients. PAs' scope of practice corresponds to their training, experience, state law, and the supervisory physician's type of practice.

MEDICAL RECORDS

General Information

All accredited hospitals are required for medical/legal purposes to keep medical records on patients. Medical records

- Provide a vehicle for communication and coordination among physicians, nurses, and other staff members concerned with the patient's care.
- Can provide valuable information if the patient needs future medical care.
- Are used in medical education and research to promote better understanding and more effective treatment of diseases and conditions.
- Can protect the health care providers, hospital's, or patient's interests in legal cases.

With some variations in breakdown and nomenclature, hospital records throughout the United States follow the recommendations for adequacy and order of arrangement stated in the [Standards for Hospital Accreditation of the Joint Commission on Accreditation of Hospitals](#)

CONFIDENTIALITY OF MEDICAL RECORDS

A few basic principles apply to the availability and confidentiality of hospital records. The records themselves are the property of the hospital and remain with the hospital even when the patient changes physicians. The hospital is obligated to the patient to maintain the confidentiality of the records unless the patient gives specific written authorization to release them.

Requests to the hospital for medical information can be made in writing, but most inquiries are made in person or by telephone. When telephoning, surveillance staff should identify themselves fully and make clear the precise information needed. Even though certain non-medical information, such as the number and dates of prior admissions, can be obtained by telephone, hospital personnel might be hesitant to provide more comprehensive medical information unless they have developed rapport with the surveillance staff for their area.

Requests for information will be more readily answered if surveillance staff have made prior contact with medical records personnel. Sending introductory letters from the local health director, attending medical staff meetings, and personally visiting hospital records staff are ways for surveillance staff to become known. Telephone requests for comprehensive medical information should not compromise the integrity of hospital personnel regarding confidentiality.

Reviewing Medical Records



Information in this section is intended for staff new to HIV surveillance or without clinical backgrounds.

There are many ways to review medical records for HIV surveillance information. The following outline for reviewing medical records was developed by field staff experienced in HIV surveillance.

FACE SHEET

Review the face sheet, and obtain the following information:

- Patient's name and date of birth
- Address, Social Security number, age, race/ethnicity, sex
- Marital status and next of kin (relative or significant other)
- Person who brought the patient to the hospital (for risk information)
- [International Classification of Diseases, Ninth and Tenth Revisions \(ICD-9, ICD-10\)](#) codes on records that list the admitting, and/or discharge diagnosis (for possible new or updated diagnostic information)
- Insurance information
- Medical record number



HISTORY AND PHYSICAL EXAMINATION FOR MOST RECENT ADMISSION

Review the following information:

- History and physical (H&P) section of the medical report for the most recent admission
- Earlier H&Ps, if indicated, to confirm prior diagnoses and baseline weights and values
- Consultant findings and recommendation
- Progress notes
 - ▶ Dates of specific diagnostic tests
 - ▶ Risk information
- Physician orders
 - ▶ Tests ordered
 - ▶ Medications ordered
- Nurses' records
 - ▶ Observations made by nursing staff
 - ▶ Treatments provided
- Medication sheets
- Nutrition record
 - ▶ Patient's weight and height
 - ▶ Usual body weight
 - ▶ Decrease or increase in weight
- Social worker's notes
 - ▶ Risk information
 - ▶ Discharge plans
- Consent form: tests ordered

LATEST DISCHARGE SUMMARY AND CONSULTATION REPORTS

These reports can be a good source for

- Possible diagnosis
- Baseline values
- Risk factors

LABORATORY INDICATORS

Confirm AIDS indicators by reviewing all laboratory results relating to HIV:

- Chest radiographs: bilateral interstitial infiltrates
- Results of computed tomographic scans and/or magnetic resonance imaging
- Sputum cultures and smears: Pneumocystis jirovecii pneumonia (PCP), acid-fast bacilli
- HIV test results: ELISA (EIA), Western blot, IFA, PCR, culture
- Titers: Toxoplasma gondii; cytomegalovirus (CMV); hepatitis A, B, C viruses
- Viral load
- Viral cultures: herpesvirus, CMV
- Bacterial cultures: Mycobacterium tuberculosis/M. avium complex/M. kansasii
- Fecal exam: Cryptosporidium sp., AFB, ova and parasites, Isospora belli
- Biopsy: Kaposi sarcoma, lymphoma, tuberculosis, MAC, toxoplasmosis, CMV, progressive multifocal leukoencephalopathy

- Bronchoscopy: PCP, lymphoid interstitial pneumonitis, Candida sp., AFB
- Endoscopy: Candida sp., herpesvirus, Kaposi sarcoma, CMV
- Cerebrospinal fluid exam: Cryptococcus neoformans, herpesvirus, T. gondii, CMV, AFB, Treponema pallidum
- Additional serologic tests: CD4 count and percentage, T. pallidum

RISK ASSESSMENT

If a risk has not been identified, check the following records:

- Summary sheet
- Social worker notes
- Nurse's notes (including visitors)
- Emergency and outpatient notes
- Nutrition and pharmacy notes

ICD CODES

ICD codes were developed to provide a framework for classifying morbidity and mortality information for statistical purposes and for indexing hospital records. Codes are required in the administration of government health-care programs and for private health insurance billing. There are two related classifications of diseases with similar titles: **ICD** is used to code and classify mortality data from death certificates; **ICD-CM** (clinical modification) is used to code and classify morbidity data from such sources as inpatient and outpatient records and physician offices. ICD codes have undergone a number of revisions and continue to be updated periodically. Surveillance staff are likely to encounter codes from both ICD-9 and ICD-10; details are provided below. **Note that the ICD codes do not match the CDC definition for HIV disease in all instances, but they do indicate HIV infection, including Stage 3 (AIDS).**

Mortality Data—[ICD-9](#) codes apply to death certificates from 1979 through 1998. The first three digits of codes for symptomatic HIV infection are 042, 043, and 044. In addition, 795.8 is for a positive HIV laboratory test result (interpretation could be either asymptomatic infection or inconclusive diagnosis). [ICD-10](#) codes apply to death certificates from 1999 onward. The first three characters of codes for symptomatic HIV infection are B20–B24.

Morbidity Data—[ICD-9-CM](#) codes apply to hospital discharge abstracts and other morbidity data files (i.e., most health-care provider data sources other than death certificates) from 1979 through September 30, 2013. [ICD-10-CM](#) codes were to be applied beginning October 1, 2013. However, in February 2012, the Department of Health and Human Services announced its intent to delay adoption of ICD-10-CM beyond that date. The new compliance date has not been announced. Surveillance programs are advised to consult with epidemiologists from the CDC HIV Incidence and Case Surveillance Branch (HICSB) about the future implementation of ICD-10-CM codes.

Since 1994, the only correct codes for HIV infection in ICD-9-CM have been

- 042: symptomatic infection (may include 079.53 to indicate HIV-2)
- V08: asymptomatic infection (may include 079.53 to indicate HIV-2)
- 795.71: inconclusive positive HIV test (such as a positive screening test not yet confirmed by a supplemental test, or a perinatally exposed child <18 months of age whose positive antibodies could have been passively acquired from its mother and who has not yet had a positive virologic test to confirm the infection)

Codes 042, V08, and 795.71 are mutually exclusive; only one at a time is used for an individual patient.

Any known prior diagnosis of an HIV-related illness should be coded to 042. Once a patient has developed an HIV-related illness, he/she should always be assigned code 042 on every subsequent encounter. Any previously diagnosed HIV illness (042) should never be assigned to codes 795.71 or V08.

ICD-10-CM codes differ from ICD-9-CM codes:

- B20: symptomatic HIV infection
- Z21: asymptomatic HIV infection
- Z20.6: exposure to HIV (no evidence of infection yet)
- R75: inconclusive serologic evidence of HIV

These codes are mutually exclusive.

ICD-9-CM code 795.71 and ICD-10-CM code R75 are supposed to be used only for inconclusive test results, not for a confirmed positive test result, but they might be misused to indicate a definite positive test result if the physician does not want to commit to a definite diagnosis. Therefore, follow-up of records that contain such codes might be worthwhile to look for more conclusive evidence of HIV infection.

The Medical Examination and Medical Record



Information in this section is intended for staff new to HIV surveillance or without clinical backgrounds.

Medical records and diagnostic reports provide the organization, communication, and coordination needed to ensure good patient care. The foundation of the medical record is the physician's examination, and the record of information from the exam becomes the body of the medical record.

A medical examination, often referred to as the history and physical, or H&P, comprises four basic sections:

- Medical history
- Physical examination
- Diagnostic impression
- Treatment plan

Most physicians follow a general pattern or structure during the exam, and the information in the medical record follows that pattern. In hospitals, many medical exams follow a similar, if sometimes abbreviated, format.

To understand the medical record, you need to know the process and procedures used in the exam.

MEDICAL HISTORY

The starting point of the medical exam is customarily the “chief complaint” that brought the patient to the physician's office or the hospital. Ordinarily, this complaint and its duration are recorded exactly as the patient expresses them.

c.o. [complains of] “*Weak and tired*”—3 weeks' duration

The physician then asks about the present illness and encourages a full description of all symptoms and the circumstances under which they become more acute, subside, or persist unchanged.

p.i. [present Illness]: *Three weeks ago, this 40-year-old, married WF [white female] had a cold with associated mild cough and T° [temperature] that lasted 2 days. 100.1° taken orally by pt. [patient]. At this time, there was loss of appetite, and food intake was decreased. After the cough and temp. elev. subsided, pt. noted increasing weakness and general malaise. Exercise, which was tolerated well before URI [upper respiratory infection], now tires her considerably.*

One week ago, she noticed excessive thirst and a feeling of nausea. She had nausea and vomiting yesterday (×2) of clear, yellow liquid. Stools soft but no diarrhea. Increased frequency of urination. Denies any difficulty or burning with urination. There has been a 25–30-pound unintentional wt. [weight] loss during the past year.

After the immediate health problem is discussed thoroughly, the physician broadens the field of inquiry to view the patient in relation to a full range of environmental and hereditary factors.

Medication

The physician inquires about any drugs being taken. He asks the patient to be as explicit as possible about the names, doses, and effect of current medications.

Pt. took 2 ASA [aspirin] BID [2 times daily] while T° increased.

Allergies

The physician inquires in detail about known sensitivity to food, pollen, or medication.

NKA [no known allergies].

Past Medical History (PMH)

Next, the physician obtains extensive information about the patient's past medical history: diseases of childhood, serious illnesses, injuries, and surgical procedures. If the patient is a woman, the physician asks about pregnancies, both completed and interrupted.

P.H. [past history]: *UCHD [usual childhood diseases]. Pneumonia, age 31. Appendectomy, age 24 (8/75), Bigtown Memorial Hospital, C.J. Green, M.D. Grav IV [four pregnancies], Para III [has had three children], Ab. I at 2 mo. [abortion, one in second month].*

Social History

The patient's personal habits with respect to food; smoking; consumption of coffee, tea, and alcohol; hours of sleep; and self-medication are recorded. To obtain a total personal profile of the patient, the physician seeks information about social history: education, geographic sites of past residence, marital history, past and present occupations, and place of work.

S.H. [social history]: *Born in Peru, Indiana, 1951. High school education. Congenial family life. Habits; smokes 1½ pks/day. Denies use of alcohol and drugs O.H.* [occupational history]: *Pt. has been a housewife all of working life.*

Family History

The physician inquires about family history, including information about parents, grandparents, siblings, spouse, and children. Familial diseases can provide major clues, as can causes family members' causes of death. The physician might enter family composition in the chart as a diagram.

F.H. [family history]: Mother A&W [alive and well] age 67. Father died age 55 of “heart trouble.” An aunt has diabetes. Fourth of 5 sibs [siblings]—two and three. Mother of three children, one, two.

At this point in the interview, the physician might have arrived at a hypothetical diagnosis of the illness, which will be more precisely differentiated on the basis of the findings of the physical exam, subsequent laboratory testing, and radiographs.

Review of Systems

The medical history continues with a review of present and past disorders through the full range of organs or systems: head, eyes, ears, nose, throat; oral, respiratory, cardiovascular, gastrointestinal, genitourinary, menstrual, metabolic, neuromuscular, dermatologic, lymphatic, and neuropsychiatric.

R.O.S. [review of systems]

HEENT [head, ears, eyes, nose, throat]

General: 30-lb. decrease × 1 yr (nonvoluntary)

Intermittent dull headaches over the last 2 weeks

Ears—NSA [no significant abnormalities]

Eyes—NSA

Nose—NSA

Throat—NSA

Neck—NSA

C.R. [cardiorespiratory system]: Dyspnea on slight exertion. Palpitation on exertion. No orthopnea.

G.I. [gastrointestinal system]: See P.I.

G.U. [genitourinary system]: Frequency and nocturia, ×4 [four times] no hematuria.

Venereal disease: Denies. Menstrual history: Menarche 13 [menses began at age 13 years], q 28–30 ×5 [periods every 28–30 days lasts 5 days] of mod. heavy flow.

N.M. [neuromuscular system]: Excessive drowsiness past 2–3 weeks. Has had pp [after meals] drowsiness past 1–2 years. Vague pains in muscles of thighs and calves.

Endocrine: See above for weakness, excessive thirst, wt. loss, nocturia, dyspnea, tachycardia, etc.

THE PHYSICAL EXAMINATION

General Impression

On initial inspection, the physician registers a general impression of the patient: apparent state of health and nutrition, posture and muscular development, and evidence of emotional reaction to the illness.

P.E. [physical examination]: Wt. 108. T° 97.4

P [pulse] 106, R. [respiration] 32

B.P. [blood pressure] 100/60

General appearance: Pt is FWD [fairly well developed] PN [poorly nourished], WF, appearing both acutely and chronically ill. Respiration is rapid, and pt. is restless.

The physician inspects the skin for complexion, texture, abnormalities of turgor, pigmentation or folds, eruptions, moisture, and hair distribution pattern.

Skin: Dry. Poor turgor, some patches of vitiligo on back of neck and forearms.

HEENT

Examination of the head identifies any dermatologic disorders of the scalp; the texture of the hair; and sensitivity to pressure over the paranasal sinuses, which would indicate possible sinusitis.

Head: Some dry, desquamating elevated areas of reddening at the hairline of the scalp. No tenderness to pressure over sinuses or mastoid areas.

Gross examination of the eyes establishes their alignment and the coordination of the extraocular muscles. The physician examines the corneas for the possibility of scarring or ulceration. The ophthalmoscope enables the physician to examine the background or fundus of the eye by a lens system and a beam of light. The condition of the blood vessels of the retina provides important diagnostic information.

Eyes: EOM [extraocular movements] intact, PERRLA [pupils equal, round, react to light and accommodation] Fundi neg.

External examination of the ear establishes its size, configuration, and evidence of infection. Using an otoscope, the physician looks into the ear canal for obstruction or infection and checks the condition of the eardrum or tympanic membrane.

Ears: T.M.s [tympanic membranes] intact

In checking the nose, the physician looks for evidence of impaired breathing, checks the condition of the nasal septum and the turbinates, and inspects the mucosa for inflammatory changes or discharge.

The physician examines the mouth for changes or tumors of the lips and the mucous membrane and notes the condition of the teeth.

Nose: Septum with some impairment of breathing space. No discharge. MM [mucous membranes] dry.

Mouth: Tongue red. Odor of acetone on breath. Edentulous.

The physician palpates the neck to detect enlargement of the thyroid gland. The chains of lymph nodes in the neck are checked. The position of the trachea is noted, and the condition of the blood vessels is checked.

Neck: Supple. Thyroid not palpable. Trachea in midline Lymphatics: WNL [within normal limits]



Chest and Cardiovascular System

The chest exam establishes the condition and functioning level of the heart and lungs. The physician notes whether the respiratory excursion is normal. The sounds evoked by percussing and the sensation of movement or vibration detected by the palpating hand of the examiner convey information about the size and position of the organs and the presence of fluid, air, or solid structures. With the aid of the stethoscope, the physician gathers information about the character and intensity of the breath sounds; the relative duration of inspiration and expiration; and the presence of wheezes, rales, and other abnormal findings. Auscultation of the heart reveals the intensity of the heart sounds, character of the cardiac rhythm, and presence and location of murmurs.

Chest: Symmetrical, Resp. rapid

Lungs: Clear to P & A [percussion and auscultation]

Heart: PMI [point of maximum impulse] in 5th LICS. [left intercostal space]. Area of cardiac dullness normal, rate of 136/min, reg. R [rhythm] A2.P2 [aortic second sound greater than pulmonic second sound]. No Ms [murmurs].

Abdomen, Breasts, Genitalia

With the patient lying on his/her back, the physician palpates the abdomen for signs of tenderness and for masses. The exam determines whether the spleen, kidneys, or liver are enlarged. The physician investigates the possible presence of a hernia and determines the size of the lymph nodes.

If the patient is a woman, the physician palpates the breasts for masses and examines the nipples for ulceration, secretion, or inversion.

The physician examines the external genitalia. With woman, a pelvic exam may be conducted manually, with particular attention to the size and location of the organs, presence of tumors, and evidence of discharge.

Breasts: NSA

ABD: [abdomen] Flat. LKS [liver, kidneys, and spleen] no abnormalities to palpation. B.S. [sowel sounds] normal, 10 cm. lower abd. healed incisional scar, RPM [right paramedian].

Pelvic: Deferred at patient's request.

Extremities, Rectum, Neuromuscular System

The upper and lower extremities are inspected for swelling, deformity of joints, and range of motion at the joints. Examination of the upper extremities includes the notation of moisture and color of the palms and condition of the fingernails. In the lower extremities, the physician checks for varicose veins, fungus infection of the skin and nails, edema, and state of the arterial pulsation.

The rectum is examined for sphincter tone, hemorrhoids, and new growths. In male patients, the rectal exam also permits palpation of the prostate gland.

Unless otherwise indicated by presenting symptoms and findings, the initial neurologic exam is usually limited to the biceps, triceps, radial periosteal, patellar, the Achilles reflexes (deep tendon reflexes), and the Babinski reflex of the toes. The physician might enter neurologic data in the chart in a diagram.

To conclude the physical exam, the physician observes the patient's gait and checks the range of motion of the spine in flexion extension, lateral bending, and rotation.

Extremities: No edema, trophic changes, or ulcerations.

Rectal: NSA

Neuro: D.T.R. [deep tendon reflexes] physiologic

B & J [bones and joints]: Full ROM [range of motion]. No H.R.S.T. [heat, reddening, swelling, or tenderness] of joints

DIAGNOSTIC IMPRESSION

The physician records an impression subject to further studies.

40-year-old female c wt loss, polydypsia, polyuria, F.H. of diabetes.

H&P consistent with diabetes.

Consider also:

—Other endocrine dysfunction, e.g., thyroid

—Recent acute illness suggests possible UTI [urinary tract infection]

Further Diagnostic Studies

Depending on the nature of the impairment, the physician might request additional studies and laboratory tests. Specific requirements will be listed here.

1. *FPG [fasting plasma glucose]*
2. *Quantitative urine culture*
3. *CBC [complete blood count], SMAC [blood chemistry profile]*

TREATMENT PLAN

Based on the findings of the medical history, physical examination, and diagnostic results the physician will draw up a treatment plan focused on improving the patient's overall health and well-being. Related to the fictional scenario described above, the treatment plan for adult-onset diabetes might include use of prescription medicines to control blood glucose levels, along with counseling on proper diet, exercise, and other recommended lifestyle modifications.



MODULE FOUR

Presenting
Surveillance Data

OBJECTIVES:

1. Teach proper interpretation of surveillance data.
2. Present ways to improve the quality of surveillance data.
3. Discuss the interpretive uses of surveillance data.
4. Present approaches to analyzing HIV surveillance data.
5. Describe considerations for effectively presenting surveillance data.
6. Demonstrate how to process data requests and how standard reports are useful.
7. Describe the importance of disseminating surveillance data.
8. Reiterate considerations for displaying data, and provide examples:
 - Tables
 - Graphs
 - Charts
 - Maps
9. Describe the advantages and limitations of computer-generated graphics.
10. Describe various epidemiologic terms and concepts.

Proper Interpretation of Surveillance Data

UNDERSTANDING THE DATA

The art of conducting surveillance lies in interpreting the data. Data need to be interpreted in the context of the etiology, epidemiology, and natural history of the condition or disease under study, and the interpretation should lead to improved control of that condition or disease. By proceeding from the simple to the complex, investigations can use surveillance data as a basis for appropriate public health action. The key to interpretation is knowing the limitations of the data and meticulously describing them.

Because of the descriptive nature of surveillance data, correlation does not equal causation. Not all apparent increases in disease occurrence represent true increases. For example, an increase in population size, improved diagnostic procedures, or changes in the surveillance system could all increase the number of case reports during a given time period.

LIMITATIONS TO DATA

Although no surveillance system is perfect, most can be useful. Several problems inherent in data obtained through surveillance must be recognized if the data are to be interpreted correctly, including

- **Underreporting.** Most surveillance systems are based on conditions reported by health-care providers, and underreporting is inevitable. Depending on the condition, a large or small percentage of cases that actually occur will be reported. Disease trends by time, place, and person frequently can be detected even with incomplete data. As long as the underreporting is relatively consistent, incomplete data can be applied to derive useful inferences. For diseases or conditions that occur infrequently, completeness becomes more important.
- **Nonrepresentativeness.** Health conditions are not reported randomly. For example, illnesses diagnosed in a public health facility are reported disproportionately more frequently than those diagnosed by private practitioners. Additionally, a disease is more likely to be reported in the advanced stages when it leads to hospitalization than when it is managed early on an outpatient basis by a private physician. Collecting data from multiple sources and conducting validation studies to evaluate the completeness of reporting is necessary to provide ways to improve the representativeness of the information and reduce bias.
- **Lack of Timeliness.** For a variety of reasons, delays can occur at each phase of surveillance. Some delays are caused by cumbersome or inefficient reporting procedures. Delays in analysis are common when the surveillance system is considered a rote function rather than a source of information for action. Delays at any step can culminate in delays in dissemination, resulting in lack of the information needed by the medical and public health communities for prompt action.
- **Inconsistent Case Definitions.** Different practitioners frequently use different case definitions for health problems. The more complex the diagnostic syndrome, the greater the difficulty in reaching consensus on a case definition. Moreover, changes in case definitions over time lead to greater inconsistency of reporting. Broad consensus exists for the [HIV case definition](#). Despite its complexity, measures have been taken to make providers aware of case definition changes. Persons who interpret surveillance data must be aware of such changes and adjust their interpretations accordingly.

APPROACH TO INTERPRETATION

Creative interpretation of surveillance data requires more common sense than sophisticated reasoning. Ask questions to test the validity of the data.

- Has the nature of reporting changed?
- Have the surveillance staff changed?
- Have new providers or new geographic areas entered the surveillance system?
- Has the case definition changed?
- Has a new intervention, such as drug therapy, been introduced?

Ways to Improve Surveillance Data

The preceding limitations of surveillance data suggest several steps that a local or state health department could take to improve reporting and thus improve the quality of data from the surveillance system.

- Improve awareness of practitioners concerning their responsibility to report.
- Simplify reporting for providers by giving them copies of partially completed case report forms that include their facility information on the form; providing them with a simplified version of the case report form; or offering them the opportunity, when feasible, to phone in a case report.
- Give frequent feedback to the providers, such as newsletters, presentations, and phone calls.
- Widen the net of reporting by reaching out to local hospitals, laboratories, community-based organizations, and other relevant organizations and by targeting infection control personnel for assistance in the reporting process.

Interpretive Uses of Surveillance Data

IDENTIFYING CHANGES IN THE EPIDEMIC

A major use of surveillance data is to determine whether changes (increases or decreases) in numbers of cases of a health condition at the local, state or national level indicate a change in the epidemic. This determination might not be straightforward; however, if adjustments need to be made for reporting delays, changes in case definition, and other associated changes (as with HIV surveillance data). For this reason, interpreting HIV or AIDS trends often is confined to demographic variables by period of diagnosis, with caveats about limitations of the data.

EVALUATING PUBLIC POLICY

To a certain extent, surveillance data can help assess the health impact—pro or con—of specific interventions or of public policy. Although trends in disease to monitor the impact of community interventions or drug therapies are tempting to use, such use becomes increasingly suspect when several factors contribute to the disease being monitored. In addition, if only a portion of the population accepts an intervention, analysis and interpretation of surveillance data are even more difficult. Frequently, surveillance of process measures or other health problems can be proxies for the intended outcome. For example, decreases in unsafe sexual behaviors or other sexually transmitted diseases (STDs) after HIV campaigns have been used as markers

for trends in HIV incidence. Moreover, finding comparability in data from several populations that have attempted similar public health programs strengthens evidence that the interpretation is correct.

PROJECTING FUTURE NEEDS

Surveillance data are key to projecting the future needs of the affected population, such as the use of AZT (zidovudine) by HIV-infected pregnant mothers to reduce the vertical transmission of HIV to children. The use of protease inhibitors to improve survival rates of HIV-infected persons is another example for using surveillance data to predict future needs.

Analyzing Surveillance Data

Historically, the core processes of public health surveillance have evolved by using appropriate methods to organize the data being collected and analyzed. Surveillance data are used to detect epidemics, suggest hypotheses, characterize trends in disease or injury, evaluate prevention programs, and project future public health needs. A substantial portion of this module was developed by using excerpts from two sources: 1) *Principles and Practice of Public Health Surveillance* (Teutsch SM, Churchill RE, eds. New York, NY: Oxford University Press; 1994) and 2) [Principles of Epidemiology in Public Health Practice](#) (on-line training course offered through CDC). These resources are highly recommended for all surveillance staff.

After case report data are organized, they are analyzed to identify changes or differences in the occurrence and distribution of cases over time, by place, and possibly by personal characteristics. Major changes identify situations that need further study and are used to formulate hypotheses about the etiologic agent, source, and means of transmission, which in turn are used to determine appropriate control measures.

The organization and subsequent analysis of case data by time can be performed in two ways: by period of report and by *period of diagnosis*. The temporal distributions of cases of any specific disease organized by using both methods can differ considerably, depending on the variation in the interval between time of onset and time of report. Prior to 2002, most publications of HIV surveillance data by CDC were by period of report. However, this scheme presents some serious difficulties in data interpretation in that cases reported during a certain period (usually calendar year) might have been diagnosed during an earlier period (sometimes many years earlier). Presenting data by year of report is thus more representative of the efficiency of the surveillance system than of the true nature of changes in the HIV epidemic. CDC now shows data by year of diagnosis and encourages state and local surveillance programs to do the same.

Surveillance staff and audiences who use the data need to understand that recent *diagnosis* of HIV does not necessarily equate to recent *infection* with HIV (for the reasons stated above). If data are not organized and analyzed accurately, a potentially serious situation might go undetected or a hypothesis selected as a basis for control measures might be invalid.

APPROACHES TO ANALYZING HIV SURVEILLANCE DATA

Because of staffing and time constraints and lack of analytic skills of staff, surveillance programs might not assign data analysis a high priority. Nonetheless, analysis of surveillance data is a vital component of a successful surveillance program and must be properly conducted by surveillance staff. Approaches to analyzing surveillance data include the following steps:

1. **Assess the quality of the data.** Know the inherent idiosyncrasies of the surveillance data set. Although beginning to immediately examine trends over time is tempting, intimate knowledge of the day-to-day strengths and weaknesses of the data collection methods and reporting process can provide a real-world sense of trends that emerge.
2. **Proceed from the simplest to the most complex.** Examine each condition separately by numbers and crude trends. How many cases were reported each year? How many cases were reported in each age group each year? What are the variable-specific rates? Only after looking at each variable separately should one examine the relationships among these variables.
3. **Realize inaccuracies in the data that preclude more sophisticated analyses.** Erratically collected or incomplete data cannot be corrected by complex analytic techniques. Differential reporting by different regions or by different health facilities renders the resulting surveillance data set liable to misinterpretation.

METHODOLOGIC CONSIDERATIONS

Analysis of surveillance information depends on the accuracy of that information. Attempts to analyze data that are haphazardly collected or have varying case definitions waste valuable time and resources. The two key concepts that determine the accuracy of surveillance data are reliability and validity. Reliability (i.e., reproducibility) refers to whether a particular condition is reported consistently by different observers; validity refers to whether the condition as reported reflects the true condition as it occurs. Ideally, both reliability and validity can be achieved, but in practice reliability is easier than validity to assess. For conditions for which biologic measures complement clinical case definitions, such as laboratory testing for infectious disease, the accuracy of the data can be more completely ensured. However, in the context of more subjective behavioral aspects, such as those associated with lifestyles, accuracy is more difficult to confirm.

