Appendix A: Data Sources

Core Data Sources

AIDS Surveillance

Overview: AIDS is a reportable condition in all states and territories. AIDS cases, reportable since the early 1980s, have been defined according to the prevailing CDC surveillance case definition (last revised in 1993). The AIDS surveillance system was established to monitor incidence and the demographic profile of AIDS, describe the modes of HIV transmission among persons with a diagnosis of AIDS, guide the development and implementation of public health intervention and prevention programs, and assist in the assessment of the efficacy of public health interventions. AIDS surveillance data are also used to allocate resources for Titles I and II of the Ryan White CARE Act.

State and local health departments actively solicit disease reports from health care providers and laboratories. Standardized case report forms are used to collect sociodemographic information, mode of exposure, laboratory and clinical information, vital status, and referrals for treatment or services.

Population: All persons whose conditions meet the 1993 CDC AIDS surveillance case definition

Strengths: Only source of AIDS information that is available in all areas (states), these data reflect the effect of AIDS on a community and the trends of the epidemic in a community. AIDS surveillance has been determined to be >85% complete. The data include all demographic groups (age, race/ethnicity, gender).

Limitations: Because of the prolonged and variable period from infection to the development of AIDS, trends in AIDS surveillance do not represent recent HIV infections. Asymptomatic HIV-infected persons are also not represented by AIDS case data. In addition, incomplete HIV or CD4+ T-cell testing may interfere with the representativeness of reporting. Further, the widespread use of highly active antiretroviral therapy complicates the interpretation of AIDS case surveillance data and estimation of the HIV/AIDS epidemic in an area. Newly reported AIDS cases may reflect treatment failures or the failure of the health care system to halt the progression of HIV infection to AIDS. AIDS cases represent late-stage HIV infections.

Where available: All 50 states; US territories; Chicago, District of Columbia, Houston, Los Angeles, New York City, Philadelphia, San Francisco

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator

Reference: CDC. Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome. *MMWR* 1999;48(RR No. 13):1–31.

HIV Surveillance

Overview: Reporting of HIV infections to local health authorities as an integral part of AIDS surveillance activities has been recommended by CDC and other professional organizations since HIV was identified and a test for HIV was licensed. As part of ongoing active HIV surveillance, state and local health departments educate providers on their reporting responsibilities, establish active surveillance sites, establish liaisons with laboratories conducting CD4+ T-lymphocyte cell analysis and enzyme immunoassay and Western blot testing and follow-up of HIV cases of epidemiologic importance.

Population: All persons who test positive for HIV

Strengths: HIV surveillance data, compared with AIDS surveillance data, represent more recent infection. According to state evaluations, HIV infection reporting is estimated to be >85% complete for persons who have tested positive for HIV. HIV surveillance provides a minimum estimate of the number of persons known to be HIV infected and reported to the health department, may identify emerging patterns of transmission, and can be used to detect trends in HIV infections among populations of particular interest (e.g., children, adolescents, women). These trends may not be evident from AIDS surveillance. HIV surveillance provides a basis for establishing and evaluating linkages to the provision of prevention and early intervention services and can be used to anticipate unmet needs for HIV care.

Limitations: HIV surveillance data may underestimate the number of recently infected persons because some infected persons either do not know they are infected or have not sought testing. Persons who have tested positive at an anonymous test site and have not sought medical care, during which they would be confidentially tested, are not eligible to be reported to the surveillance system. HIV surveillance data represent infections in jurisdictions that have reporting laws for HIV. HIV reporting laws differ by jurisdiction; therefore, consultation with local surveillance staff on how to interpret local HIV surveillance data is advised. Furthermore, reporting of behavioral risk information may not be complete.

Where available: As of April 2003, 34 states (Alabama, Alaska, Arizona, Arkansas, Colorado, Florida, Idaho, Indiana, Iowa, Kansas, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Pennsylvania, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, West Virginia, Wisconsin, Wyoming); American Samoa, Guam, Northern Mariana Islands, Puerto Rico, and the US Virgin Islands have implemented HIV case surveillance, using the same confidential system for name-based case reporting for both HIV infection and AIDS.

Connecticut implemented mandatory HIV reporting in January 2002. For adults and adolescents ≥ 13 years of age, reporting is by name or code (if patients or physicians prefer this method). For children <13 years of age and for persons who are coinfected with tuberculosis (TB), reporting is by name. In New Hampshire, a case may be reported by name or code.

Four states use names to initiate case reports and then convert to codes (Delaware, Maine, Montana, Oregon), and 9 areas are using a coded identifier rather than patient name to report HIV cases (California, Hawaii, Illinois, Kentucky, Maryland, Massachusetts, Rhode Island, Vermont, and District of Columbia). In Washington, reporting of persons with symptomatic HIV infection and of persons with AIDS is by name; a name-to-code system is used to report asymptomatic HIV cases. Georgia plans to initiate HIV case surveillance.

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator

Reference: CDC. Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome. *MMWR* 1999;48(RR No. 13):1–31.

Supplemental Data Sources

Adult/Adolescent Spectrum of Disease (ASD)

Overview: An ongoing longitudinal surveillance cohort study that describes the spectrum and progression of HIV disease, including severe illness and death. Information on AIDS-defining conditions, other illnesses and symptoms, treatments, and lab parameters are abstracted from medical records by using a standardized form. In addition, gynecologic information (e.g., Pap smear, cervical cytology) is collected for women. Data are collected for the 12 months preceding enrollment, and re-abstractions are done every 6 months, until the patient either dies or is lost to follow-up.

Population: Persons 13 years and older with diagnosed HIV infection or AIDS who receive health care at a participating facility in the project area are eligible to participate in ASD. In each project area, facilities serving HIV-infected persons (clinics, hospitals, neighborhood health centers, private medical practices, and emergency rooms) are selected to participate as project sites. ASD project areas have designed sampling schemes to be as representative of the HIV/AIDS population in that area as possible.

Strengths: ASD data describe the spectrum of HIV disease that is documented in the medical chart. Data since January 1990 are available. ASD data are useful for assessing the use of prophylactic and antiretroviral treatment over time and for describing the occurrence of opportunistic illnesses and other conditions in persons infected with HIV. As of December 2002, more than 50,000 persons had been included in the ASD project.

Limitations: ASD data describe morbidity among persons who received medical care for HIV infection at a participating site (i.e., not population-based). The morbidity information in the medical chart may not be complete. Gynecologic information may be underreported because this information may appear elsewhere (woman may have gone to her Ob/Gyn rather than her HIV care provider). ASD data rely on the thoroughness of diagnostic testing and recording and the accuracy and completeness of medical records. Treatment and prophylaxis regimens in ASD refer to prescribed therapies: information on adherence is not collected.

Where available: Atlanta, Dallas, Los Angeles County, Denver, Detroit, Houston, New Orleans, New York City, Seattle; and Bayamon (Puerto Rico)

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or ASD site coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

AIDS Progression Study

Overview: The AIDS Progression Study was designed to help in understanding the characteristics of HIV-infected persons in whom HIV infection progresses to AIDS and to explain why the progression to AIDS occurs. This study examines data on persons who died with AIDS to learn the reasons for the progression from AIDS to death. Data are abstracted from medical records during the 12 months preceding AIDS diagnosis. Data collected for this study include patient characteristics, HIV/AIDS–related history, testing history, AIDS-defining conditions, HIV exposure, and laboratory data.

Population: All persons with a diagnosis of AIDS or who died of AIDS, who were reported to the HIV/AIDS Reporting System after January 2000, and whose diagnosis of AIDS was made no earlier than January 1, 1999

Strengths: Data from the AIDS Progression Study are population-based and can be used to explain reasons for the progression from HIV infection to an AIDS diagnosis and to death from AIDS. The time frame for participation excludes persons whose diagnosis was made when appropriate treatment regimens were not available. Therefore, this study can examine whether progression is due to lack of adherence to treatment, failure to seek or receive appropriate care, infection with a resistant strain, or resistance to treatment. The 12-month period of review before diagnosis allows investigators to examine a patient's medical history.

Limitations: The quality of information on a patient depends on the completeness of documentation in the patient's medical chart. Locating all medical charts may not be possible; thus, the data may not represent all cases of AIDS diagnosed within the study time frame.

Where available: Boston, Chicago, Denver, Hartford (Connecticut), Los Angeles, San Francisco

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or AIDS Progression Study site coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

Antiretroviral Drug Resistance Testing (ARVDRT) Study

Overview: The ARVDRT study will evaluate the prevalence of antiretroviral drug resistance (ARVDR) and non-B HIV-1 subtypes among persons with a recent diagnosis of HIV infection. The study will be conducted in public health settings for 5 years in participating areas. The project will also evaluate the feasibility and usefulness of incorporating ARVDR surveillance into routine public health surveillance systems.

Population: Study population will be enrolled from HIV testing and care sites supported by the participating health departments and from additional sites where diagnostic testing is performed in the public health laboratories or other health department-supported laboratories. These sites may include confidential or anonymous HIV counseling and testing sites, HIV early intervention clinics, sexually transmitted disease clinics, hospital clinics, or health maintenance organizations.

Strengths: Data from the ARVDRT study are representative in publicly supported settings. The methods differentiate recently infected and chronically infected persons, making it possible to evaluate both the ARVDR transmission rate (approximated by rate for persons recently infected) and overall prevalence. The research study will also evaluate the feasibility of implementing ARVDRT. Additional primers will be developed if necessary to evaluate mutations in non-B HIV-1 subtypes.

Limitations: The participating areas are too few to produce a national picture. This study may also underestimate the prevalence of mutations among the chronically infected group of persons with a recent diagnosis because some mutations do not persist in the absence of drug pressure.

Where available: Colorado, Illinois, Maryland; and Seattle

Contact person(s): State or local health department, ARVDRT coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

Arrestee Drug Abuse Monitoring (ADAM*)*

Overview: ADAM was established in the late 1990s by the National Institute of Justice to provide participating communities with information for developing drug-control strategies and related public policy responses. ADAM measures the extent of drug use among persons who have recently been arrested. Four times a year, local research teams in participating study counties interview arrestees at booking facilities; the arrestees are asked to provide a urine specimen. The ADAM questionnaire concerns drug use, frequency of drug use, housing during the past year, financial support, health insurance, how and where drugs are purchased, and demographic information. ADAM adopted a probability-based sampling scheme to enable inferences to the general population of arrestees in participating counties and to increase the reliability of the data collected.

During 1999 and 2000, 3 ADAM sites added an addendum of HIV-related questions to their ADAM questionnaire. These questions concern HIV testing; sexual behavior; needle sharing; history of sexually transmitted diseases, tuberculosis, or hepatitis; receipt of care (for HIV-infected participants); and exposure to HIV prevention messages.

Population: Arrestees booked at facilities in 38 participating counties. However, the sampling scheme is not yet sufficient to enable estimates of the information from female adults or juveniles.

Strengths: ADAM provides population-based information on drug use, patterns of use, socioeconomic factors, and health insurance among arrestees in a participating county. The project collects self-reported information through a confidential interview and collects a urine specimen that is tested for the presence of 10 commonly used illicit drugs. At sites where the HIV addendum is used, ADAM collects information on testing patterns; history of sexually transmitted disease, tuberculosis, and hepatitis; risk behaviors and awareness of HIV prevention messages, all of which are valuable for designing prevention programs and policies focused on incarcerated populations.

