

APPENDIX A: DATA SOURCES

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Core HIV/AIDS Surveillance

AIDS Surveillance

Overview: AIDS is a reportable condition in all states and territories. Since 1993, all states and territories base their reporting practices on the 1993 CDC case definition for AIDS surveillance. The AIDS Surveillance system was established to monitor incidence of the disease and the demographic profile of AIDS cases; describe the modes of HIV transmission among persons with AIDS; guide the development and implementation of public health intervention and prevention programs; and to assist in the evaluation 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 who meet the 1993 CDC AIDS surveillance case definition

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

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 completeness of reporting. Further, the widespread use of HAART complicates the interpretation of AIDS case surveillance data and the 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.

HIV Surveillance

Overview: Since the human immunodeficiency virus was identified and a test for HIV was licensed, CDC and other professional organizations have recommended the reporting of HIV infections to local health authorities as an integral part of AIDS surveillance activities. As part of ongoing, active HIV surveillance, state and local health departments educate providers on their reporting responsibilities, establish active surveillance sites, and establish liaisons with laboratories that perform HIV testing of samples. Moreover, HIV/AIDS surveillance programs routinely evaluate the completeness of HIV reporting and conduct follow-up on HIV cases that are of epidemiologic importance.

Population: All persons who test positive for the human immunodeficiency virus (HIV)

Strengths: HIV surveillance data represent more recent infections, compared with AIDS surveillance data. Previous evaluations have estimated that HIV infection reporting in Louisiana is >85% complete for persons who have tested positive for HIV. Consequently, HIV surveillance provides a minimum estimate of the number of persons known to be HIV infected and reported to the health department, identifies emerging patterns of transmission, and can be used to detect trends in HIV infections among populations of particular interest (e.g., children, adolescents, or women) that may not be evident from AIDS surveillance. Additionally, 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 level 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, where they would be confidentially tested, are not included in HIV surveillance statistics. HIV surveillance data represent infections in jurisdictions where reporting laws for HIV are in place. HIV reporting laws differ by jurisdiction; therefore, consultation with local surveillance staff is advised on how to interpret local HIV surveillance data. Furthermore, reporting of behavioral risk information may not be complete.

Enhanced Perinatal Surveillance

Overview: Perinatal HIV/AIDS surveillance is the ongoing and systematic collection of information on HIV-infected pregnant mothers and perinatally exposed and HIV-infected children. Extensive medical record abstractions are conducted for all HIV-exposed children and their mothers, and the children are followed up until their infection status is determined. These data address the prevention of perinatal transmission, including prenatal care, HIV counseling and testing during pregnancy, and the use of zidovudine or other antiretroviral medications for pregnant mothers and neonates. The data also address questions regarding treatment issues for HIV-infected women and their children.

Population: All HIV-exposed children and their mothers

Strengths: Enhanced perinatal surveillance data provide perinatal-specific information that can be used to examine patterns in HIV testing and in the use of zidovudine in clinical practice, as well as to identify barriers to the implementation of Public Health Services guidelines. Perinatal surveillance data may also be used to help ascertain mother-infant pairs by matching data in the HIV/AIDS registry to the state birth registry each year.

Limitations: Perinatal data may underestimate the number of mother-infant pairs because some pregnant women may not know they are HIV infected and others may not have been tested for HIV. Perinatal data includes only those women who have had a positive confidential HIV test result. HIV-exposed infants must be followed up until sufficient laboratory information is available, so infants who are lost to follow-up cannot be classified as infected or not infected.

Supplemental HIV/AIDS Surveillance Projects

Adult/Adolescent Spectrum of HIV Disease (ASD)

Overview: The Adult/Adolescent Spectrum of Disease (ASD) project is an ongoing, longitudinal surveillance cohort study that describes the full 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 onto 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 ascertainment and re-abstractions are done every 6 months until the patient dies or is lost to follow-up.

Population: ASD participants must be ≥ 13 years, have a diagnosis of HIV infection, and receive health care at a participating facility in the funded area. In each funded area, facilities serving HIV-infected persons (clinics, hospitals, neighborhood health centers, private medical practices, and emergency departments) are selected to participate as project sites. At each project site, all HIV-infected women and persons belonging to a racial/ethnic minority group are included.