TIME, PLACE, AND PERSON

Surveillance data allow public health officials to describe health problems in terms of the basic epidemiologic parameters of time, place, and person. Specifically, data analyses of diagnosed cases of HIV indicate that persons in different transmission categories, geographic locations, or racial/ethnic groups have demonstrated distinctive patterns of occurrence and manifestations of HIV infection. Use of [census data](#) as denominators allows calculation of rates, which facilitates comparison in terms of the parameters of time, place, and person. Moreover, use of fundamental variables permits long-term trends to be monitored, seasonal patterns to be assessed, and future occurrence of disease to be projected, thus facilitating a timely public health response.

Time

Analysis of surveillance data by time can reveal trends in disease. The easiest analysis is usually a comparison of the number of cases diagnosed during a particular period (e.g., months or years). Such data can be organized into a table or graph to assess whether an abrupt increase occurs, whether the trends are stable, or whether the number of cases gradually rises or falls. Another simple method of analysis compares the number of diagnoses for a current period (e.g., a given quarter or year) with the number diagnosed during the same period for the past several years.

Graphing surveillance data over time facilitates analysis of long-term (secular) trends. Events that influence secular trends—such as changes in the surveillance case definition, changes in reporting requirements or

practices, publicity about a particular condition or new intervention programs—can be indicated on the graph.

As described earlier, both the surveillance staff and the audience must understand the differences in data analyzed by period of report versus period of diagnosis and whether the data have been adjusted to compensate for delays in reporting.

Place

Analysis of surveillance data by place can suggest the type of environment in which a person resided at time of diagnosis or reporting. The location from which the condition was reported might not be the place where the exposure occurred. This point is evident with diagnosed AIDS cases. Because of the time lag between HIV infection and AIDS diagnosis (usually several years), a person can be infected in county A and move to county B, where HIV infection or AIDS is later diagnosed.

Person

Analyzing surveillance data by the characteristics of persons who have the condition provides further specification. The demographic variables most frequently used for analyzing HIV data are age, sex, and race/ethnicity. Other variables, such as transmission category, often are used as well.

If possible, the characteristics of persons included in any surveillance system should be related to denominators. Even though assessing the number of cases alone can be sufficient, variable-specific rates are more helpful in comparisons of the risk involved. Thus, if the number of cases of a particular condition is higher in one segment of a population, the rate might be lower if that group represents a large proportion of the population. Although the populations (denominators) of some groups might not be available (e.g., population of men who have sex with men or injecting drug users), examining the rates of cases by subpopulations that are available (e.g., sex, race, age group) will prove useful when trends of the epidemic are analyzed.

Presenting HIV Surveillance Data

Presenting HIV surveillance data to others provides many benefits:

- Provides community-based organizations and government agencies with valuable information they can use to secure funding
- Supports HIV service assessment and community planning efforts
- Assists health educators and public health workers in targeting specialized information to at-risk populations
- Increases awareness and interest of the general public by effective presentation of data through the media
- Provides technical assistance and in-service education to the health-care community while increasing opportunities to promote active surveillance of HIV infection, including AIDS

Effective HIV interventions must approach education in a manner that is age-appropriate and culturally sensitive, diverse in scope, and focused in purpose. Therefore, preparation of HIV surveillance data—whether for designing presentation graphics, assisting with a grant proposal, or addressing the local medical society—must always be tailored to the specific audience. This section addresses dissemination of information and the tools to make presenting/disseminating data successful and rewarding.

SELECTING DATA FOR A PRESENTATION

Background Information

- Focus on your topic for the presentation.
- Know your audience.
- Consider what materials you will use.
- Know what equipment will be available to display the presentation.
- Determine the variables of data that you want to review, and identify the time periods you want to examine.
- Lay out the data request in a check-off format so you can add or delete the data reports that you generate.
- Generate your first set of data runs.

Strategic Information Gathering

1. Decide what you are trying to present, or to substantiate or what your goal is.
2. Write the research question clearly and concisely.
 - a. Example 1: “What is the percentage of minorities in the geographic area of interest in whom HIV has been diagnosed and what are their modes of exposure?”
 - b. Example 2: “What are the current trends in the newly diagnosed cases of HIV infection in the geographic area of interest?”
 - c. Example 3: “During the past 3 years, what are the changes (increases or decreases) in HIV diagnoses by age, race/ethnicity, sex, and modes of exposure in the geographic area of interest?”
 - d. Example 4: In preparing a grant proposal for women of childbearing age in the geographic area of interest,
 - 1) “What is the exact age group? (15–44 years?)”
 - 2) “What is the racial/ethnic distribution?”
 - 3) “What are the modes of transmission or risk behavior distributions?”
 - 4) “What is the time period? (Cumulative? Last 3 years? Last 5 years?)”

Other Sources of Information

- State surveillance reports or fact sheets
- CDC’s annual HIV surveillance reports, slide series, or fact sheets
- Studies published in respectable peer-reviewed journals

After All the Data are Gathered

Once you gather all the information and data:

- Determine whether the data report(s) and other information sources contain what you need to answer all of the question(s)
- Assess whether comparisons are substantive or of little importance in answering the question(s)
- Determine the need to run additional analyses
- Determine whether more information is needed from other sources, and seek them out
- Decide how best to express the information:
 - ▶ Tables?
 - ▶ Pie charts?
 - ▶ Bar graphs?
 - ▶ Trends (line or area graphs) over time?
 - ▶ Maps?

Considerations for Effective Presentations

WHO IS THE AUDIENCE?

When you receive a request for a presentation, first—and most important—**define the audience and its needs**. Preparation, type of information, and delivery style all depend on the audience.

For a general request, ask

- How many persons will attend?
- What are their characteristics (e.g., age, sex, race, profession, education, HIV knowledge base)?
- What type of presentation is needed?

For example, a hospital education department requests a 1-hour presentation to physicians. You should ask

- How many physicians will attend?
- What kind of physicians are they? (The answer enables you to focus on information that will be of most interest or use to them.)
- What are the content requirements, if any?
- Do these physicians have limited (or frequent) contact with persons with HIV or AIDS?

As you continue this line of questioning, you are likely to think of other questions, the answers to which will enable you to present exactly what the audience needs and can appreciate.

Helpful Hint! When making a presentation to physicians, always include a discussion of reporting protocol, and allow time for questions and answers on the subject to make the most of the opportunity to promote active surveillance for HIV and AIDS.

Here's another example. A church secretary tells you that the church's youth group would like a presentation on HIV statistics. You should ask

- How many young persons will attend?
- What are their characteristics (e.g., age, race, sex)?
- Are there restrictions on subject matter? (This is a critical question from a public relations standpoint.)
- Are there preferences as to the desired format (e.g., lecture, group discussion, showing of audiovisual materials)?

Again, as you elicit more information, you will be better able to anticipate and effectively target the information to your audience.

Documenting educational requests is always recommended and might be required for periodic reporting of your activities. Ask the person requesting the presentation to formalize the request in writing (e.g., with a letter). Alternatively, create a form for this purpose.

Clearly state in advance the type of facility and equipment you need. Confirm a day or so before the engagement that these arrangements have been made.

Once you have adequately identified your audience, preparing the presentation is relatively simple:

- Confirm the engagement in advance. If you absolutely cannot keep an engagement, always give as much notice as possible or arrange for someone to cover it for you. A responsible surveillance program will make a policy of “never cancel, always reschedule.”

- Allow adequate time to prepare for your presentation. Give support staff time to make copies or other materials.
- Arrive early to set up, get familiar with the facility, and solve any problems.
- If you are bringing your own audiovisual equipment, make sure that it works and that you have spare bulbs, batteries, or other supplies that might need replacement. Preparedness says a great deal to an audience about a speaker.

When preparing a presentation for delivery to a population at risk, **emphasize the information that will formulate prevention messages relevant to the audience.** For example, if you are presenting to high school-aged students, show local-, state-, and national-level data that illustrate facts about acquisition of HIV infection by age group (explaining how HIV data must be adjusted to indicate age at acquisition of HIV infection).

AT THE PRESENTATION

Accurately gauge the appropriate knowledge level of your audience. Do not use technical language or acronyms unless you know your audience is familiar with them. Fully define or explain abbreviations and acronyms as you go along. Most importantly, **KEEP IT SIMPLE!** Even health-care professionals with extensive training understand the value of simplicity in predicting the ability of persons to understand and comply with protocols and procedures. Prepare your handout materials, slides, and other training aids with this focus in mind. A large part of being a successful presenter is ensuring that you will be easy to understand.

Answer questions clearly and directly. Complicated responses with too much information can be confusing and cause your audience to lose interest and stop listening.

Be courteous to your audience.

- **Speak to the audience on its level.** Talking over people's heads or down to them might be offensive and can kill a presentation in seconds.
- Always **repeat questions** so that everyone in the room knows what you're answering.
- Regardless of whether you are speaking with or without a microphone, **be conscious of the volume and tone of your voice.** Ask people in the back of the room whether they can hear you. Change the inflection in your voice so you do not lapse into a monotone. If you are prone to "dry mouth" during public speaking, keep water nearby; don't use lozenges or candy because they can garble your speech.
- **Address logistical issues immediately after introducing yourself or being introduced.** Let people know how long you will talk and what topic you will address. Tell them if and when breaks will occur and where restrooms, and refreshments are located.
- **Recognize each person who has a question.** If time is limited, invite the audience to remain after the presentation to talk with you individually. If the situation will not allow that, leave business cards or display an overhead transparency or slide with your contact information. Apologize if time or other constraints do not allow you to address each participant's questions.
- **Gauge the audience's comfort level with the subject matter, and make provisions to accommodate their needs.** If attendees seem hesitant to ask questions, perhaps they are afraid to be perceived as asking a "dumb," "silly," or "inappropriate" question—but remember, the only stupid question is the one not asked. To break through this barrier, distribute index cards and pencils to solicit written questions that a monitor can bring to you.

- Warm up to your audience. A smile or appropriate humor can increase the audience's perceptions of your accessibility. Although professionals should be serious in educational undertakings, being viewed as a warm person with a sense of humor can enhance your audience's attention level.

When You Don't Know the Answer. . . There is nothing wrong with not knowing an answer. Tell the person asking the question that you don't know the answer but will be happy to research it or direct him/her to the appropriate resource. Saying, "I think the answer is . . ." can cause you to lose credibility. There is nothing more damaging than an expert who gives misinformation, guesses, or tells an audience what he/she thinks the audience wants to hear.

Receiving and Processing Data Requests

An essential function of HIV surveillance programs is the dissemination of data to individuals and groups who need and use the information. The numbers of these requests for data vary widely and are influenced by many factors, including press releases, publication of research findings, articles, public disclosure of HIV status by prominent persons, and availability of new treatments. **Surveillance programs should develop standard reports to issue periodically or on request**, either alone or as part of a newsletter. Such reports are useful in establishing beneficial and reciprocal relationships with the reporting network of physicians, infection control personnel, and others.

Publishing your office phone and fax numbers and email address in such publications enables persons who need data to reach you easily. To keep your telephone as free as possible for active surveillance, you also might want to publish a form to facilitate efficient requests and provide you with enough detail to accommodate the needs of the person or agency requesting information. The state health department might have a form you can use or adapt for this purpose.

Documentation of all requests is recommended as a record of your activities; this documentation also can benefit preparation of semiannual progress reports. **Always document requests for confidential information** (according to state laws and operating policies and procedures set by the state health department). Always review such requests with your supervisor and state health department to receive guidance and ensure compliance with restrictions regarding data release. When filling requests, always determine what the information is being used for and who else will subsequently receive the information (dissemination trail). In addition, always give yourself ample processing time to ensure careful research, analysis, and proofing of the final product to be disseminated.

If you receive a request for information that is obviously highly confidential, refuse to process it. Document the request as you would any other and respond in writing, clearly citing your reasons for not answering and citing applicable laws. Keep a copy of your response on file.

PREPARING STANDARD REPORTS

Most requests can be satisfied with general reports (public domain information), which can be set up as living documents in a computer for quick and easy distribution by fax or email. In addition, presentation graphics in electronic or slide transparency format can be set up as ongoing products for use by health educators, HIV outreach workers, and others.

If you have the resources, you might even choose to publish a website where the public can access information without contacting your office. Whatever the method, persons needing your services appreciate efficient processing, and their appreciation often translates into cooperation and reciprocation when you need information from your reporting network.

PROVIDING INFORMATION TO THE NEWS MEDIA

Occasionally you might be asked to prepare information for, or be interviewed by, the news media. Document these requests as you would any other, and copy the request to the person in your health department or program office who tracks public information requests. In addition, you might need to authorize response to such contacts through your immediate supervisor or health department director. All data must be released in accordance with your state's health information security policy.

When preparing a press release, answer only what is asked, and be brief and to the point. The more concise your statement is, the less likely it is to be edited and possibly altered. Again, avoid using terms with which the general public might not be familiar (or adequately explain such terms). When asked for statistical data, consider that graphics draw more attention than tables or discussions of numbers and are easier for the general public to understand. Occasionally, giving a little more information than is requested might be beneficial. For example, for a request for a case count, instead of just giving the number, you could provide a graph that shows the accumulation of cases and growth trends over time with, the cumulative number (total) predominantly shown. Such information speaks more clearly than a number alone to the general public.

You are advised to request control over the information or comments that are published or broadcast, but whether the request is granted will depend on the policies of the media outlet. You should approach the journalist with this request on the common grounds of good reporting and professional ethics. Inform him/her of your intent to help ensure that the report is disseminated in a manner consistent with the public's need for accurate and meaningful information. Building a relationship with your local media on the basis of mutual understanding, trust, respect, and cooperation can be extremely beneficial to your local HIV care and prevention programs.

If you are asked to be interviewed on camera, keep the following tips in mind:

- Avoid live telecasts.
- When being taped, ask the interviewer for a run-through before taping so you can take notes and formulate a focused, clear response.
- Check your appearance before taping.
- Keep your responses brief; a lengthy response can lose its intended meaning through editing.

INFORMATION RESOURCES

Cite your sources, and select them for accuracy and utility. Use only resources that have an acknowledged reputation for accuracy and that are considered "official" sources. Avoid quoting statistics that appear in print without citation.

The recommended resources for HIV information and surveillance data are

- Your state HIV surveillance program and state health department
- [CDC](#)

- [Council of State and Territorial Epidemiologists](#)
- [National Institutes of Health](#)
- [National Institute of Allergy and Infectious Diseases](#)
- [World Health Organization](#)

The CDC [National Prevention Information Network](#) (NPIN) is the U.S. reference and referral service for information about HIV/AIDS, viral hepatitis, STDs, and tuberculosis (TB). NPIN collects and disseminates data and materials to support the work of HIV/AIDS, viral hepatitis, STD, and TB prevention organizations and workers in international, national, state, and local settings.

All NPIN services are designed to facilitate sharing of information and resources on education and prevention services, program collaboration and service integration across the four diseases, published materials, research findings, and trends among users for CDC and its partner organizations. Such sharing allows partners to easily access and leverage existing materials and to conserve resources.

NPIN can be accessed at <http://www.cdcnpin.org/> or 1-800-458-5231 and 1-800-243-7012 (TTY).

DISSEMINATION OF SURVEILLANCE DATA

Standard definitions for public health surveillance specify the need for timely dissemination of findings to persons who have contributed and to others who need to know. Surveillance has been characterized as a process that provides “information for action.” Public health programs must ensure more than the mere transmission or dissemination of surveillance results to others; rather, surveillance data should be presented in a manner that facilitates their consequent use for public health actions.

Dissemination of surveillance data is a critical component of a surveillance system but, unfortunately, the component most frequently overlooked. The audience for such data should include persons who do (or should) provide reports, e.g., health-care providers and laboratory directors; interested persons; and persons who need to know for administrative, program planning, and decision-making purposes.

A surveillance report that targets both the medical and public health communities serves two primary purposes: to inform and to motivate. A surveillance report that summarizes a disease or condition by time, place, and person informs local physicians about their probability of encountering those diseases or conditions in their patients. Clear graphical presentations tend to be more appealing and more easily understood than detailed tables. Other useful information might include reports of antibiotic resistance patterns, revised recommendations for treatments and other prevention and control strategies, and summaries of investigations and other studies. In addition, a surveillance report demonstrates that the health department actually looks at the submitted case reports and acts on those reports.

CDC publishes national HIV and AIDS surveillance findings through the annual [HIV Surveillance Report](#), which summarizes the diagnoses of HIV infection and AIDS in the United States and dependent areas. CDC also publishes surveillance findings periodically in the *Morbidity and Mortality Weekly Report* ([MMWR](#)) series and through a variety of journals. Additionally, CDC prepares [slides series](#) and [fact sheets](#) of national HIV surveillance data by race/ethnicity, sex, behavioral risk groups, and other variables. Each state and territory also publishes reports on HIV, STD, and TB data through periodic releases. Some local surveillance units throughout a particular state publish monthly and/or quarterly findings in a local publication or newsletter. All data should be released in accordance with state information security policies, protocols, and procedures.

BASIC CONCEPTS FOR DISSEMINATING AND COMMUNICATING SURVEILLANCE INFORMATION

The terms *dissemination* and *communication* are not interchangeable. Dissemination is a one-way process through which information is conveyed from one point to another. In contrast, *communication* is a loop involving at least a sender and recipient and is collaborative. The communicator’s job is completed when the targeted recipient of the information acknowledges receipt and comprehension of that information.

A basic framework for disseminating the results of public health surveillance with the intent of communicating can be adapted from fundamental models for communications. One such model—which emphasizes the effect of communications—includes the sender, the message, the recipient, the channel, and the impact (Table 4.1). The sender is the person responsible for surveillance of the health condition being monitored. For applications in public health practice, this model can be modified.

STEP	QUESTION TO BE ANSWERED
Establish the message	What should be said?
Define the audience	To whom should it be said?
Select the channel	Through what communication medium should it be relayed?
Market the message	How should the message be stated?
Evaluate the impact	What effect did the message create?

Each step is discussed in detail in the following paragraphs, which should be read with the understanding that you should never disseminate more information than can be evaluated and revised, as needed, during the communications process.

Establish the Message

The primary message (i.e., communications objective) for the findings of any public health surveillance effort should reflect the basic purpose of the surveillance system. Information that should be disseminated or communicated to the public as it becomes available includes

- Routine data reports
- Routine analyses of the data, including discussion of changes in trends of occurrence or modes of exposure
- Notification about recent changes in the course of disease, new treatments, or other new or updated information regarding prevention and/or control measures

Epidemiologic trends and patterns that are based on surveillance findings must be conveyed to persons involved in control efforts to refine control activities and to guide the allocation of resources that support those activities.

Define the Audience

Identification of target groups is an essential part of the process of developing strategies for communicating surveillance results. Delivering ongoing surveillance findings and other pertinent information to relevant audiences is essential to public health practice. In general, key audiences include

- The population at risk for exposure or disease
- Public health practitioners
- Health-care providers
- Professional and voluntary organizations
- Policy makers
- News media
- General public

Select the Channel

Specifying the messages and the audiences for surveillance results enables selection of the most suitable channels of communication for the information. Traditionally, surveillance information has been disseminated through published surveillance reports. However, in addition to conventional means for communicating with traditional audiences, new methods and technologies have made improved communications possible with both old and new audiences. Surveillance programs will find that electronic channels of communication—particularly the Internet, and social media, such as [Twitter](#) and [Facebook](#)—could be the most efficient way to relay their information to various audiences. Other communications options include professional and trade publications (such as journals, news bulletins, vital statistics reports), broadcast and/or print media (such as newspaper, radio, and television ads and billboards) and public forums (such as briefings, conferences, and meetings).

Market the Message

Once the message has been defined and the target audience and channel selected, the information needs to be communicated and marketed—not merely disseminated. To ensure communication to intended audiences, public health agencies should use techniques that are most effective for marketing information.

First, in general, graphical formats and other visual displays are likely to be more effective than conventional tabular presentations in conveying information. Such formats include maps, bar graphs, histograms, diagrams, and other visual depictions of data.

Second, selecting the most important point, then stating that point as a simple declarative sentence, can focus the principle components of the message. The main point should answer these three questions:

- What is new?
- Who is affected (or infected)?
- What works best?

Third, techniques must be used that present (or package) the surveillance information in a manner that captures an audience's interest and draws attention to a specific issue. Examples include use of introductory phrases such as "A new study...", "Recent findings...", and "Information recently released..." These phrases are likely to appeal to an intended audience more than is a presentation that begins with a conventional phrase, such as "On the basis of surveillance findings..."

Fourth, the method and forum of release of surveillance information can be critical, particularly when a timely release is required or when the target audiences include the news media, the public, or policy makers. Under such circumstances, news conferences or other news releases can be considered, and they should be held when they are likely to be attended. The presenter needs to involve the audience in the public health process by walking the audience through it. Important adjuncts for presenting the information include handouts and effective but simple visuals.

Evaluate the Impact

Because public health surveillance is oriented toward action, evaluation should consider whether

- Surveillance information has been communicated to persons who need it;
- The information benefitted the public health problem or condition of interest.

Surveys often are used to address the first point. Addressing the second requires use of outcomes (e.g., knowledge or practices) within specific audiences.

Effective communication of public health surveillance information is the critical link in translating scientific information into public health practice. Recognizing the key components in this process—the medium, the message, the audience, the response, and the evaluation of the process—is essential to completing the communications loop.

Displaying Epidemiologic Data

Data analysis is a major component of epidemiologic practice. As the first step in analysis, familiarize yourself with the data by visually examining summarized **data tables**. Sometimes the tables are the only analyses needed, particularly when the amount of data is small and relationships are straightforward. When the data are more complex, **graphs** and **charts** can help you visualize trends in the data.

Visual tools play a critical role in public health surveillance. Data graphics display measured quantities by using points, lines, numbers, symbols, words, shading, and color and are essential to organizing, summarizing, and displaying information clearly and effectively. A graph is a kind of statistical snapshot that helps depict patterns, trends, aberrations, similarities, and differences in the data. Also, graphs are an ideal way to present data—your audience will remember the important aspects of your data better from a graph than from a table. The design and quality of such graphics largely determine how effectively scientists present their information.

Many visual tools are available to assist in analysis and presentation of results. The data presented and the purpose of the presentation are key factors in determining the visual tools to use. The availability of computers has made simple computation of descriptive statistics extremely easy. Still, how best to display such computations must be decided. This section discusses principles of constructing tables and graphs and provides guidelines and illustrations for the best presentation of data. For the sake of simplicity, only the most frequently used graphs and charts for displaying HIV or AIDS data are discussed here.

CONSTRUCTING TABLES

A table arranges data in rows and columns and is used to demonstrate data patterns and relationships among variables and to provide information for other types of data graphics. Table entries can be counts, means, rates, or other analytic measures. Almost any quantitative information can be organized into a table.

A table should be simple; two or three small tables are easier to understand than one large one. A table should be self-explanatory so that, if taken out of context, the data remain understandable. It should be easy to read and not overly complex. By using the following guidelines, you can increase the effectiveness of a table and ensure it is self-explanatory.

- Use a clear and concise title that describes the what, where, and when of the data. When appropriate, precede the title with a table number.
- Label each row and each column clearly and concisely, and include the units of measure for the data (e.g., years, rate per 100,000 persons).
- Show totals for the rows and columns (e.g., N = ?) where appropriate. If you show percentages (%), also give their total (always 100%); if totals are slightly above or below 100% because of rounding, state that in a footnote. When HIV seropositivity data are shown, the total is often not 100% (see example below for counseling and testing data).
- Whenever possible, use columns rather than rows for numbers to be added. (Adding columns of numbers is human nature.)
- Explain codes, abbreviations, acronyms, and symbols in a footnote (e.g., “NIR = no identified risk”).
- Note any exclusions in a footnote (e.g., “Data from persons with unknown ethnicity are excluded”).
- If the data are not original, cite their source in a footnote.

Table Shells

As part of an analysis plan, develop *table shells*—tables that are complete except for the data—that show how the data will be organized and displayed (Table 4.2). Table shells show titles, headings, and categories and can be laid out in a one- or two-variable format (see following examples). Once the data are available, they are simply plugged into the table shell. This preorganization step enables you to create generic table shells that can be used repeatedly merely by altering the components of the shell to meet the data needs.

One-Variable Table

The most basic table is a simple frequency distribution with only one variable (Table 4.3).

Table 4.2	Example of a table shell
HIV Cases by Year of Diagnosis, State X, 2003–2006	
YEAR OF DIAGNOSIS	NO. CASES
2003	
2004	
2005	
2006	

Table 4.3	Example of a one-variable table
HIV Cases by Year of Diagnosis, State X, 2003–2006	
YEAR OF DIAGNOSIS	NO. CASES
2003	7,257
2004	8,013
2005	8,442
2006	10,418



Two- and Three-Variable Tables

When needed, data also can be displayed in a two- or three-variable format (Tables 4.4 and 4.5):

Table 4.4 Example of a two-variable table				
<p>Number* and percentage of persons who reported using noninjection drugs and being under the influence of noninjection drugs while having sex during the preceding 12 months, by type of drug used, United States, National HIV Behavioral Surveillance System: Men Who Have Sex with Men, November 2003-April 2005</p>				
NONINJECTION DRUG	USED DRUG		UNDER INFLUENCE DURING SEX	
	NO.	(%)	NO.	(%) [†]
Marijuana	3,331	(77)	1,975	(59)
Cocaine	1,605	(37)	868	(54)
Ecstasy	1,255	(29)	656	(52)
Poppers (amyl nitrate)	1,226	(28)	1,097	(89)
Stimulant (e.g., amphetamine or methamphetamine)	1,168	(27)	786	(66)
Downer (e.g., valium, ativan, or xanax)	531	(12)	154	(29)
Other club drug (e.g., GHB [§] or ketamine)	505	(12)	291	(58)
Pain killer (e.g., oxycontin or percocet)	433	(10)	119	(27)
Crack	377	(9)	241	(64)
Hallucinogen (e.g., LSD [¶] or mushrooms)	197	(5)	54	(27)
Heroin	124	(3)	60	(49)

* N = 4,322. Participants could report more than one drug type.
[†] Proportion reported is that of participants who used that type of drug during the preceding 12 months.
[§] Gamma hydroxybutyrate.
[¶] Lysergic acid diethylamide.

Source: Human Immunodeficiency Virus (HIV) Risk, Prevention, and Testing Behaviors --- United States, National HIV Behavioral Surveillance System: Men Who Have Sex with Men, November 2003--April 2005. MMWR Surveill Summ 2006; 55(SS06):1-16.

Table 4.5 Example of a two-variable table		
HIV Counseling and Testing Data, by Race/Ethnicity, State X – 2010		
RACE/ETHNICITY	NO. TESTS	POSITIVE TESTS, NO. (%)
White	99,039	1,358 (1.4)
Black/African American	74,296	3,011 (4.1)
Hispanic/Latino	28,603	604 (2.1)
Asian	1,462	18 (1.2)
American Indian/Alaska Native	226	7 (3.1)
Native Hawaiian/other Pacific Islander	37	2 (5.4)
Multiple	366	10 (2.7)
TOTAL	204,029	5,010 (2.5)

Because three-variable tables tend to be busy, use one- or two- variable tables when possible.

CONSTRUCTING GRAPHS

A graph visually displays quantitative information involving a system of coordinates. Graphs are primary analytic tools used to help the reader visualize patterns, trends, aberrations, similarities, and differences in data. Two-dimensional graphs are generally depicted along an x-axis (horizontal orientation) and y-axis (vertical orientation) coordinate system.

- The **x-axis** (independent variable) usually records the interval of occurrence or time periods (e.g., months, years),
- The **y-axis** (dependent variable) usually records the number or rate of cases (on an absolute scale) or the proportions (of 100%) of the total cases.

The x- and y-axes are labeled to show what they represent (the name of the variable and the units in which the variable is measured) and mark a scale of measurement along the line.