Limitations: The ADAM survey instrument relies upon self-reported data; thus, the data may be subject to recall bias or may not be reliable because of participants' sensitivity about the topics. Although not all ADAM participants agree to submit a urine specimen, the refusal rate is low (10%). For sites without the HIV addendum, HIV status among ADAM participants is not known.

Where available: Albuquerque, Anchorage, Atlanta, Birmingham, Cleveland, Denver, Des Moines, Indianapolis, Laredo (Texas), Las Vegas, Miami, Minneapolis, New Orleans, New York City, Oklahoma City, Omaha, Philadelphia, Phoenix, Portland (Oregon), Sacramento, Salt Lake City, San Antonio, San Diego, San Jose (California), Seattle, Spokane (Washington), Tucson.

1999–2000 HIV addendum sites: Denver, Miami, Portland (Oregon).

Additional information available at http://www.ojp.usdoj.gov

Contact person(s): CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

Reference: Methodology Guide for ADAM (May 2001) available at http://www.adam-nij.net/report.asp

Behavioral Risk Factor Surveillance System (BRFSS)

Overview: A state-based random-digit-dialed telephone survey that monitors state-level prevalence of the major behavioral risks associated with premature morbidity and mortality among adults. Each month, a sample of households is contacted, and 1 person in the household who is 18 years or older is randomly selected for an interview. Multiple attempts are made to contact the sampled household. A Spanish translation of the interview is available. Respondents are asked a variety of questions about their personal health behaviors and health experiences. Since 1994, the BRFSS questionnaire has included questions related to HIV/AIDS for respondents aged 18 to 49 years. These questions include perceived risk of getting an HIV infection; use of HIV testing; reasons for testing; if tested, the type of place where tested, receipt of posttest HIV counseling; attitudes about condoms; and attitudes about when to initiate HIV/AIDS education in schools. As of 2001, respondents have been asked about their perception of the importance of HIV testing.

Population: All noninstitutionalized adults, 18 years and older, who reside in a household with a telephone

Strengths: Data are population based; thus, estimates about testing attitudes and practices can be generalized to the adult population of a state. The sample is large (212,501 respondents in 2001). Information collected from the BRFSS survey may be useful for planning community-wide education programs.

Limitations: BRFSS data are self-reported; thus, the information may be subject to recall bias. Respondents are contacted by telephone survey; thus, the data are not representative of households without a telephone. In addition, BRFSS data are representative of the general noninstitutionalized adult population in an area, not just persons at highest risk for HIV/AIDS. The extent of HIV behavioral risk information collected by the BRFSS questionnaire is limited, and inferences can be made only at the state level.

Where available: Since 1994, all 50 states and the District of Columbia have conducted BRFSS. As of 2001, Guam, Puerto Rico, and the US Virgin Islands have participated in BRFSS**.**

Contact person(s): BRFSS coordinator for your state or territory. Additional background and information on whom to contact in your area is available at http://www.cdc.gov/brfss.

CARE Act Data Report (CADR)

Overview: The CADR is an annual data report form used to collect information from grantees and service providers funded under Titles I, II, III, or IV of the Ryan White CARE Act. The CADR is used to collect general information on provider and program characteristics, including the types of organizations providing services (such as ownership status), sources of revenue, expenditures, paid and volunteer staff. The form is also used to collect aggregate unduplicated demographic information (e.g., gender, race, age, HIV exposure category) on total numbers of clients served by each provider as well as health insurance coverage and utilization data about medical and support services.

Strengths: Only source of Ryan White CARE Act data that is available in all states and eligible metropolitan areas (EMAs). These data provide demographic information and service utilization data on all Ryan White CARE Act clients.

Limitations: Unless a Title I or Title II grantee has access to unduplicated data from an entire EMA or state, the data are duplicated across the EMA or the state. Because the CADR is a summary report by provider, it cannot generate demographic cross-tabulations.

Where available: All 50 states and all 51 EMAs

Contact person(s): Local Ryan White Title I or Title II grantee

CDC National HIV Behavioral Surveillance

Overview: This system will assess risk behaviors and trends in behaviors among persons older than 18 years of age who are at increased risk for HIV infection through injection drug use and sexual activity between men. In later cycles, these studies will be expanded to include high-risk heterosexual adults. In addition, access to, and the use of, HIV prevention programs, including HIV testing, will be assessed. A subset of these areas will conduct studies to estimate HIV prevalence and incidence in high-risk populations.

Population: Men who have sex with men and injection drug users

Strengths: Among men who have sex with men, venue-based systematic sampling will be used to obtain a representative sample. Among injection drug users, respondent-driven sampling will be piloted. Behavioral data will be available in the same metropolitan statistical areas over time, allowing analysis for trends.

Limitations: At-risk persons who do not attend venues are not sampled.

Where available: 15 metropolitan statistical areas where AIDS prevalence is highest: Atlanta, Baltimore, Boston, Chicago, Dallas, District of Columbia, Fort Lauderdale, Houston, Los Angeles, Miami, New York City, Newark, Philadelphia, San Francisco; and San Juan (Puerto Rico)

Contact person(s): Local study site coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

CDC Wide Ranging Online Data for Epidemiologic Reporting (WONDER)

Overview: The WONDER Web site may be useful for obtaining population estimates from the Bureau of the Census (through 1999) at the county level, by age and sex for a given race or by age and sex for Hispanics (all races combined).

Other data available through WONDER:

- Vital statistics mortality data from the National Center for Health Statistics (through 1999) at the county level, by age, sex, and race
- AIDS public use data
- Census state population projections
- Sexually transmitted disease morbidity

Strengths: The tabulations from CDC WONDER can be printed, and some of the data sets can be downloaded in an Excel-compatible format. They provide numbers and rates, but not percentage distributions (which you would have to calculate yourself). WONDER allows users to quickly query large data sets across several years in order to identify trends. The Compressed Mortality application allows users the option of customizing the calculation of age-adjusted rates, selecting the demographic attributes for the standard population.

Where available: http://wonder.cdc.gov

CDC/HRSA Demonstration Project (CDP)

Overview: The CDP, jointly funded by CDC and HRSA, consists of a network of 7 community demonstration projects. The purpose of CDP is to develop model programs that increase collaboration among public health departments, correctional facilities, and community-based organizations in order to enhance prevention and care services to incarcerated persons at high risk for HIV or living with HIV/AIDS. The primary objective is to expand and enhance HIV-related services to inmates in correctional facilities, especially these preparing for release or recently released from prisons, jails, or juvenile facilities.

Population: Individuals, specifically members of racial minority groups, in correctional settings

Strengths: CDP collects prevention and care services information from HIV-positive incarcerated and recently released persons as well as HIV-negative incarcerated and recently released persons who are engaging in high-risk behaviors. Data from CDP may be useful both to prevention and care planning groups interested in developing programs specifically designed to meet the needs of incarcerated or recently released populations.

Where available: California, Florida, Georgia, Illinois, Massachusetts, New Jersey, and New York

Contact person(s): Local study coordinators, HRSA, Special Projects of National Significance (SPNS) program; CDC, Division of HIV/AIDS Prevention

Collaborative Injection Drug Users Study (CIDUS)

Overview: A prospective cohort study that was established to describe the epidemiology of HIV and other blood-borne and sexually transmitted infections among young injection drug users (IDUs) who recently began injecting drugs and to describe factors in the initiation into injection drug use. Persons recruited to participate in CIDUS completed a baseline questionnaire on the following: frequency of injection drug use, needle sharing, number of sex partners, unprotected sex, history of sexually transmitted diseases, and exchange of money or drugs for sex. At baseline, blood was drawn from study participants and tested for HIV and hepatitis B and C viruses. Participants were followed up every 6 months for 1 year. At each follow-up, participants completed a questionnaire, and blood was drawn. The 3 phases of the study are CIDUS I (1994–1996), CIDUS II (1997–1998), and CIDUS III (Drug Users Intervention Trial).

Population: Persons aged 15–30 years who had injected any drug during the preceding 12 months

Strengths: CIDUS collected information on sexual behaviors and drug injection behaviors that put young persons who had recently begun to inject drugs at high risk of acquiring HIV infection or, if they were HIV infected, increased the risk of transmitting the virus. The longitudinal study design permitted estimation of the incidence of HIV, hepatitis B, and hepatitis C infections in a high-risk population and assessment of the behavioral risks associated with infection.

Limitations: CIDUS relied on self-reported data for behavioral information. Study results may not be representative of all young, recently initiated IDUs in the project area.

Where available: Baltimore, Chicago, Los Angeles, New Orleans, New York City (Harlem and Lower East Side)

Contact person(s): CDC, Division of HIV/AIDS Prevention, Epidemiology Branch

Context of HIV Infection Project (CHIP)

Overview: CHIP is a case-control study designed to investigate risk behaviors associated with recent HIV infection, to identify both HIV prevention opportunities and missed opportunities for HIV prevention and to ascertain the usefulness of the serological testing algorithm for recent HIV seroconversion (STARHS) as a method for identifying recent HIV infections. Persons classified as cases are those recently infected with HIV who are identified through health provider networks, public health clinics, hospitals, and HIV health providers; controls are noninfected persons recruited from similar locations. To achieve sufficient statistical power, 200 cases and 600 controls (1-to-3 ratio for cases and controls) will be recruited. STARHS will be used to analyze the test results of study participants, and quantitative and qualitative questionnaires will be used in interviewing participants. The quantitative questionnaire will collect information on sociodemographic characteristics, HIV testing history, risk behaviors (substance use and sexual behavior), perceived needs for HIV prevention, incarceration history, and history of other diagnoses. The qualitative questionnaire will capture information on the participant's experience with HIV testing, exposure to HIV prevention materials, discrimination, violence, perceived exposure to HIV or high-risk situations, history of life events, religiosity, mental health, intentional behaviors, coping skills, and HIV therapy. In addition, medical records of all participants will be abstracted.

Population: Persons aged ≥ 19 years with a recent HIV infection as defined by STARHS are classified as cases. Controls are persons aged ≥ 19 years who are HIV-negative and have been recruited from locations comparable to those where cases were recruited.

Strengths: CHIP offers information on behavioral risk factors, health status, perceived HIV risk, mental and psychosocial health, and life experiences among persons recently infected with HIV. Because the CHIP questionnaire includes questions about participants' prevention experiences, the effect that prevention messages have had on them, their HIV testing history, and their perceived need for services, CHIP data are valuable for prevention planners who are focusing services on persons at high risk and those who are already infected. The statistical power of the study will enable researchers to detect differences between cases and controls.

Limitations: CHIP interview data are self-reported, and the accuracy of the information cannot be validated with another source of information. The study is not population based; thus, inferences about findings from CHIP cannot be made to all persons recently infected with HIV. In addition, cases may be misclassified because of errors in analyzing test results when STARHS is applied, very recent infections may remain undetected if the antibody level is not detectable by the less sensitive test used with STARHS, or an older infection may inadvertently be classified as a recent infection.

Where available: Chicago, Dallas, Los Angeles; and North Carolina

Contact person(s): Local CHIP principal investigators; CDC, Division of HIV/AIDS Prevention, Prevention Research Branch

Drug Abuse Warning Network (DAWN)

Overview: DAWN is a national data system that collects information on drug-related deaths from participating medical examiner offices and information on drug-related visits to hospital emergency departments from a nationally representative sample of short-stay general hospitals throughout the coterminous United States. Emergency department estimates are produced for 21 large metropolitan areas and for the nation. Drug-related death data are produced for more than 40 metropolitan areas.