Strengths: ASD data describe the spectrum of HIV disease that is documented in the medical chart. Data have been available since January 1990. ASD data are useful for assessing the prescription of prophylactic and antiretroviral treatment over time and for assessing the level of AIDS-defining conditions for case definition purposes. As of December 2001, 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 on the medical chart may not be complete. Gynecologic information may be underreported because this information may appear elsewhere (e.g., women may have been cared for by gynecologists rather than HIV specialists). ASD data rely on the thoroughness of diagnostic testing and recording.

HIV Testing Survey (HITS)

Overview: HITS assesses HIV testing patterns among persons at high risk for HIV, evaluates reasons for seeking or avoiding testing, and examines knowledge of state policies for HIV surveillance. In addition, HITS collects behavioral risk information from persons at high risk for infection. The data can also be used to evaluate the representativeness of HIV surveillance data by determining the characteristics of persons who delay testing, are tested anonymously, or are not tested at all.

HITS is an anonymous, cross-sectional survey of populations at high risk for HIV infection. The core populations include MSM, IDUs, and heterosexual adults. To recruit HITS 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 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 report that they are HIV-positive are interviewed.

In 2001, HITS was conducted in New Orleans (Orleans Parish), Baton Rouge (East Baton Rouge Parish), and Monroe. The sample of 300 persons was distributed among these 3 areas: 50 persons in each population group in New Orleans, 40 in Baton Rouge, and 10 in Monroe.

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, behavioral criteria apply to each risk group: men at MSM venues are eligible if they have had sex with a man within the past 12 months; injection drug users must have injected drugs within the past 12 months; and high-risk heterosexual clients 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.

Strengths: HITS collects public health information from groups at high risk for HIV; the information includes HIV testing attitudes, history and behaviors, as well as knowledge of testing and risk behaviors.

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. For example, in Louisiana, information on MSM was collected in only 3 areas of the state (New Orleans, Baton Rouge, and Monroe) and therefore may be limited in its representativeness. Furthermore, data on MSM were collected only in gay bars; MSM who frequent gay bars may not be representative of the entire population of MSM.

Survey of HIV Disease and Care (SHDC)

Overview: SHDC, a cross-sectional review of medical records of HIV-infected persons reported to 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 proportions of patients receiving

therapy recommended by current treatment guidelines and of those who receive preventive services. Information in the medical records of sampled patients are reviewed for the preceding 12 months and documented on a standardized abstraction form.

Population: Health care providers who have reported an HIV-infected person(s) to HARS are eligible for sampling. Among sampled providers, a listing of their HIV-infected patients is prepared and then sampled systematically with a random start. Women and racial/ethnic minorities 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 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 record sources in order to obtain information on the prescription of HIV antiretroviral therapies, receipt of medical care and social services, and laboratory testing history. Data from SHDC are used to estimate the proportion of persons who received appropriate standards of care for their HIV disease.

Limitations: SHDC is a cross-sectional review, and medical records are the source of the data. Estimates of care cannot be assessed over time, and the quality of the data obtained is dependent on the completeness of documentation in the patient's medical record. SHDC's sampling frame is patients who have sought medical care; therefore, population-based inferences about HIV-infected persons who are not in care cannot be made. Although SHDC collects some behavioral information, self-reported adherence to therapies documented in the medical chart may not be 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 this care from a provider who is not an HIV specialist.

Behavioral Surveys

MSM Outreach Survey (MOS)

Overview: During 1995–2000, outreach surveys were conducted across Louisiana at bars that serve MSM. The survey was a 1-page, self-administered questionnaire distributed by outreach workers from local CBOs. Each CBO surveyed 50 to 150 MSM twice per year at 1 to 2 bars where they conducted outreach activities. Every person at the bar was approached. However, if the bar was very busy, workers chose a representative sample of persons at the bar (e.g., they approached every third person who entered the bar). Respondents were asked about sex partners, history of condom use, history of receptive and insertive anal sex, and HIV status.

Population: MSM men who attend bars that serve gay and bisexual men

Strengths: Data on HIV-related behaviors among MSM are very limited. The MOS is one of the only sources of statewide behavioral data for MSM. Because the survey was

conducted every year for 6 years, trends in risk behaviors can be analyzed. Information collected from the MOS is useful for planning prevention strategies for MSM.

Limitations: MOS data are self-reported; thus, the information may be subject to recall bias. Because these data were collected in bars, the data are representative only of MSM who go to gay bars and cannot be generalized to all MSM.