Numerical relationships and trends often can be grasped more quickly and easily from graphs than from tables. Simplicity is the key to designing graphs. Simple, uncluttered graphs are more likely than complicated presentations to convey information effectively. When constructing graphs, consider that they should

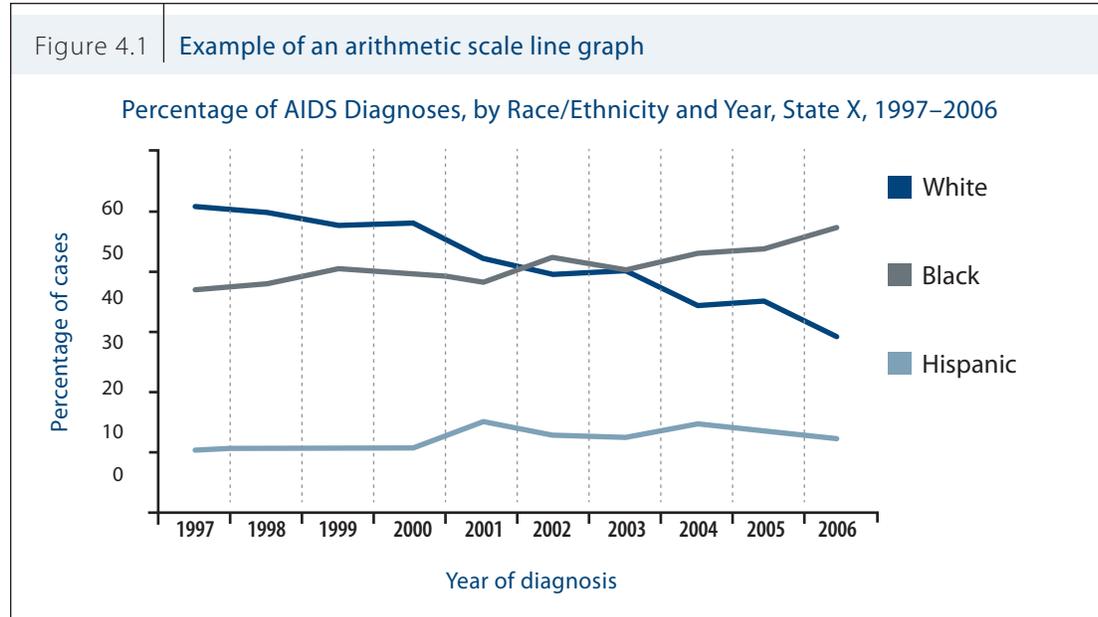
- Be reasonably self-explanatory, clear and accurate.
- Not be overly complex.
- Be correctly and concisely labeled with title, axes, scales, and legends.
- Clearly differentiate variable by legends or keys.
- Minimize the number of coordinate lines.
- Portray frequency on the vertical scale, starting at zero, and the method of classification on the horizontal scale.
- Ensure that scales for each axis are appropriate for the data.
- Clearly indicate scale division, any scale breaks, and units of measure.
- Define abbreviations and symbols.
- Note data exclusions.

Line Graphs

Arithmetic Scale Line Graphs

An arithmetic scale line graph shows patterns or trends over some variable, usually time (Figure 4.1). This type of graph is commonly used to show a long series of data and to compare several series (see below). It is the method of choice for plotting rates over time. The scale used on the x-axis depends on the intervals used to collect the data.





Guidelines for Creating the Axes

x-axis

- The intervals used to collect the data determine the scale used on the x-axis.
- Usually, time data are plotted with the same specificity used to collect them, e.g., monthly, annually.
- For small intervals (e.g., days or months) of data collection, those intervals can be collapsed into larger ones to display the data graphically (e.g., months or years).

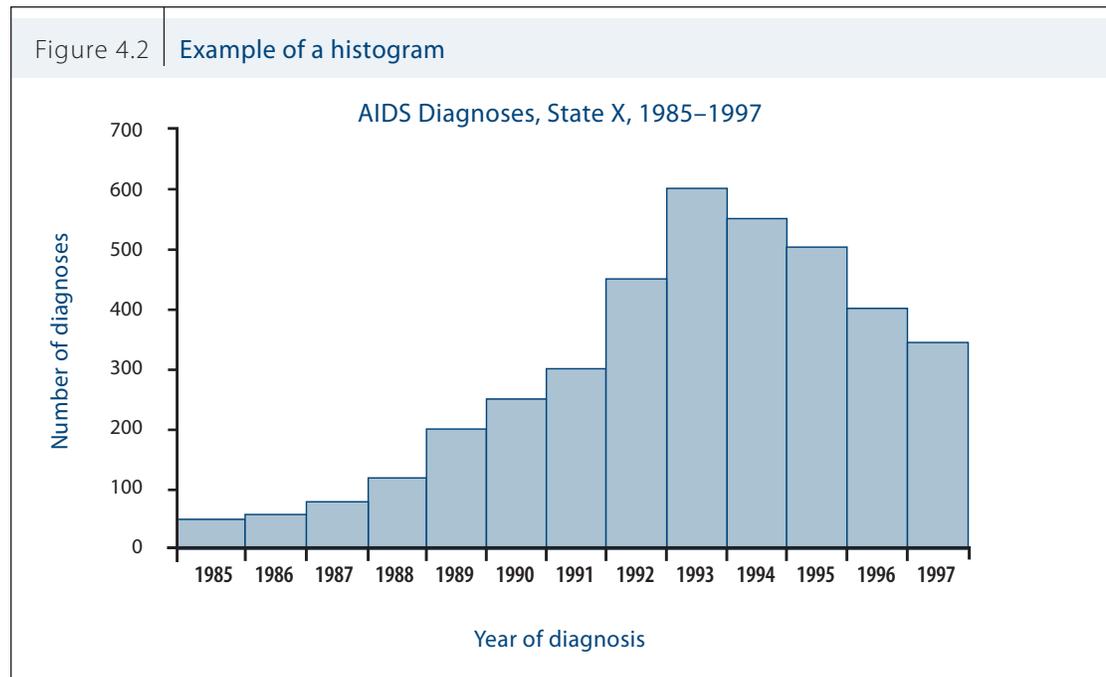
y-axis

- Make the y-axis shorter than the x-axis so that the graph is horizontal, and make the two axes in good proportion; an x:y ratio of about 5:3 is often recommended.
- Start the y-axis with zero. (In specific circumstances it may be appropriate to start the y-axis with a non-zero value to make the data easier to understand, provided the scale and interpretation of the graph are the same whether starting at zero or a non-zero value. Regardless of the axis starting point the interval of values should be consistent along the axis.)
- Determine the range of values needed to show on the y-axis by identifying the largest value you need to graph on the y-axis and rounding that figure to a number slightly larger than that.
- Select an interval size that will give you enough intervals to show the data in enough detail for your purposes.

A computer-based program, such as PowerPoint, will automatically format the graph in accordance with these guidelines.

Histograms

A histogram shows the frequency distribution of a continuous variable, such as age or dates of onset during an epidemic (Figure 4.2). It uses adjacent blocks with widths proportional to the class interval (x-axis) and with areas proportional to the number of cases (y-axis). The area represented by each bar is proportional to the frequency for that interval (i.e., the height multiplied by the width of each bar yields the number of events for that interval).

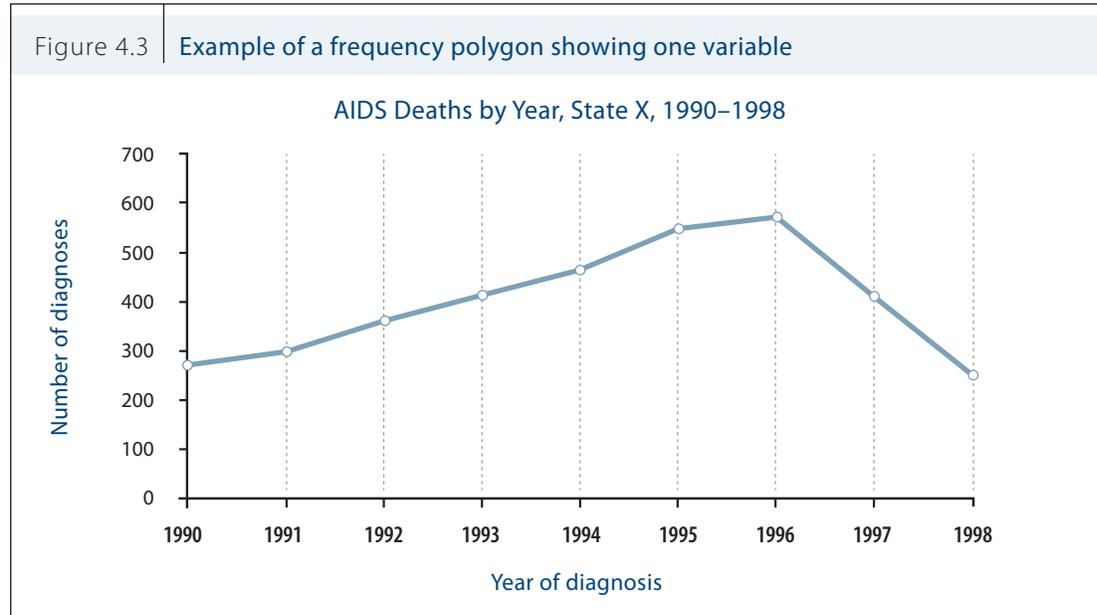


The epidemic curve is a special type of histogram in which time is the variable plotted on the x-axis. The epidemic curve represents the occurrence of cases of disease during an outbreak or epidemic by date of onset or date of report. The most common x-axis variable is time. The y-axis generally represents the number of cases measured.

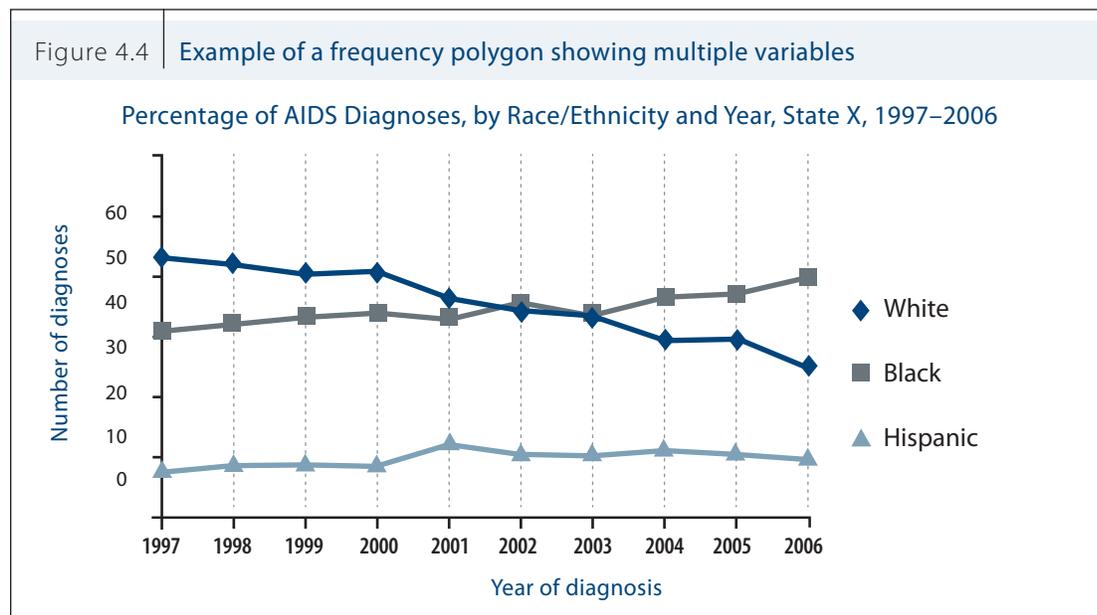
Histograms are best shown with equal class intervals. Scale breaks should never be used in histograms because they show relative frequencies deceptively.

Frequency Polygons

A frequency polygon, like a histogram, is the graph of a frequency distribution (Figure 4.3). In a frequency polygon, we mark the number of observations within an interval with a single point placed at the midpoint of the interval and then connect each set of points with a straight line. As demonstrated below, frequency polygons present a simple picture of the shape of the distribution of observations and thus provide information about the underlying characteristics of the data.



One major advantage of using frequency polygons is that curves for two or more sets of data can easily be constructed on the same graph to facilitate direct comparisons (Figure 4.4). For example, another way to depict the data shown in the arithmetic line graph showing the percentage of AIDS diagnoses for three separate racial/ethnic groups is to use a frequency polygon.

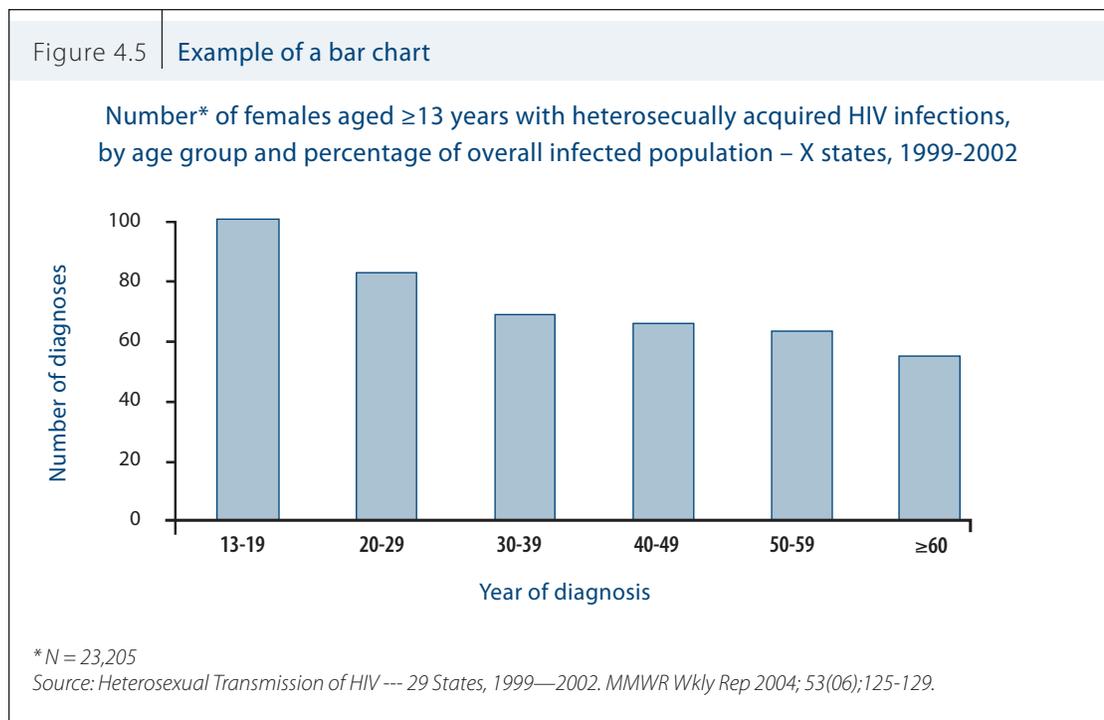


CONSTRUCTING CHARTS

Charts are useful for illustrating statistical information. They are best suited and most helpful for comparing magnitudes of events in categories of a single variable. In the illustrations below, several of the most frequently used types of charts are described.

Bar Charts

A bar chart is one of the simplest and most effective ways to present comparative data (Figure 4.5). A bar chart uses bars of the same width to represent different categories of a variable. Bars can be arranged in ascending or descending length or in some other systematic order. The chart below shows the number of AIDS cases reported in State X by age group. This presentation of the data makes it easy to compare the relative size of the different age groups and to see that the highest percentage of AIDS cases has occurred in the 30–39-year age group.

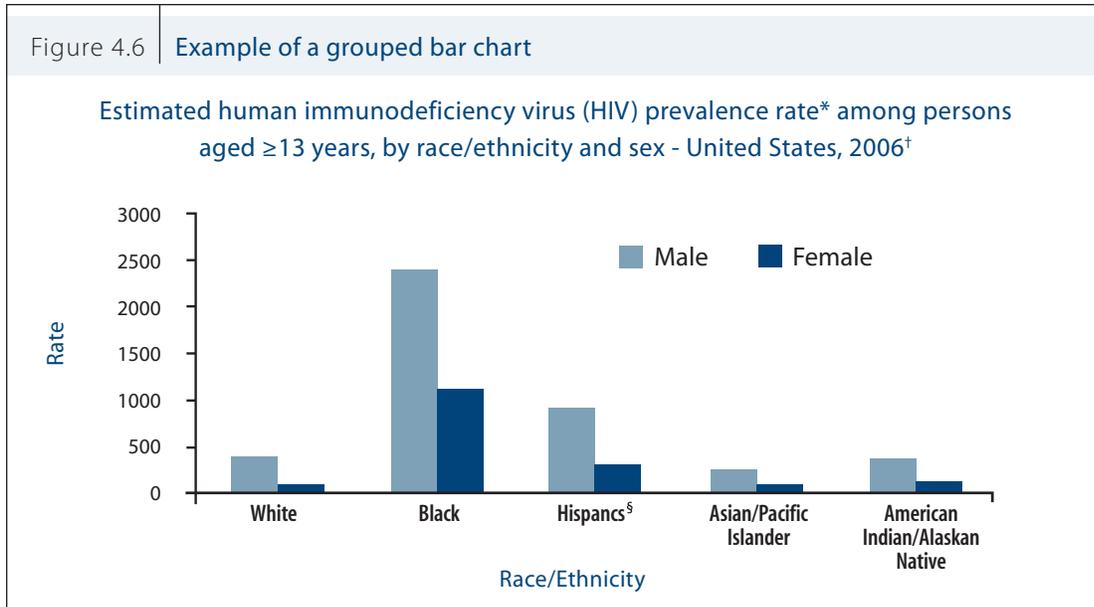


Additional considerations include the following:

- Variables shown in bar charts are both discrete and noncontinuous (e.g., age groups).
- Bars can be either horizontal or vertical. The length or height of each bar is proportional to the frequency of the event in that category.
- A vertical bar chart differs from a histogram in that the bars of a bar chart are separated, whereas the bars of a histogram are joined. This distinction follows from the type of variable used on the x-axis.
- Scale breaks should not be used with bar charts because doing so can lead to misinterpretation in comparing the magnitude of different categories.

Grouped Bar Charts

A grouped bar chart illustrates data from two- or three-variable tables (Figure 4.6). Bars within a group are usually adjoining. The bars must be illustrated distinctively and described in a legend.



* Per 100,000 population.

[†]HIV prevalence at the end of 2006 for the 50 states and the District of Columbia, estimated from national HIV/AIDS reporting system data.

[§] Might be of any race.

Source: HIV Prevalence Estimates -- United States, 2006. *MMWR Wkly Rep* 2008; 57(39):1073-1076.

Other Bar Charts

- **Stacked bar charts** compare different groups within each category of a variable. Data in stacked bar charts usually are difficult to interpret because, except for the bottom component, the components do not rest on a flat baseline.
- **Deviation bar charts** show deviations in a variable, both positive and negative, from a baseline.
- In **100% component bar charts**, all bars are the same height (or length), and the components are shown as percentages of the total rather than as actual values.

How to Construct a Bar Chart

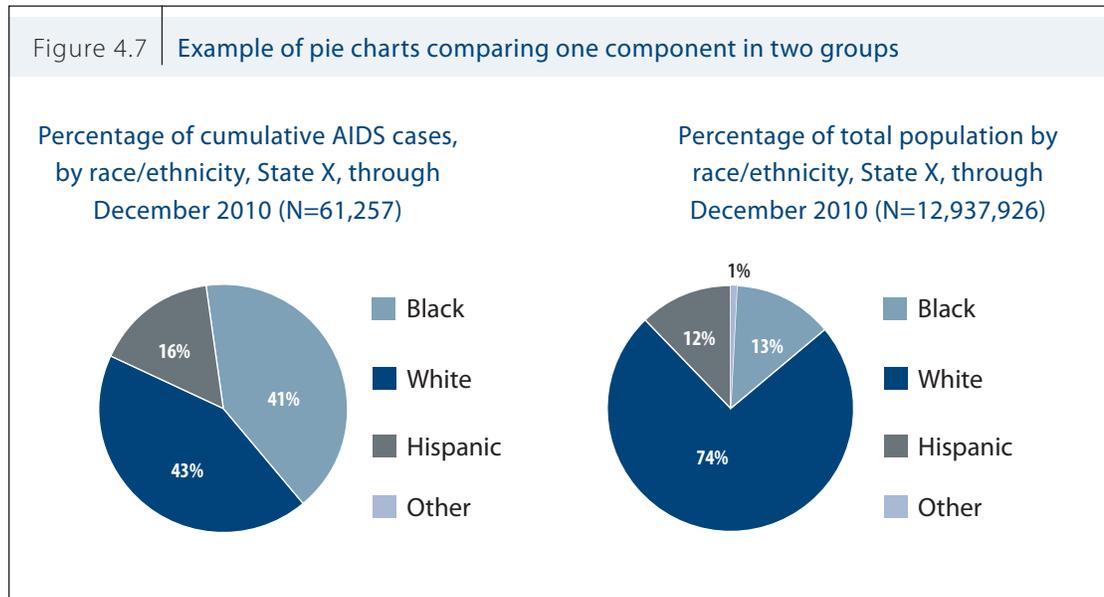
To construct a bar chart,

- Arrange the categories that define the bars, or groups of bars, in a natural order, such as alphabetically or by increasing patient age, or in an order that produces increasing or decreasing bar lengths.
- Position the bars either vertically or horizontally as you prefer, except in deviation bar charts, in which the bars usually are positioned horizontally.
- Make all bars the same width, which can be whatever appears most proportional.
- Make the length of bars proportional to the frequency of the event. Do not use a scale break because it can lead to misinterpretation when the sizes of different categories are compared.
- Minimize the bars in a group to a reasonable number.
- Leave a space between adjacent groups of bars but not between bars within a group.
- Code different variables with different bar colors, shading, or cross-hatching, and include a legend that explains the code.

Pie Charts

A pie chart is a simple, easily understood chart in which the sizes of the slices show the proportion of each component of a single group or variable. The slices usually are indicated by different colors or shading, and the percentages are written inside or outside the slices to enable the reader to make accurate comparisons. The total of all slices of the pie should equal 100%.

Multiple pie charts (Figure 4.7) are useful for comparing the same components in more than one group or variable. However, depending on the number of the components, a bar chart might be more useful.



CONSTRUCTING MAPS

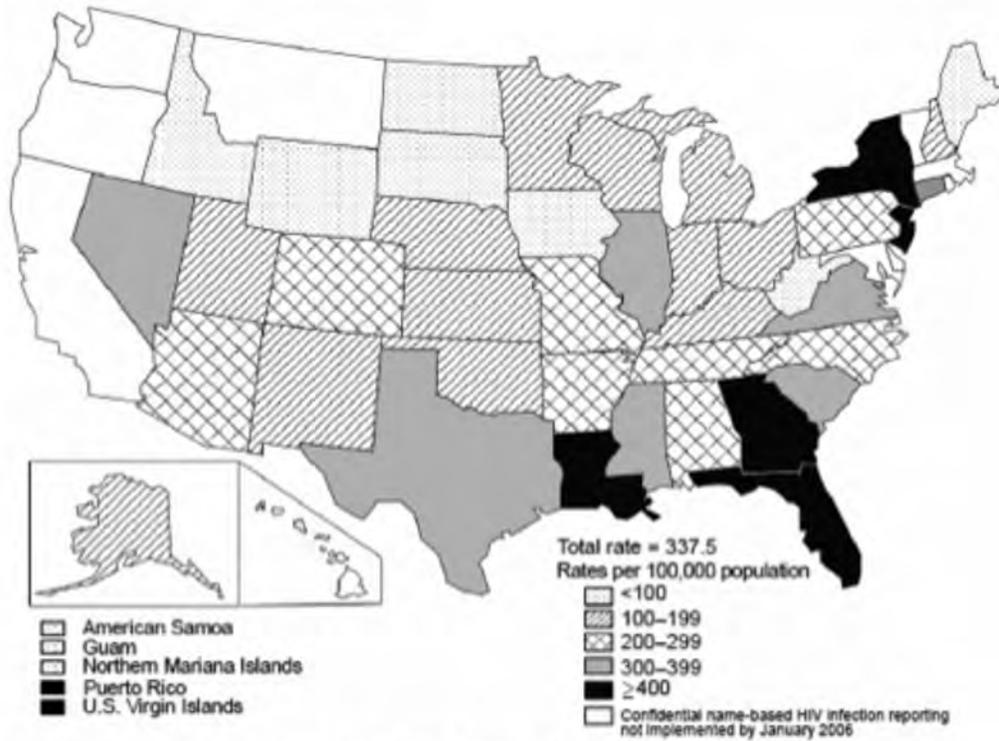
Maps are the graphic representation of data shown by location and geographic coordinates. A map generally provides a clear method for grasping data and is particularly effective for readers familiar with the physical area being portrayed.

For reasons of confidentiality and privacy, mapping cases below the county level might be controversial, especially for HIV or AIDS data. Because visually locating cases in a small geographic area (clustering) could be inflammatory and harm local community relationships, be sensitive to issues of community confidentiality. If a map must be provided, consider designing one that displays data for a combination of subcounty areas. When in doubt, consult with the HIV surveillance program or state health department before releasing any data so as to not breach confidentiality of individuals.

An area map uses different colors, shading, or hatching to portray range-graded values to depict rates of health conditions in specific areas (Figure 4.8). Care must be taken in interpreting area maps because each area is coded (e.g., colored, shaded) uniformly regardless of demographic differences within an area. Either numbers or rates can be displayed with an area map; the map below displays rates of HIV diagnosis among adults and adolescents per 100,000 population by state. By showing rates, you can illustrate the difference in disease condition (here rates of HIV diagnosis) by a specific geographic area (in this case, states with name-based HIV reporting as of January 2003). Often a standardized rate is calculated for each area, i.e., the number of cases in each area is divided by the population at risk in the same area and then multiplied by a standard population size (frequently 100,000).

Figure 4.6 | Example of an Area Map

Estimated rates of adults and adolescents living with a diagnosis of HIV infection, by area of residence, year-end 2008 – 40 states and 5 U.S. dependent areas with confidential name-based HIV infection reporting (N=679,590)*



* Estimated rates resulted from statistical adjustment that accounted for reporting delays, but not for incomplete reporting.

Using Computers to Creative Graphs and Charts

A large number of software packages are available that can help make tables, graphs, and charts. Most of these packages enable the user to redraw a graph with only a few keystrokes.

On the other hand, allowing the software to dictate the graph can be tempting (Tables 4.6 and 4.7). For example, many packages can draw bar charts and pie charts that appear three-dimensional. Does this mean a three-dimensional chart is appropriate? Also, a problem common to three-dimensional bar charts is that a bar in the front row can block a bar in the back row. Remember that the purpose of a graph is to simply and effectively information simply and effectively. Determine whether a three-dimensional chart presents the information better than a two-dimensional chart. If the aim is to compare trends over time for confirmed and reported cases, perhaps a three-dimensional bar chart is preferable. However, an arithmetic scale line graph with two lines would be more than adequate.

For pie charts, the same question of usefulness needs to be asked. Often a three-dimensional pie chart will skew the relative sizes of the individual pie slices, making it difficult to see which slice is bigger—and size is the purpose of using a pie chart.

Technology is often misused in selecting color, particularly for slides that accompany oral presentations. If colors are to be used, follow these recommendations:

- Select colors so that all components of the graph—title, axes, data plots, and legends—stand out clearly from the background and each plotted series of data can be distinguished from the others.
- Avoid contrasting red and green because up to 10% of men in the audience can have some degree of color blindness.
- When possible, select colors that aid in communicating the information. For example, consider an area map in which states are divided into four groups according to rates for a particular disease. Rather than choosing colors solely for appearance, use a lighter color or shade for states with the lowest rates and progressively darker colors or shades for states with increasingly higher rates so that the colors contribute to, rather than distort or distract from, the information.

Finally, some software packages do not enable you to produce some of the types of graphs covered in this section. In particular, some software packages cannot create a histogram; instead they produce a bar chart (although some software programs enable you to adjust the “gap width” between the bars to zero, essentially allowing you to display a histogram). The data and the relationships they visually communicate, not the technology, should dictate the graphs used. If the software cannot accommodate the data, don’t compromise the integrity of the data or its presentation. Use different software!