DAWN was established to provide national, state, and local areas with data for program planning and policy; to identify substances associated with drug abuse deaths; to monitor drug abuse patterns and trends and detect new drugs of abuse; and assess adverse health outcomes associated with drug abuse.

Population: Persons who died at 6–97 years of age, whose death was drug induced or drug related, and who had used the substance because of dependence, to commit suicide, or to achieve psychic effects

Strengths: DAWN provides ongoing data on the patterns of drug-induced and drug-related deaths from many areas of the United States. Standardized data collection and data management procedures are used to ensure the accuracy of DAWN data. Because of concerns about the accuracy of DAWN data, the methods were revised, and the protocol modifications were delivered in 2001.

Limitations: Participation in DAWN is voluntary; thus, counts of deaths do not represent the entire service area if participation is not universal. DAWN collects information only about drug abuse episodes that have resulted in a death and deaths that have been identified as drug induced or drug related. Finally, because DAWN relies on death investigation case files for reporting, the drugs may be underreported (if not reported), or the drug information may not be specific (if drug name is recorded differently).

Where available: Atlanta, Baltimore, Boston, Buffalo, Chicago, Dallas, Denver, Detroit, District of Columbia, Los Angeles, Miami, Minneapolis, Newark, New Orleans, New York City, Philadelphia, Phoenix, San Diego, San Francisco, Seattle, St. Louis.

Available at http://www.samhsa.gov

Enhanced Perinatal Surveillance (EPS)

Overview: The project was established to monitor the implementation and effect of the Public Health Service recommendations for preventing perinatal HIV transmission on pediatric HIV/AIDS trends, provide a data collection system that enables states to respond to selected requirements of the Ryan White CARE Act, and assist with timely evaluation of perinatal prevention efforts. The project collects data by the use of the HIV/AIDS case report form and collects additional information from supplemental records by the use of a medical record abstraction form. The enhanced surveillance methods used to identify HIV-infected mothers and their perinatally exposed children include matching the birth registry to the HIV/AIDS surveillance registry and the linking of mother-infant pairs. Information on HIV-infected mothers and their perinatally exposed children is abstracted from multiple sources: the maternal HIV record, prenatal care records, labor and delivery records, birth records, pediatric HIV records, birth and death certificates, and laboratory reports. The data that are collected include maternal and prenatal care, mother's HIV test history, prenatal and neonatal antiretroviral therapy, other interventions to prevent transmission, receipt of prophylaxis and treatment of the infant, appropriate follow-up care of the mother and child, and other interventions relevant to the evaluation of recommended public health actions to prevent perinatal HIV transmission. Infants identified through enhanced surveillance are followed up every 6 months until their HIV infection status is determined; if they meet the case definition, they are followed up to determine their vital status.

Population: All HIV-exposed infants born during 1999 or later years and their HIV-positive mothers

Strengths: The project is population based in most areas. In the facility-based project areas, the selected facilities were those where most of the births to HIV-positive women take place. Data from population-based areas are complete. In a study that included data from 4 population-based project areas (Louisiana, Michigan, New Jersey, and South Carolina), 90% ascertainment of infants born to HIV-infected women was found when data were compared with data from the Survey of Childbearing Women. The project collects information on HIV-exposed infants every 6 months until HIV infection is diagnosed. Study sites are able to characterize trends in perinatal HIV/AIDS, monitor the implementation and effect of perinatal prevention guidelines, assess resource needs, assess missed prevention opportunities, and monitor the effect of prevention programs.

Limitations: Data for the project rely upon the ability to identify an HIV-exposed infant and locate the supplemental medical charts needed to complete the abstraction form. The completeness of data elements relies upon the level of documentation in each of these medical records. Because the Survey of Childbearing Women was discontinued in 1994, no population-based seroprevalence data are available to estimate the completeness of ascertainment of infants born to HIV-infected mothers for birth cohort years 1999 and later.

Where available: Chicago, District of Columbia, Houston, Los Angeles, New York City, Philadelphia; Alabama, California, Connecticut, Florida, Louisiana, Maryland, Michigan, Mississippi, North Carolina, New Jersey, New York, Ohio, Pennsylvania, South Carolina, Tennessee, Texas, Virginia; and Puerto Rico

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or EPS site coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

Expanded HIV Risk Assessment Project (EHRAP)

Overview: EHRAP was designed to evaluate the ability of HIV/AIDS reporting areas to collect indicators of behavioral risk factors from existing records, compare indicators of behavioral risks across HIV/AIDS Reporting System (HARS) risk groups, evaluate the best source of data for indicators of behavioral risks and current definitions, and develop standard definitions of high-risk heterosexual behaviors. EHRAP specifically focuses on persons who are reported in HARS as men who have sex with men (MSM), injection drug users (IDUs), persons with heterosexually acquired infection, or persons with no identified risk. CDC provides each project area with a random sample of HIV cases reported during a 12-month period, stratified by gender and risk. Risk information is extracted from numerous medical records (e.g., case report form, sexually transmitted disease records, tuberculosis records, inpatient and outpatient records, counseling and testing records, hepatitis registry, autopsy records) for each case onto a standardized abstraction form.

Population: All persons in an HIV reporting area who are reported as having HIV infection

Strengths: Population-based estimates of behavioral risk factors for persons reported as HIV infected are available because EHRAP reviews the behavioral information in records from numerous sources. EHRAP informs areas of data sources with the most complete behavioral risk information about persons reported as having a case of HIV infection.

Limitations: Risk information from different record sources may be difficult to locate, and risk information may be incomplete. The project relies on the documentation of risk by health care providers.

Where available: Mississippi and South Carolina conducted a pilot study of EHRAP and extracted data from 1999 HARS information. FY 2000 funds were awarded to Alabama and Virginia, and FY 2001 funds were awarded to New Jersey and Houston to conduct EHRAP.

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

Gonococcal Isolate Surveillance Project (GISP)

Overview: Established in 1986 to monitor trends in antimicrobial susceptibilities of strains of *N. gonorrhea* in the United States in order to establish a rational basis for the selection of gonococcal therapies. GISP is a collaborative project among selected sexually transmitted disease (STD) clinics in 25 cities, regional laboratories, and CDC. Each month, *N. gonorrhea* isolates are collected from the first 25 men with urethral gonorrhea at 25 STD clinics in the United States. Patient demographics, sexual orientation, history of gonorrhea, reason for clinic visit, and gonorrhea treatment received are abstracted from the medical chart. At regional laboratories, the susceptibilities of these isolates to a panel of antimicrobials are determined by agar dilution and minimum inhibitory concentration techniques according to criteria recommended by the National Committee for Clinical Laboratory Standards.

Population: The first 25 men with urethral gonorrhea each month at participating STD clinics

Strengths: GISP offers ongoing data on the level of antimicrobial susceptibilities among men who seek care at public STD clinics and who have urethral discharge. Despite the convenience sampling used by GISP, the data are useful for assessing trends in gonorrhea among men who have sex with men and the level of repeat infections.

Limitations: GISP uses a convenience sample of men at public STD clinics to obtain patient isolates. Thus, inferences concerning the general population of men with urethral gonorrhea cannot be drawn. Depending upon the level of gonorrhea morbidity, the 25 men may represent all or a fraction of the patients seen in the public clinic. In addition, men who seek care from STD public clinics may not be representative of men who seek care elsewhere.

Where available: Albuquerque, Anchorage, Atlanta, Baltimore, Birmingham, Chicago, Cincinnati, Cleveland, Dallas, Denver, Fort Bragg (North Carolina), Honolulu, Kansas City (Missouri), Long Beach, Miami, Minneapolis, New Orleans, Philadelphia, Phoenix, Portland (Oregon), San Diego, San Francisco, Seattle, and St. Louis; and Orange County (California).

Contact person(s): State or local STD program manager; CDC, Division of STD Prevention, Epidemiology and Surveillance Branch

Hepatitis C Surveillance

Overview: Surveillance for hepatitis C includes reporting of acute hepatitis C and hepatitis C virus (HCV) infection (past or present) to CDC's National Notifiable Diseases Surveillance System. The purpose of hepatitis C surveillance is to identify new cases, determine risk factors for infection, identify infected persons who can be counseled and referred for medical follow-up, and evaluate prevention efforts.

Population: All persons whose reported cases of acute hepatitis C, or HCV, infection meet the case definitions approved by the Council of State and Territorial Epidemiologists

Strengths: Surveillance for acute hepatitis C provides information needed to determine incidence trends, transmission patterns, and persons at highest risk for infection. Persons can be characterized by gender, race/ethnicity, age, and risk behavior for HCV. Surveillance for HCV infection can be used to provide infected persons with information on how to reduce both their risk of transmitting HCV to others and their risk for further liver injury and to provide them with referral for medical evaluation. It also can be used to evaluate prevention efforts by providing estimates of the proportion and characteristics of persons with HCV infection.

Limitations: Hepatitis C surveillance data should be interpreted cautiously because many reporting areas do not have the resources required for case investigations to determine whether a laboratory report represents acute infection, chronic infection, resolved infection, repeated testing of a person previously reported, or a false-positive result.

Where available: All 50 states and US territories

Contact person(s): State or local hepatitis C (if available) or hepatitis B coordinator; CDC, Division of Viral Hepatitis

References:

CDC. Recommendations for prevention and control of hepatitis C virus (HCV) infection and HCV-related chronic disease. *MMWR* 1998;47(No. RR-19):1–39.

CDC. *Guidelines for Viral Hepatitis Surveillance and Case Management*. Atlanta: CDC; 2002. Available at: http://www.cdc.gov/ncidod/diseases/hepatitis/resource/pubs.htm.

HIV Counseling and Testing System (CTS)

Overview: All states, territories, and selected cities receive funding to support HIV counseling, testing, and referral programs as part of HIV prevention cooperative agreements with CDC. To monitor these programs, the CTS collects information to quantify and characterize services delivered at CDC-funded sites. Data include information on demographics and on counseling and testing (testing history, test result). Personal identifying information is not collected. Several locations collect client-based counseling and testing data by using a nonidentifying client code to link the tests of a person who repeatedly seeks HIV services.

Population: All clients who receive confidential or anonymous HIV counseling and testing services at a site funded through a CDC cooperative agreement

Strengths: Standardized data on clients who are tested for HIV are available at the local level. Data may offer insights into HIV infection rates for a high-risk population in that area. CTS testing data may highlight the effect of a prevention program upon the populations being targeted and the effect of prevention programs upon routine HIV/AIDS surveillance.

Limitations: In most areas, the CTS collects test-based, rather than person-based, data and collects information only from persons who seek counseling and testing services at a CDC-funded site. However, areas using a system with a nonidentifying client code can estimate client-based data. Population estimation of HIV seroprevalence is not possible at sites where CTS data are test based. However, at sites where client-based estimates are used, HIV positivity may be used to estimate HIV prevalence for that population. In test-based systems, because a person can repeatedly seek testing, it is not possible to distinguish persons who have been tested multiple times; however, an estimate of the number of persons may be made by using the self-report of a previous HIV-positive test result on the client abstract form. Because the CTS gathers data on prevention activities, changes may reflect changes in program priorities rather than testing patterns of individuals.

Where available: Test-based counseling and testing projects are conducted in 50 states, 6 city health departments, and US territories. Client-based systems are available in California, Colorado, Florida, Louisiana, Maryland, Michigan, Texas; and Houston, San Francisco, and Seattle.