Street Outreach Survey (SOS)

Overview: SOS has been administered by CBOs in every region of the state since 1995. The survey was a 1-page, self-administered questionnaire distributed each quarter by outreach workers at 3 sites where they actively conducted street outreach activities. These sites were in neighborhoods with 1 or more of the following characteristics: high rates of HIV/STDs, high levels of drug use, exchange of sex for money or drugs, or "crack" houses. Questionnaires were collected between 3:00 p.m. and 8:00 p.m. at outdoor locations (i.e., street corners, bus stops, public housing developments, and locations outside convenience stores and apartment complexes). The survey was generally conducted at the same sites each quarter. Every person at the site was approached, but a representative sample of persons was selected if the site was very busy (e.g., every third person was approached). Respondents were asked about sex partners, history of condom use, drug use, HIV testing history, and exposure to prevention programs.

Population: High-risk persons in neighborhoods where street outreach activities are actively conducted

Strengths: This survey provides data on the sexual and drug-use behaviors of persons at particularly high risk for HIV. These persons are likely to be missed by other survey approaches (e.g., BRFSS telephone survey). Because the survey is conducted every year, trends in risk behaviors can be analyzed. Data from the SOS may be used to help plan prevention strategies for persons at high risk for HIV and STDs. The data can also be used to determine the extent to which persons have been exposed to prevention activities and to monitor and evaluate state and local prevention programs.

Limitations: SOS data are self-reported; thus, the information may be subject to recall bias. These data represent persons at particularly high risk for HIV and are not generalizable to the general population in the local community.

Behavioral Risk Factor Surveillance System (BRFSS)

Overview: The BRFSS is a state-based random-digit-dialed telephone survey of adults that monitors state-level prevalence of the major behavioral risks associated with premature morbidity and mortality. 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 to the BRFSS questionnaire are asked a variety of questions about their personal health behaviors and health experiences. A sexual behavior module was added to this survey in 1994, 1995, 1996, 1998, and 2000.

The questions in this module, for adults (aged 18-49), concerned number of sex partners, condom use, and treatment for STDs.

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

Strengths: Data from the BRFSS survey are population-based; thus, estimates about testing attitudes and practices can be generalized to the adult population of a state. 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. Because BRFSS respondents are contacted by telephone, the data are not representative of households that do not have telephones. 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.

Youth Risk Behavior Surveillance System (YRBSS)

Overview: The YRBSS was established to monitor 6 high-risk behaviors that contribute to the leading causes of mortality, morbidity, and social problems among youth and young adults in the United States. YRBSS was developed to collect data that are comparable nationally, statewide, and locally. It is a self-administered questionnaire that is given to a representative sample of students in grades 9 through 12 at the state and local levels. In Louisiana, the survey is administered at the state level and in Orleans Parish public schools. However, only the survey administered to Orleans Parish high school students includes questions related to sexual behavior. The Orleans Parish Youth Risk Behavior Survey (YRBS) collects information on 6 categories of behaviors; sexual behaviors that contribute to unintended pregnancy and STDs, including HIV, constitute 1 category. Questions are also asked about exposure to HIV prevention education materials, sexual activity (age at initiation of sexual activity, number of partners, condom use, past drug or alcohol use), contraceptive use, and pregnancy history.

Population: A representative sample of students in grades 9 through 12 at the state and local level

Strengths: In New Orleans, YRBSS samples adolescents in public schools and is population-based. The YRBS questionnaire is administered to students anonymously during school. Repeated attempts are made to contact students who are not in attendance. Inferences from YRBSS estimates can be drawn about behaviors and attitudes of adolescents in school, which makes the information useful for developing community-wide prevention programs aimed at younger persons. YRBSS uses a standardized questionnaire so that comparisons can be made across participating jurisdictions. Jurisdictions have the option of asking specific questions to meet local needs.

Limitations: The YRBSS project relies upon self-reported information; therefore, reporting of sensitive behavioral information may not be accurate (may be underreported or overreported). Also, because the YRBSS questionnaire is administered in school, the data are representative only of students and cannot be generalized to all youth. For example, students at highest risk, who may be more likely to be absent from school or to drop out of school, may be underrepresented in this survey, especially among upper grades. The questionnaire does not include questions about homosexual or bisexual behavior.

STD Surveillance

STD Case Reporting

Overview: The Louisiana Office of Public Health STD Control Program conducts statewide surveillance to determine sexually transmitted disease (STD) incidence and to monitor trends. It also conducts partner counseling and makes referrals for examination and treatment in order to reduce the spread of STDs. In Louisiana, chancroid, chlamydia, gonorrhea, lymphogranuloma venereum, and syphilis are reportable STDs.