Presenting Surveillance Data

TYPE OF GRAPH OR CHART	WHEN TO USE
LINE GRAPHS	
Arithmetic scale line graph	Trends in numbers or rates over time
Histogram	<ul style="list-style-type: none"> • Frequency distribution of continuous variable • Number of cases during epidemic (i.e., epidemic curve) or over time
Frequency polygon	Frequency distribution of continuous variable, especially to show components
BAR AND PIE CHARTS	
Simple bar chart	Comparison of size or frequency of different categories of single variable
Grouped bar chart	Comparison of size or frequency of different categories of two to four series of data
Stacked bar chart	Comparison of totals and depiction of component parts of the total among different groups
Deviation bar chart	Illustration of differences, both positive and negative, from baseline
Pie chart	Components of a whole
MAPS	
Area map	Display of events or rates geographically

IF DATA ARE		AND THESE CONDITIONS APPLY		THEN CHOOSE
Time series		Numbers of cases (epidemic or secular trend)	One set	Histogram
Time series		Numbers of cases (epidemic or secular trend)	Two or more sets	Arithmetic scale line graph
Time series		Rates	Range of values ≤ 2 order of magnitude	Arithmetic scale line graph
Continuous data other than time series		Frequency distribution		Histogram or frequency polygon
Discrete categories (other than place)				Bar chart or pie chart
Place	No. cases	Not readily identified on a map		Bar chart
Place	No. cases	Not readily identified on a map	Specific site unimportant	Area map
Place	Rates			Area map

Source: U.S. Department of Health and Human Services, Principles of Epidemiology, 2nd ed. (CDC Self Study Course #3030-G); p. 263–4.

CHECKLIST FOR CONSTRUCTING TABLES, GRAPHS, CHARTS, AND OTHER VISUALS

Checklist for Tables

- Title
 - ▶ Does the table have a title?
 - ▶ Does the title describe the content, including subject, person, place, and time?
 - ▶ When appropriate (e.g., for publications, reports), is the title preceded by the designation “Table #”? (“Table” is used for typed text; “Figure” is used for graphs, charts, and maps. Separate numerical sequences are used for tables and figures in the same document [e.g., Table 1, Table 2, Figure 1, and Figure 2]).
- Rows and columns
 - ▶ Are each row and each column labeled clearly and concisely?
 - ▶ Are the specific units of (e.g., years, mm Hg, mg/dL, rate per 100,000) shown?
 - ▶ Are the categories appropriate for the data?
 - ▶ Are the row and column totals provided?
- Footnotes
 - ▶ Are all codes, abbreviations, and symbols explained?
 - ▶ Are all exclusions noted?
 - ▶ If the data are not original, is the source cited?

Checklist for Graphs and Charts

- Title
 - ▶ Does the graph or chart have a title?
 - ▶ Does the title describe the content, including subject, person, place, and time?
 - ▶ When appropriate (e.g., for publications, reports), is the title preceded by the designation ‘Figure #’? (“Table” is used for typed text; “Figure” for graphs, charts, and maps. Separate numerical sequences are used for tables and figures in the same document [e.g., Table 1, Table 2, Figure 1, and Figure 2]).
- Axes
 - ▶ Is each axis labeled clearly and concisely?
 - ▶ Are the specific units of measurement (e.g., years, mm Hg, mg/dL, rate per 100,000) included as part of the label?
 - ▶ Are the scale divisions on the axes clearly indicated?
 - ▶ Are the scales for each axis appropriate for the data?
 - ▶ Does the y-axis start at zero?
 - ▶ If a scale break is used with a scale line graph, is it clearly identified?
 - ▶ Has a scale break been used with a histogram, frequency polygon, or bar chart? (Answer should be no!)
 - ▶ Are the axes drawn heavier than the other coordinate lines?
- Coordinate lines: Does the figure include only as many coordinate lines as are necessary to guide the eye? (Often, these are unnecessary.)

Presenting Surveillance Data

- Data plots
 - ▶ Are the plots drawn clearly?
 - ▶ If more than one series of data or components are shown, are they clearly distinguishable on the graph?
 - ▶ Is each series or component labeled on the graph or in a legend or key?
 - ▶ If color or shading is used on an area map, does an increase in color or shading correspond to an increase in the variable being shown?
- Footnotes
 - ▶ Are all codes, abbreviations, and symbols explained?
 - ▶ Are all exclusions noted?
 - ▶ If the data are not original, is the source cited?
- Visual display
 - ▶ Does the figure include any information that is not necessary?
 - ▶ Is the figure positioned on the page for optimal readability?
 - ▶ Do font sizes and colors improve readability?

Checklist for Effective Visuals

- Legibility
 - ▶ Can your overhead transparencies be read easily from 6 feet when not projected?
 - ▶ When projected, can your visuals be read from the farthest parts of the room?
- Simplicity
 - ▶ Have you used plain words?
 - ▶ Is the information presented in the language of the audience?
 - ▶ Have you used only “key” words?
 - ▶ Is each visual limited to only one major idea, concept, or theme?
 - ▶ Does each visual have no more than three colors?
 - ▶ Have you minimized letters and numbers on each visual?
 - ▶ Have you minimized lines of narration and words per line?
- Colorfulness
 - ▶ Have you selected appropriate colors for your visuals (Table 4.8)? Use warm/hot colors to emphasize, to highlight, to focus, or to reinforce key concepts. Use cool/cold colors for background or to separate items.

	HOT	WARM	COOL	COLD
COLOR	Reds	Light orange	Light blue	Dark blue
	Bright orange	Light yellow	light green	Dark green
	Bright yellow	Light gold	Light purple	Dark purple
	Bright gold	Browns	Light gray	Dark gray
EFFECT	Exciting	Mild	Subdued	Somber

- Are you using the best color combinations? The most important item should be in the most important color and have the greatest contrast with its background. The most legible color combinations are
 - ▶ Black on yellow
 - ▶ Black on white
 - ▶ Dark green on white
 - ▶ Dark blue on white
 - ▶ White on dark blue
- Accuracy: Has someone who has not previously seen the visual checked for typos, inaccuracies, and errors in general?
- Durability:
 - ▶ Have you backed up your visuals? Keep backup copies of PowerPoint slide presentations in various locations on a protected computer network.
 - ▶ Transparencies are fairly durable visual aids but require some protection from scratches from a clear sheet of acetate or Mylar. Transparencies are not easily modified without changing the source computer file and reprinting.

Source: U.S. Department of Health and Human Services, Principles of Epidemiology, 2nd ed. (CDC Self Study Course #3030-G); p. 263–4.

SUMMARY

Tables, graphs, and charts are effective tools for summarizing and communicating data. Tables are commonly used to display numbers, rates, proportions, and cumulative percentages. Because tables are intended to communicate information, most should have no more than two variables and no more than eight categories (class intervals) of any variable. Tables are sometimes used out of context, so they should be properly titled, labeled, and referenced.

Graphs and charts are even more effective for communicating data rapidly. Although some people use the terms graph and chart interchangeably, in this module graph refers to a figure with two coordinates, a horizontal x-axis, and a vertical y-axis. In other words, both variables are continuous. For example, the y-axis commonly features number of cases or rate of disease; the x-axis usually represents time. In contrast, a chart is a figure with one continuous and one nominal variable. For example, the chart might feature number of cases (a continuous variable) by sex (a nominal variable).

Arithmetic scale line graphs traditionally have been used to show trends in disease over time. Histograms and frequency polygons are used to display frequency distributions. A special type of histogram known as an epidemic curve shows the number of cases by time of onset of illness or time of diagnosis during an epidemic period.

Simple bar charts and pie charts are used to display the frequency distribution of a single variable. Grouped and stacked bar charts can display two or even three variables. The purpose of these tools is to summarize and to communicate. Glitzy and colorful are not necessarily better; sometimes less is more!

Epidemiologic Terms, Definitions, and Calculations Relevant to HIV Surveillance Data

Familiarize yourself with terms specific to HIV surveillance data. Section 14, Appendix A, of the *Technical Guidance for HIV/AIDS Surveillance Programs, Volume I: Policies and Procedures*, includes many of these definitions and terms.

MODULE FIVE

Risk Factor
Ascertainment

OBJECTIVES:

1. Explain the background of and need for risk factor ascertainment.
2. Explain the process of risk ascertainment.
3. Define the terminology and classification associated with risk factor ascertainment.
4. Describe the importance of educating and training health-care providers in risk ascertainment.
5. Describe importance of educating and training surveillance staff in risk ascertainment.
6. List the standards for risk factor ascertainment.
7. Explain the need for providing feedback to reporting sites.
8. Define a case of public health importance.
9. Show how to find information for determining risk factors.
10. Demonstrate general interviewing strategies and techniques.
11. Provide expanded terminology for categorizing HIV risk factors.

Background

Text in this Module is taken from Section 3 of the [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](#).

An essential component of public health surveillance for any condition is an understanding of the behaviors that put people at risk for infection or disease. At the beginning of the AIDS epidemic (early 1980s), AIDS cases were diagnosed among homosexual men. Shortly thereafter AIDS was diagnosed in injection drug users, transfusion recipients, and children born to mothers with AIDS. Case investigation and follow-up helped to establish that the causative agent (HIV) was transmitted through exchange of infected body fluids, including semen, blood, and breast milk.

Core surveillance activities include epidemiologic follow-up to obtain complete information, such as demographics, risk factors, and clinical information, about reported cases of HIV disease. A critical component of epidemiologic follow-up is identification of all known risk factors. The risk factors correspond to the period “before the first positive HIV test or diagnosis” and no longer correspond to the period “after 1977 and preceding the first positive HIV antibody test or diagnosis,” as stated on the adult case report form. Today many HIV-positive adults were either very young or not yet born in 1977, and those who might have been exposed before 1977 might not remember whether risk behaviors occurred before or after the cutoff date.

Process of Risk Factor Ascertainment

Risk factor ascertainment begins when the surveillance program receives a report of an actual or suspected HIV case without any risk factor information (also known as “no reported risk” [NRR]). Risk factor ascertainment should include usual follow-up activities, such as calling a reporting facility or delegating field staff to inquire about a laboratory or provider report received by the surveillance program. Routine case follow-up should include inquiry about all HIV risk factors for each case (or a sample of cases, for surveillance programs that use the sampling protocol). The investment of time and resources to educate providers/reporters and surveillance staff about proper risk factor ascertainment should reduce the number of cases for which follow-up is needed and help acquire complete and accurate information about all cases reported to the surveillance system.

The surveillance program should follow up all NRR cases, if feasible, prioritizing facilities with the largest number of NRR cases. Alternatively, the surveillance program should select a representative sample of cases and follow up that sample.

All NRR cases should be reclassified as no identified risk (NIR) if

- All reasonable data sources have been reviewed or contacted and no risk factor identified, or
- Epidemiologic follow-up has not been initiated or completed, and 12 months have elapsed since the date of the initial case report.

All cases (or all cases in the selected representative sample) are used to measure progress toward achieving the national [outcome standard for risk ascertainment](#).

All risk factor variables listed in the Patient History section of the adult and pediatric HIV confidential case report forms (see also [Expanded Terminology for Categorizing HIV Risk Factors](#) section, at the end of this module) should be populated with a response (i.e., “yes,” “no,” or “unknown”). A lack of indication for a risk factor cannot be assumed to be “no.” Select “no” only if the data source (e.g., medical record, surveillance interview) specifically states the item is not a risk factor; and select “unknown” only for those for which investigation failed to yield an answer.

Within 1 month after the date of the initial case report, if an HIV risk factor has not been documented (i.e., NRR), follow-up should begin by conducting a medical chart review at the initial case report facility or, if a laboratory was the initial facility of report, then at the next subsequent facility of case report. Surveillance programs should prioritize new cases over old cases for follow-up. Within 3 months after the date of the initial case report, epidemiologic follow-up should expand beyond the reporting facility to include other available data sources or other facilities at which the HIV-infected person has received care and other reporting sources, such as counseling and testing sites and sexually transmitted disease (STD) databases. These sources should be prioritized according to where risk factors are most likely to be found. Surveillance program staff should develop standardized, systematic procedures for searching data sources, including database matches, beyond the initial reporting facility. On the basis of data from the Centers for Disease Control and Prevention (CDC)’s Ascertainment of Transmission Risk project in 10 states, risk factor information was most likely to be found from the following six sources:

- Review of medical charts at a health-care provider who did not test or report the patient for HIV but for whom the reported person is a patient. (According to the Ascertainment of Transmission Risk project sites, this provider is most likely the patient’s current HIV treatment provider.)
- Review of medical charts at the health-care provider who tested the patient for HIV.
- Telephone calls or visits to the health-care provider who did not test or report the patient for HIV but for whom the reported person is a patient (most likely the patient’s current HIV treatment provider) but where medical charts were not reviewed.
- Telephone calls or visits to a social services case manager providing physical and emotional assistance to the HIV-infected person.
- Review of medical charts at the health-care provider who reported, but did not test, the person for HIV.
- Telephone calls or visits to the health-care provider who reported, but did not test, the person for HIV but where medical charts were not reviewed.

The procedure for investigating NRR cases should continue until all reasonable sources of information have been exhausted or until 1 year after the date of initial case report. Cases that remain without risk factor information 1 year after the date of the initial case report must be counted as NIR cases for measuring progress toward the national outcome standard for risk ascertainment.

If risk factors are found on an NIR case more than 1 year after the date of the initial case report, the risk factors must be updated, which will result in reclassification of the case.

Terminology and Classification

The routes of HIV transmission and the classifications of HIV-infected persons that summarize those routes have been subject to much inconsistency and ambiguity. Multiple terms have been used to refer to the same thing, and the same terms have been used to refer to different things. Terms that end in the word “risk” are especially ambiguous because they can refer to categorical (men who have sex with men, injection drug use) rather than numerical (relative risk = 1.2) variables.

To avoid confusion, standard terminology should be used. After consideration of a variety of alternatives, the following standard terms and definitions are recommended by the HIV Incidence and Case Surveillance Branch.

RISK FACTORS

“Risk factors” is the collective term for the individual routes of exposure (before the person found out he/she was HIV positive) on which data are routinely collected for surveillance of HIV. They comprise the following categories:

- **Male sexual contact with another male.** This risk factor is based on two variables: male sex and sex with a male.
- **Receipt of nonprescribed drugs by injection.** The nonprescribed drugs could have been injected intravenously, intramuscularly, or subcutaneously. The drug itself is not the source of the HIV infection, but the context of the drug being taken illicitly (i.e., without a prescription) is likely to be associated with sharing of injection equipment (e.g., syringes, needles, cookers), which can result in transmission of bloodborne pathogens, such as HIV.
- **Heterosexual contact.** This risk factor recently was redefined as HIV transmission due to heterosexual sexual activity but *without* the requirement to know that the partner was HIV-positive or the partner’s HIV risk history. This definition replaced the definition that the heterosexual contact risk factor required knowledge that the partner had HIV infection or was at increased risk for HIV infection.

Previous variables that described the risk factor of the heterosexual sex partner included the following:

- ▶ Heterosexual contact with a partner who has received nonprescribed drugs by injection.
 - ▶ Heterosexual contact with a bisexual male (applies only to females).
 - ▶ Heterosexual contact with a partner who had received blood products for treatment of a coagulation disorder, such as hemophilia.
 - ▶ Heterosexual contact with a transfusion recipient with documented HIV infection.
 - ▶ Heterosexual contact with a recipient of a transplanted organ or tissue with documented HIV infection.
 - ▶ Heterosexual contact with a partner not known to have any of the above risk factors for HIV infection but known, nonetheless, to have HIV infection.
- **Receipt of an infusion of clotting factor blood product for treatment of hemophilia or other chronic coagulation disorder.** “Hemophilia” or “coagulation disorder” refers only to a disorder of a clotting factor; factors are any of the circulating proteins named factor I through factor XII. These disorders include hemophilia A and von Willebrand disease (factor VIII disorders) and hemophilia B (a factor IX disorder). This risk factor generally is documented in the history and physical section of the patient’s medical chart.
 - **Receipt of transfusion of blood or blood components (other than clotting factor).** According to the [American Society of Hematology](#), “blood” is a specialized body fluid composed of a fluid portion (plasma) with suspended formed elements (erythrocytes [red blood cells,] leucocytes [white blood cells,] and thrombocytes [platelets]). “Blood components” that can be transfused include white blood cells, red blood cells, platelets, and plasma.
 - **Receipt of a transplant of organ or tissue or of artificial insemination.**

- **Work in a health-care or clinical laboratory setting.** This risk factor usually is termed “occupational exposure” to HIV. This category also can include other forms of occupational exposure, such as that experienced by a police officer, firefighter, or sanitation worker, or nonoccupational exposures, such as contact with another person’s blood or an open wound as a result of providing informal health care to another person or as a result of a fight.
- **Perinatal mother-to-child transmission.** This category applies to children born to women known to have HIV infection or at increased risk for HIV infection. The mother’s HIV infection could be a result of a risk factor that she had before the child’s birth or that confirm her infection status, i.e.,
 - ▶ Mother had received injection of nonprescribed drugs.
 - ▶ Mother had heterosexual contact with a male who injected nonprescribed drugs.
 - ▶ Mother had heterosexual contact with a male who had sexual contact with another male (bisexual male).
 - ▶ Mother had heterosexual contact with a male who had received blood products for treatment of a coagulation disorder.
 - ▶ Mother had heterosexual contact with a male known to have HIV infection who had received a blood transfusion.
 - ▶ Mother had heterosexual contact with a male known to have HIV infection who had received an organ or tissue transplant.
 - ▶ Mother had heterosexual contact with a male known to have HIV infection but not known to have any of the above risk factors for HIV infection.
 - ▶ Mother had received a transfusion of blood or blood components and was known to have HIV infection.
 - ▶ Mother had received a transplant and was known to have HIV infection.

The above variables are used in conjunction with the variable “mother’s HIV infection status.” In the absence of knowledge that the mother had one of the above risk factors for HIV infection, a value for mother’s HIV infection status indicating that she had HIV infection is necessary to infer that the child had perinatal exposure. Conversely, a value for mother’s HIV infection status indicating she did not have HIV infection after the child’s birth would mean the child did not have perinatal exposure.

- “Supplemental risk factors” is the term for other behaviors or proxies associated with various routes of transmission, such as number of sex partners, lack of condom use, noninjection drug use, selling of sex in exchange for money or drugs, history of other STDs, time spent in prison, and diagnosis of viral hepatitis. This information is not collected on the current HIV case report form; however, individual surveillance programs may elect to collect these data and store as Local/Optional Fields in eHARS.

TRANSMISSION CATEGORY

“Transmission category” applies to the classification of cases that summarizes a person’s possible HIV risk factors; the summary classification results from selecting, from the presumed hierarchical order of probability, the one risk factor most likely to have been responsible for transmission. Persons with more than one reported risk factor for HIV infection are classified in the transmission category listed first in the hierarchy. The exception is for men who report both sexual contact with other men *and* injection drug use; this group makes up a separate transmission category.

1. **Male-to-male sexual contact (MSM).** This category consists of men who report sex with other men exclusively, as well as men who report sex with both men and women.
2. **Injection drug use (IDU).**

3. **Male-to-male sexual contact and injection drug use (MSM/IDU).**
4. **Heterosexual contact (HET)**, defined as heterosexual contact with a person of the opposite sex but without known history of MSM or IDU.
5. **Perinatal transmission**, comprising children born to women known to have HIV infection or at increased risk for HIV infection. Through implementation of U.S. Public Health Service [guidelines on HIV testing/appropriate treatment for pregnant women](#), this transmission category is increasingly rare.
6. **Other** combines data on persons with a risk factor for HIV, including receipt of clotting factors, blood transfusion, or organ or tissue transplant; artificial insemination; and other rare transmission circumstances, such as exposure to potentially infective body fluids. Through implementation of universal screening of blood and tissue products in the United States, this transmission category is increasingly rare.
7. **Risk factor not reported or not identified (NRR/NIR).** Persons with no reported exposure to HIV through any of the routes listed in the hierarchy of transmission categories are classified as “no risk factor reported or identified.” NRR comprises cases that were initially identified to the local surveillance program without sufficient risk information and have not undergone epidemiologic follow-up to determine risk. NIR comprises cases that have been followed up by local surveillance staff but for which no HIV risk information was available because of such reasons as patient refusal, loss to follow-up, or death.

Education and Training of Health-Care Providers in Risk Ascertainment

Health-care providers are busy and might not share or prioritize the health department’s goal of ascertaining HIV risk factors. Therefore, surveillance programs might lose their attention if their communications are not clear, realistic, and concise (and without excessive use of acronyms, jargon, and terminology unfamiliar to providers). When necessary, reporting materials should be developed for providers (Appendix D of Risk Factor Ascertainment chapter in [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](#)); an example of such material is a laminated card with the algorithm for reporting risk factors on a new case. For example, providers might not be clear about CDC-defined “heterosexual contact” and thus might note “multiple sex partners” in the medical record and believe, incorrectly, that they are providing risk factor information.

Communications about risk factor ascertainment must be directed to the appropriate person or persons at the reporting facility. No single job title adequately describes the appropriate contact person (e.g., administrators, social workers, counselors, nurses, or physicians could be the contact person). Furthermore, at many facilities, staff turnover is high, so keeping abreast of staff changes is necessary. Training and education of staff at reporting facilities should assist surveillance programs in heightening awareness and visibility and will foster collaboration with health-care providers. Training staff at reporting sources, if done well, can reduce the initial time, money, and other resources expended by a surveillance program to ascertain risk factors.

Risk Factor Ascertainment

All nonlaboratory reporting facilities should have at least one person trained in the proper procedures for ascertaining HIV risk factors (including knowledge of CDC-defined risk factors).

- Surveillance staff should identify the designated reporter or primary contact at each reporting facility known to the surveillance program.
- Ideally, on-site training should be conducted at all nonlaboratory reporting facilities. However, surveillance programs might not have field staff or resources to conduct active surveillance (regular site visits, field staff to follow up each case). For that reason, at a minimum, a trained surveillance staff member should complete a telephone call and follow up with mailing, including electronically distributing, educational materials, to the reporting facility (Appendix D of Risk Factor Ascertainment chapter in [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](#)).
- Surveillance staff should maintain a reference file (electronic or hard copy) of reporting facilities, which includes training and materials provided to each facility (Appendix D of Risk Factor Ascertainment chapter in [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](#)).

Identify and work with reporting facilities that might not be documenting or reporting risk factors because of concerns or misperceptions about the Health Information Portability and Accountability Act ([HIPAA](#)), confidentiality, or related issues.

- Discussion about confidentiality and the reporting process should be included in all provider contacts (i.e., telephone calls, site visits, mailing, email) and as part of core surveillance activities. Surveillance programs should use general disease reporting resources to discuss with providers their concerns about the collection, management, and dissemination (data release) of confidentially reported information.
- For reticent reporting sites, surveillance programs should use “Dear Colleague” letters signed by public health officials describing HIPAA as it relates to public health disease surveillance (Appendix D of Risk Factor Ascertainment chapter in [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](#), HIPAA Letter).

The surveillance program should communicate with health-care providers at least annually to educate them on their responsibilities for reporting risk factors. As much as possible, communication related to risk factors should be incorporated into existing calls, emails, visits, and other contacts.

- At a minimum, all providers should be contacted annually to ensure that they understand their responsibility to report HIV cases and the importance of reporting complete information. The form of this communication (i.e., mailings, emails, telephone calls, face-to-face) and its frequency depend on a number of factors, including the number of different sources reporting to the health department, their volume of reports, and the opportunities they present for conducting active surveillance. For example, contacting high-volume providers at more regular intervals and scheduling face-to-face meetings might be most cost effective.
- For low-volume reporters, such as private medical doctors who report only one or two cases annually, yearly mailing or email might be a better use of resources.
- Presentations to professional associations at national, regional, and state meetings and publications in professional journals would reach a larger audience of health-care providers.
- Risk factor ascertainment material should be incorporated into the education and training centers’ programs for health-care providers treating persons with HIV infection. Present epidemiologic data that include to risk factor data.

All newly identified HIV care providers and facilities should have at least one person trained in HIV risk factor ascertainment (including knowledge of CDC-defined risk factors) within 1 month after being identified as a reporting source.

- The surveillance program should identify any previously unknown HIV care provider and initiate contact to inform him/her about and discuss HIV reporting rules, process, and general programmatic information, e.g., statistics, care services.
- Surveillance program staff will most likely benefit by establishing face-to-face contact with a newly identified HIV care provider. Surveillance programs should extend the offer for program staff to conduct a site visit at first contact to establish a relationship with the provider. This expenditure of time and resources at first report (newly identified) is likely to maximize the surveillance program–provider relationship and facilitate complete case reporting in the future.
- A reference list (electronic or hard copy) with the name, contact information, and training dates of the contact person should be maintained to facilitate regular communication and track reporting sources who have received training.

Education and Training of Surveillance Staff in Risk Ascertainment

State and local HIV surveillance coordinators are considered to have experience and expertise in collecting, analyzing, and disseminating population-based data on the HIV epidemic. Therefore, surveillance coordinators and experienced surveillance staff should routinely provide training on risk factor ascertainment to internal staff and to staff at external reporting sources, both laboratory (when appropriate) and nonlaboratory (e.g., health-care provider).

In most areas, surveillance staff do not have direct contact with HIV-infected persons, and the opportunity to interview those persons or otherwise ascertain their risk factors rests with the provider. Nonetheless, surveillance staff play a pivotal role in risk factor ascertainment through their relationships with providers. This role includes ensuring that providers clearly understand CDC- and local health department–defined risk factors, actively ascertain risk factors from clients, and provide the information to surveillance staff through verbal communication or chart notes.

The surveillance program should have a written manual of procedures for risk factor ascertainment. The manual should be specific and include

- Sources of information that are to be searched and the order in which they are to be searched.
- Evidence and/or documentation that is acceptable for a particular risk factor.
- Reasons for collecting information about multiple risk factors, i.e., not stopping after identifying one risk factor.
- Performance expectations, such as turnaround time and communication with providers at assigned sites.

The surveillance program should conduct risk factor ascertainment training for new surveillance staff within 1 month after their start date and make the manual of procedures for risk factor ascertainment available to them. This training provides an early and important opportunity to teach new staff about their critical role in risk factor ascertainment and provide them with the tools to implement the process. New staff should be told that ascertaining risk factors is as important as other elements of case reporting, such as obtaining demographic information, and examples of how risk factor data are used and why they are important should be provided.

Risk Factor Ascertainment

As part of orientation and training, staff should be given a package of written reference materials that includes definitions of risk factors (Appendix D of Risk Factor Ascertainment chapter in [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](#), CDC-defined HIV risk factors) and a manual of procedures regarding the conduct of risk factor ascertainment at the local level.

Orientation and training also should include a presentation or discussion of risk factor ascertainment by a senior surveillance staff member. The presentation can address the “big picture” in terms of how the program uses risk factor information and the consequences of inadequate information.

Sample risk factor ascertainment exercises can provide a context for applying policies and procedures, reinforcing key points, and answering questions.

- The on-the-job trainer should address risk factor ascertainment as a separate element of the review of the new staff member’s case reports to ensure that risk factor definitions are well understood and to identify strategies for actively eliciting risk factor information from providers.
- Surveillance programs also can use re-abstraction to test training efficacy. For example, a specific number of cases a new staff member has recently completed can be re-abstracted to ensure standards have been met. The cases should be re-abstracted by a different, preferably experienced, staff member.

The surveillance program should retrain and evaluate all appropriate staff at least annually.

- Although training in risk factor ascertainment should be ongoing, annual training also should be conducted to ensure that all staff receive the same message. Annual training is also an opportunity to update staff on new initiatives or materials related to risk factor ascertainment, and to review the progress of the program toward outcome and process objectives.
- Use role-playing with staff on talking with and educating providers about risk factor documentation.
- Avoid protocol drift—slow but steady unintentional movement away from the original protocol—by providing regular feedback to staff about the consistency of their work within the requirements of the protocol. After the initial training of staff, opportunities must be found to integrate feedback on risk factor ascertainment into the routine activities of the surveillance program. These might include supervisors reviewing submitted case reports, giving group and individual feedback on the success of risk factor ascertainment activities, and discussing difficult aspects of the protocol at staff meetings.
- Create a summary report illustrating progress by each surveillance staff member who is responsible for risk factor ascertainment. The report should provide information about the total number of NRR cases for which the staff member is responsible for following up and the percentages of NRR cases successfully reclassified, still under investigation, reclassified as NIR because all available sources were contacted/reviewed, and reclassified as NIR because epidemiologic follow-up was incomplete but 12 months had elapsed since the date of the initial case report.

Standards for Risk Factor Ascertainment Procedures

Please see [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](#) for details about the standards for risk factor ascertainment procedures.

Providing Feedback to Reporting Sites

Surveillance program staff should use every opportunity, such as telephone contact and site visits, to reemphasize to HIV reporting sites and service providers the importance of conducting HIV surveillance to appropriate standards. This emphasis includes providers' responsibility to submit complete case reports that collect all known HIV risk factors by using CDC- and locally defined terms.