Contact person(s): State, territorial, or city health department HIV program manager or AIDS director

Reference: Report of 1997–1998 data available at http://www.cdc.gov/hiv/pubs/cts98.pdf

HIV Epidemiology Research Study (HERS)

Overview: A cohort study of HIV-infected women and women who were not infected but who reported injection drug use or sexual behaviors that placed them at high risk for HIV infection. Women aged 16–55 years were enrolled at participating sites, interviewed, and given a physical examination every 6 months. The HERS interview collected information on medical history, medications, reproductive history, contraceptive use, drug use, health care utilization, pyschosocial health, functional abilities, life events, sexual behavior, social behavior, and HIV-related beliefs. The physical exam focused on weight, skin, breast, oral, abdominal, and pelvic findings. Blood, oral, vaginal, cervical, and rectal samples were obtained for a variety of laboratory tests. In addition, medical records were abstracted for all hospitalizations and AIDS-related outpatient visits.

Population: Women aged 16–55 years who were HIV infected or who reported injection drug use or high-risk sexual behavior were eligible for enrollment.

Strengths: HERS collected detailed information on a cohort of HIV-infected women and noninfected women who were at high risk for HIV. Data from the study can be used to measure the effects of HIV infection on the physical, emotional, and social health of women and identify intervention components that may improve the quality and duration of the lives of HIV-infected women.

Limitations: HERS data are not representative of all HIV-infected women in a service area because enrollment took place at a participating study site. Loss to follow-up may have compromised the precision of study findings.

Where available: Baltimore, Detroit, Providence (Rhode Island), and New York City

Contact person(s): CDC, Division of HIV/AIDS Prevention, Epidemiology Branch

HIV Incidence Surveillance

Overview: The goals of HIV incidence surveillance are to (a) collect and test diagnostic blood specimens from all persons with newly diagnosed HIV infections who have been reported to HIV surveillance, (b) collect the HIV testing history needed for the statistical estimates of incidence, and (c) link incidence test data and testing history data in order to make population-based estimates of HIV incidence. The serologic testing method that will be used to distinguish between recent and long-standing HIV infection is the serologic testing algorithm for recent HIV seroconversion (STARHS).

Population: All persons with newly reported HIV infections who do not have advanced disease, such as AIDS, and who are not taking antiretroviral medications for HIV prevention or hepatitis B

Strengths: The comparison of incident and prevalent infections will allow monitoring of emerging trends in the epidemic, targeting and evaluation of prevention programs, and population-based estimation of HIV incidence.

Limitations: Currently, a less sensitive HIV enzyme immunoassay, the serologic test that will be used to detect newly diagnosed HIV infections, is not licensed by the Food and Drug Administration; thus, consent is required if it will be linked to personal identifiers. For population-based estimates of incidence, the testing history must also be obtained from the persons tested. Estimates of the number of persons who are HIV-positive and do not know their status must still be derived from information on persons who are tested. STARHS is currently available only for blood tests. However, oral testing is often used in interventions that target populations thought to be at high risk because of their behavior; therefore, high-risk persons may not be tested with the less sensitive HIV enzyme immunoassay. Although STARHS cannot be applied to analyze the results of their tests, statistical modeling can be used to account for these persons in estimates of incidence.

Where available: Pilot sites funded 2001—Alabama, Colorado, Michigan, New Jersey; and Seattle. Funded 2002—Arizona, Florida, Indiana, Louisiana, Maryland, Massachusetts, Mississippi, Missouri, New York State, Ohio, Oklahoma, South Carolina, Tennessee, Texas, Virginia; Chicago, Houston, New York City; and Puerto Rico

Contact person(s): Local HIV incidence surveillance site coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

HIV Prevalence and Incidence and Associated Risk Behaviors among Incarcerated Illicit Drug Users

Overview: Survey to assess HIV prevalence, trends, and related risk behaviors and estimates of HIV incidence among illicit drug users booked into a correctional facility. Systematically sampled persons booked into the correctional facility and determined, during a brief interview, to be IDUs are referred for HIV counseling and testing (C&T) according to standard health department and C&T protocols for correctional facilities. The persons who are referred and all other IDUs who seek C&T in the health clinic are invited to participate in the survey by completing a brief supplemental standardized interview about drug use, travel patterns, and related risk behaviors.

Population: All IDUs referred for HIV C&T and other IDUs who seek HIV C&T in the health clinic of the correctional facility

Strengths: This observational study is a cross-sectional face-to-face interview survey of risk behaviors among IDUs booked into correctional facilities. Interview data are linked to HIV antibody test results obtained through standard HIV C&T according to local protocols. A non-name identifier, which protects the confidentiality of study enrollees, allows linkages between data from participants who are repeatedly booked and re-enrolled in the survey, so that HIV incidence and changes in drug-use behaviors can be monitored and assessed.

Limitations: Volunteer bias may affect results. Potential participants intercepted in the booking area may be hesitant to reveal information about drug-use history because of fear of self-incrimination.

Where available: Chicago, Philadelphia, Seattle; and California, Colorado, and New York State

Contact person(s): Local study site coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

HIV Seroprevalence Surveys

Overview: From 1988 through 1999, CDC monitored HIV seroprevalence through a national serosurveillance system. As part of this system, anonymous unlinked surveys (AUSs) were designed to estimate the prevalence of HIV infection among selected populations, such as patients attending sexually transmitted disease (STD) clinics and persons entering drug treatment centers. Residual sera, originally collected for other purposes and which otherwise would have been discarded, were tested for HIV after all personal identifiers were permanently removed from the specimens. All sites that conducted AUSs offered voluntary counseling and testing, allowing anyone who participated in the surveys the opportunity to learn his or her HIV status. In addition to AUSs, CDC monitored HIV prevalence in 3 other populations in which HIV testing is routinely performed. Data were provided by the US Department of Labor (Job Corps entrants), the US Department of Defense (military applicants), and the American Red Cross (blood donors).

Populations: Populations included in the AUS component of the surveillance system through 1997 included MSM and high-risk heterosexuals at STD clinics, IDUs entering drug treatment programs, and clients of adolescent medicine clinics. Earlier surveys included the Survey of Childbearing Women and sentinel hospital surveys (emergency department and outpatient services).

Routine HIV screening results are provided for youth (16–21 years of age) entering the Job Corps, military applicants (all persons applying for active duty or reserve military service, the service academies, or ROTC), and American Red Cross first-time blood donors.

Strengths: AUSs allow estimates of HIV infection without the participation bias that results from a person's decision to seek or not seek HIV testing. Because testing behavior may differ considerably in racial and ethnic, socioeconomic, and behavioral risk groups, AUSs are especially important in providing data that are representative of specific subgroups of the population. Demographic and risk information, linked to the residual specimens through a unique study number, were abstracted from routine medical records and intake forms. Data from these surveys have been instrumental in describing populations with the greatest need for preventive services and future care. Results from the Survey of Childbearing Women (discontinued in 1995) could be used to infer the magnitude of HIV in the general childbearing population.

Results from routine HIV screening of military applicants, Job Corps entrants, and first-time blood donors provide important additional information on the epidemic. Each of these geographically diverse groups is composed of persons with particular demographic and socioeconomic characteristics.

Limitations: Persons attending the participating AUS clinics may not be representative of the selected population. For example, persons attending STD clinics are likely at higher risk for HIV than are MSM or heterosexual persons who do not attend the clinics. Also, because of the nonrandom selection of venues, results cannot be generalized to persons who do not attend these venues. However, trend data are less subject to bias within a particular group.

HIV prevalence among Job Corps entrants may not be indicative of prevalence among other economically and socially disadvantaged youth because applicants with current drug addictions or serious medical or behavioral problems and those on supervised probation are not accepted into the program. Applicants who are HIV-positive or who use drugs are not accepted into the military; therefore, self-selection bias among persons at high risk is likely.

Where available: CDC funded AUSs through 1999. In 1997, 16 metropolitan areas conducted surveys at STD clinics, 12 conducted surveys in drug treatment centers, and 4 conducted surveys in adolescent medicine centers. Some areas continue to support local AUSs. Since 1987, all Job Corps entrants have been tested, and since 1985, all military applicants have been screened through serosurveys.

Contact person(s): State or local health department, HIV/AIDS seroprevalence coordinator

References

CDC. *HIV Prevalence Trends in Selected Populations in the United States: Results from National Serosurveillance, 1993–1997*. Atlanta: CDC; 2001:1–51. Also available at: http://www.cdc.gov/hiv/pubs/hivprevalence/hivprevalence.htm.

CDC. *National HIV Prevalence Surveys: 1997 Summary.* Atlanta: CDC; 1998:1–25. Also available at: http://www.cdc.gov/hiv/pubs/hivsero.htm.

Copies of both documents are available from the National Prevention Information Network (NPIN), 800-458-5231.

HIV Testing Survey (HITS)

Overview: Established to monitor HIV testing patterns by assessing reasons for seeking or avoiding testing, examining knowledge of state policies for HIV surveillance, and assessing HIV testing patterns among persons at high risk for HIV infection. In addition, HITS collects behavioral risk information from persons at high risk for infection and can be used to evaluate the representativeness of HIV surveillance data.

HITS is an anonymous cross-sectional survey of populations at high risk for HIV infection. The core populations are men who have sex with men (MSM), injection drug users (IDUs), and high-risk heterosexual adults. Areas have the option of sampling a population of local interest. To recruit participants, the study is conducted in several cities in a state (generally) at 3 venues: gay bars, street locations in areas of heavy drug use, and sexually transmitted disease (STD) clinics. At a minimum, 100 persons in each population group are interviewed; thus, states have a minimum sample of 300 persons. Persons who are not tested or who self-report as HIV-positive are interviewed. Persons who are HIV-negative may be interviewed as well.

Native American HITS: A special project of HITS was conducted in 2000 in Portland, Oregon. HITS methods were used for this project; however, focus groups of Native Americans were used to modify the general HITS questionnaire so that the questionnaire content was culturally appropriate.

In 2002, HITS was conducted on 3 reservations in Idaho, Oregon, and Washington. An additional Native American project was conducted in Houston, Texas.

Population: Regardless of the venue, persons who are at least 18 years of age, able to give informed consent, and have been a resident of the state for at least 1 year are eligible for a HITS interview. In addition, the following behavioral criteria apply for each risk group: men at MSM venues are eligible if they have had sex with a man within the past 12 months; IDUs must have injected within the past 12 months; and high-risk heterosexual adults who seek care at an STD clinic are eligible if they are at the clinic because of a suspected STD, have not been treated during the past 90 days, are not at the clinic because of referral or follow-up, and have not had homosexual sex within the past 12 months.

Native American HITS: Native Americans living in Portland, Oregon, were sampled at venues identified through formative research. Participants were recruited by the use of social network sampling (participants are asked to recommend other persons like themselves who could be recruited to participate).

Strengths: The survey collects valuable public health information about HIV testing attitudes, history and behaviors, as well as knowledge about testing, and risk behaviors from population groups at high risk for HIV.

Limitations: HITS is a cross-sectional survey and relies on a convenience sample for participation. Information collected is self-reported and may be subject to recall bias. Further, HITS data may not represent the entire high-risk population of an area.