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

Strengths: STD surveillance data (e.g., data on rectal gonorrhea) can serve as a surrogate marker for unsafe sexual practices and demonstrate the prevalence of, or changes in, a specific behavior. STD data are widely available at the state and local level. Because of shorter incubation time 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 the transmission or the acquisition of HIV infection. Finally, changes in trends of STDs may indicate changes in community sexual norms, such as unprotected sex.

Limitations: STDs are reportable, but state requirements for reporting differ. The 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.

HIV Counseling and Testing Data

Counseling and Testing System (CTS)

Overview: The Louisiana Office of Public Health provides funds for the HIV CTS at more than 150 sites in Louisiana. These sites include CBOs, drug treatment centers, and STD, prenatal, family planning, and TB clinics. The CTS collects information on counseling and testing services delivered, as well as the characteristics of clients receiving the services. The characteristics include demographics, insurance, risk information, and testing information (data, testing history, test result). However, no personal identifying information is collected. All sites offer both anonymous and confidential testing. However, 84% of persons that were tested in 2000 were tested confidentially.

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

Strengths: CTS provides standardized data, available at the local level, on clients who are tested for HIV. The data may offer insights into HIV infection rates in an area's high-risk population. The CTS testing data may also highlight the effect of prevention programs focused on specific populations.

Limitations: CTS collects test-based, rather than person-based data. Information is collected only from persons who seek counseling and testing services or agree to be tested after consultation with a counselor at a testing site. Therefore, estimation of HIV statewide seroprevalence is not possible with CTS data because the clients self-select for testing. However, at sites where testing is universal, persons who are HIV-positive may reflect the prevalence in that population. Because a person can repeatedly seek testing, it is not possible to distinguish persons who have been tested multiple times; however, a variable called previous HIV test on the client abstract form allows prior testing to be quantified. Because the CTS gathers data on HIV testing or program activities, changes in testing patterns may reflect changing program priorities rather than the testing patterns of individuals.

Substance Abuse Data

Treatment Episode Data Set (TEDS)

Overview: TEDS is a national data set maintained by the Office of Applied Studies, Substance Abuse and Mental Health Services Administration (SAMHSA). Data are obtained annually on more than 1.5 million records of treatment admissions for substance abuse. TEDS comprises data that are routinely collected by states to help monitor their individual substance abuse treatment programs. TEDS collects information on client demographics, information about the number of prior treatments, the usual route of administration for each problem substance, frequency of use, age at first use, and services provided. Facilities that report TEDS data usually receive state funding for the provision of substance abuse treatment.

Population: Persons admitted to substance abuse treatment facilities that report to TEDS

Strengths: Although TEDS does not represent the total demand for substance abuse treatment, it does include a significant proportion of all admissions to substance abuse treatment. It includes admissions that constitute a burden on public funds.

Limitations: TEDS is based on records of admissions and does not represent individuals. Because of this, a person admitted to treatment twice within the same calendar year would be counted as 2 admissions. Also, because most states cannot identify persons who have been assigned a unique identifier at the state level to protect their confidentiality, TEDS is unable to follow individual clients through a sequence of

treatment episodes. TEDS does not represent the total substance abuse treatment burden or the prevalence of substance abuse in the general population.

Drug Abuse Warning Network (DAWN)

Overview: DAWN is an ongoing, national data system that collects information on drug-related deaths from the offices of participating medical examiners. Data are also collected 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 collected in more than 40 metropolitan areas.

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

Population: Persons who died at 6–97 years of age and whose death was drug induced or drug related. Also, the decedent must have 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 a large number of areas in 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 the data, the methods were revised and new protocol modifications were implemented in 2001.

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

National Household Survey of Drug Abuse (NHSDA)

Overview: The NHSDA is an ongoing source of statistical information on the use of illicit drugs by the US civilian population aged 12 or older. The survey collects data by administering questionnaires to a representative sample of the population. Face-to-face computer-assisted interviews are conducted at the respondent's residence. Information obtained by the NHSDA questionnaire includes use of cocaine, receipt of treatment for illicit drugs, and need for treatment because of 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.

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 or older.