Identify resources developed to assist providers in collecting missing variables. For example, indicate whether resources such as the risk factor ascertainment materials, are available on websites.

Designated surveillance program staff should prepare and review a summary of cases by reporting facility and compare the completeness of risk factor reporting at the time of initial report to the process standard of 75% for all reporting facilities. Reporting facilities with less than 75% completeness should be identified, and a printout specific to the respective facility should be generated that shows the risk factor category distribution of cases reported by that facility, highlighting the NRR proportion.

- For active surveillance sites, designated field staff should complete another chart review and/or a follow-up with the provider to ascertain patients' risk factors. If no risk factor information is available, request that the provider ascertain risk factor information and inform the provider that follow-up contact will be made with him/her about risk factor information for the NRR patients.
- For passive surveillance sites, providers should be contacted to explain that cases that they have reported lacked sufficient epidemiologic information and to emphasize the importance of risk factor information for public health purposes. If the provider does not respond within 3 weeks, another contact should be made requesting the information (e.g., through "Dear Colleague" letter, email, phone call).

On a quarterly basis, surveillance programs should send each reporting facility statistical reports summarizing the percentage of cases reported by that facility for which risk factors are missing. Surveillance programs might choose to prioritize facilities with the largest number of cases reported without any risk factor information. Feedback should be positive but should indicate what aspects of reporting need work. Once a facility has attained a desirable level of complete risk factor reporting, feedback can be provided less often; however, at least annual feedback should be given. A statistical report can be created that shows recent trends in HIV for the surveillance or geographic area, as well as a facility-specific report of missing variables.

Cases of Public Health Importance

The vast majority of contemporary HIV infections are eventually assigned to commonly defined transmission categories as described earlier: male-to-male sexual contact, injection drug use, male-to-male sexual contact and injection drug use, heterosexual contact, and perinatal exposure. However, uncommon modes of transmission occur that surveillance programs can encounter. HIV cases with unusual transmission circumstances should be brought to the attention of CDC and should be a top priority for follow-up.

Risk Factor Ascertainment

As part of routine public health practice and routine HIV surveillance, investigations of cases of public health importance (COPHI) meet at least one of the following criteria:

- Clusters of unusual clinical, laboratory, or geographic cases that have potential public health significance.
- Possible unusual transmission circumstances where scientific evidence can confirm or refute the possibility of transmission (where possible).
- Cases without detectable antibody response on standard testing.
- Cases of HIV-2 and unusual non-B subtypes in the United States.
- Infections in children (aged <13 years) not attributed to perinatal exposure.

Investigations of COPHI often provide evidence to confirm or refute the possibility of HIV transmission in certain settings or under certain circumstances and thus contribute to the health of the public.

Initial case reports with information suggesting a COPHI should be the first priority for follow-up by surveillance areas. The COPHI coordinator in the CDC HIV Incidence and Case Surveillance Branch should be notified about any potential special investigation. For COPHI the surveillance program should initiate a thorough investigation by using trained personnel and following CDC procedures described in the Risk Factor Ascertainment chapter and in the HIV-2 section of the Special Diagnostics Problems chapter, both in the [*Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures*](#).

In the absence of other known risk factors, case reports must be investigated when identified risk factors include

- Receipt of transfusion of blood or blood components after March 1985.
- Receipt of clotting factor injection for hemophilia or another chronic coagulation disorder and date of birth is after March 1985.
- Receipt of transplant of tissue or organs or of artificial insemination.
- Work in a health-care or clinical laboratory setting with possible exposure to human blood or other body fluids.
- Women whose only sexual contact has been with another woman.
- Other exposure to human blood or body fluids, including the following
 - ▶ Household or other casual contact
 - ▶ Patient exposure in a health-care setting
 - ▶ Physical interaction where blood or body fluids were exchanged
 - ▶ Occupational exposure other than in the health-care industry
 - ▶ Tattoo, piercing, or other cosmetic exposures
 - ▶ Intentional self-inoculation or intentional inoculation by another person
 - ▶ Human bite
 - ▶ Other unusual circumstance (not previously identified as a risk factor)

Risk factors for pediatric cases (cases in children aged <13 years) that must be investigated regardless of whether the reported person has another risk factor are

- Sexual contact with a male.
- Sexual contact with a female.
- Injected illicit or nonprescribed drugs.
- Mother known to be seronegative after the child's birth.

Case also should be investigated when HIV-2 and variant strains of HIV are diagnosed; these include

- HIV-2.
- Unusual strains, including Group O.
- Negative HIV-antibody test or other laboratory test inconsistent with the clinical picture.

See *Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures* for details about COPHI outcome and process standards.

Finding Information for Determining Risk Factor

The first step in investigating NRR/NIR cases is to collect background information. The purposes of collecting background information are 1) to identify risk information, if available; and 2) if an interview is necessary, to approach the interview with as much information as possible about the HIV-infected person. **Most risk factor determinations are “found” (transmission risks identified and cases reclassified) from background information**, without the need to interview the HIV-infected person or a proxy. Background information can come from a variety of sources, as described below.

CONTACTING THE HEALTH-CARE PROVIDER(S)

Risk for HIV infection can be identified for many cases by contacting the health-care providers of the HIV-infected person. Some surveillance programs make this contact only in person; others prefer telephone or mail contact. Your policies and procedures may vary. Regardless of how contact is made, determine any risk the health-care provider might know about or suspect and the reasons he/she suspects this risk. Inquire about the attitude of the HIV-infected person when questioned about risk. Be aware that the transmission risk for an HIV-infected person often is not of great concern to clinicians and that some clinicians might be reluctant to reveal risks while the patient is alive.

Private Practice Setting

In the course of routine surveillance activities, you might already have had contact with the private physician and or his/her staff about the HIV-infected person with unclassified risk factors. If not, having a staff member familiar to the physician make the contact might be preferable. Alternatively, ask to speak directly with the physician or his/her staff. Identify yourself and the agency for which you work. Inform the physician that you are inquiring about the HIV case report of his/her patient by name and that you need further information about transmission risks. If the physician (or staff person) does not know the patient's risk information, ask other questions that might help the investigation. The information you receive might help you decide a follow-up approach with the physician or other health-care providers or if an interview becomes necessary.

Below are examples of questions that experienced investigators have found helpful when trying to ascertain risk factors:

- ✓ “How did this HIV-infected person become infected with HIV?” or
- ✓ “How do you think this HIV-infected person became infected with HIV and why do you suspect this risk?”
- ✓ “How did the HIV-infected person indicate to you that he/she might have become infected with HIV?”

Risk Factor Ascertainment

- ✓ “Does the HIV-infected person have a history of other illnesses or lab or physical exam findings that indicate a risk for HIV infection?” If so, ask what they are. Ask about conditions such as hepatitis B or other STDs; evidence of rectal disorders, trauma, lesions; stigmata of injecting drug use (e.g., skin abscesses, track marks, or bacterial endocarditis) or drug screen chemistries in the lab findings.
- ✓ “With whom did the HIV-infected person come to the hospital/clinic/office?”
- ✓ “With whom does the HIV-infected person live?”
- ✓ “Do the spouse and/or children of the HIV-infected person know about the HIV diagnosis?”
- ✓ “Have the spouse and/or children been tested for HIV?”
- ✓ “What other health-care providers have cared for this HIV-infected person, know the diagnosis, and might have knowledge of risks: Infectious disease physician? Referring physician? Social worker? Infection control practitioner (ICP)? Others?”

Politely and tactfully answer the provider’s questions, if any, about the purpose of your investigation. **If requested, cite appropriate state HIV reporting requirements.** Keep a copy of these statutes with you, and offer to provide him/her a copy upon request. If you encounter serious problems with a provider, be tactful and friendly, and discuss with your supervisor whether and how you should proceed.

Inpatient or Outpatient Setting

When contacting a hospital about an HIV-infected person, you can start with the ICP. The ICP might know risk information, and he/she might be the person who completed the case report. The ICP also might know other providers (e.g., nurses and social workers) who have cared for the patient in the hospital and who might be able to assist you.

In an outpatient setting, you can contact the physician of record. The clinic manager, ICP, social worker, or other providers who cared for the HIV-infected person also might be a source of information.

Never contact other providers if they do not already know about the HIV diagnosis of the HIV-infected person.

Document every contact (or attempted contact) with health-care providers, and include the following details:

- Date and time of contacts.
- Results of attempted contacts, such as no answer, message left, and party with whom message was left.
- Information discussed with each person about transmission risk.
- Reason you spoke with each person.

Be accurate, complete, and clear in your notations. Another employee should be able to pick up the NRR/NIR case, know which contacts have been made and what information has been collected, and proceed with the investigation.

REVIEWING MEDICAL AND OTHER RECORDS

Most NRR/NIR cases are resolved by review of medical records (Table 5.1). A remark regarding risk can appear anywhere in the medical record but is most likely in the general history section, nurses notes, or social services notes. Review the lab section for evidence of blood transfusion and for any positive tests for hepatitis B or C or STDs, or drug screen chemistries. Look through the chart for any physical findings suggestive of illness most often experienced by men who have sex with men and by injection drug users (i.e., anal condyloma, pericarditis). Although this information alone might not be sufficient to reclassify an NRR/NIR case, it could suggest possible modes of transmission for follow-up with the health-care providers and/or the patient.

Review health department and other records, such as STD records, death certificates, autopsy reports, and hepatitis B registries, that are available to you. For example, if you discover that the HIV-infected person has a history of syphilis, you might be able to determine a risk (e.g., same-sex partner). Because HIV is transmitted similarly to hepatitis B, a hepatitis B report might contain risk information. In some areas, NRR/NIR case investigators review correctional facility medical records and contact correctional facility medical staff to learn HIV risk information for deceased prisoners.

If the HIV-infected person has died, review the death certificate for clues about risk factors. Was he/she hospitalized at the time of death? Was an autopsy performed? Is a spouse listed? What are the names and addresses of the parents? Does the death certificate list an alias? Answers to these questions might identify additional medical records to investigate or proxies or additional health-care providers to contact. Review the death certificate to determine who the informant is; it is not unusual for the significant other to be the informant.

Table 5.1 | Reviewing Records in an NRR/NIR Investigation

SOURCE	CHECK WITH	CHECK FOR
Hospital medical records	Inpatient records	Risk information (e.g., previous medical histories; previous surgeries, transfusions, conditions common among injection drug users) Attending physician Infectious diseases physician/other Social services referrals
	Outpatient records	Risk information
	Emergency department records	Risk information
	Autopsy reports	Risk related findings
	Billing records	Verify address Emergency locating information Next of kin/spouse Employment
Medical personnel	Infectious disease physician/other	Risk information
	Attending physician	Risk information
	Infection control practitioner/ RN staff	Risk information
	Social worker	Referrals due to risk
Hospital department records	Sexually transmitted diseases clinic records	Risk information
	Counseling and testing site records/partner notification logs	Risk information
	Hepatitis B records	Risk information
	Social services	Referrals due to risk
	HIV clinic records	Risk information
Other public records	Social services/welfare	Risk information
	Law enforcement/jail records	Risk information
	Medicaid/disability records	Risk information
	Death certificates	HIV-related cause of death Marital status Spouse name/address Alias or other names used by person with HIV or AIDS

General Interviewing Strategies AND Techniques



Information in this section is intended for staff new to HIV surveillance or without clinical backgrounds.

HIV surveillance programs most likely will find that they do not have the time or resources to interview HIV-infected persons to determine risk factors. However, circumstances might exist in which an interview is necessary and desirable to elicit information. Following are general techniques for effective interviewing, whether for risk factor determination for NRR/NIR cases or for other interviewing situations.

BASIC PRINCIPLES OF COMMUNICATION

An effective interview often depends more on how it is conducted than on what is said. The way we communicate promotes positive or negative interactions. Effective interviewing requires application of principles of verbal and nonverbal communication and of effective listening skills.

Following these basic principles of communication can establish rapport with an HIV-infected person or a proxy:

- Be on time, or call if you will be late.
- Be courteous and concerned.
- Always take the lead by introducing yourself. You might want to shake hands to show you are not afraid to touch the person.
- Conduct the interview in private.
- Do not stand if the interviewee is seated.
- Maintain appropriate eye contact.
- Be aware of how the interviewee seems to be perceiving you
- Clarify the understanding of the interviewee by asking him/her to rephrase information back to you.
- Ask open-ended questions.
- Be prepared to explain the questions that you ask.
- Give permission for the interviewee to express feelings and ask questions.
- Be empathetic toward the feelings and fears of the interviewee.
- Be flexible.
- Maintain rapport.
- Listen attentively.
- Be objective.
- Be aware of the body language and tone of voice of yourself and the interviewee.
- Try to match the awareness and level of understanding of the interviewee.
- Be sensitive to racial/ethnic, cultural, socioeconomic, and religious values that might affect the interviewee's responses. For example, Hispanic males might be particularly reluctant to admit having sex with another male.
- Be particularly aware of your own feelings and ideas and the effect they might on the interview.

Nonverbal Communication

Nonverbal messages can be more powerful than verbal messages, and their meanings are usually unmistakably clear. Use body language that sends positive messages and communicates nonverbal messages that are consistent with verbal messages.

Every interaction includes nonverbal messages. The first message the receiver gets from the sender is nonverbal, and the receiver's first and perhaps lasting impression of the sender is based on that initial nonverbal message. People respond to perceptions they have of others before verbal communication begins.

Following are examples of body language that can send positive nonverbal messages.

- **Open body stance.** Be approachable. Do not back away from or sidestep the person. Sit directly across from or beside the other person. Avoid placing physical barriers (e.g., a desk) between you and the other person, and guard against erecting other “barriers,” such as folded arms, crossed legs, or hand over your mouth.
- **Relaxed posture.** Ramrod straight posture is not appropriate, but neither is slumping or slouching. Practice good posture, and move your head, arms, and legs naturally. Good posture conveys that you are a positive person interested in the other person.
- **Eye contact.** Maintain comfortable, natural eye contact with the interviewee. However, remember that in some cultures (e.g., American Indian, Hispanic), maintaining eye contact might not be appropriate.
- **Positive facial expressions.** You can lift spirits by projecting a smile at the appropriate times. Slight nodding of your head at appropriate intervals indicates you are listening. Just as you punctuate written sentences, so should you punctuate your verbal sentences with appropriate facial expressions.
- **Dress.** Dress comfortably and professionally. Do not dress too formally or wear excessive jewelry, which could convey an air of elitism. Also avoid dressing too casually.

Listening

Possibly the most important element of communication is listening. Too often communication becomes two people waiting for the other to stop talking so each can start talking again. An NRR/NIR case interview should focus on the HIV-infected person HIV or a proxy and on encouraging this person to talk about himself/herself.

Listening also involves paying attention to nonverbal clues. By listening, you will learn about that person's values and beliefs, which will help you direct the interview appropriately. If silence during an interview is uncomfortable for you, practice sitting through silence. Well-placed silence can be effective in making the interviewee uncomfortable enough to start talking.

Reflective Listening

Reflective listening is a communication technique designed to help you learn what a person is thinking and feeling and what he/she would like to do about a problem. The more you know what is affecting a person the better able you are to resolve conflicts and problems. Reflective listening involves six activities: attending, labeling nonverbal cues, rephrasing, asking open-ended questions, prompting, and accurately empathizing. Using reflective listening skills during interviews can enhance the interview.

SPECIAL ISSUES

Death and Dying

Many interviewers report that issues of death and dying are the most difficult and uncomfortable aspect of NRR/NIR case investigation and follow-up. You can increase your comfort and effectiveness in addressing these issues by learning more about the stages of death and dying, especially as they relate HIV-infected persons. New surveillance staff may want to read background information about coping mechanisms used by dying persons, such as *On Death and Dying* by Elisabeth Kubler-Ross (New York: Simon & Schuster, 1997).

The normal stages of emotion experienced when faced with death is not intended to be a complete guide to dealing with the issues of death and dying. Nor is this information provided to enable you to “diagnose” a person’s stage in the death/dying process. Rather, this information is provided to give you some insight into the reactions you may experience when interacting with HIV-infected persons or proxies during NRR/NIR case investigations. Some people you may interview move through all of these stages; others experience only one or a few of them.

Culture and Race/Ethnicity

Every cultural and racial/ethnic group has characteristic styles of verbal and nonverbal communication (e.g., use of eye contact, body language, and direct versus indirect discussion), responses to and beliefs about health/illness and medical care (e.g., viewing illness as a punishment, not believing in preventive health care), and beliefs about sexual and drug-using behaviors that place a person at risk for HIV. Furthermore, within every cultural and racial/ethnic group are many subgroups, with varying styles, beliefs, and behaviors.

HIV surveillance staff should be sensitive to each person encountered. Treat each person as an individual. Try to understand and respect each individual’s styles, beliefs, and behaviors. When appropriate, express your unfamiliarity with the culture of the HIV-infected person or proxy, and communicate your interest and willingness to learn from them.

Help the HIV-infected person use his/her cultural norms in a positive way, instead of focusing on how they impede the process of the interview or gathering of information. For example, in the Hispanic community, religious beliefs might be considered an impediment to safe sex; on the other hand, religious faith might bring strength in the face of a crisis. Know your own limitations. If possible, refer persons with HIV infection or proxies to another interviewer when they require culturally sensitive communication beyond what you can provide.

Expanded Terminology for Categorizing HIV Risk Factors

If the HIV-infected person was exposed by any of the following routes before his/her first positive HIV test or diagnosis, then the exposure is considered a CDC-defined risk factor for HIV infection:

RISK FACTORS SPECIFIC TO ADULTS

1. Male who had Sex with Another Male

This wording is intended to avoid the issue of sexual orientation or identity (whether the man considered himself homosexual, bisexual, “gay,” “on the down-low,” or basically heterosexual but occasionally having sex with other men). The important consideration here is not how this male perceived himself but simply whether he had sex with another man.

In this context, “having sex” or “sexual contact” means penis-to-mouth, penis-to-anus, or mouth-to-anus contact (but not mouth-to-mouth contact) regardless of which role (insertive or receptive) the male in question has played. It does not include contact only with skin (not a body orifice). However, if explicit information about whether the man had sex with another man is unavailable, the man can be assumed to have done so if he stated that he was “homosexual” or “bisexual” or described himself with a similar term that implies he had sex with another man. In addition, male-to-male sex can be inferred if he was diagnosed with any rectal STD (e.g., gonorrhea) before or at the time of HIV diagnosis.

2. Injected Illicit or Nonprescribed Drug(s)

This means receiving an injection, either self-administered or given by another person, of a drug that was not prescribed by a physician for this person. It generally includes illicit drugs used for producing euphoria, but it might also include prescription drugs that were not prescribed (e.g., estrogen, testosterone, anabolic steroids, or human growth hormone). It does not include injection of prescribed drugs (e.g., insulin for treating diabetes). The drug itself is not the source of the HIV infection, but the context of it being taken illicitly (i.e., without a prescription) is likely to be associated with sharing of injection equipment (e.g., syringes, needles, cookers), which can result in transmission of bloodborne pathogens, such as HIV. The case report form does not include a separate question asking whether injection equipment was shared.

3. Had Sex with Someone of the Opposite Sex who had Either of the Two Risk Factors in Items 1 or 2 (MSM and/or IDU)

In this context, “having sex” or “sexual contact” means contact of one person’s penis or mouth with the vagina or anus or penis of another person. It does not include mouth-to-mouth contact or contact of the penis or mouth with skin (not a body opening). Because the prevalence of HIV infection is high among men who have had sex with men and among injection drug users, such sex partners will be presumed to have HIV infection, and documenting their infection is not necessary.

4. Had Sex with Someone of the Opposite Sex but May Not Have Known whether HIV Infection was Diagnosed in that Person, or Any of the Risk factors of Sex Partners Described in Items 3 or 5

Having sex is defined as previously in item 3.

5. Had Sex with Someone of the Opposite Sex in whom HIV Infection was Diagnosed after Having Any Risk Factor for HIV Infection in Items 6 (Receipt of Clotting Factor for Coagulation Disorder), 7 (Receipt of Blood Transfusion), or 8 (Receipt of Transplant or Artificial Insemination)

Having sex is defined in item 3. Because HIV infection has an extremely low prevalence among recipients of clotting factors who were born after March 1985, recipients of blood transfusions, and recipients of transplants or artificial insemination, such sex partners will not automatically be presumed to have HIV infection. Instead, their HIV infection must be documented (e.g., by the history given by the HIV-infected person reported by his/her health-care provider), but it does not require confirmation by a special investigation. For the sex partner’s HIV infection to be attributed to any of these risk factors (e.g., receipt of clotting factor, transfusion, or transplant), the sex partner’s HIV infection should have been diagnosed after the sex partner’s exposure to these risk factors (the exposure must not have occurred only after the diagnosis). If the time relationship between the sex partner’s HIV infection diagnosis and the sex partner’s exposure to the risk factor cannot be ascertained, the risk factor can be assumed to have preceded the sex partner’s diagnosis.

6. Received Clotting Factor Injection for Hemophilia or Another Coagulation Disorder

This risk factor mainly involves factor VIII and factor IX. In the United States, screening of blood donors for antibody to HIV began in March 1985, which reduced the likelihood that clotting factor obtained after that month would be contaminated with HIV. In addition, clotting factor blood products for hemophilia began to be more effectively heat-treated around that time. More recently, clotting factors have been synthesized without using donated blood. Therefore, it would be unexpected for persons with hemophilia born in or after March 1985 to acquire HIV infection by this route, and such an occurrence must be confirmed by an investigation under the protocol for COPHI.

7. Received Transfusion of Blood or Blood Components (e.g., Platelets)

Because screening of blood donors in the United States for antibody to HIV began in March 1985, it would be unexpected for persons who received a transfusion after March 1985 to acquire HIV infection by this route. Therefore, such an occurrence must be confirmed by an investigation under the protocol for COPHI.

8. Received a Transplant of Tissue or Organ or Artificial Insemination

Because of its rarity and public health implications, any acquisition of HIV by this route must be confirmed by an investigation under the protocol for COPHI.

9. Worked in a Health-Care or Clinical Laboratory Setting with Possible Exposure to Human Blood or Other Body Fluids

This risk factor has been reworded to clarify that it includes work that involves physical contact with patients, blood, or body fluids. For example, it does not include work as a clerk, secretary, or administrator who does not have physical contact with patients. It could include a custodian, however, who could be exposed to contaminated materials that have been discarded. Because of its rarity and public health implications, any acquisition of HIV by this route must be confirmed by an investigation under the protocol for special COPHI.

10. Had Other Exposure to Human Blood or Body Fluids

This risk factor could include other forms of occupational exposure, such as that experienced by a police officer or firefighter, or nonoccupational exposures, such as contact with another person's blood or an open wound as a result of providing informal health care to another person or as a result of a fight. Any acquisition of HIV by this route must be confirmed by an investigation under the protocol for special COPHI.

RISK FACTORS SPECIFIC TO CHILDREN

1. Perinatal (Mother-to-Child) Exposure with Specified Maternal Risk Factors

The child's mother had any of the risk factors described previously in items 2–5, 7, or 8 in adult risk factors before her first positive HIV test or diagnosis and was not known to be uninfected after the child's birth:

- Maternal injection drug use.
- Maternal sexual contact with a man known to have had HIV infection or at high risk because he
 - ▶ was an injection drug user, or
 - ▶ was a man who had sex with other men, or
 - ▶ had HIV infection after receiving clotting factor blood products, a transfusion, or a transplant.
- Maternal receipt of a transfusion (and mother known to have had HIV infection).
- Maternal receipt of a transplant (and mother known to have had HIV infection).
- Maternal receipt of clotting factors (item 6 of adult risk factors) is not included among these possible maternal risk factors because hemophilia tends to be an X-linked hereditary disorder that does not occur among females. If the mother's experience of one of these risk factors is known to have occurred only after her diagnosis of HIV infection, then it should not be accepted as the route by which she became infected.
- Maternal perinatal exposure.

2. Perinatal (Mother-to-Child) Exposure without Specified Maternal Risk Factors

The child's mother has or had (if deceased) HIV infection, but she was not known to have any of the risk factors described previously in items 2–5, 7, or 8 of adult risk factors before her first positive HIV test or diagnosis, and she was not known to have been uninfected after the child's birth.

3. Risk Factors for Children, Other than the Mother's HIV Infection

These all require confirmation under the protocol for special COPHI.

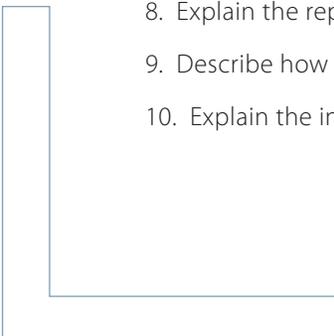
- Received clotting factor injection for hemophilia or another coagulation disorder as defined in adult risk factor item 6.
- Received transfusion of blood or blood components (e.g., platelets) as defined as in adult risk factor item 7.
- Received a transplant of tissue or organ or artificial insemination as defined in adult risk factor item 8.
- Was the victim of sexual abuse by an HIV-infected adult: This risk factor is defined as sexual contact of the child with a man or woman who had HIV infection. The case report form asks whether the child had sexual contact with a male or a female, but does not ask whether that sex partner had HIV infection because the infection status of the perpetrator of the sexual abuse is not expected to be known when the form is initially completed. A “yes” answer to the question about sexual contact will then result in an investigation under the COPHI protocol, which should reveal the infection status of the sex partner. So far, no case of pediatric HIV infection has been reported in which a child had sex with a female; therefore, in practice, this risk factor is limited to sexual abuse by an HIV-infected man.
- Injected illicit or nonprescribed drug(s) as defined in adult risk factor item 2, except that its rarity in children requires it not be accepted as such until it is confirmed by COPHI investigation.
- Had other exposure to human blood or body fluids, similar to adult risk factor item 10. Such exposures among children can involve physical contact between children while playing or fighting in which blood or serum from an injury of one child might come into contact with an open wound of the other child.



MODULE SIX eHARS

OBJECTIVES:

1. Provide an overview of eHARS.
2. Explain how eHARS collects HIV surveillance data.
3. Explain how eHARS presents HIV surveillance data.
4. Describe the documents that make up eHARS.
5. Highlight key points of editing eHARS documents.
6. Describe the eHARS importing process.
8. Explain the reports capability of eHARS.
9. Describe how to change a password.
10. Explain the investigations capability in eHARS.



Introduction

The national HIV surveillance reporting and data systems have undergone several versions. As of April 2008, all state and local HIV surveillance programs use the current Enhanced HIV/AIDS Reporting System (eHARS) to collect and manage electronic data.

Material in this module is taken from the User Guide/Student manual for [“Introduction to eHARS, the HIV/AIDS Reporting System,”](#) version 3.2.0.0, 8/2011. Surveillance staff should review the User Guide for detailed information about the operation and functions of eHARS.

Overview of eHARS

eHARS is a computer application for collecting, storing, and retrieving the data the Centers for Disease Control and Prevention (CDC) has identified as necessary to monitor the HIV epidemic and evaluate HIV prevention policies and programs.

Monitoring the HIV epidemic relies heavily on reports of individual cases of HIV (including Stage 3 [AIDS]). HIV case surveillance and epidemiologic studies are essential to meeting federal, state, and local needs for targeting and allocating billions of dollars of federal resources, which are distributed on the basis of number and characteristics of persons with HIV and/or AIDS. The data collected provide health departments with concrete information about the outcome of HIV prevention activities within their jurisdictions.

eHARS encompasses core HIV surveillance data activities and projects and provides tools to assist in

- Investigation of potential HIV cases.
- Management of current data.
- Import and export of data.
- Transfer of data to CDC.
- Reporting.
- Analysis.

eHARS gathers information from documents entered or imported into the system and links them to a particular person. Each HIV case is assigned a system-generated unique identifier (ehars_uid), and each entered document for that case is linked by the eHARS UID. A system-generated identifier (document_uid) also is assigned to each document in the system, including the summary document (the Person View document) that eHARS automatically creates when the first document is entered for a case. eHARS maintains the Person View document for each case, regenerating the document and calculating certain values, such as diagnostic status, as new documents are added.

KEY POINTS TO REMEMBER

- eHARS is an application for collecting, organizing, storing, and retrieving the data CDC has identified as necessary to systematically analyze HIV prevention policies and programs.
- Data are entered into eHARS through documents entered into the system.
- An entered document is linked to a particular case by its system-generated identifier.
- eHARS presents data in summary documents and individual forms.
- eHARS uses Web-based technology and a browser window to display documents and data.
- eHARS can be launched in a number of ways, including by double-clicking the **eHARS** icon on the desktop.
- When eHARS is launched, the browser displays a Login page.
- To keep data secure, users must log on to eHARS with a valid ID and password.