Where available: HITS-I (1996)—Arizona, Colorado, Maryland, Mississippi, Missouri, New Mexico, North Carolina, Oregon, Texas. HITS-II (1998)—Arizona, Colorado, Mississippi, Missouri, New Mexico, Oregon, Texas. HITS-2000—Florida, Illinois, Kansas, Nevada, New York State, Texas, Washington; New York City. HITS-2001—California, Louisiana, Vermont; Philadelphia. HITS-2002—Florida, Illinois, Michigan, New Jersey, Washington; Los Angeles County; Houston, New York City, Philadelphia. Asian/Pacific Islander HITS (2002)—Seattle/King County (Washington). Migrant Farm Worker HITS (2002)—California. Native American HITS 2002—Houston and Portland (Oregon). Transgender HITS (2002)—San Francisco.

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or HITS site coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

Hospital Outpatient Study (HOPS)

Overview: HOPS is a longitudinal cohort study established in 1993 to describe and monitor trends in demographics, symptoms, diagnoses, and treatments in a population of HIV-infected outpatients in clinics across the United States. HOPS abstracts clinical, immunologic, and virologic information through periodic reviews of medical records to enhance the understanding of prolonged survival, the metabolic problems associated with highly active antiretroviral therapy (HAART), adherence to HAART, and the occurrence of comorbidities. At baseline, HOPS collects demographic information and information on risk behaviors such as smoking, alcohol consumption, and drug use.

Population: HIV-positive outpatients seeking care at HIV clinics

Strengths: Because HOPS uses a longitudinal study design and collects extensive clinical information and laboratory clinical markers, the data illustrate patterns of clinical outcomes over time, particularly among long-term survivors of HIV disease and patients who are taking HAART. In addition, HOPS data have been used to document adverse outcomes from HAART.

Limitations: HOPS is not a population-based study of HIV-infected persons. Thus, information from this study may not be representative of all HIV-infected patients in a service area. The quality of the data depends upon the completeness of documentation in the medical chart and the ability of abstractors to locate the chart.

Where available: Chicago, Denver, District of Columbia, New York City, Oakland (California), Philadelphia, and Tampa

Contact person(s): Local study investigators; CDC, Division of HIV/AIDS Prevention, Epidemiology Branch

Impact of Ryan White CARE Act Title I Funding on HIV Services Utilization and Health Outcomes in Newly Eligible Metropolitan Areas

Overview: The objective of the Ryan White Evaluation Project is to evaluate the impact of Ryan White Title I funding on the availability, accessibility, quality, and continuity of HIV care in 2 communities newly designated Ryan White Title I eligible metropolitan areas (EMAs) as of March 1, 1999. This project will determine whether Ryan White funding improves adherence to treatment guidelines for HIV.

The project is divided into 2 periods (Phase I and II) and involves a 1-year medical chart review of eligible HIV-infected patients. Phase I is defined as the period before Ryan White funding and includes patients whose HIV diagnosis was made during September 1996 through November 1997. Medical chart review of patients included in Phase I includes the period March 1998 through February 1999. Phase II refers to the period after Ryan White funding and includes patients whose diagnosis was made during April 1998 through November 1999. Phase II patient chart review took place during March 2000 through February 2001. The data include demographic characteristics, vital status, insurance coverage, AIDS-defining conditions, laboratory data, antiretroviral and prophylactic therapies**,** immunizations, access to health care, mental health, substance abuse, dental care, and case management.

Population: Persons ≥ 13 years of age with a diagnosis of HIV infection

Strengths: The evaluation study collects information on HIV care among populations of interest to Ryan White EMAs (e.g., persons who are homeless, abuse substances, or are mentally ill). The project examines information documented by health care providers to determine whether HIV-infected patients who are known to surveillance programs are receiving standards of care for HIV. One can infer that persons with no identified source of health care have not sought care.

Limitations: The cross-sectional design of the study does not allow the comparison of changes in the quality of health care delivered to HIV-infected patients over time as a result of Ryan White funding. The quality of the data depends upon the completeness of chart documentation by providers and the ability of staff at the study sites to locate the medical records. Consequently, the study may underestimate the amount of HIV care received. As is true of any project that uses surveillance to identify persons, the data will not reflect persons whose infection has not been reported to surveillance programs.

Where available: Las Vegas, and Norfolk (Virginia), and Ryan White EMAs

Contact person(s): CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch; HRSA, HIV/AIDS Bureau, Office of Science and Epidemiology

MSM Interview Project

Overview: A one-time study focused on men who have sex with men (MSM) who have a recent diagnosis of HIV infection. The purpose of the study is to assess the usefulness of the serological testing algorithm for recent HIV seroconversion (STAHRS) in identifying recent HIV infection among MSM who have a new diagnosis and who have been reported with HIV infection through the national HIV/AIDS Reporting System and to characterize behaviors, including risky sexual behaviors during the likely time of infection, HIV testing behaviors, and health-care-seeking behaviors. In addition, the study will determine the prevalence of sexually transmitted diseases (STDs) through self-report, matching of HIV and STD registries, and medical record review. HIV/AIDS surveillance data and laboratory and demographic criteria will be used to identify MSM who may be recently infected with HIV: (a) recently documented HIV seroconversion (within 18 months), (b) younger age (18–29 years), (c) higher CD4 count or percentage (>700 or >36%). MSM meeting any 1 of these criteria are eligible for the study. After informed consent is obtained, eligible participants will be interviewed, and attempts will be made to retrieve the stored HIV diagnostic blood specimen for testing.

Population: All HIV-infected men newly reported to HARS in Alabama and New York City who have had sex with men and who meet any 1 of the 3 criteria for recent infection. Approximately 100 eligible men per site will be enrolled.

Strengths: The MSM Interview Project will allow sites to use STAHRS to identify recently infected MSM (within 180 days of infection). The project makes it possible to compare the behaviors of those who have been infected most recently (past 6 months) and the behaviors of those who have been infected longer.

Limitations: The interview data are self-reported and therefore subject to recall bias. Data from this project may not represent all recently infected MSM because of either refusal to participate or the lack of availability of the diagnostic blood specimen. In addition, there may not be a sufficient number of MSM from the Alabama site.

Where available: New York City and Alabama

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or MSM interview project site coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

MSM Prevalence Monitoring Project

Overview: Created to monitor trends in STDs, TB, and HIV risk behaviors among men who have sex with men (MSM). The project aims to improve data collection, data management, and reporting of sexually transmitted diseases (STDs), tuberculosis (TB), and HIV risk behaviors among MSM. Approximately 90% of the project data have been collected at STD clinics; data have also been collected at bathhouses, HIV care clinics, and HIV counseling and testing sites.

Population: MSM with a diagnosis of an STD, TB, or HIV infection at a public STD clinic or venue selected by the project as a place frequented by MSM

Strengths: Provides project sites with additional resources to conduct active surveillance of STDs, TB, and HIV risk behaviors among MSM. This surveillance enables projects to monitor the prevalence of infections and coinfections among MSM in order to evaluate the effectiveness of current programs and to anticipate prevention needs.

Limitations: Data, currently collected mostly in STD clinics, may not reflect STDs in the general population of MSM.

Where available: 1999—Chicago, District of Columbia, Long Beach (California), Philadelphia; 2000—Boston, Denver, Houston, San Francisco, Seattle; 2001—New York City

Contact person(s): Local or state STD program manager; CDC, Division of STD Prevention, Epidemiology and Surveillance Branch

National Death Index (NDI)

Overview: This national database of state death record information cannot be accessed directly; however, NCHS does perform searches for health investigators (for a fee) to determine whether their study subjects' records are potential matches to records in the NDI. If the match is accepted by the investigator as a true match, the database provides the following information: the fact that the person has died, the date of death, the US state of death, and the death certificate number. For an additional fee, an enhanced service, named NDI-Plus, may be used, which additionally provides the International Classification of Diseases (ICD-9 or ICD-10) codes for the causes of death (e.g., underlying cause, multiple causes).

Population: Deaths since 1979 in the entire United States, Puerto Rico, and the US Virgin Islands

Strengths: NDI is a nationwide, population-based index in which the causes of death are properly classified according to the rules of the NCHS and the ICD-9 or ICD-10.

Limitations: This database cannot be searched to look for deaths of, or with, particular causes of death, such as HIV infection. It can be searched only for potential matches with the investigator's records, which the investigator must identify by variables such as name, date of birth, and Social Security number. If information on such identifiers is missing, it may be impossible to know for certain whether a partial match is a true match. The identifying variables of the potential matches will not be revealed directly—only the extent to which they match or do not match. The data are available from 1979 onward. The most recent data are usually added to the NDI 15 months after the end of the calendar year. Use of this service can be expensive, particularly if NDI-Plus is used to find the causes of death. Before investigators use either the routine NDI or the NDI-Plus services, they should first search for matches in the death-certificate database of the Office of Vital Statistics of their state or local health department. Records, for which good matches are found, need not be submitted for a search for matches in the NDI database.

Where available: National Center for Health Statistics

Contact person(s):
National Death Index
National Center for Health Statistics
Division of Vital Statistics
6525 Belcrest Road, Room 820
Hyattsville, MD 20782
Phone: 301-458-4101
fax: 301-458-4034

National Household Survey of Drug Abuse (NHSDA)

Overview: The NHSDA is a source of statistical information on the use of illicit drugs by the US civilian population ≥ 12 years of age. The survey collects data by administering questionnaires to a representative sample of the population through face-to-face computer-assisted interviewing at the respondent's residence. The information includes use of cocaine, receipt of treatment for illicit drugs, and need for treatment for illicit drug use during the past year; use of alcohol, tobacco, or marijuana during the past month; and perceived risk for binge drinking, marijuana use, or smoking during the past month.

The NHSDA uses a 50-state sampling design; for the 8 states with the largest populations, the sampling design provides a sample large enough to support direct state estimates. For the 42 remaining states and the District of Columbia, small-area estimation techniques are used to calculate state estimates. Youths and young adults are oversampled so that each state's sample is approximately equally distributed among 3 age groups: 12–17 years, 18–25 years, and ≥ 26 years.

Population: Noninstitutionalized, civilian US population aged ≥ 12 years

Strengths: National standardized survey of drug use behaviors of the general population. To increase the level of honest reporting, information since 1999 has been collected by using a combination of computer-assisted interviewing methods to provide respondents with highly private and confidential means of responding to questions about substance use and other sensitive behaviors.

Limitations: Direct state-level estimates are available for only 8 states; other states must rely on statistical estimates. NHSDA estimates represent behaviors in the general population; thus, the survey may underestimate the level of substance use in the population at highest risk for HIV. Further, data from the NHSDA are self-reported and thus subject to recall bias and underreporting of the level of a sensitive behavior.

Where available: Annual nationwide survey conducted by the Substance Abuse and Mental Health Services Administration (SAMHSA)

Reference: http://www.samhsa.gov

National Neighborhood Indicators Project (NNIP)

Overview: The NNIP is a collaborative effort by the Urban Institute and local partners to further the development and use of neighborhood-level information systems in local policymaking and community building.

All local partners have built locally self-sustaining information systems with integrated and recurrently updated information on neighborhood conditions in their cities. These systems facilitate the direct use of information by local government and community leaders to build the capacities of distressed urban neighborhoods. Current NNIP activities are sponsored by the Annie E. Casey Foundation and the Rockefeller Foundation.

Strengths: NNIP partners maintain a large warehouse of local administrative data that include vital statistics, law enforcement, taxes, education, public housing, and public assistance information. Much of the information is geo coded. NNIP offers materials on how to access and analyze the warehoused data.

Limitations: NNIP data come primarily from administrative data systems. The accuracy of nonessential information that is not required for program eligibility may be less accurate than other sources of data (e.g., education attainment in public assistance records). Reporting bias may affect specific records (e.g., crime—many crimes are underreported, and reporting practices may differ by jurisdiction).