Population: Noninstitutionalized civilian US population aged 12 years or older

Strengths: NHSDA is a national, standardized survey of drug-use behaviors among the general population. To increase the level of honest reporting, information has been collected since 1999 by using a combination of computer-assisted interviewing methods. This provides respondents with a more 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 infection. Further, data from the NHSDA are self-reported and are subject to recall bias, which may result in the underreporting of a sensitive behavior.

Vital Statistics Data

Birth Data

Overview: The National Center for Health Statistics (NCHS) receives information on births and deaths in the United States through a program of voluntary cooperation with state government agencies (e.g., state departments of health, state offices of vital statistics) called the Vital Statistics Cooperative Program. States use a standard form (U.S. Standard Certificate of Live Birth) to collect birth data and report this information annually to NCHS. The birth certificate form collects demographic information on the newborn and the parents, insurance, prenatal care, prenatal risk factors, maternal morbidity, mode of delivery, pregnancy history, and clinical characteristics of the newborn.

Population: All live births in Louisiana

Strengths: Vital records contain data on all births in an area. Because reporting is approximately 100% complete, inferences can be made about the population of live births in a service area. The revised birth certificate collects additional information on maternal insurance status, smoking, and morbidity, which may be useful for allocating prevention resources.

Limitations: Birth certificate data are often not complete for data that are obtained from patient medical records (e.g., smoking history, morbidity).

Death Data

Overview: NCHS receives information on births and deaths through a program of voluntary cooperation with state government agencies (i.e., state departments of health, state offices of vital statistics) called the Vital Statistics Cooperative Program. A standard certificate of death is used to record death information on each decedent. A

death certificate bears demographic information about the decedent, the underlying cause of death (using an *ICD-10* code [*International Classification of Diseases*, 10th rev.]), and contributions of selected factors to the death (e.g., smoking, accident, or injury).

Population: All deaths that occur in Louisiana

Strengths: The reporting of deaths in Louisiana is universal and 100% complete. The data are widely available and can be used to determine the effect of deaths related to HIV infection in a service area. Standardized procedures are used nationwide to collect death certificate data.

Limitations: Deaths resulting from, or whose underlying cause was, HIV infection may be underreported on death certificates. Clinical information related to HIV or AIDS may be missing. Death records are not available as promptly as AIDS case reports are.

Population Data

U.S. 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 Census Bureau's Web site (<http://www.census.gov>) 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 proportion 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 information for states and counties are provided, as are analytical reports on population change, race, age, family structure, and apportionment.

Population: U.S. population

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

Limitations: The downloading of some large files may require a significant amount of time.

Louisiana State Census Data Center

Overview: This data center is administered by the State of Louisiana. The Web site for the center (<http://www.state.la.us/census>) includes current population estimates and projections; socioeconomic, income, and poverty status information; demographic profiles and rankings; and geographic units from which census data are obtained (parishes, cities, and metropolitan areas). Parish population trends are also provided.

Population: Louisiana population

Strengths: A wide range of online statistical data on the Louisiana population are available in different formats (e.g., tables, maps). Links to local affiliates of the state census data center and to other Web sites with census information are provided.

Limitations: The downloading of some large files may require a significant amount of time.

Ryan White CARE Act Data

Title I and II Statewide HIV/AIDS Needs Report

Overview: Every 2 years, Ryan White Title I and Title II programs administer a detailed survey to persons living with HIV/AIDS in Louisiana. The purposes of the survey are to gain a greater understanding of the current level of HIV/AIDS service needs and to provide insight into consumers' perceptions of the availability and quality of HIV/AIDS services throughout the state. Representatives and consumers from Titles I and II jointly developed the methods and the instrument for the statewide needs assessment. The 2000–2001 survey included a variety of demographic questions (residence, age, race, gender, income levels and sources, and type of health insurance coverage), as well as questions about HIV-related primary care, illness severity, and experiences with combination therapy. Respondents were also asked specific questions about housing, transportation, child care, drug or alcohol abuse, and needs and opinions regarding various medical and social services. Each region in the state received a predetermined number of surveys according to the response goal (a minimum of 10% of persons known to be living with HIV/AIDS in a given region).

Population: Persons living with HIV/AIDS who agreed to complete the needs assessment survey. The sample population was weighted heavily toward persons who were in care (potential respondents were encountered in primary care clinics, social service agencies, community health centers, Medicaid enrollment centers, substance abuse or mental health treatment facilities, homeless or transitional shelters, and local jails). Most of the participants received services through the Ryan White–funded service delivery system, although some sought services at Veteran's Administration hospitals only, private clinics, or other private providers.