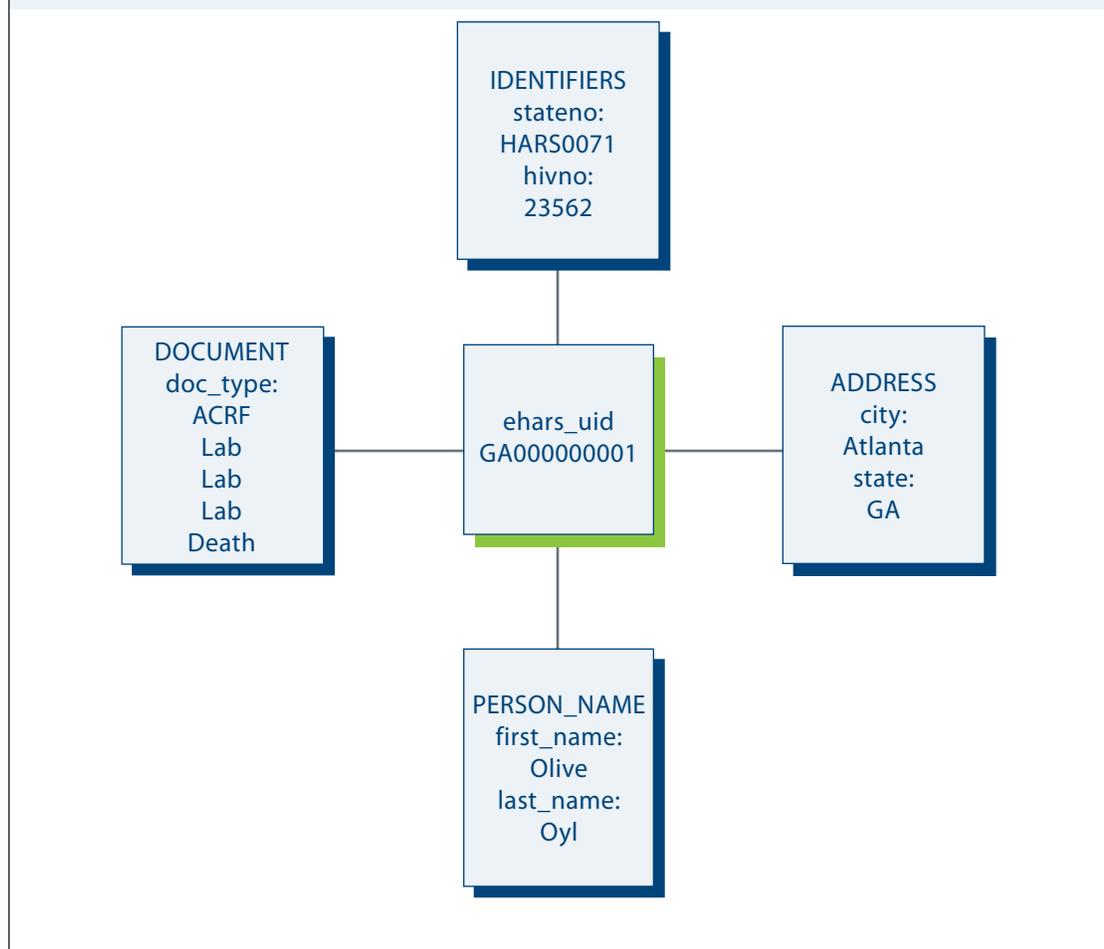
How eHARS Collects HIV Surveillance Data

eHARS uses a relational database to collect, store, and organize data. A relational database consists of tables linked by unique identifiers common to the tables. A case in eHARS consists of an identifier (typically `ehars_uid` or `document_uid`) linking data stored in many tables. As new data are collected for a case, the case summary—the Person View document—is updated to reflect the current information, but historical data remain in their tables and available for review and analysis.

Each table in eHARS is, in effect, a flat file database containing intersecting rows and columns. Because these tables are linked to many others, a relational database transcends the limitations of flat files and has exponentially greater capabilities and flexibility. In the previous HIV surveillance data system known as HARS, redundant data (for example, city and facility names) were entered again and again, row after row. Redundant data entered by multiple users can result in errors and nonstandardized information. (For example, Is La Fayette the same city as Lafayette or LaFayette? Is Grady Hospital the same facility as Grady Memorial Hospital or Grady ER?) In eHARS, redundant data are stored in dedicated tables. (For example, the `FIPS_CITY` table in eHARS stores city names and FIPS (Federal Information Processing Standards) codes. This table populates the City list, and during data entry, users select a city from the list rather than type the name in a field. Selecting cities, counties, states, and countries from a list ensures uniformity of data throughout the system. It also saves time during data entry.) If a universal change ever needs to be made to a city or county name, a lab code, or any other standardized value, it is changed in one table and the change is applied throughout the system.

Similar information in eHARS is stored in four tables (`IDENTIFIERS`, `ADDRESS`, `PERSON_NAME`, and `DOCUMENT`) and linked to each other by a common identifier, `ehars_uid`, which is the unique ID assigned to each case (Figure 6.1).

Figure 6.2 | Data Tables Linked by eHARD UID

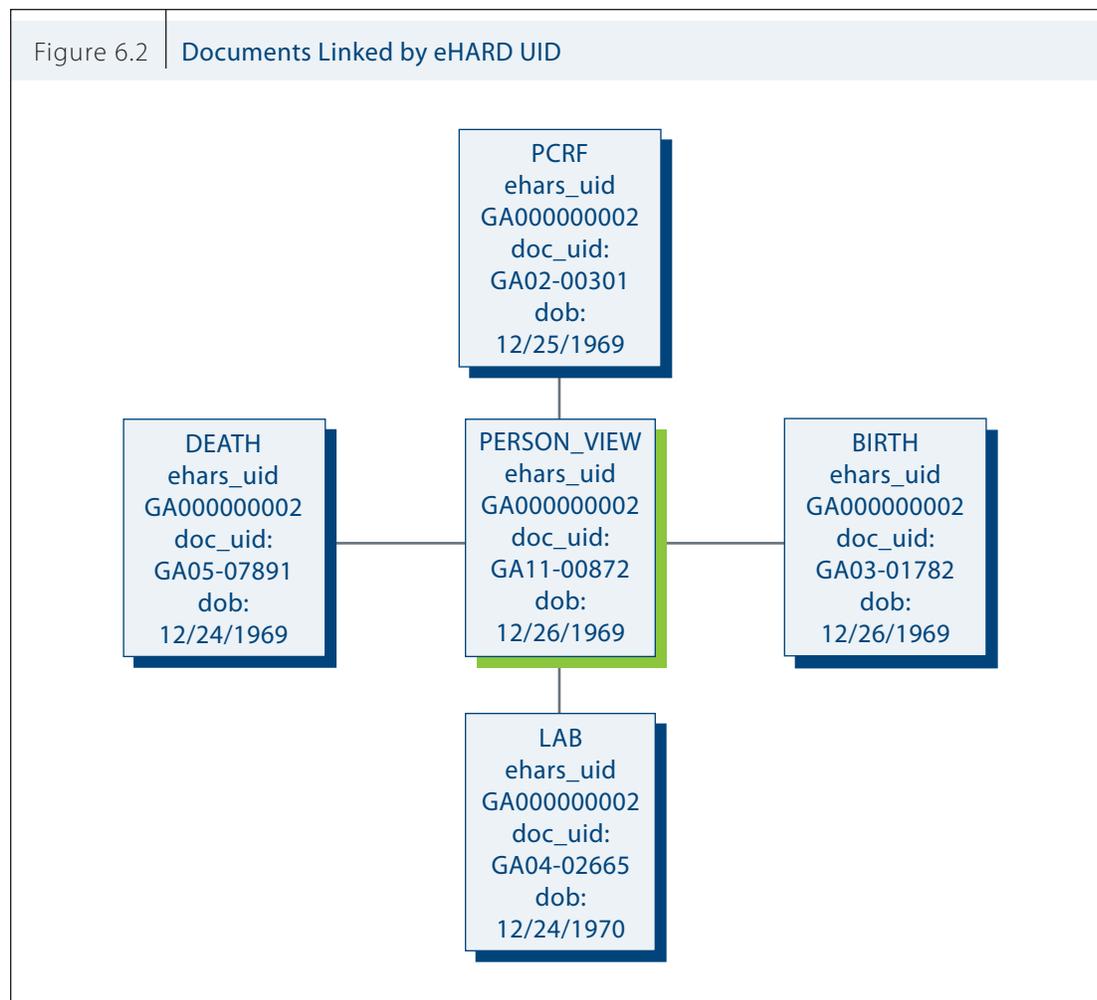


How eHARS Presents HIV Surveillance Data

eHARS presents data in a summary document and in documents that correspond to the paper forms from which data were initially collected. Multiple documents can be entered for each case in eHARS. For example, an unlimited number of laboratory reports can be stored for each case. As additional documents and their data are added to a case, information—such as a person’s residential address—is updated in the summary document, known as the Person View document. Instead of discarding the previously entered address, eHARS saves all contributing documents and their data so they can be retrieved and viewed. These include legacy documents from HARS, the previous HIV surveillance data management system.

Documents are linked to a case by the eHARS UID. Linking a document’s data to a case and maintaining that data without overwriting previously entered information are important features of eHARS. If information comes to light that a document should be linked to another case, the document can be transferred without loss of data, and the calculated data of both cases involved in the transfer are recalculated.

eHARS maintains documents (in this example, the Pediatric Case Report, Birth Certificate, Laboratory Report, Death Certificate, and Person View documents) and their data separately, yet all are linked by the eHARS UID (Figure 6.2).

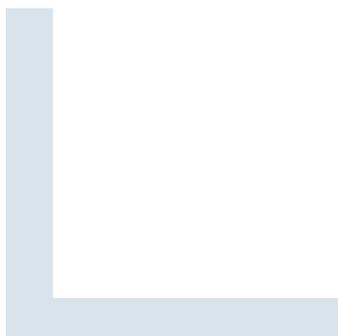


eHARS collects and presents HIV data through fields displayed in electronic documents, such as the eHARS versions of case reports, birth certificates, death certificates, and lab reports. When you add a document to eHARS, you must choose to create a new case or add the document to a case already in the system. All data entry documents in eHARS are linked to a case, and linking is done manually during data entry in eHARS. Before adding a document to eHARS, search the system for the case that is the subject of the corresponding paper form. If a match is found, add a new document to the existing case eHARS record; if a match is not found, add a new case to eHARS. The data entry document is then linked to the eHARS UID of the new case.

The document-based design of eHARS links separate documents to the many sources of information gathered and entered for a single case. Each case entered in the system is associated with the documents collected for a particular case and with a summary data document (the Person View document) that is created when the first document for a case is entered. Possible duplicate cases can be tracked in eHARS, and documents can be transferred to other cases if subsequent research indicates the need for a change. When importing documents, such as lab reports, eHARS uses identifiers in the imported data to determine whether matches exist in eHARS. The data from the imported documents are then linked to the matching case(s).

For each case entered into eHARS, the Person View document displays a summary of data collected from documents associated with that case. eHARS uses an algorithm, the Person View hierarchy algorithm, to calculate which values are displayed in the fields of the Person View document. Many of these primary values are the data transferred to CDC that comprise the national dataset.

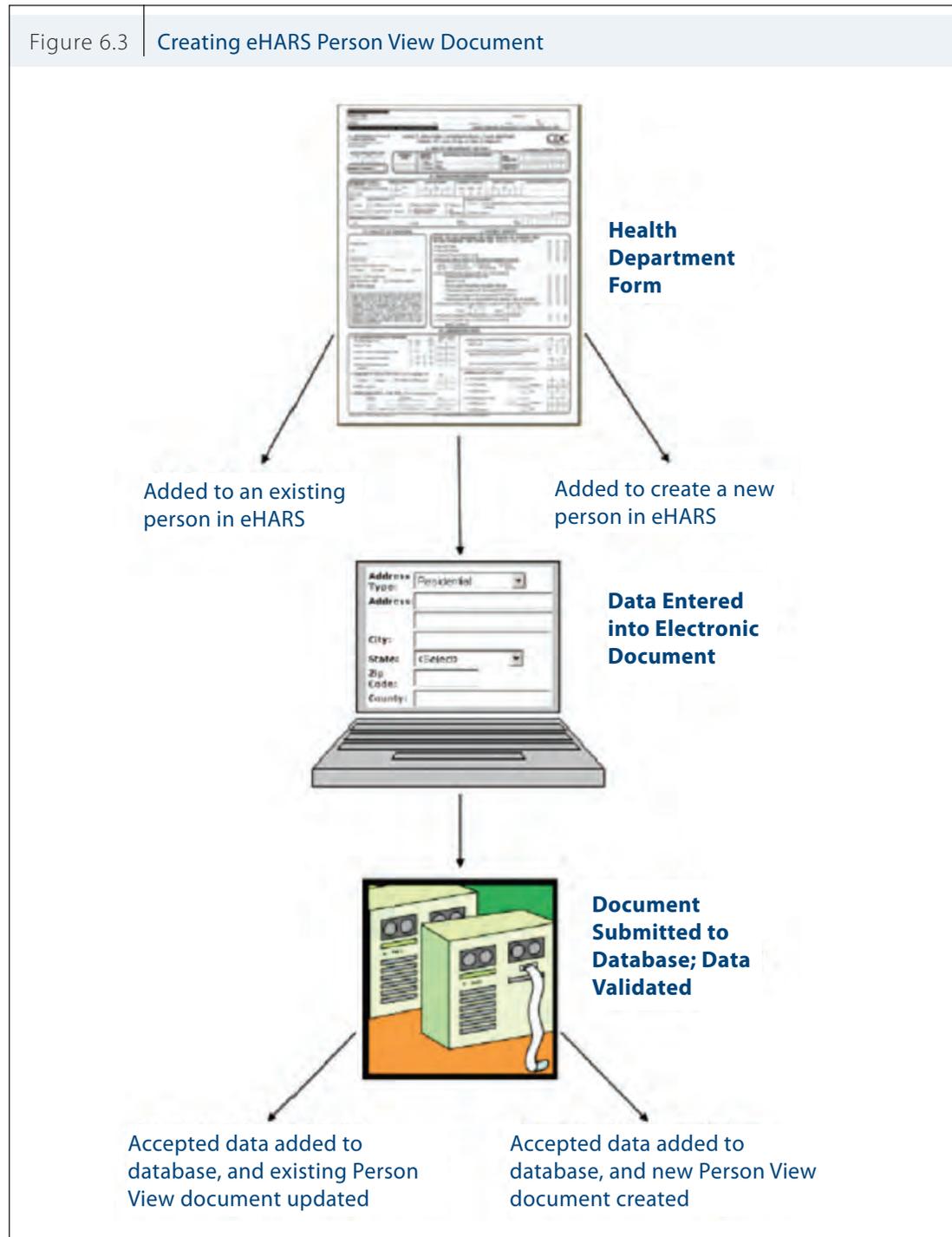
In the final steps of the data entry process, a document is submitted to the database for validation and storage. eHARS then displays a Document Summary and Person View Summary page that itemizes the validation process. The Document Summary and Person View Summary page displays any errors and warnings, such as invalid dates. After reviewing the Summary page, a user can return to the document, make changes, and submit the changed document to the database. The Summary page also lists changes that resulted from the entered and submitted data, such as new values for calculated variables. For example, if the mode of transmission changes because of the data entered in the submitted document, eHARS notes that change on the Summary page.



Documents that make up eHARS

EDITABLE DOCUMENTS

As part of the process of linking a health department form to a case through an electronic document, eHARS validates the entered data and calculates a Person View document (Figure 6.3).



Seven documents are available for data entry in eHARS (Table 6.1):

- Adult Case Report Form
- Pediatric Case Report Form
- Birth Certificate Document
- Death Document
- Laboratory Document
- Testing and Treatment History Document
- Consent Form

DOCUMENT	DESCRIPTION
Adult Case Report Form	The Adult HIV Case Report document.
Pediatric Case Report Form	The Pediatric HIV Case Report document.
Birth Certificate Document	A birth document that enables collection of birth details, including birth weight, type, and delivery method.
Death Document	A death document that enables recording of death details, including ICD code and ICD code type. Death documents can be imported into eHARS (see “Importing Documents” later in this module). Imported death documents can be displayed, but their data cannot be edited.
Laboratory Document	A laboratory report that enables capture of an unlimited number of results from common types of lab tests. Lab reports also can be imported into eHARS.
Testing and Treatment History Document	The HIV Testing History Questionnaire administered during the HIV testing process. This document captures the why, when, and where details of HIV testing, along with information about antiretroviral medications taken.
Consent Form	A legacy document associated with Incidence data. Information about these documents can be changed.

LEGACY DOCUMENTS

As noted earlier, eHARS saves legacy documents (Table 6.2) from HARS, the previous HIV surveillance data management system. Legacy documents can be retrieved and viewed but cannot be changed or deleted.

DOCUMENT	DESCRIPTION
HARS Adult	The legacy HARS adult case reports as they were when imported into eHARS. Users can search for these documents and review their data. Also, these documents can be transferred to another case or transferred to create a new case. HARS System Adult documents are used in generating the Person View document.
HARS Pediatric	The legacy HARS pediatric case reports as they were when imported into eHARS. Users can search for these documents and review their data. HARS System Pediatric documents are used in generating the Person View document.
HARS NDI (National Death Index)	The legacy HARS NDI documents as they were when imported into eHARS. Users can search for these documents and review their data. HARS NDI documents are used in generating the Person View document.
Person View	A document that displays summary data for a case. The Person View document comprises information from all documents associated with the case. The Person View document cannot be added as a stand-alone document; it is generated by eHARS whenever a new case is added to the system. If multiple documents are entered for a case, eHARS uses a hierarchy algorithm to determine the primary values to display on the tabs of the Person View document. A primary value in the Person View document can be overridden by a user with appropriate authority.

CALCULATED DATA

In addition to capturing information, eHARS calculates data entered from the various electronic documents and generates values for calculated fields, such as Transmission Category (`trans_categ`) and Diagnostic Status (`dx_status`). These fields are displayed on the “**Calculated variables**” tab, which is part of the Person View document.

KEY POINTS TO REMEMBER

- eHARS collects and presents HIV data through documents linked to a specific case.
- Paper-based forms are represented as electronic documents in eHARS.
- Each eHARS document uses fields to capture and present data.
- eHARS calculates the data entered in document fields and generates new fields for display in the Person View document, such as Current Diagnostic Status, AIDS Category, and HIV Category.

Editing eHARS Documents

The national HIV surveillance reporting and data systems have undergone several versions. As of April 2008, all state and local HIV surveillance programs use the current Enhanced HIV/AIDS Reporting System (eHARS) to collect and manage electronic data.

EDITING

If an error was made in entering document information, you can return to the eHARS document, make the necessary changes, and submit the document's data to the database. Making and submitting changes results in eHARS' recalculating the Person View document for a case.

CAUTION: A document should be edited only to correct errors made during data entry or to add information that was unclear or illegible during data entry but was subsequently clarified. If additional information is received from another source, use the **Add Document** command to enter the new data by using the appropriate data entry document.

HARS legacy documents *cannot* be edited.

KEY POINTS TO REMEMBER

- If an error was made in entering document information, you can return to the eHARS document, make the necessary changes, and submit the document's data to the database.
- Making changes to a document and submitting those changes results in eHARS recalculating the primary values of variables displayed on the Person View document for a case.

The Importing Process

IMPORTING DATA

Health departments can receive thousands of HIV case documents electronically, and eHARS enables the importation of these files into the system. Electronic importation of data reduces time spent manually entering data and can enhance the quality of information by reducing data entry errors. Additionally, most future surveillance data collection activities will involve electronic transfer of information, such as laboratory data transmitted through the [Public Health Information Network Messaging System \(PHINMS\)](#).

To import data, eHARS uses workflows and their templates to map fields from imported files to eHARS variables and the corresponding fields on documents and forms. In addition, these workflows determine the criteria available for matching records from imported files to cases in eHARS. Workflows specify the fields that are used to determine matches and how specific a match must be to an existing case. For example, the work flow for importing death certificates and other death documents makes Social Security numbers (SSNs) available for selection as matching criteria. eHARS sets the probability level for a match on SSNs at 90%, which means the results should match 90% of the number by digit and position. This allows a slight margin of error (10%) consistent with transposition and other data entry errors.

Steps to Importing Data

The process of importing a document's information into eHARS comprises the following tasks:

- Specifying the type of source file (such as **Lab** or **Death**).
- Selecting a template to use to identify imported fields and their order.
- Specifying **Auto Match** to automatically match imported records to existing cases by using STATENO as the criterion; **Manual Match** to select alternative matching criteria when STATENOs are unavailable and to use the selected criteria to manually match import records to existing records; or **Hybrid Match** to select alternative matching criteria and to use the selected criteria to
 - ▶ Automatically create new cases if matching records cannot be found, or
 - ▶ Automatically add imported data to a single match, or
 - ▶ Manually match imported records to existing records if multiple matches are returned.
- Entering the source file location and name.
- Uploading the file:
 - ▶ If **Auto Match** was selected: reviewing the Imported and Rejected Record reports.
 - ▶ If **Manual Match** was selected: creating new cases from imported records or adding imported records to existing cases.
 - ▶ If Hybrid Match was selected: creating new cases from imported records or adding imported records to existing cases if the **1-0** or **1-1** hybrid matching options did not resolve the status of all records on the import file, and reviewing the Imported and Rejected Record reports (when the selected hybrid matching options do result in imported records being added to existing eHARS cases or creating new eHARS cases).
 - ▶ If uploading fails: reviewing error messages, editing and saving the import file, and importing the renamed file.

When a file is imported, its data are held in a staging area database, and certain validations are run against the file's data. For example,

- Dates must be mm/yy, mm/dd/yy, or mm/dd/yyyy (except for enter_dt, which must be mm/dd/yyyy).
- SSNs must be 4 digits (the last 4 digits of the SSN), 9 digits, or nnn-nn-nnnn.
- Patient STATENOs are validated against the eHARS database.
- Document type codes must be 3 digits and match valid Document values in the LOOKUP_CODE table, such as 004 (Lab). Excel often drops leading zeroes, so attention must be paid to such values.

Key Points to Remember

- Import files can contain errors, such as incorrect collection dates or erroneous county names; importing data with errors can result in many hours of work to resolve these errors. For this reason, you should import files in your test system first and check the results by searching for and displaying some of the imported documents and related Person View documents before importing the file in your production system.
- If the imported file can be uploaded but some records are rejected, you can generate a new file containing fixed records from the original source, or you can save the file that eHARS generates (RejectedRecordsFile.txt). After correcting errors in the records, import the corrected file.
- If the specified matching criteria do not result in successful matches, you can select other criteria—if using the **Manual Match** option—and reimport the file.

- When a record is successfully matched to a case in eHARS (or used to create a new case), the **Entered By** field on the **Form Info** tab of the document is populated with the user ID of the person logged in when importing the file.
- Match codes are used to find possible matches within eHARS, but match code generation occasionally fails. If that process does fail, possible matches can be missed during importing. Before importing files, check for documents missing match codes if you have the proper access to the Admin module and the **Match Code Generator** utility. If you do not have proper access, send a request to the eHARS administrator to check for missing match codes before you proceed with importing.

Reports

INTRODUCTION

eHARS has extensive capability for generating automated reports from the data. The basic steps for running a report are 1) select the report, 2) specify the criteria, and 3) submit the report.

Standard reports generated against eHARS datasets and tables are available from the Reports module in eHARS. Reports are grouped by headings displayed in the Main Menu bar. Click one of the following headings in the Main Menu bar to display the available standard reports:

- **Administrative.** The most recent version of the Administrative dataset is the data source for the Administrative reports. The Administrative dataset contains tables that store data related to administrative tasks, such as data transfers, events, groups, users, and system preferences.
- **Operational.** The most recent version of the Document-based dataset is the data source for the Person View Status report; the Unresolved Inter and Intrastate Pending Duplicates report; the New, Updated, Moved, Deleted, and Purged Documents report; and the Transmission Category Tracking report, among others. The Document dataset contains tables that store data directly related to eHARS documents, such as a document's status and creation date. Other operational reports, such as the Person View Override report, access current data stored in eHARS tables.
- **Surveillance.** The most recent version of the Person-based dataset is the data source for the Surveillance Summary report. The Person dataset is a flat-file format dataset for which data for one case are stored on a single row. The Person dataset is created from Person View documents and contains all data identified as part of the Person View. The central site's Person dataset contains all data, but a satellite site's Person dataset contains only data identified as belonging to that site. All cases assigned an identifier and stored in eHARS are included on the Person dataset.

A few of the standard reports that can be run by using the eHARS Reports function are illustrated below.

PERSON VIEW STATUS REPORT

The Person View Status report returns a summary table (Figure 6.4) and a series of listings run against the most recently updated Document-based dataset. The table summarizes the distribution of Person View documents by status. The listings display the values of certain variables from each Person View document in the dataset. The Person View Status report can be customized to display listings for only a selected status. The report also can be run against a specific date range, either the documents' creation or modification dates. By default, results are sorted by document status, but a secondary sort (such as by date first created) can be selected and applied.

The Person View Status report needs to be run to determine which Person View documents do not have either an Active or Warning status. Only data from Person View documents with a status of Active or Warning are considered for transfer to CDC.

DATA TRANSFER REPORT

The Data Transfer report is run against the TRANSFER_DETAIL and TRANSFER_LOG tables on the eHARS Structured Query Language (SQL) database. The Data Transfer report lists details of the specified transfer file, including the names of the export and acknowledgment files and the acknowledgment date. Other details in the report's table are listed under State and CDC column headings:

- Transfer Status
- Transfer UID
- Record Count
- Error Code
- Error Description

The Data Transfer report displays details for a specified source file (Figure 6.5). The most recent source file is specified by default, but a date range can be entered to select a different transfer file. The Data Transfer report needs to be run to determine the status of a data transfer and to display the number of records transferred and any errors.

Figure 6.4 Example of summary table returned in eHARS Person View Status

Person View Status		
Status	Frequency	%
Active	9788	41
Deleted	44	0
Error	420	2
Purged	23	0
Required field missing	162	1
Warning	13366	56
Total number of documents	23804	100

Figure 6.5 Information displayed on a Data Transfer report in eHARS

Data Transfer Report:		
Export File:	document_export_73_GA00_05-11-06.zip	
Acknowledgement File:	No response file found for this request.	
Acknowledgement Date:		
	State:	CDC:
Transfer Status:	Transfer Completed	Unknown Import Status
Transfer Uid:	73	
Record Count:	12668	
Error code:	0	
Error Description:	-	

SURVEILLANCE SUMMARY REPORT

The Surveillance Summary report returns a series of tables listing numbers and percentages of cases in the Person-based dataset. The purpose of the Surveillance Summary report is to list numbers of cases and deaths (death for this report is defined as vital_status = 2 and date of death has a non-missing year) for a selected diagnostic status. The Surveillance Summary report lists the following:

- In Table 1, the number of cases and deaths by diagnostic status and patient age category (adults or adolescents; children <13 years of age) (Figure 6.6).
- In Table 2, the number of cases by patient age at diagnosis and sex (Figure 6.6).
- In Table 3, the number of cases by patient race/ethnicity and age category.
- In Table 4a, the number of cases among adults or adolescents by transmission category and sex.
- In Table 4b, the number of cases among children by transmission category and sex.
- In Table 5, the number of cases, deaths, and case-fatality rates by time of diagnosis.

Figure 6.6 Table 1 and Table 2 of the Surveillance Summary report in eHARS

Surveillance Summary												
Table 1. Number of cases and deaths ^a by diagnostic status and age category												
Diagnostic status	Adults or adolescents				Children (<13 yrs)				Total			
	No.	%	Deaths	%	No.	%	Deaths	%	No.	%	Deaths	%
HIV infection (not AIDS)	1651	100	69	4	63	100	1	2	1714	100	70	4
Total	1651	100	69	4	63	100	1	2	1714	100	70	4

Table 2. Number of cases by age at diagnosis and sex ^b						
Age at diagnosis (yrs)	Males		Females		Total	
	No.	%	No.	%	No.	%
<13	28	2	35	7	63	4
13-14	3	0	2	0	5	0
15-24	127	10	103	21	230	13
25-34	452	37	183	37	635	37
35-44	389	33	119	24	518	30
45-64	162	13	34	7	196	11
55-64	31	3	13	3	44	3
>=65	15	1	5	1	20	1
Total	1217	100	494	100	1711	100

KEY POINTS TO REMEMBER

- Most standard reports are run against the Document-based dataset or real-time data; surveillance reports are generated against the Person-based dataset; administrative reports are run against the Administrative dataset.
- The basic steps for running a report are 1) select the report, 2) specify the criteria, and 3) submit the report.
- Most standard reports can be customized to report only the data you want to see.
- The **Valid SAS Subsetting “if” Statement** box displayed for the Surveillance Summary report allows you to enter “IF” SAS statements referencing macros, variable names, and values.