Where available: Atlanta, Baltimore, Boston, Cleveland, Denver, District of Columbia, Indianapolis, Miami, Milwaukee, Oakland (California), Philadelphia, and Providence (Rhode Island)

Reference: http://www.urban.org/nnip

Outcome Assessment through Systems of Integrated Surveillance (OASIS)

Overview: Promotes the integrated use and interpretation of state and local surveillance data. Depending on the jurisdiction, these may include surveillance data for sexually transmitted disease (STD), HIV/AIDS, and tuberculosis; vital statistics; behavioral surveys; and other enhanced surveillance. OASIS includes an examination of comorbidity through geographic mapping of disease and through registry matching of surveillance data.

Population: Persons reported to a surveillance system

Strengths: Through an examination of multiple surveillance data sources, OASIS may provide a description of morbidity and risk in the community, including geographic patterns of morbidity and comorbidity.

Limitations: Analyses of data from multiple sources differ by jurisdiction. Analyses are limited by limitations inherent in each surveillance system.

Where available: California, Indiana, Massachusetts, Michigan, Missouri, New York State, North Carolina, Ohio, Oregon, Texas, Virginia, Washington; and Baltimore, New York City, San Francisco

Contact person(s): State or city health department or state or city STD surveillance staff; CDC, Division of STD Prevention, Epidemiology and Surveillance Branch

Pediatric Spectrum of Disease (PSD)

Overview: The PSD study is an active surveillance project designed to increase understanding of the pediatric HIV epidemic by providing epidemiologic data on the characteristics, magnitude, pattern, and spread of HIV exposure or disease in children; follow trends in disease characteristics, patterns of recognition, and treatment; and follow response to national guidelines for prevention and treatment. All HIV-infected children and children born to HIV-infected mothers are eligible for enrollment and are ascertained by participating health care providers. Data are abstracted from medical records every 6 months.

Population: All HIV-infected children and children born to HIV-infected mothers

Strengths: PSD is a population-based source of data describing the spectrum of HIV disease documented in the medical charts of children infected with HIV or born to an HIV-infected mother. The project has been conducted since 1988, and more than 14,600 children have been enrolled. Data from PSD have been used to design and revise the pediatric AIDS definition, estimate the prevalence of HIV disease in US children, establish guidelines for prophylaxis for opportunistic infections, and understand the natural history of HIV infection in children.

Limitations: PSD relies upon both the amount of morbidity information available in the medical chart, which may not be complete, and upon the thoroughness of diagnostic testing and recording. Loss to follow-up may occur.

Where available: District of Columbia, Los Angeles, New York City, San Francisco; Massachusetts, North Carolina, Texas; and Puerto Rico

Contact person(s): PSD study site coordinator; CDC, Division of HIV/AIDS Prevention, Epidemiology Branch

Pregnancy Risk Assessment Monitoring System (PRAMS)

Overview: A population-based survey that collects perinatal information, including information on prenatal HIV prevention through counseling and testing. Each month, a random sample (from state birth certificate files) of state-resident mothers are mailed a standardized 14-page questionnaire to gauge the extent of prenatal care, including counseling and testing of all pregnant women who delivered a live-born infant. Repeated questionnaire mailings are sent to the mother to encourage participation. Attempts to interview the mother by telephone are made soon thereafter. A Spanish translation of the mailed questionnaire and telephone interview are available. Since 1996, mothers who received any prenatal care were asked whether their health care provider discussed HIV prevention and HIV testing with them during a prenatal care visit. In 15 states, all mothers are asked whether they were tested for HIV during prenatal care or at the time of delivery.

Population: All state-resident women who have given birth to a live-born infant are eligible for the PRAMS sample.

Strengths: Population-based survey that collects information on prenatal HIV prevention and test counseling, along with other perinatal information. Estimates from PRAMS can be used to gauge the extent of provider HIV test counseling of all pregnant women who gave birth to a live-born infant. For states collecting actual HIV testing information (an elective question), the level of HIV testing can be assessed in this population.

Limitations: PRAMS data rely on self-reported information; thus, the information is subject to recall bias. PRAMS data are representative only of mothers who gave birth to a live-born infant; pregnancies that were terminated or ended in fetal loss are not represented. Because PRAMS samples all mothers in a state, the data are less representative of mothers at high risk for HIV infection or HIV-positive mothers. Mothers who did not seek prenatal care will not have information on prenatal HIV counseling. Finally, information on HIV test result, posttest counseling, and HIV prophylaxis for HIV-infected women is not gathered.

Where available: 31 states (Alabama, Alaska, Arkansas, Colorado, Florida, Georgia, Hawaii, Illinois, Louisiana, Maine, Maryland, Michigan, Minnesota, Mississippi, Montana, North Carolina, North Dakota, Nebraska, New Jersey, New Mexico, New York, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, Texas, Utah, Vermont, Washington, West Virginia); and New York City

Contact person(s): PRAMS coordinator for your state. Additional background and information on whom to contact in your area available at: http://www.cdc.gov/nccdphp/drh.

Reference*:* Gilbert B, Shulman HB, Fischer LA, Rogers MM. The pregnancy risk assessment monitoring system (PRAMS): methods and 1996 response rates from 11 states. *Maternal and Child Health Journal* 1999;3(4):199–209.

Project One

Overview: Project One is a multicomponent project designed to estimate the incidence of HIV infection among men who have sex with men, injection drug users, and high-risk heterosexual adults, and to characterize persons with recent HIV infection. The project components consist of multiple incidence studies, behavioral characterization of persons with a recent diagnosis of HIV infection, and a study of drug-resistant strains and subtyping of new cases.

Population: Persons ≥ 18 years of age residing in the study area whose HIV infection was diagnosed within the past 6 months

Strengths: For 3 important population segments, this study provides key information on HIV incidence and, among those found to be HIV infected, the extent of exposure to prevention services and missed opportunities for HIV prevention; behavioral, individual, and contextual factors associated with HIV transmission; and the viral characteristics of recently transmitted HIV infection.

Limitations: This study has limited generalizability beyond the 3 US metropolitan areas in which it is conducted.

Where available: Chicago, Dallas, Los Angeles

Contact person(s): Project One research managers; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

Rapid Assessment and Response and Evaluation (RARE) – Crisis Response Team Initiative

Overview: Local crisis response teams work in partnership with local community, public health and community leaders to describe the local HIV/AIDS epidemic and its effect upon vulnerable populations. The teams use rapid assessment methods such as focus groups and street intercept surveys during a period of 8 to 10 weeks. The process, conducted at the microlevel, complements surveillance and data-gathering systems by providing data describing the epidemic from the perspective of the neighborhood and the individual. After focus groups and surveys are completed, the findings are presented to the community so that prevention strategies can be identified and prioritized for its specific geographic area.

Population: Persons in community groups of interest in participating cities

Strengths: Provides limited information about prevention and care needs in the defined geographic area

Limitations: Results from this project cannot be generalized to the entire geographic area.

Where available: Phase I cities—Atlanta, Baltimore, Chicago, Detroit, District of Columbia, Miami, New Haven (Connecticut), Newark, Oakland (California), Philadelphia, West Palm Beach; US Virgin Islands

Phase II cities—Birmingham, Cleveland, Columbia (South Carolina), Corpus Christi (Texas), Dallas, Houston, Jacksonville (Florida), Memphis, Mercedes (Texas), Phoenix, Portland (Oregon), St. Louis (Missouri), San Antonio; Puerto Rico

RARE projects have been conducted in conjunction with municipal governments (typically the mayor's office and the health department) in Atlanta, Chicago, Detroit, District of Columbia, Los Angeles, Miami, Newark, New Haven (Connecticut), Oakland (California), Philadelphia, and West Palm Beach.

Contact person(s): Local health department or office of the mayor

Reference: Trotter RT, Needle RH, Goosby E, Bates C, Singer M. A methodological model for rapid assessment, response, and evaluation: the RARE program in public health. *Field Methods* 2001;13:137–159.

Note: A variety of manuals of rapid assessment methods are available: for example, the University of Texas Southwestern Medical Center's *Community-Based Assessment: A Guide for HIV Prevention Workers* is available at http://www3.utsouthwestern.edu/preventiontoolbox/assess/assess.htm.

School Health Education Profiles

Overview: The profiles monitor characteristics of health education in middle or junior high schools and at senior high schools in the United States. The profiles are surveys conducted by state and local education agencies to collect representative data on schools serving students in grades 6–12. The survey includes questions about required health education classes, content of health education, coordination of health education, qualifications of health educators, and parental involvement in health education. Questions about health education content include HIV prevention, substance use, pregnancy prevention, alcohol and tobacco use, diet, physical activity; and violence. Data from states with overall response rates of ≥ 70% were statistically weighted, enabling population-based inferences.

Population: High school and middle or junior high schools in a state or city are eligible for sampling. The profiles use a systematic equal-probability sampling strategy. At a sampled school, the principal and the lead health educator complete a survey. Profile surveys have been conducted biennially since 1996 (1996, 1998, and 2000).

Strengths: The project provides population-based information on the provision of health education offered to students in school, collecting information on whether HIV education is required, whether teachers are trained to teach HIV prevention education, the extent to which parents are informed about HIV prevention education, and other broad topics pertaining to HIV prevention. The profile serves as a springboard for developing community-wide prevention activities or enhancing activities in the school system or both. A minimum 70% response rate is required.

Limitations: Data are self-reported and available in selected areas. Information collected is not in-depth on any specific topic. The profiles are unable to evaluate the effect of the health education provided and are applicable only to students in school. In addition, the unit of analysis is the schools, not the students.

Where available: States with weighted 1998 data—Alabama, Alaska, California, Delaware, Georgia, Hawaii, Idaho, Illinois, Iowa, Louisiana, Maine, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, New Hampshire, New Mexico, New York, North Dakota, Ohio, Pennsylvania, South Carolina, Utah, Virginia, West Virginia, Wisconsin, Wyoming. Local areas with weighted 1998 data—Dallas, Fort Lauderdale, Los Angeles, Miami, New Orleans, Philadelphia, San Diego, and San Francisco

Contact person(s): State department of education. CDC, Division of Adolescent and School Health

Reference: http://www.cdc.gov/mmwr/PDF/SS/SS4908.pdf

Sentinel Surveillance for Variant and Drug-Resistant Strains (SSVRS)

Overview: SSVRS was conducted to describe the prevalence of mutations associated with reduced drug susceptibility among antiretroviral drug–naïve persons with a recent diagnosis of HIV infection. Genotypic resistance testing and HIV subtyping were conducted for all eligible persons. These data may help guide recommendations for baseline (before therapy) antiretroviral resistance testing in a given area.

Population: Persons with a diagnosis of HIV infection during the past 12 months, antiretroviral drug–naïve, at HIV counseling and testing sites, in HIV care clinics, and other clinical settings

Strengths: To date, SSVRS is the largest and most diverse study to monitor the prevalence of antiretroviral drug resistance in the United States.

Limitations: Because the sample was not a random sample of persons with a recent diagnosis, the data may not be representative of all HIV-infected persons in the United States. Also, the study may underestimate the prevalence of mutations among the chronically infected group of persons with a recent diagnosis because some mutations do not persist in the absence of drug pressure.