Strengths: The needs assessment is a valuable tool for understanding consumers' perceptions of care in Louisiana. The survey instrument is flexible and can be modified to accommodate new questions as services and care recommendations change.

Limitations: The survey was administered only to persons who visited one of the care sites during the 8 weeks in which the survey was administered. Respondents also had to be willing to participate in the survey. Persons who were not in care during that time, not in care at all, or who were unwilling or unable to complete the questionnaire were not surveyed. Thus, the survey provides a measure of the needs of persons who were receiving some type of care but does not adequately address the needs of those who were not seeking care at all. Because the survey also deals with perceptions of care, many of the responses are qualitative and cannot be generalized to the statewide population.

Ryan White Title I CAREWare

Overview: Since 1993, the HIV/AIDS Program of the Louisiana Office of Public Health has collected data on persons served through Louisiana Ryan White Title I funding. Until 1999, data for Consortia-funded services were collected through the DOS-based ToolBox data collection system provided by the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA). This data collection system was not designed to obtain information about persons who received pharmaceuticals through the state-administered AIDS Drug Assistance Program. In 1996, the HIV/AIDS Program contracted with a local computer programmer to design and implement a comparable data system for persons receiving funds through ADAP. In late 1999, the ToolBox data collection system became obsolete because of “Y2K” noncompliance. The ADAP data collection system was then expanded into a more comprehensive database that was named Louisiana CAREWare.

This database includes key information on all persons receiving assistance through any of the programs funded by Ryan White Title II as well as through programs funded by State Formula HOPWA. Such programs include Health Insurance Continuation, Home-Based Care, Consortia-funded Services (e.g., case management, transportation and medication assistance, child care, mental health therapy counseling); pharmaceuticals provided through ADAP; State Direct Services (legal services, 3 primary care contracts and a copayment and deductible assistance program); and limited emergency rent, mortgage and utility payments. Information collected from service providers throughout the state includes basic demographic and risk information on each of the clients, eligibility verification data (current address, current income, HIV/AIDS diagnosis, Louisiana Medicaid number), the type of services received, the date and quantity of services received, the cost of these services, and other pertinent information (history of substance abuse or mental health treatment, veteran status and, for women, current pregnancy status). The data collected are used by the HIV/AIDS Program staff to perform monthly service delivery and fiscal monitoring activities, conduct an annual disparity analysis, track regional utilization trends for quality assurance purposes, and to meet the HAB/HRSA requirements set forth in the Annual Administrative Report and in the new CADR. It is also the expectation of the HIV/AIDS Program that providers use these data internally to consistently assess and reassess their agency’s performance.

Population: All HIV-infected persons receiving services funded by Ryan White Title II. To be eligible for Ryan White Title II services, a person must be living with HIV/AIDS, be a resident of Louisiana, and have an income that is equal to or less than 200% of the current year’s federal poverty level. The only exception is the Health Insurance Continuation Program, for which financial eligibility may be as high as 300% of the federal poverty level.

Strengths: CAREWare is a comprehensive database that includes key fields of information on all persons receiving Ryan White Title II services. The CAREWare database is an important tool for monitoring which Ryan White resources are being used, how often, and by whom. CAREWare is now the model data collection system provided

to grantees free of charge by the HIV/AIDS Bureau at HRSA. It has been modified specifically for the HIV/AIDS Program. Louisiana CAREWare also provides opportunities to review information on comorbidity and to track the changing needs of the client population from year to year. The program is able to eliminate duplicate records of clients in a particular service or service area and can also eliminate duplicate records of clients of all services and in all geographic regions. This provides a more accurate picture of how many people seek care through services provided by Ryan White Title II.

Limitations: The Louisiana CAREWare data are provided or downloaded monthly; therefore, it is not a “real time,” or Web-based, data collection system. In addition, the customized fields established for Louisiana CAREWare make future versions of this database provided by HAB/HRSA incompatible with the system the HIV/AIDS Program has developed. The data in Louisiana CAREWare also cannot be generalized to all HIV-infected persons living in the state because it collects data only on persons who (1) know their HIV serostatus, (2) are not eligible for health coverage through private insurance or Louisiana Medicaid, (3) are currently seeking care and treatment services through Ryan White Title II–funded providers, and (4) are financially eligible to receive services. Historically, the population data in the Louisiana CAREWare database have comprised approximately 30% of persons known to be living with HIV/AIDS in the state.