Administrative Tasks

Administrative Tasks allow an administrator to manage and maintain eHARS. The administrative tasks available include adding users and groups, exporting data, and updating facility and provider information.

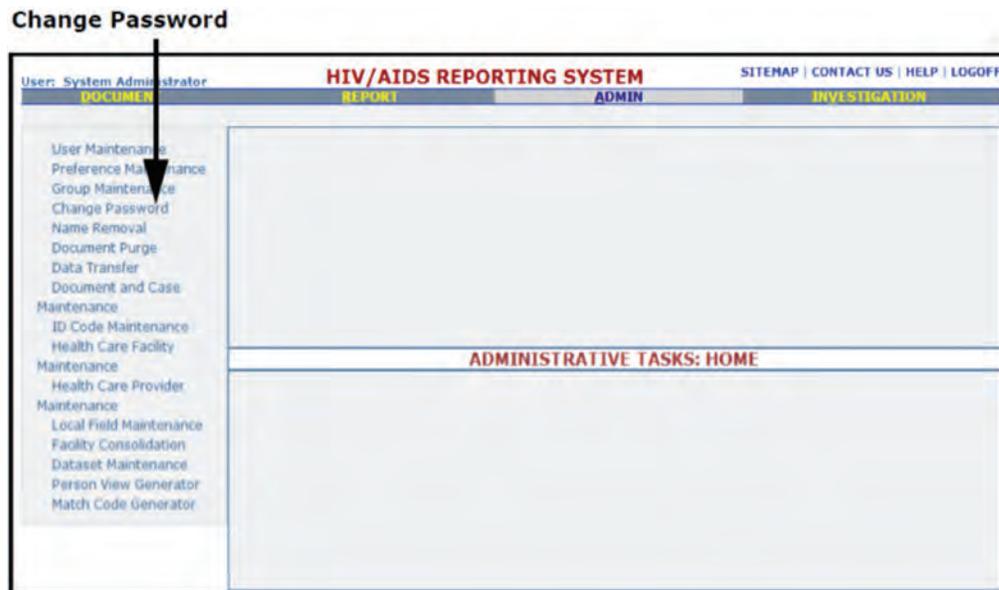
Administrative tasks are displayed in the Main Menu bar. Tasks displayed are determined by the rights assigned to the logged-on user. Complicated administrative tasks—such as updating, merging, and exporting datasets—are beyond the expected skill level of most HIV surveillance staff and should be delegated to personnel with the necessary advanced training/experience. Most eHARS users have access only to the Change Password task that allows them to change their user name and password. System administrators have access to all tasks.

HOW TO CHANGE YOUR eHARS PASSWORD

The Change Password task enables you to maintain your eHARS password. You should change your password immediately after the system administrator creates your account.

To change your eHARS password, do the following:

1. Click **Admin** on the Navigation bar. eHARS displays the Administrative Tasks Home page.
2. In the Main Menu bar, click **Change Password**:



eHARS displays the Change Password page:

Change Password

User Information

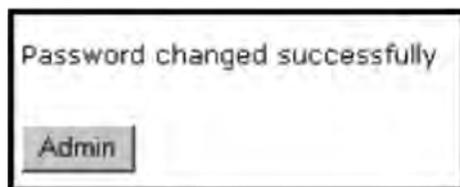
User Name:	<input type="text" value="ehars general user"/>
Current Password:	<input type="password"/>
New Password:	<input type="password"/>
Confirm Password:	<input type="password"/>

3. In the **Current Password** box, enter your current password.
4. In the **New Password** box, enter the new password:

The eHARS system administrator sets the password requirements. Requirements can include a minimum number of characters, special characters, and numbers. If the entered password is not valid, eHARS displays a requirements message prompting you to enter a valid password.

5. Enter the new password in the **Confirm Password** box.
6. Click **Save**.

If the password change is successful, eHARS displays the following message:



7. Click **Admin** to return to the Administrative Tasks Home page.

The next time you log in, you are required to enter your new password. If you cannot recall your password, contact the system administrator. The User Maintenance task enables the system administrator to assign you a new password.

KEY POINTS TO REMEMBER

- Administrative Tasks pages feature tasks that allow an administrator to manage and maintain eHARS.
- The administrative tasks displayed in the Main Menu bar are determined by the rights assigned to the logged-on user.
- Most eHARS users have access only to the Change Password task.

Investigations

OVERVIEW

The Investigation module in eHARS enables collection of information from reports that have not initiated a case or do not yet constitute a case. You can use the features in the Investigation module to initiate, track, and manage an investigation.

The following illustrates the Investigation home page:

Select Investigation	
ALL	37
OPEN	19
CLOSED	13
ASSIGNED	5

[CREATE NEW INVESTIGATION]

The Select Investigation table lists the number of investigations in the system by status and in total. Each link in the Select Investigation table leads to a corresponding page of investigations:

- All
- Open
- Closed
- Assigned

The Investigation home page also displays **Create New Investigation**, a link to the Create New Investigation page and the Investigation Details form. The Investigation Details form enables investigation information to be entered and displayed

Clicking a status (or **All**) in the Select Investigation table displays a corresponding Investigations Status page. The columns displayed on the Investigations Status page vary depending upon the selected status, but three columns are always displayed:

- **Investigation ID:** the unique identifier for each investigation.
- **Document ID:** the unique identifier of the eHARS document initiating the investigation.
- **Investigation Type:** such as a No Identified Risk (NIR) investigation.

The number displayed in the Investigation ID column links to the Create New Investigation page and the Investigation Details form. The Investigation Details form collects and displays information related to an investigation (Table 6.3).

Table 6.3 | Information collected and displayed in the Investigation Details form

FIELD	DESCRIPTION
Investigation ID	The unique identifier associated with every investigation in eHARS. For a new investigation, the field displays New , and an identifier is generated only when the investigation is saved to the database.
Document ID	The unique identifier of the data entry (eHARS) document involved in the investigation. An investigation might or might not be tied to an eHARS document.
Investigation Status	The current status of an investigation.
Investigation Type	The type of investigation, such as No Identified Risk (NIR) . eHARS supports the following types of investigation: <ul style="list-style-type: none"> • Pregnancy • Birth • Death • NIR • Lab Report Follow-up • Out of State
Investigation Description	Comments regarding the purpose or current disposition of the investigation or any notes that might help resolve the investigation.
Date Opened	The date an investigation was initiated. Enter all dates in Investigation Details fields in the mmddyyyy or mmddyy format.
Investigation Source	The type of document or information received. eHARS displays the following options: <ul style="list-style-type: none"> • Birth • Death • Lab • NIR • CRF (case report form)
Date Assigned	The date an investigator was assigned.
Assigned To	The name of the person assigned to the investigation.
Date Closed	The date an investigation was closed.
Closed By	The name of the staff member who determined the investigation was complete.
Information Source	The source code for the document leading to the investigation, such as an acute care facility or laboratory. For example, enter <i>A01.01</i> if the source of the report is an acute care facility. When you press the TAB key or click in another field, eHARS displays an Information Source Results dialog box listing possible matching source codes. <ul style="list-style-type: none"> • To choose a match from the dialog box, click the appropriate entry. • To close the dialog box without selecting a match, click the dialog box's Close button. • To search for an information source code, enter the first few characters of the code or description, such as <i>A01</i> or <i>Lab</i>, and then press the TAB key. Select the appropriate source from the Information Source Results dialog box eHARS displays.
Date of Last Medical Review	The date the medical record was last reviewed.
Date of Last Contact with Local Health Department	The date of last contact with the local health department.
Date of Last Contact with Provider	The date of last contact with the provider.

Continued on following page 3.

FIELD	DESCRIPTION
Search Provider	Enables searching for a matching provider. Enter a name or partial name in the Search Provider box, and click Search ; eHARS returns a list of possible matches at the bottom of the Investigation Details form. Click the appropriate name in the search results to enter the corresponding information in the provider fields. To search again, enter another name in the Search Provider box, and click Search .
Provider Name	The selected provider's name, including prefix, first and last names, and suffix.
Provider Number	The phone number of the provider.
Investigation Priority	The priority assigned to an investigation.
Resolution	Any comments or notes regarding the conclusion and closing of an investigation.

After entering or modifying information in the Investigation Details form, click the **Save** button to write the data to the eHARS database.

KEY POINTS TO REMEMBER

- The Investigation module enables you to collect information from pending reports that do not yet constitute a case.
- The Investigation home page displays a summary table of investigations by status and frequency.
- The Investigation home page also displays a **Create New Investigation** link that leads to the Create New Investigation page and the Investigation Details form that collects information, such as investigation source, status, priority, and resolution.

MODULE SEVEN

Evaluating HIV Surveillance Programs

OBJECTIVES:

1. Explain aspects of evaluation of core surveillance activities:

- Completeness and timeliness of case reporting
- Interstate duplicates
- Intrastate duplicates
- Completeness of risk factor ascertainment
- Completeness of CD4 reporting
- Data quality

2. Propose additional surveillance activities to evaluate

- Data analysis and dissemination.
- Cases of public health importance.
- Timeliness of laboratory reporting.
- Death ascertainment.
- Electronic lab reporting.
- Case residence.
- Data collection for children <13 years of age.

Evaluation of HIV Surveillance Activities

Evaluation of a public health surveillance system provides information needed to

- Improve the system.
- Interpret the data collected.
- Promote the best use of public resources.

To assess the quality of HIV case surveillance as specified in the Centers for Disease Control and Prevention (CDC) outcome standards (Table 7.1), states and local surveillance programs must conduct periodic evaluation studies. States also should evaluate the representativeness of their HIV case reports and review the extent to which surveillance data are used for planning, targeting, and evaluating HIV prevention programs and services. The goal of these performance evaluations is to enhance the quality and usefulness of surveillance data for public health action.

SYSTEM ATTRIBUTES	OUTCOME STANDARDS
Completeness and timeliness of case reporting	<p>≥85% of expected cases for a diagnosis year are reported by 12 months after the diagnosis year, and</p> <p>≥66% of expected cases for a diagnosis year are reported within 6 months after diagnosis</p>
Interstate duplicates	<5% duplicates in the national database, assessed at 12 months after the report year
Intrastate duplicates	<5% duplicates in the local/state database, assessed at 12 months after the report year
Completeness of risk factor ascertainment	≥85% of cases or a representative sample for a report year have an identified HIV risk factor, measured at 12 months after the report year
Completeness of initial CD4 reporting after a diagnosis of HIV infection	≥50% of cases in adults and adolescents (aged ≥13 years) for a diagnosis year have an initial CD4 count reported, measured at 12 months after the diagnosis year
Data quality	≥97% case records pass all standard data edits, measured at 12 months after the diagnosis year

CDC evaluates proposals and awards grants for federal funding of state and local HIV surveillance programs on the basis of programs' capacity to meet performance standards. Among these activities, CDC requires that recipients of federal funds for HIV case surveillance use surveillance methods and practices that enable them to achieve the standards to ensure that federal funds are awarded responsibly.

This module displays the performance standards for the HIV surveillance programs funded under the core HIV surveillance grants. Additionally, this module also includes information about other activities that programs should consider for evaluating various aspects of their HIV surveillance system.

Surveillance programs will submit an assessment of their progress toward meeting outcome standards for core HIV surveillance activities in their interim and year-end progress reports. Progress reports will be evaluated by the CDC epidemiology consultant assigned to the respective surveillance programs, and feedback will be provided. CDC consultants will work with their state and local surveillance counterparts to maximize performance for HIV surveillance activities.

COMPLETENESS AND TIMELINESS OF CASE REPORTING

Completeness of case ascertainment and timeliness of reporting are used to assess the quality of HIV data collected and reported to the national HIV surveillance system. Results of these evaluations should be used to improve the system at the state and local levels.

Completeness

Completeness of case ascertainment for a diagnosis year is measured at 12 months after the diagnosis year, comparing the number of cases diagnosed and reported to the surveillance system for a given year to the number of cases expected to be diagnosed during that year.

Outcome Standard

At least 85% of the expected number of cases for a diagnosis year are reported by 12 months after the diagnosis year.

Process Standard

Completeness of case ascertainment for the most recent diagnosis year is calculated at 12 months after the diagnosis year, and expressed as a percentage ($p \times 100$). P is estimated by:

$$\frac{\text{Number of cases diagnosed and reported for a diagnosis year}}{\text{Number of cases expected to be diagnosed in that diagnosis year}}$$

Capture-recapture methods are used to estimate the expected number of cases, provided that document-based surveillance has been correctly implemented. In capture-recapture methods, the overlap of reporting of cases from different sources and the number of cases reported solely by each source are determined. From this determination, the total number of cases that were not reported by any source is estimated. The total number of cases expected to be diagnosed in the population is the sum of the number of cases that were not reported from the capture-recapture analyses and the number of cases reported (see [Bibliography](#) in this section for in-depth descriptions of capture-recapture analyses). Programs to conduct capture-recapture analyses are available from CDC.

Timeliness

Timeliness should be assessed, in conjunction with completeness, as the number of expected cases that have not been reported at a given time point added to the proportion of cases that are not reported in a timely manner.

Timeliness can be measured in two ways: 1) as the time from diagnosis to report to surveillance program and 2) as the number of expected cases reported at the time completeness is assessed.

Outcome Standard

At least 66% of the expected number of cases for a diagnosis year are reported within 6 months after diagnosis.

Process Standard

Determine the number of cases with a time to report of <6 months, and then calculate timeliness of case reporting:

$$\frac{\text{Number of cases diagnosed within a year and reported within 6 months after diagnosis}}{\text{Number of cases diagnosed and reported for that diagnosis year}}$$

At less than 100% completeness, this measure overestimates timeliness from diagnosis to reporting.

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INTERSTATE AND INTRASTATE DUPLICATE REVIEW

The ability of a surveillance system to correctly distinguish newly reported persons from persons previously reported should be measured to determine accuracy of case counts. Failing to properly link case reports to existing cases leads to overcounting; incorrectly linking reports to existing cases can lead to undercounting and contamination of existing records with data from another case. At the local level, surveillance software and other routine surveillance practices are used to eliminate duplicate reports. At the national level, CDC does not receive patient names or other specific patient identifiers, such as Social Security number (SSN), so duplicate reports cannot be eliminated with the same degree of accuracy as at the state and local levels where patient identifiers and other details are maintained.

Interstate Duplicate Review

Outcome Standard

Less than 5% duplicates in the national database, assessed at 12 months after the report year.

Process Standard

- **Frequency of Procedure.** Biannual reports distributed to surveillance programs by CDC (see [Routine Interstate Duplicate Review \[RIDR\]](#) below).
- **Out-of-Jurisdiction Case Handling.** States should enter information about out-of-jurisdiction cases into eHARS. Often, persons whose HIV was diagnosed in one state might be receiving care and services in another jurisdiction. Use policies and procedures for state residence assignment to ensure that cases are counted appropriately.
- **Resolution of Potential Duplicates.** Contact the surveillance coordinator or designee from the appropriate state, and use additional case information (such as patient name) to determine whether a potential duplicate is the same or a different person. Persons approved to release information about HIV cases to other jurisdictions are listed on the [CSTE HIV/AIDS Contact Board](#) Web site. Contact the HIV surveillance support staff at CSTE for information about obtaining sign-on identifications and passwords to access the website. Other questions that can be asked are these:

- ▶ Do the two states share a border?
- ▶ Does the SSN prefix come from the other state?
- ▶ Are there any comments that reference the other state?
- ▶ Is there a death date match?
- ▶ Is there a current residence match?
- ▶ Is there an unusual mode of exposure?

If the cases are deemed to be in different persons, indicate this in the appropriate area in your data management system. In eHARS, a duplicate review screen captures this information.

If the cases are deemed to be the same person, assign residence at diagnosis of HIV and residence at diagnosis of AIDS (as necessary) using policies and procedures for residence assignment. The “same” and “different” tabs in eHARS on the case need to be completed to close the information loop and complete the RIDR process.

Communicate with the other state surveillance coordinator (or designee) to collect additional information (such as risk factor, death date, HIV diagnosis information, AIDS-defining conditions) to complete your case record and to support the diagnosis of HIV (including Stage 3 [AIDS]).

Contact the RIDR coordinator to resolve any case residence assignment disputes.

- **Valid Duplicates (Different Persons).** Valid duplicates are cases for which Soundex, date of birth, sex, and state of residence at diagnosis are the same, but the cases are, in fact, in different persons. Notify the eHARS help desk to flag a “valid duplicate” for intrastate and interstate duplicates. eHARS software contains a screen that allows the jurisdiction to enter information about the outcome of intrastate and interstate duplicate review.

Routine Interstate Duplicate Review

Interstate duplicate case reporting can result from HIV-infected persons moving to different states over time; as they receive care for HIV infection in the new state of residence, they are reported to that state health department in accordance with local reporting requirements. Because interstate migration can occur at any time and at multiple times throughout the course of illness and because case information is reported at several sentinel events (HIV diagnosis, AIDS diagnosis, and death), multiple opportunities exist for duplicate reporting.

The potential for duplicate reporting of cases in the national database is anticipated to increase now that all locales have adopted name-based HIV reporting, as persons with HIV remain healthier longer because of advances in therapy, and as laboratory-based surveillance increases. Therefore, routine procedures to ensure that state and national data sets do not overcount cases are necessary.

To achieve greater accuracy of local and national case counts and patients’ residence at time of diagnosis, CDC prepares a RIDR report and sends it to each jurisdiction that might have duplicate cases. The RIDR report’s primary purposes are to 1) ensure that diagnoses of HIV infection are counted only once at the national level and 2) more accurately reflect state of residence at state and national levels.

RIDR reports contain lists of pairs of potential duplicate case reports that are identified by querying the national HIV infection case report dataset (eHARS) for cases for which patient’s last name Soundex, date of birth, and sex at birth are the same. Through discussions with other jurisdictions (see the report_state_cdx column of your RIDR report), you will determine whether each pair represents one person and, if

so, that person's residence at diagnosis of HIV infection, stage 1, 2, or unknown and/or at the time of diagnosis of HIV infection, stage 3 (AIDS). Communication with other jurisdictions in accordance with RIDR procedures minimizes overcounting of diagnoses; changes to case residence as a result of RIDR report processing are reflected in eHARS data transmissions to CDC.

CDC plans to generate biannual RIDR reports (one with cases newly reported to state health departments from January through June; another with cases reported from July through December). Each jurisdiction is expected to process completely its RIDR report—including entry of their findings into eHARS—before the next round of RIDR (a minimum of 6 months).

Methods Used to Create RIDR Reports

- The CDC national HIV infection case report dataset is used to prepare the RIDR report.
- Patients who died on or before June 30, 2004, were eliminated from the December 2009 dataset.
- Cases newly reported to CDC are compared with the dataset. Comparison variables are last name Soundex (sndx), date of birth (birth), and sex (sex).
- To reduce the number of pairs in need of resolution, CDC modifies pair identification strategy in a way that can result in some discordance between states' reports. For example, some pairs for resolution by state A might not appear on state B's report because of staggered deployments of eHARS. Such discordance is most pronounced between states that recently deployed eHARS and states that deployed long ago.

Procedures for Processing RIDR Reports

For step-by-step instructions on processing RIDR reports at the state level, see Appendix A of the User Guide/Student manual for "Introduction to eHARS, the HIV/AIDS Reporting System" by [emailing the eHARS Help Desk](#).

Intrastate Duplicate Review

Outcome Standard

Less than 5% duplicates in the local/state database, assessed at 12 months after the report year.

Although CDC does not receive results of routine intrastate duplicate review procedures, jurisdictions should perform these procedures no less often than quarterly and be able to answer in the affirmative if queried about performance.

Process Standards

- **Frequency of Procedure**
 - ▶ Jurisdictions with centralized data management should perform this duplicate review process monthly.
 - ▶ Jurisdictions with disseminated data management systems should perform duplicate review monthly at the local level and quarterly at the state level.
 - ▶ Jurisdictions should perform exact and "fuzzy matching" by using tools provided by data management.
- **Valid Duplicates**
 - ▶ Valid duplicates are cases for which Soundex, date of birth, sex, and state of residence at diagnosis are the same but the cases are, in fact, in different persons.
 - ▶ Notify the [eHARS help desk](#) to flag a "valid duplicate."
 - ▶ eHARS software contains a screen that allows the jurisdiction to enter information about the outcome of intrastate and interstate duplicate review.

COMPLETENESS OF RISK FACTOR ASCERTAINMENT

“Risk factors” should be the collective term for the individual routes of exposure (before the person learned he/she was HIV positive or before HIV was diagnosed) on which data are routinely collected for surveillance of HIV. A list of risk factors was previously displayed starting on page 137 in Module 5 (expanded information is available in Appendix A, [*Technical Guidance for HIV Surveillance Programs, Volume I: Risk Factor Ascertainment*](#)):

Outcome Standard

At least 85% of cases or a representative sample for a report year have an identified HIV risk factor measured at 12 months after the close of the report year.

Process Standards

- 75% of all initial HIV case reports (if a laboratory report was the initial report, then 75% of the first subsequent reports) have at least one HIV risk factor identified.
- All initial HIV case reports are reviewed by a designated local surveillance program staff member to prioritize and determine whether epidemiologic follow-up is warranted and to ensure follow-up is conducted and appropriate cases are correctly reclassified.
- No reported risk factor (NRR) cases are followed up within 1 month after the date of the initial case report by contacting medical providers, case managers, and/or reviewing medical charts to ascertain patient risk factors.
- The surveillance program conducts audits on a regular basis (at least annually) to assess the degree to which the outcome standard was achieved.
- The surveillance program has a written manual, which is reviewed annually and updated as necessary, containing training plans for its staff and providers, as well as policies and procedures for ascertainment, collection, and evaluation of HIV risk factors.

COMPLETENESS OF INITIAL CD4 REPORTING AFTER HIV DIAGNOSIS

Laboratory testing (i.e., CD4 count and viral load) can be used as a marker of entry to receipt of health care. Conversely, the lack of laboratory testing suggests lack of entry to medical care and is an unmet health-care need for HIV-infected persons. The completeness of CD4 and viral load reporting affect its usefulness as a marker of access to health care, and wide variation in locale-to-locale estimates of access to care inevitably lead to understanding of or explanation for the variation among locales.

Laboratory reporting of CD4 counts serves many surveillance purposes. One use of CD4 reporting is for CD4 count obtained at initial HIV diagnosis to stage HIV disease. Population-based CD4 count at diagnosis has implications for prevention and outreach interventions. Although the actual obtainment of a CD4 count at diagnosis requires health-care “intervention” for the ordering of the test, a minimum level of CD4 reporting should be expected for all reporting locales. Locales not able to achieve the minimum level of CD4 reporting might need to investigate surveillance practices and adjust those practices to ensure adequate collection and reporting of CD4 count results.

Outcome Standard

At least 50% of adults/adolescents in whom HIV infection is newly diagnosed have an initial CD4 count (i.e., CD4 specimen collected within 3 months after HIV diagnosis) reported to the surveillance system, measured at 12 months after the diagnosis year.

DATA QUALITY

To monitor the HIV epidemic, state and local HIV surveillance programs collect extensive information from multiple sources over time on all persons receiving a diagnosis of HIV infection. The basic functions of such surveillance programs include quality control activities, which focus on assessing and improving the quality of the data. The surveillance program must have a quality assurance program with designated staff and a schedule of defined activities. The data quality evaluations and the outcome measures should be recorded and used to improve registry procedures if target performance levels are not met.

Outcome Standard

At least 97% of case records pass all standard data edits. The standard is assessed for the most recent diagnosis year at 12 months after that diagnosis year. The target standard is that 100% of case records pass all standard data edits.

Standard data edits include the variables most important for data analysis (sex, date of birth, date of diagnosis, race/ethnicity, state of residence at diagnosis, initial CD4 count at HIV diagnosis, vital status, and risk factors).

Process Standards

- **Adherence to Data Standards.** Data items should be collected according to standard codes as defined in the “Instructions for Completing the Data Collection Form” of the [Technical Guidance for HIV Surveillance Programs, Volume II: Data Collection Resources and Reporting](#). Using standard codes allows data exchange between local sites and aggregation of data on the national level. Adherence to standard codes is assessed with standard data edits.
- **Training.** Training is an essential component to ensure accurate, consistent, and complete data collection. Training for surveillance staff and report sources should include
 - ▶ Reporting requirements, including frequency of reporting, mechanism of reporting, and required data items.
 - ▶ Data collection, including reportable events, case-finding procedures, coding, and follow-up procedures.
 - ▶ Quality control, including visual and computer edits and feedback regarding edit results.
 - ▶ Data processing, including data entry and linkage.
- **Quality Control Activities.** The quality control activities described in this section primarily address the accuracy of the data collected. Such activities include
 - ▶ Visual editing (proofreading) of hard copy case report forms (all forms, all data items, and all comments) before data entry, if possible by a person other than the person completing the form. Visual editing includes checking readability, consistency, and coding, and verifying any inconsistent or unclear responses.
 - ▶ Duplicate data entry (all or at least 10% of hard copy forms). An alternative option is to select 10%–20% of cases and cross-reference them with the hard copy. Any discrepancies identified in reports of the results from duplicate data entry (i.e., the comparisons of the original and duplicate documents) should be resolved, and the results should guide training efforts regarding data entry.
 - ▶ Electronic edit checks of individual electronic documents (all standard data edits are applied to all documents on data entry or electronic import).
 - ▶ Electronic edit checks of the consolidated case-based records (all standard data edits [see Outcome Standard, above]) are applied to all records before data transfers to CDC, but at least quarterly), and resolution of errors.

- ▶ Duplicate abstracting (see Reabstraction Studies below).
- ▶ Data analysis and use: Inconsistencies in the data are often discovered during data analyses. These problems should be communicated to the quality control staff for follow-up and improvements of procedures.

Reabstraction Studies

Reabstraction studies assess the agreement (accuracy) between information recorded in the surveillance system and information recorded in source records (e.g., hospital medical records). Reabstraction studies are conducted to assess the quality of the data from

- Staff abstracting (active surveillance) and
- Provider reporting (passive surveillance, where it has been implemented).

At least once a year, all programs should routinely reabstract demographic, risk factor, laboratory, and clinical data from a representative sample of records to assess the quality and validity of information collected as it existed in the source file when the record was initially abstracted.

Eligibility Criteria and Study Population

To assess the quality of information collected by program staff and determine data quality for a diagnosis year, programs will use cases with documents (case report forms) obtained through active surveillance during a diagnosis year to form the study population. Only cases diagnosed and reported will be available for sampling. Sampling also can be based on report year, but records could be difficult to obtain for cases diagnosed several years earlier. Generally, cases that do not meet the HIV case definition should be excluded unless there is reason to believe that case definition criteria need to be reviewed.

To assess the quality of information reported to the program by providers, programs will include cases with documents received through passive surveillance. Generally, this will entail the reabstracting of case report forms. Information received from electronic medical records, and transmitted and imported electronically, might not need to be reabstracted unless information has been manually transcribed onto case report forms somewhere in the process (reabstracting of such records should then be considered). The accuracy of the information provided in electronic documents, however, needs to be assessed as well (e.g., coding of values or accuracy of data entry at remote site).

Selection of cases for reabstracting also depends on the date of the original abstraction. Reabstracting on the same day as the original abstraction should be avoided because bias might be introduced when staff know reabstracting is to immediately follow. However, because of the changing nature of medical records and the potential for archiving of some files, reabstracting should not be done too distantly in the future. The time frame for reabstracting should be 1–6 months after the initial case report (but can be later, depending on program resources and logistic considerations). To reabstract data that were available at initial abstraction, the program should ensure proper tracking of the dates when initial case report forms are completed and the sources of the information; such tracking allows reabstracting staff to abstract from the date the form was completed backwards at the original source.

Frequency of Reabstraction Studies

Reabstraction studies should be performed annually.