Where available: Denver, Detroit, Grand Rapids (Michigan), Houston, Miami, Newark, New Orleans, New York City, San Diego, San Francisco

Contact person(s): State or local health department, SSVRS coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

Sexually Transmitted Disease Surveillance

Overview: CDC conducts surveillance to monitor the levels of syphilis, gonorrhea, chancroid, and, more recently, chlamydia, in the United States in order to establish prevention programs, develop and revise treatment guidelines, and identify populations at risk for sexually transmitted diseases (STDs). States, local areas, and US territories submit to CDC (weekly, monthly, or annually) case reports of STDs that have met the respective case definition for the infection. Case report forms include information on patient demographics, type of infection, and source of report (private or public sector). Service areas conduct both passive and active surveillance of STDs to monitor the STD epidemic in their area.

Population: All persons with a diagnosis of an infection that meets the CDC surveillance case definition for the infection and who are reported to local health department

Strengths: STD surveillance data can serve as a surrogate marker for unsafe sexual practices or demonstrate the prevalence of changes in a specific behavior (e.g., rectal gonorrhea). STD data are widely available at the state and local level and because of shorter incubation periods between exposure and infection, STDs can serve as a marker of recent unsafe sexual behavior. In addition, certain STDs (e.g., ulcerative STDs) can facilitate transmission or acquisition of HIV infection. Finally, changes in trends of STDs may indicate changes in community sexual norms (e.g., unprotected sex).

Limitations: STDs are reportable, but requirements for reporting differ by state. Reporting of STDs from private-sector providers may be less complete. Although STD risk behaviors result from unsafe sexual behavior, they do not necessarily correlate with HIV risk. Trends in chlamydia infections may reflect changes in reporting and screening practices rather than actual trends in disease.

Where available: All 50 states and US territories

Contact person(s): State or city STD program manager

Reference: CDC**.** Case definitions for infectious conditions under public health surveillance. *MMWR* 1997;46 (No. RR-10):1–56.

Supplement to HIV/AIDS Surveillance (SHAS)

Overview: SHAS is a cross-sectional interview study that collects self-reported characteristics and behaviors of persons ≥ 18 years of age who have been recently reported with HIV infection or AIDS through routine surveillance to state or local health departments. SHAS was developed to collect information supplemental to routine HIV/AIDS surveillance. The SHAS interview module gathers information on demographic and socioeconomic characteristics; substance use; sexual behavior; access to medical and social services; use of, and adherence to, therapies for HIV and HIV-related opportunistic illnesses; disability related to HIV infection; and reproductive or child health (women only).

Eligible persons are recruited by using population-based or facility-based sampling methods, depending upon the area's HIV/AIDS case load. In areas with <500 persons eligible for interview, all persons are interviewed. Areas conducting population-based or facility-based sampling use 3 strategies in recruiting patients for interviews: (a) all persons reported to surveillance, (b) 30% random sample of HIV-infected men who have sex with men (if male-to-male sex is the predominant mode of HIV transmission) and 100% of HIV-infected persons from other risk groups, or (c) 50% random sample of all persons for whom male-to-male sex is not the primary mode of transmission.

Population: HIV-infected persons ≥ 18 years of age reported to state or local health departments are eligible for a SHAS interview. Persons who are medically or mentally unstable are excluded.

Strengths: Enhanced behavioral and social information collected from persons reported as having HIV/AIDS can be compared with information from routine surveillance. A standardized questionnaire is used to gather self-reported information on use of HIV care services and adherence to therapies. In some areas, the information is representative of all or nearly all persons reported as having HIV/AIDS. Additional gynecologic information is available. Sampling methods are flexible to accommodate local and state needs.

Limitations: SHAS gathers self-reported data; thus, the data are subject to recall bias, particularly for questions concerning injection drug use and sexual history, and cannot be validated by another source of information. SHAS is a cross-sectional survey, so changes in behavior over time cannot be examined. In project areas without HIV reporting, SHAS information may be less useful for prevention activities than it is in areas where HIV infection is reportable. SHAS is based upon a sample of convenience that is not entirely population based; project sites rely upon the cooperation of providers who have reported HIV infections to HARS to approach their patients about the project.

Where available: Since 1990, the following areas have conducted population-based SHAS: Arizona, Delaware, New Mexico, South Carolina (Richland and Charleston Counties, Edisto Health District), Washington State; Los Angeles County; and Tampa.

The following areas conduct facility-based SHAS: Atlanta, Denver, Detroit, Jacksonville (Florida), Jersey City (New Jersey), Miami, and Hartford and New Haven (Connecticut).

Since 2001, Kansas, Maryland, Minnesota, and Texas (Austin) have received funding to conduct SHAS. As of 2002, Chicago, Houston, and Philadelphia have received funding to conduct SHAS.

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or SHAS site coordinator; CDC, Division of HIV/AIDS Prevention, HIV Incidence and Case Surveillance Branch

Reference: Buehler JW, Diaz T, Hersh BS, Chu SY. The Supplement to HIV/AIDS Surveillance project: an approach for monitoring HIV risk behaviors. *Public Health Reports* 1996;111(suppl 1):133–137.

Survey of HIV Disease and Care (SHDC)

Overview: SHDC, a cross-sectional survey of HIV-infected persons reported to the HIV/AIDS Reporting System (HARS), was developed to obtain population-based estimates of the clinical characteristics of persons receiving medical care for HIV infection. SHDC collects demographic and clinical information, including the proportion of patients receiving therapy as recommended by current treatment guidelines and the proportion of patients receiving preventive services. The medical records of sampled patients are reviewed for the preceding 12 months, and the information is documented on a standardized abstraction form.

Population: Health care providers who have reported an HIV-infected person(s) to HARS are eligible for sampling. A listing of the health care providers' HIV-infected patients is prepared and then sampled systematically with a random start. Women and members of racial/ethnic minority groups are oversampled.

Strengths: SHDC is designed to collect data on a representative sample of patients receiving HIV care so that population-based estimates of the proportion of HIV-infected persons receiving recommended standards of care can be made. Women and members of racial/ethnic minority groups are oversampled to ensure that population-based estimates in these populations are valid. SHDC extracts information from a variety of records in order to capture information on prescription of HIV antiretroviral therapies, receipt of medical care and social services, and laboratory testing history.

Limitations: SHDC is a cross-sectional study, and medical records are the source of the data. Estimates of care cannot be assessed over time, and the quality of the data depends upon the completeness of documentation in the patient's medical record. Because the sampling frame is patients who have sought medical care, population-based inferences cannot be made about HIV-infected persons not receiving care for HIV infection. SHDC does not collect behavioral information; therefore, self-reported adherence to therapies documented in the medical chart is not known. In addition, data from SHDC may underestimate the amount and type of medical care a patient received if the patient received medical care from more than 1 provider; for example, gynecologic care may be underreported because women may seek a non-HIV care provider for this service.

Where available: Since 2000, Florida, Louisiana, Maryland, Michigan, Ohio, Washington; and Houston

In 2001, New Jersey and Virginia, Philadelphia, and Puerto Rico received funding to initiate SHDC.

Contact person(s): State or local health department, HIV/AIDS surveillance coordinator or SHDC site coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

Survey of HIV Disease and Care Plus (SHDC+)

Overview: SHDC+, a cross-sectional survey of HIV-infected persons reported to the HIV/AIDS Reporting System (HARS), was developed to obtain population-based estimates of clinical outcomes among persons receiving medical care for HIV infection and self-reported behavioral determinants of clinical outcomes. Using medical record abstraction, SHDC+ collects demographic and clinical information, including the proportion of patients receiving therapy recommended by current treatment guidelines and the proportion of patients receiving preventive services. In addition, participants are interviewed in person about HIV risk behaviors and adherence to treatment. The medical records of sampled patients are reviewed for the preceding 12 months, and the information is documented on a standardized abstraction form.

Population: Health care providers who have reported an HIV-infected person(s) to HARS are eligible for sampling. A listing of the health care providers' HIV-infected patients is prepared and then sampled systematically with a random start. Women and members of racial/ethnic minority groups are oversampled.

Strengths: SHDC+ is designed to collect data from a representative sample of patients receiving HIV care so that population-based estimates of the proportion of HIV-infected persons receiving recommended standards of care can be made. Women and racial/ethnic minorities are oversampled to ensure that population-based estimates of these populations are valid. SHDC+ extracts information from a variety of record sources in order to capture information on prescription of HIV antiretroviral therapies, receipt of medical care and social services, and laboratory testing history; in-person interviews are conducted to collect information on adherence to HIV therapy and behavioral risks. Data from SHDC+ are useful for estimating the proportion of persons who received appropriate standards of care for HIV disease and learning whether they adhere to their therapy. SHDC+ also offers an opportunity for methodologic research; interview data will also be used to assess the validity of selected data from chart abstraction and vice versa.

Limitations: SHDC+ is a cross-sectional study, and medical records are the source of the data. Estimates of care cannot be assessed over time, and the quality of the data depends upon the completeness of documentation in the patient's medical record and the validity of the self-reported information. Because the sampling frame is for patients who have sought medical care, population-based inferences cannot be made about HIV-infected persons who are not receiving care for HIV infection. In addition, data from SHDC+ may underestimate the amount and type of medical care a patient received if the patient received medical care from more than 1 provider.

Where available: In 2001, Michigan, New Jersey, and Washington (Seattle/King County) received funding to conduct SHDC+.

Contact person(s): State or local health department, HV/AIDS surveillance coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

Tuberculosis Surveillance

Overview: All reporting areas (the 50 states, the District of Columbia, New York City, Puerto Rico, and other US jurisdictions in the Pacific and Caribbean) report tuberculosis (TB) cases to CDC by using a standard case report form, the Report of a Verified Case of Tuberculosis. Reported TB cases are verified according to the TB case definition for public health surveillance. In 1993, the surveillance of TB was expanded to collect additional data to better monitor and target groups at risk for TB disease, to estimate and follow the extent of drug-resistant TB, and to evaluate outcomes of TB cases. The Report of a Verified Case of Tuberculosis form was revised to obtain information on occupation, initial drug regimen, HIV test results, history of substance abuse and homelessness, and residence in correctional or long-term care facilities at the time of diagnosis.

Population: All persons whose case of TB meets the public health surveillance definition

Strengths: The level of active TB disease reporting is more than 95% complete. As a result of the 1993 expansion of surveillance activities, jurisdictions have been able to evaluate the success of TB control efforts and monitor the status of the TB epidemic. TB surveillance data provide areas with a minimum estimate of the level of HIV comorbidity.

Limitations: Data on HIV infection status of reported TB cases should be interpreted with caution because these data are not representative of all TB patients with HIV infection. HIV testing is voluntary, and some TB patients may decline HIV testing. In addition, TB patients who have been tested anonymously may not share their HIV test results with their health care provider. Further, testing may be influenced by other factors, such as the extent to which testing is focused on, or routinely offered to, specific groups.

Where available: All 50 states, the District of Columbia, New York City, Puerto Rico, and other US jurisdictions in the Pacific and Caribbean

Contact person(s): State or territorial health department TB coordinator: http://www.cdc.gov/nchstp/tb. Select "Contact us" for a list of coordinators.

Reference: CDC. *Reported Tuberculosis in the United States, 2001.* Atlanta: CDC; 2002. Available at: http://www.cdc.gov/nchstp/tb

US Bureau of the Census (Census Bureau)

Overview: The Census Bureau collects and provides timely information about the people and the economy of the United States. The Web site for the Census Bureau includes data on demographic characteristics (e.g., age, race, Hispanic ethnicity, sex) of the population, family structure, educational attainment, income level, housing status, and the percentage of persons living at or below the poverty level. Tables and maps of census data are available for all geographic areas to the block level. Summaries of the most requested data for states and counties are provided, as well as analytical reports on population change, race, age, family structure, and apportionment. Links to other census-related sites are included.