Data Items Included in Reabstraction Studies

The data items for reabstracting include, at a minimum, the information required to report a case of HIV infection to eHARS. These data items are the alpha-numeric (Soundex) code of the patient's name; state-assigned patient identifier number; HIV diagnosis information, including date(s) of diagnosis; and patient's date of birth, race/ethnicity, and sex. In addition, risk factor information and key laboratory data (e.g., CD4 counts at or near diagnosis) should be collected, as should any other data items of interest to the program. See Appendix G of Data Quality chapter of the [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](#) for a detailed description of the data items.

Outcome Measures

The validity and accuracy of estimates derived from individual data elements can be limited if these data elements contain errors or if a large proportion of information is missing or unknown for them. Standards for individual data elements are measured by edits (proper values, internal consistency), the percentage of missing information, and reabstraction studies.

Outcome standards are set to indicate the minimum at which data can be reliably used for analyses and should be assessed for each diagnosis year at the specified time for all cases meeting the HIV case definition. The results should be used to improve surveillance processes.

- **Edits.** The minimum standard for passing data edits is that >97% of case records pass all standard data edits. The target standard is that 100% of case records pass all standard data edits. The edits for the standard include variables most important for data analysis (sex, date of birth, date of diagnosis, race/ethnicity, state of residence at diagnosis, initial CD4 count at HIV diagnosis, vital status, and risk factors). The standard is assessed for the most recent diagnosis year at 12 months after that diagnosis year.
- **Missing/Unknown Information.** The proportion of case records missing information is assessed for Soundex, sex, date of birth, date of diagnosis, race/ethnicity, state of residence at diagnosis, initial CD4 count at HIV diagnosis, vital status, and date of death (for persons known to be dead). The target is no missing information. Percentage of missing information is measured for each data item at 12 months after the diagnosis year. Although a code of “unknown” is not synonymous with a code for missing value, the percentage of “unknown” is also calculated. A separate standard addresses missing information for transmission category.
- **Reabstraction Studies.** Agreement rates (see previous discussion at [Reabstraction Studies](#)) are calculated from reabstraction studies as an indicator of data quality. No standards have been set for agreement rates.

Additional Evaluation of Surveillance Activities

DATA ANALYSIS AND DISSEMINATION

Decisions about public health depend on high-quality data. Accurate surveillance data are central to the effective monitoring of trends in HIV infection; identification of behavioral risk factors in populations; and successful development and evaluation of HIV intervention, prevention, and care programs. In addition, presentation of surveillance data should facilitate use of this information for public health action. Therefore, HIV surveillance data must meet specific criteria for quality before being analyzed and disseminated.

For more information about data quality, see “Data Quality” (page 10-3) in [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](#).

Structural Requirements

Minimum Performance Standards

Before analysis, HIV surveillance data should meet minimum performance standards. A framework for evaluation and evaluation standards for HIV surveillance data have been described (Hall HI, Mokotoff ED. [Setting standards and an evaluation framework for human immunodeficiency virus/acquired immunodeficiency syndrome surveillance](#). J Public Health Manag Pract 2007;13:519–23); and the standards also are listed in “Data Quality” (page 10-3) of [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](#). In addition, any report or presentation of the data should include a discussion of the quality and the limitations of the data.

Sufficient Capacity for Analyzing HIV Surveillance Data

HIV surveillance programs need the capability to properly analyze and interpret data. Programs need either their own staff who are proficient in conducting statistical analyses or access to other people who have the necessary skills (through an agreement with another group in the health department, an academic institution, contractor, or peer-to-peer consultation). All personnel involved in the analysis of HIV surveillance data must comply with all appropriate [security and confidentiality guidelines](#).

CDC provides licenses for SAS statistical software to its surveillance grantees and provides SAS code to assist with analysis. Surveillance programs need the most recent version of SAS to ensure functionality with analysis programs available from CDC. To obtain relevant SAS programs, contact the Coordinating Center for Infectious Diseases Informatics Customer Support by telephone at 877-659-7725 or by email at ccidinformatics@cdc.gov. If your program does not have sufficient staff to support data analysis (because, for example, your program is small), contact your HIV surveillance epidemiology consultant in HICSB to request technical support.

Outcome Standards

At a minimum, an HIV surveillance report should be published annually to present descriptive HIV surveillance data 1) to other units of the health department and community planning groups that use HIV surveillance data to direct or prioritize services for HIV prevention and patient care, 2) to those who report the data, and 3) to the public. Routine reports that are responsive to the needs of various data users decrease the number of individual requests for data. The frequency of publication of standard statistical reports should be determined by each program, but these reports should be published at least annually.

The statistical report should present descriptive statistics on the epidemiology of the local HIV epidemic and should complement, but not repeat, the information in the epidemiologic profiles produced in the jurisdiction.

Each statistics report should include analyses of the variables listed below. How to display them should be discussed with data users. For example, the HIV care part of the health department might want age groupings that match how it guides programs or is funded.

Race/Ethnicity

In 1997, the Office of Management and Budget (OMB) announced the Revisions to the Standards for Classification of Federal Data on Race and Ethnicity (www.whitehouse.gov/omb/fedreg/1997standards.html). For comparability, local surveillance programs should use these standards. Implementation by January 1, 2003, was mandated for federal agencies. That means the old classifications can be used for data collected before that date; the new classifications must be used for data collected after that date. However, situations exist in which surveillance programs began using the new classifications before 2003. Surveillance programs should present race/ethnicity data in a way that is pertinent and useful to their jurisdictions. However, all racial/ethnic groups must be able to be collapsed into the OMB's revised classifications.

The new OMB race categories are as follows:

- American Indian or Alaska Native
- Asian
- Black
- Native Hawaiian or Other Pacific Islander
- White

Two ethnicity categories (Hispanic and not Hispanic) should be collected regardless of race. For more information, consult the U.S. Census Bureau Guidance on the Presentation and Comparison of Race and Hispanic Origin Data (www.census.gov/population/www/socdemo/compraceho.html).

If large numbers of persons of other racial or ethnic groups reside in a jurisdiction, rates of HIV among these groups might differ from the rates among other racial/ethnic groups. This may include locally relevant populations, such as foreign-born persons, that might impact a regional epidemic. To improve the quality of information available to local prevention efforts, programs should consider collecting and displaying this information.

To obtain relevant SAS programs that enable better analysis of data on race/ethnicity, contact the Coordinating Center for Infectious Diseases Informatics Customer Support by telephone at 877-659-7725 or by email at ccidinformatics@cdc.gov.

Age

Data by age are often displayed in groups; data also are commonly displayed for the categories “adults and adolescents” and “children.” The age category for adults and adolescents comprises persons aged >3 years; the age category for children comprises persons <13 years. Age at time of diagnosis is most often used for prevention purposes; current age is most often used for care purposes.

Sex

Sex is most commonly expressed as assigned sex at birth. Male and female are the standard designations for sex; however, programs can choose to collect, analyze, and display data for subcategories according to local needs; for instance, for transgender populations.

HIV Transmission Category

Transmission category is the term for the hierarchical classification that summarizes a person's possible HIV risk factors; the summary classification results from selecting, from the presumed hierarchical order of probability, the risk factor on the case report form that is most likely to have been responsible for transmission.

Data on risk factors are typically displayed in the following transmission categories:

- Male-to-male sexual contact.
- Injection drug use (IDU).
- Male-to-male sexual contact and IDU.
- Heterosexual contact (recently redefined as HIV transmission due to heterosexual contact but without the requirement to know that the partner was HIV positive or the partner's HIV risk history).
- Perinatal exposure (from HIV-infected mother to infant).
- Other (typically includes transmission through blood transfusion or hemophilia; since the advent of stringent blood screening tests in 1985, the number of such transmissions has become negligible).
- NRR: cases in which risk factor information is absent from the initial case report
- No identified risk factor (NIR): cases for which epidemiologic follow-up has been conducted and sources of data have been reviewed but no risk factor information has been identified. (Any case without a reported risk factor 12 months after report date is considered NIR.) Surveillance programs should consider whether keeping the NRR and NIR categories separate is relevant or helpful to data users.

For other ways to display information about HIV transmission, review CSTE position statements on the [CSTE website](#).

Risk Factor Redistribution

Because recently diagnosed cases of HIV are more likely to be reported without sufficient risk factor information and risk factor information might never be reported for some cases, some transmission categories will be underestimated unless adjustments are made. Historically, CDC has adjusted risk factor information in analyses of the national HIV surveillance data on the basis of risk factor redistributions of cases diagnosed 3–10 years earlier and initially classified as NRR but that were later reclassified because a risk factor was found through chart review or follow-up investigation. CDC now uses multiple imputation to redistribute HIV risk factors for cases reported without risk factor information (McDavid Harrison K, Kajese T, Hall HI, Song R. [Risk factor redistribution of the national HIV/AIDS surveillance data: an alternative approach](#). Public Health Rep 2008;123:618–27).

As part of this activity, CDC provides analysis programs and technical assistance for implementing multiple imputation locally. The most important determinants of whether a state or locality might reasonably redistribute risk factors are the overall number of cases reported, the proportion reported without risk factor, and the initial risk factor distribution.

Geographic Area

At a minimum, surveillance programs should analyze and display data for their entire jurisdiction (e.g., state) and, in most areas, by designated geographic subdivision (e.g., health district, county, or census unit). Surveillance programs should conform to security and confidentiality guidelines when displaying small cell sizes. For further assistance, see www.cdc.gov/hiv/topics/surveillance/resources/guidelines/guidance/index.htm.

Spectrum of Disease

Analyses and reports should describe various aspects of the spectrum of HIV disease.

- **HIV infection:** refers to 3 categories of HIV diagnoses collectively:
 - ▶ A diagnosis of HIV infection alone.
 - ▶ A diagnosis of HIV infection and a later diagnosis of AIDS.
 - ▶ Concurrent diagnoses of HIV infection and AIDS (i.e., diagnoses of HIV infection and AIDS during the same calendar month).
- **HIV infection, Stage 3 (AIDS)** refers to the end-stage of HIV disease and is less representative of the current state of the HIV epidemic than are HIV diagnoses in Stages 1 or 2. However, data on advanced HIV disease (i.e., Stage 3 [AIDS]) still provide valuable information about late testing, inadequate care, and potential differences in access to HIV testing and care services. [An updated HIV case definition \(including AIDS\)](#) was published in 2008.

Suggested Additional Analyses

These depend on availability of data and analytic ability of surveillance staff.

- **Unmet Need or Not in Care.** Data on persons who have an HIV diagnosis but who are not accessing available services or not currently receiving medical care can be used to identify barriers to care and services. Programs can establish different parameters for defining unmet need or not in care. For example, unmet need for HIV primary medical care might be defined as no evidence within a 12-month period of 1) CD4 cell count, 2) viral load testing, or 3) prescription for prophylactic or antiretroviral medications (if that information has been collected). For the CD4 cell counts and viral load levels, the surveillance program will need to obtain the laboratory results, including reports of undetectable viral load. Analyses of adequate care and unmet need should be stratified by basic demographic variables (e.g., race, age, sex). For more information, see [ftp://ftp.hrsa.gov/hab/unmetneedpracticalguide.pdf](http://ftp.hrsa.gov/hab/unmetneedpracticalguide.pdf).
- **Late Testers.** Knowing the proportion of persons who receive a diagnosis of HIV infection and then receive a diagnosis of Stage 3 (AIDS) within the next 12 months is helpful in focusing routine testing in many settings (e.g., clinical settings, counseling and testing programs at health departments, community-based organizations). Stratifying the analyses by race/ethnicity, sex, transmission category, age group, or country of origin also might be useful.
- **Diagnoses by Country of Origin.** Several states have reported increases in the number of diagnoses among foreign-born persons. HIV-infected foreign-born persons can differ from HIV-infected U.S.-born persons in age, transmission category, race/ethnicity, and sex. Subpopulations in states also might differ, so some states might want to include analyses of subpopulations. Changes in the rate of immigration of HIV-positive persons can influence trends among diagnoses in some populations. Auxiliary data sources (such as the [U.S. Census Bureau](#)) should be reviewed to allow complete and accurate interpretation of the data.
- **Topics of Local Interest.** In addition to collecting standard HIV surveillance data, local programs can collect information about additional topics of interest. For example, a potential topic of local interest is transgender persons with a diagnosis of HIV infection.

Process Standards

Surveillance programs should have clear policies and procedures for analyzing and disseminating data. These policies and procedures should include

- Guidance to prevent the release of information that could identify a person.
- Rules on the minimum cell sizes for reporting. For example, cell sizes of five or more may be released. However, whether to provide breakdowns with lower than the established threshold in a given category should be decided in consultation with staff supervisors. Decisions about reporting cell size should be based on the size of the denominator (e.g., geographic area, time period). For additional guidance on cell size, see “Important considerations for presenting data in tables and figures” in Appendix B: Techniques for Analyzing and Displaying HIV Surveillance Data in *Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures*.
- Rates calculated from numerators of less than 20 are considered unreliable and thus should be denoted as such in a footnote. In addition, numerators of less than 5 should be suppressed in accordance with local procedures.
- Guidance that addresses data requests for which a meaningful interpretation of the data is not possible, such as data requests that are epidemiologically inappropriate because of small cell sizes, incomplete or uncertain data, or data unsuitable for the type of inquiry.
- A policy for review of products (e.g., reports, guidance documents, presentations).
- A list of job positions involved in data analysis and the position of the person who approves the release of data.
- A mechanism that ensures that all staff comply with security and confidentiality procedures and policies.
- A policy on authorship.
- A policy on access to data by researchers outside the health department.

CASES OF PUBLIC HEALTH IMPORTANCE

Investigation and follow-up of cases of public health importance (COPHI) remain a priority at CDC. The COPHI coordinator in the CDC HIV Incidence and Case Surveillance Branch should be notified about any potential special investigation. For detailed instructions on conducting investigations and risk factor definitions, see Protocol 776 in Appendix C of Risk Factor Ascertainment chapter of *Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures*.

Outcome Standard

Annual progress reports (prepared 12 months after a reporting year) should list all COPHI from the previous year with status and include the following:

- Number of cases reported (for example, the yearly progress report for 2003 would reflect COPHI cases reported during January 1–December 31, 2003).
- Number of cases for which investigation was initiated.
- Number of cases that have a final disposition or status.
- Number of CDC-confirmed cases (if any).
- Percentage of cases still open (number of cases reported minus the number of cases that have a final disposition/number of cases reported).

Process Standards

- The state or jurisdiction should have documentation describing its legal authority to investigate COPHI.
- All COPHI must be investigated to confirm the reported exposure. There is no minimum performance standard.
- Investigation of cases should be initiated within 3 months after the date of initial case report or at the time of notification from the patient or provider if sooner.
- A risk factor for a COPHI can be considered confirmed by CDC only in consultation with the health department, after its investigation, on the basis of criteria outlined in Protocol 776 (see [reference](#) above).
- All cases should be either in “active” investigation status or closed with a final disposition.
- Cases should be closed after 1 year if no further information becomes available but later can be reopened to confirm risk factors.
- The state or jurisdiction should run reports of all nonconfirmed COPHI at least quarterly or more frequently, depending on morbidity, by using case data from the HIV surveillance system or equivalent software that is reported to CDC.

TIMELINESS OF LABORATORY REPORTING

When timeliness of reporting is assessed from a specific source (for example, mandated laboratory reporting within a specific time frame), completeness is not taken into account. An example of such a calculation would be (use tests reported from specific source)

$$\frac{\text{Number of (reportable HIV-related) tests received within (3) days after test date during specified period}}{\text{All tests reported during same period}}$$

DEATH ASCERTAINMENT

Outcome Measures

Evaluating death ascertainment itself is impractical because no standards are available against which to assess its quality or quantity. However, the data collected through death ascertainment should be used to evaluate other components of surveillance (e.g., gaps in reporting). The outcome measures below are recommendations to assess program performance.

Proportion of Cases for which the Initial Source of Report Was a Death Certificate Record

The proportion of cases initially reported through death certificate records (DCRs [first document received is a death certificate]) among all cases, by year of report, is calculated. For less than 1% of cases should the death certificate be, or be entered on the same date as, the earliest reported document for the case. The Death-Certificate-First percentage measures, not the adequacy of death ascertainment, but the adequacy of surveillance by methods other than death ascertainment. A high proportion (5% or more) indicates the need to strengthen reporting from other sources of information.

Effectiveness of the HIV-Specific Record Linkage in Finding Cases

Also of interest might be a measurement of how many DCRs with mention of HIV are confirmed as newly identified cases (% confirmed = number of cases confirmed/number of DCRs with mention of HIV). Confirmed cases are those for which follow-up was successful, and additional information from other sources has been obtained to confirm the case meets the HIV case definition. Following some of the potential unreported cases among the nonlinked records might be impossible through review of medical records or contact with health-care providers to assess whether they meet the criteria of the HIV case

definitions. No target goal has been set for this outcome measure because the number of DCRs that have complete information to enable case follow-up is unknown. However, surveillance programs might want to determine the reasons for failure to follow up on DCRs.

Delay between Death and Report of Death

Conducting annual searches of death certificate records will probably eventually lead to an annual death-to-report interval ranging from 1 to 30 months, with a mean delay of 1–2 years, depending on when the multiple-cause database becomes available and when the search is conducted. This death-to-report interval should be evaluated by calculating the annual mean and median interval between death and report (or data entry) and the proportion of deaths for which this delay exceeded 36 months. Trends in this interval should be examined by year of death and can be assessed by source of information (death reports from providers/medical records vs. death certificate linkage [all cases will have the same delay time]). The target goal is to obtain death information for cases within 24 months after the year of death. However, availability of death certificate files varies by state. In calculations of the reporting delays for recent years, the delay will be underestimated if any death files are not yet linked to eHARS.

Outcome Standards

These are applied to data entered in the year 2 years before the last full year in the dataset.

- **Timeliness.** At least 85% of reported deaths should be reported within 24 months after the deaths occurred.
- **Death-Certificate-First Percentage.** Less than 1% of cases should have the death certificate being, or entered on the same date as, the earliest reported document for the case.

Process Standards

States should conduct an annual linkage with

- **State/Local Death Certificate Data File.** States should search for all death certificates that match previously reported cases, including deaths for which HIV was not a cause of death. Also, search for potential new HIV cases among death certificates that do not match previously reported cases.
- **Social Security Death Master File.**
- **National Death Index (NDI-Plus).**

ELECTRONIC LAB REPORTING

Because electronic reporting of cases and lab results are relatively new practices to enhance surveillance and not used by all reporting areas, this guideline provides only process standards. Over time, with more experience and as these practices become universal to HIV surveillance programs, outcome measures may be developed.

Quality of Laboratory Reporting

- HIV surveillance programs should send a completeness and data quality “report card” of lab data elements regularly (no fewer than two times a year) to reporting laboratories that meet a minimum reporting volume. For examples of report cards used by surveillance areas, see Appendix E.2 from the Electronic Reporting chapter of *Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures*.
- HIV surveillance programs should receive batched electronic lab reporting at least monthly. Reporting occurring less frequently than monthly should be followed up by the surveillance program to determine reason for lapse.

Use the report card to indicate:

- The total number of records reported by the laboratory.
- The number of records containing all of the essential elements outlined in Case Follow-up from a Lab Report from Electronic Reporting chapter of the [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](#).
- The number of records rejected because they did not report appropriate HIV tests or results.
- The number of records returned to the laboratory for clarification because of missing essential elements.

Use the report card to indicate the completeness of the nonessential variables:

- Indicate the completeness (presence) of each variable required by law or regulation.
- Indicate the completeness (presence) of each variable requested by surveillance staff.

CASE RESIDENCE

Cases of HIV are reported on the basis of place of patient residence at diagnosis of HIV, regardless of where exposure might have occurred. Unless different residence information is reported or provided from other sources, the address given by the person at diagnosis; recorded in the medical chart; and subsequently reported by physicians, laboratories, or surveillance staff for case surveillance purposes can be assumed to be the “usual residence.” When there is only one report for a case, and only one jurisdiction, this residence determination is not an issue. Complexity is introduced when a case is reported by more than one jurisdiction, as often occurs in HIV surveillance.

HIV diagnosis date is the earliest date at which HIV infection was diagnosed from either a positive confirmatory laboratory test result or, in the absence of laboratory documentation, a documented physician diagnosis date. This date is used for epidemiologic monitoring in population estimates of incidence and prevalence of HIV. The revised [2008 HIV surveillance case definition](#) now requires a confirmed positive result from an HIV antibody screening test, positive result or detectable quantity of HIV virologic material, or HIV infection diagnosed by a physician on the basis of documented laboratory criteria to be counted as a case of HIV infection.

Process Standards

Residence Information

This information is entered at the local jurisdiction and should reflect residence at the time of HIV diagnosis. The home address given by the patient at diagnosis is considered his/her usual residence.

Circumstances in Which Questions Might Arise about Residence Assignment

- **Multiple Residences.** Residence for people who move regularly between residences should be assigned by using the address where they live most of the time. If their time is equally divided, residence assignment should be based on where they were living at the time of diagnosis. If a person assumes a new residence for an indefinite period without intending to return to the previous residence, the address of the new residence should be considered as the usual residence, even if this change occurred shortly before HIV diagnosis.
- **Homeless Persons.** People without a usual residence should be reported by the jurisdiction where they were staying at the time of diagnosis.
- **Vacation.** Residence for people in whom HIV is diagnosed while they are on vacation should be assigned by using the usual residence, not the vacation residence.

- **Students.** Residence for college or boarding school students on a typical yearly academic cycle should be assigned by using the address where they live most of the time. Intermittent or part-time students without a regular schedule for moving between parental and school residences should be assigned by using the address where they were living at the time of diagnosis.
- **Live-ins.** For foster children, residence should be assigned by using the address where they were living at the time of diagnosis.
- **Military or Merchant Marine Personnel in the United States.** For people in the military residing in the United States, residence should be assigned by using the address where they were living at the time of diagnosis, either on the base or off the base. For crew members of military or U.S. flag merchant vessels, residence should be assigned by using the address where they live most of the time when they are onshore, if available. If the only available address is the temporary port in which the person resided at diagnosis, then that should be used.
- **Institutionalized Persons.**
 - ▶ For persons incarcerated in state or federal correctional facilities at the time of diagnosis, residence of diagnosis should be defined as the address of the correctional facility.
 - ▶ For persons incarcerated in city or county jails for short-term stays (<1 year), place of residence should be assigned by using the home address. Facility address should be used only if home address is not available.
 - ▶ For persons who are institutionalized for indefinite or long-term stays, residence should be assigned by using the address of the facility where they are staying at the time of diagnosis. Examples of facilities include
 - ▶ Chronic-care or long-term hospitals.
 - ▶ Hospices.
 - ▶ Nursing or convalescent homes.
 - ▶ Inpatient drug/alcohol recovery facilities.
 - ▶ Homes, schools, hospitals, or wards for the physically or mentally disabled.
 - ▶ Orphanages and residential care facilities for neglected/abused children.
- **Foreign Citizens.** Persons whose HIV is diagnosed in the United States while they are residing in the United States, regardless of citizenship, should be reported to CDC. CDC does not forward case reports to other countries for persons whose country of residence is not the United States. Foreign citizens visiting in the United States and not considered residents should not be reported. Residence for foreign citizens who have established a household or *are part of an established household in the United States, including those here for work or study*, should be assigned by using the address of their usual residence in the United States. Residence for foreign citizens who live on diplomatic compounds (e.g., embassies, consulates) should be assigned by using the address of the facility.
- **Immigrants whose HIV Infection is Diagnosed Overseas.** As long as the patient provides documented lab results, then date of diagnosis should be the date of the original lab test done in a foreign country. Because the Health Resources and Services Administration uses residence at diagnosis for funding allocation purposes, however, states should use the person's current in-state address as the residence at diagnosis to correctly categorize the case.
- **U.S. Residents Whose HIV Infection is Diagnosed Abroad.** HIV diagnosed abroad in U.S. residents is notifiable only in the United States if treatment and care occur in the United States, reportable diagnostic tests are performed, and/or HIV-related conditions are diagnosed by a physician in the United States. The residence at diagnosis should be based on the location of the usual residence at the time of treatment or care in the United States. If the usual place of residence for a U.S. citizen at the time of diagnosis is another country but diagnosis and/or care were in the United States, the case is

reportable by the jurisdiction of usual residence in the United States. If there is no usual residence in the United States, the case should be reported by the jurisdiction where the person was staying at the time of diagnosis. Assignment of residence is based as closely as possible on U.S. [Census](#) guidelines. For answers to further questions, contact the CDC Routine Interstate Duplicate Review (RIDR) coordinator for clarification.

Designation of State or Territory

For any given case reported to CDC, only one state or territory can be listed under HIV Residence at Diagnosis and only one state or territory under AIDS Residence at Diagnosis. Because residence at diagnosis of HIV and AIDS can have implications for funding, every effort should be made to obtain accurate information. On the basis of [CSTE position statements 17 and 01-ID-04](#), state health departments should follow reciprocal notification guidelines and communicate with each other about possible out-of-jurisdiction (OOJ) cases. Case information for persons whose home is outside the reporting state should be forwarded to the appropriate state. State health departments should provide updated information to one another (such as updates on vital status) on an as-needed basis.

If a case is reported in multiple jurisdictions with a diagnosis date in the same year and one jurisdiction has only the year of diagnosis but the other jurisdiction has the month and year of diagnosis, residence will be assigned to the jurisdiction with the month/year date.

Maintaining Out-of-Jurisdiction Cases

Surveillance units should enter information about OOJ cases into the eHARS database. Maintaining OOJ cases using surveillance software eliminates the need to create additional space for a hard copy file. Routine computerized record searches can match OOJ cases along with resident case reports so that they will not be investigated and/or reported again. States should use their surveillance software to track the date the information was given to the state of residence. OOJ cases can be easily excluded from local data analysis.

DATA COLLECTION FOR CHILDREN <13 YEARS OF AGE

Completeness of case ascertainment as described in Access to Source Data and Completeness of Reporting from the [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](#)

- Minimum performance standard of >85% of expected number of cases for a diagnosis year are reported by 12 months after the diagnosis year.
- Target performance standard of >95% of expected number of cases for a diagnosis year are reported by 12 months after the diagnosis year.

Timeliness standards as described in Access to Source Data and Completeness of Reporting from the [Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures](#): Minimum performance standard of >66% of cases for a diagnosis year are reported within 6 months after diagnosis and assessed at >85% completeness 12 months after the diagnosis year.

Annually, the program monitors the sources of pediatric HIV cases as specified by the outcome standards. Results of these evaluations should be used to improve the system. Checks on the source of HIV cases include

- Audits.
- Measures to record and tally the number of HIV cases identified through passive or active surveillance or through a registry match, e.g., through creation of a tracking database.
- Regular quarterly assessments of reported vs. expected number of cases received from a reporting source.

Data Dissemination

- Use pediatric surveillance data for planning purposes for HIV prevention and care services.
- Use pediatric surveillance data for allocation of funds.

Data Collection for HIV Exposure Reporting

Completeness of Case Ascertainment

Completeness of case ascertainment is described in Access to Source Data and Completeness of Reporting from the [*Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures*](#):

- Minimum performance standard of >85% of expected number of cases for a diagnosis year are reported by 12 months after the diagnosis year.
- Target performance standard of >95% of expected number of cases for a diagnosis year are reported by 12 months after the diagnosis year.
- Minimum performance standard of >85% of cases of indeterminate serostatus are identified as being a positive or negative case by 3 years after the diagnosis year.

Timeliness Standards

Timeliness standards are described in the Access to Source Data and Completeness of Reporting from the [*Technical Guidance for HIV Surveillance Programs, Volume I: Policies and Procedures*](#): Minimum performance standard of >66% of cases for a diagnosis year are reported within 6 months after diagnosis, and assessed at >85% completeness 12 months after the diagnosis year.

Annually, the program monitors the source of mother/infant pairs as specified by the outcome standards. Results of these evaluations should be used to improve the system. Checks on the source of mother/infant pairs include

- Audits.
- Measures to record and tally the number of mother/infant pairs identified through passive or active surveillance or through a registry match, e.g., through creation of a tracking database.
- Regular quarterly assessments of reported vs. expected number of mother/infant pairs received from a reporting source.

Data Management

Staff follow up on expected births in the pregnancy tracking database to determine outcome of pregnancy and initiate abstraction of pediatric records (if applicable).

Staff should review pediatric records until a definitive HIV infection status is found or every 6 months for 18 months after birth or loss to follow-up.

Data Analysis

Analyses are used to set priorities for follow-up on indeterminate cases and check progress from previous period.