Population: US population

Strengths: A wide range of online statistical data on the US population is available in different formats (e.g., tables, maps). State- and county-specific information is easily accessible, and links to other census Web sites are provided.

Limitations: Some files may not download quickly.

Where available: All states and US jurisdictions

Contact person(s): http://www.census.gov/main/www/contacts.html

References: http://www.census.gov

Vital Records – Birth Data

Overview: In the United States, state laws require that birth certificates be completed for all births, and federal law mandates the national collection and publication of births and other vital statistics data. The National Vital Statistics System is the federal compilation of the data, in cooperation with the National Center for Health Statistics (NCHS) and states. States use a standard form (US Standard Certificate of Live Birth) to collect birth data and report this information to NCHS annually. As of 2003, states will adopt a revised standard form. The 2003 form collects demographic information about the newborn, the mother, and the father; insurance; prenatal care; prenatal risk factors; maternal morbidity; mode of delivery; pregnancy history; and clinical characteristics of the newborn. States have the option of collecting additional information on their birth certificates; some states have elected to include information on HIV testing.

Population: All live births in the 50 states, the District of Columbia, and US territories. Tabulated state birth tables are available at the Web site.

Strengths: Vital records include all births in an area. Reporting is approximately 100% complete. Therefore, inferences can be made concerning the population of live births in a service area. The revised birth certificate collects additional information on the mother's insurance, smoking, and morbidity—information that may be useful for focusing prevention resources.

Limitations: Data obtained from patient medical records (i.e., smoking history, morbidity) are often not complete.

Where available: All states and local areas maintain birth registries

Contact person(s): State vital records registrar; CDC, National Center for Health Statistics

Reference*:* http://www.cdc.gov/nchs

Vital Records – Death Data

Overview: In the United States, state laws require that death certificates be completed for all deaths, and federal law mandates the collection and publication of deaths. The National Vital Statistics System produces a federal compilation of death data reported to the National Center for Health Statistics by states. A standard certificate of death is used to record death information on each decedent. As of 2003, states will adopt a revised death certificate that includes demographic information on the decedent, underlying cause of death (using an International Classification of Diseases [ICD-10] code), and contributions of selected factors to the death (i.e., smoking, accident, or injury).

Population: All deaths in the 50 states, the District of Columbia, and US territories

Strengths: Reporting of deaths in the United States is universal and 100% complete. The data are widely available and can be used to determine the impact of HIV-related deaths related in a service area. Standardized procedures are used throughout the nation to collect death certificate data.

Limitations: Deaths resulting from, or whose underlying cause was, HIV infection may be underreported on the death certificate. Clinical information related to HIV infection or AIDS may be missing. Death records are less timely than AIDS case reports.

Where available: All states and local areas maintain death registries

Contact person(s): State vital records registrar; CDC, National Center for Health Statistics

Reference: http://www.cdc.gov/nchs

Young Men's Survey (YMS)

Overview: YMS was established in the early 1990s to enumerate, sample, and estimate prevalence outcomes of a population of young men who frequent public venues and have sex with other men. YMS, a cross-sectional, multisite, venue-based survey, was conducted in 2 phases. In Phase I (1994–1998), young men aged 15–22 years were enrolled in 7 US metropolitan areas. In Phase II (1998–2000), men aged 23–29 years were enrolled in 6 US metropolitan areas. Before the phases of the survey were implemented, formative research was conducted to identify all potential venues and the times those venues were frequented by young men who have sex with men (MSM). Venues include street locations, dance clubs, bars, businesses, social organizations, bathhouses, health clubs, and other public places. Venues and associated time periods that were estimated to yield enough young MSM were included in monthly sampling frames. Each month, sampling events were conducted at 10–15 venues, and their associated time periods were randomly selected from the time frame. During sampling events, participants responded to an anonymous standardized questionnaire, and a blood specimen was obtained. The YMS questionnaire captured information on client demographics; venue attendance and frequency; HIV-related risk behaviors, including condom use, use of alcohol, drugs, and needles; medical history; and psychosocial factors. Blood specimens were tested for HIV antibody, evidence of past or current hepatitis B infection, and syphilis.

Population: Young men aged 15–29 years who frequent a public venue in the sampling frame and who have sex with other men. Eligible men must be residents of the county in which the study is being conducted.

Strengths: The YMS sampled a large population of young MSM and collected baseline measures of HIV infection and risk factors that can be used to allocate resources to meet HIV-related medical care, social services, and HIV/AIDS prevention needs for young MSM. Although YMS used venue-based sampling, 2 population-based surveys have found that most young MSM attend 1 or more public venues that are included in the YMS sampling frame. Further, because many types of venues (in addition to bars) are included in the YMS sampling frame, it is likely that most young MSM are eligible for sampling.

Limitations: YMS data are generalizable only to the population of young MSM who attend venues included in the YMS sampling frame. Young MSM who frequent low-volume or unidentified venues or do not frequent venues are not represented. In addition, YMS data are self-reported and thus subject to recall bias.

Where available: Miami (1995-2000); Baltimore (1996–2000), Dallas (1994–2000), Los Angeles (1994–2000), New York City (1997–2000), San Francisco Bay Area (Phase I only, 1994–1995), Seattle (1997–2000)

Contact person(s): Local YMS study coordinator; CDC, Division of HIV/AIDS Prevention, Behavioral and Clinical Surveillance Branch

Reference: MacKellar D, Valleroy L, Karon J, Lemp G, Janssen R. The Young Men's Survey: methods for estimating HIV seroprevalence risk factors among young men who have sex with men. *Public Health Reports* 1996;111(suppl 1):138–144.

Youth Risk Behavior Surveillance (YRBS) among Native Americans

Overview: Conducted to monitor 6 priority high-risk behaviors that contribute to the leading causes of mortality, morbidity, and social problems among Native American youth living in the Navajo Nation and in the continental United States. The Native American YRBS projects are conducted by (a) the Navajo Nation in collaboration with the Indian Health Service and CDC, (b) South Dakota, (c) Montana, and (d) the Bureau of Indian Affairs.

Using a self-administered questionnaire, the Native American YRBS collects information on 6 categories of behaviors, 1 of which comprises sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV. Questions are also asked about exposure to HIV prevention education, sexual activity (age at initiation, number of partners, condom use, preceding drug or alcohol use), contraceptive use, and pregnancy history.

Population: The Navajo Nation YRBS methods included a sample of students attending public high schools on the Navajo Nation reservation and Navajo students attending public high schools (bordering the reservation) with ≥ 50% Navajo student enrollment. South Dakota sampled middle schools (grades 6–8) receiving funding from the Bureau of Indian Affairs (BIA) or with ≥ 25% Native American enrollment (public and private), as well as high schools receiving funding from the BIA or with ≥ 25% Native American enrollment (public and private). Montana sampled self-identified Native Americans attending public high schools outside Montana Indian reservations and high school students enrolled in schools within a reservation or bordering one. The BIA nationwide survey of high school and middle school students was implemented in all schools receiving BIA funding, except Alaska.

Strengths: The Native American YRBS is a population-based survey that samples Native American adolescents enrolled in public schools. The questionnaire is administered anonymously to students during school. Inferences from the Navajo, South Dakota, and Montana YRBS results can be drawn about the behaviors of adolescents in school, making the information useful for developing community-wide prevention programs aimed at adolescents in the Navajo Nation or Native American adolescents living in South Dakota and Montana. The estimates from the BIA survey can be generalized to Native American students attending BIA-funded schools in the continental United States. The YRBS questionnaire is a standardized instrument.

Limitations: Limitations of the YRBS conducted in Native American populations include those identified with the YRBS project among the general population. Principal limitations are that the data are self-reported; reporting of sensitive behavioral information may not be accurate (underreporting or overreporting may occur); the data are representative only of children and adolescents who are enrolled in school; and answers to

questions about behaviors during the past year may be subject to recall bias. The BIA survey samples students attending BIA-funded schools; thus, survey estimates cannot be generalized to students who attended schools not funded by the BIA.

Where available: 1997 and 2000—Navajo Nation and selected bordering high schools; 1997 and 2000—South Dakota middle and high school surveys; 1999—Montana high school survey; 1994, 1997, and 2001—BIA nationwide survey of high school students (excluding Alaska); 1997 and 2000—BIA nationwide survey of middle school students (excluding Alaska)

Contact person(s): Navajo Nation Department of Health and Indian Health Service, 505-368-6308 for Navajo YRBS. South Dakota, 605-773-6898. Montana, 406-444-1963. For National Native American YRBS, call the BIA at 202-208-3601, or go to http://www.oiep.bia.edu

Youth Risk Behavior Surveillance System (YRBSS)

Overview: Established to monitor 6 priority high-risk behaviors that contribute to the leading causes of mortality, morbidity, and social problems among youth and adults in the United States. YRBSS was developed to collect data that are comparable among national, state, and local samples of youth. CDC conducts national surveys among students in high schools and alternative high schools. In addition, state, territorial and local school-based surveys are conducted by education and health agencies.

Using a self-administered questionnaire, YRBSS collects information on 6 categories of behaviors, 1 of which comprises sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV. Questions are also asked about exposure to HIV prevention education, sexual activity (age at initiation, number of partners, condom use, preceding drug or alcohol use), contraceptive use, and pregnancy history.

Population: YRBSS surveys a representative sample of students in grades 9–12.

Strengths: YRBSS is a population-based survey that samples students in public and private high schools. The YRBSS questionnaires are self-administered, and anonymous inferences from YRBSS estimates can be drawn about behaviors of young people in high school, making the information useful for developing community-wide prevention programs focused on adolescents. YRBSS uses a standardized questionnaire so that participating states can be compared, and the questionnaire is flexible so that states can ask specific questions to meet their needs.

Limitations: YRBSS relies upon self-reported information; reporting of sensitive behavioral information may not be accurate (underreporting or overreporting may occur). Because the questionnaires are administered in schools, the data are representative only of young people who are enrolled in school and cannot be generalized to all young people. Answers to questions about behaviors during the past year may be subject to recall bias; however, this bias may be minimal because of the young age of the respondents.

Where available: YRBSS surveys have been conducted since 1990 in selected areas and biennially thereafter. In 1990, 23 states participated in YRBSS; as of 1999, 41 states participated, 22 of which achieved a minimum overall response rate of 60% (Alabama, Alaska, Arkansas, Delaware, Hawaii, Massachusetts, Michigan, Mississippi, Missouri, Montana, Nevada, New York, North Dakota, Ohio, South Carolina, South Dakota, Tennessee, Utah, Vermont, West Virginia, Wisconsin, Wyoming). In 1999, the 14 cities that conducted YRBSS achieved the minimum overall response rate of 60% (Boston, Chicago, Dallas, Detroit, District of Columbia, Fort Lauderdale, Houston, Miami, New Orleans, New York City, Palm Beach, Philadelphia, San Diego, and Seattle).

Contact person(s): State department of education; CDC, Division of Adolescent and School Health, Surveillance and Evaluation Research Branch

References: CDC. Youth Risk Behavior Surveillance—United States, 2001. *MMWR* 2002;51(SS-4):1–64. Also available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5104a1.htm