

## Appendix A: Profile Data Sources

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### AIDS Surveillance

**Overview:** AIDS is a reportable condition in all states and territories. AIDS cases have been reportable since the early 1980s and cases have been defined according to the Centers for Disease Control and Prevention's (CDC) case definition. In Ohio, physicians are required to report diagnoses of AIDS. In addition, reporting laws were expanded in 2002 to include laboratory and physician reporting of CD4 T-lymphocyte cell counts of less than 200 or 14 percent. The AIDS surveillance system was established to monitor incidence of the disease and the demographic profile of the AIDS cases; describe the modes of HIV transmission among persons diagnosed 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 reports are used; these forms are used to collect socio-demographic information, mode of transmission, laboratory and clinical information, vital status and referrals for treatment services.

**Population:** All persons who 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 impact of AIDS on a community and trends of the epidemic in a community. AIDS surveillance has been determined to be >85 percent complete. The data include all demographic groups (age, race/ethnicity, gender).

**Limitations:** Due to the long 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, widespread use of HAART 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 progression of HIV infection to AIDS. AIDS cases represent late-stage HIV infections.

### HIV Surveillance

**Overview:** Reporting of HIV infections to local health authorities as an integral part of AIDS surveillance has been recommended by CDC and other professional organizations since the human immunodeficiency virus was identified and a test for HIV was licensed. As part of ongoing active HIV surveillance, health departments educate providers on their reporting responsibilities, establish liaisons with laboratories conducting CD4+ lymphocyte cell analysis and EIA and Western Blot testing and follow up upon HIV cases of epidemiologic importance.

Ohio law requires physicians to report diagnoses of HIV infection, perinatal transmission to HIV and subsequent seroreversion. Laboratories are required to report lab finding indicating HIV

infection. In addition, laboratories are required to report a CD4+ T lymphocyte count below 200 cells per microliter or a CD4+ T lymphocyte percentage of less than 14 when HIV infection has not been ruled out as the cause.

**Population:** All persons who test positive for the Human Immunodeficiency Virus (HIV).

**Strengths:** HIV surveillance data represent more recent infection, compared with AIDS surveillance data. Based upon state evaluations, HIV infection reporting is estimated to be >85 percent 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) that may not be evident from AIDS surveillance. HIV surveillance provides the 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 in an anonymous test site and have not sought medical care, where they would be confidentially tested, are not eligible to be reported to the surveillance system. HIV surveillance data represent infections in jurisdictions where reporting laws for HIV are in place. Reporting of behavioral risk information may not be complete.

## **Behavioral Risk Factor Surveillance System (BRFSS)**

**Overview:** The BRFSS is a state-based, random-digit dialed telephone survey that monitors state-level prevalence of the major behavioral risks among adults associated with premature morbidity and mortality. Each month, a sample of households is contacted and one 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. Since 1994, the BRFSS questionnaire has asked questions related to HIV/AIDS of 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 post-HIV test counseling; attitudes toward condoms; and attitudes about when to initiate HIV/AIDS education in school. As of 2001, respondents have been asked about their perception of the importance of HIV testing.

**Population:** All non-institutionalized adults, 18 years and older that 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. BRFSS respondents are contacted by telephone, thus the data are not representative of households without a telephone. In addition, BRFSS data are representative of the general

non-institutionalized 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.

## HIV Counseling and Testing System (CTS)

**Overview:** All states, territories and select cities receive funding to support HIV counseling, testing and referral programs as part of the HIV prevention cooperative agreements they have entered into with CDC. To monitor these programs, the CTS collects information to quantify and characterize counseling and testing services delivered at CDC-funded testing sites. Data captured include demographic, insurance, risk information, testing information (testing history, test result). Personal identifying information is not collected.

**Population:** All clients who receive confidential or anonymous HIV counseling and testing services at a counseling and testing 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 in an area's high-risk population. CTS testing data may highlight the impact of a prevention program upon the populations being targeted.

**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. Population estimation of HIV seroprevalence is not possible with CTS data because data are test-based. In test-based systems, it is not possible to distinguish individuals who have been tested multiple times; however a 'previous HIV test' variable is available on the client abstract form to quantify prior testing. Because the CTS system gathers data on HIV testing or program activities, changing testing patterns may reflect changing program priorities rather than testing patterns of individuals.

## National Household Survey of Drug Abuse

**Overview:** The National Household Survey of Drug Abuse (NHSDA) is an ongoing source of statistical information on the use of illicit drugs by the U.S. civilian population aged 12 or older. The survey collects data by administering questionnaires to a representative sample of the population through face-to-face computer-assisted interviewing (CAI) method at their place of residence. Information captured by the NHSDA questionnaire includes use of cocaine; receipt of treatment for illicit drugs and need of treatment for illicit drugs during the past year; use of alcohol, tobacco, or marijuana during the past month; and past month perceived risk of binge drinking, marijuana use or smoking during the past month.

The NHSDA employed a 50-state sampling design; for the eight states with the largest populations, the sampling design provides the sample large enough to support direct state estimates. Youths and young adults were over-sampled so that each state's sample was approximately equally distributed among three major age groups: 12-17 years, 18-25 years and 26 years or older.

**Population:** Noninstitutionalized, civilian U.S. population ages 12 years or older.

**Strengths:** National standardized survey of drug use behaviors among the general population. To increase the level of honest reporting, since 1999 information has been collected 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:** 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 are subject to recall bias and may under-report the level of a sensitive behavior.

## Ohio HIV Drug Assistance Data

**Overview:** HIV CARE Services Section (HCS) collects information on HIV-positive persons enrolled in Ohio HIV Drug Assistance Program (OHDAP) or Health Insurance Premium Payment (HIPP) program. Demographic information, program enrollment history, insurance information and some medical information are available from 1998 on clients enrolled in the programs. In October 2001, the Medicaid Spenddown Payment program was established under HIPP.

**Population:** HIV-infected persons living in Ohio who meet the eligibility requirements of the programs.

**Strengths:** These data represent the persons utilizing payment assistance for their medication, private insurance and public insurance. Demographic information is close to 100 percent complete.

**Limitations:** Interpretation of these data is limited to those who meet the eligibility requirements of the programs.

## Ryan White Title II Case Management Program Data

**Overview:** The Ryan White Title II Case Management Program data contain information on clients using case management services, emergency financial assistance and home health. They include applicants' demographic information, their program history and claims utilization. There are no names with the data, but each client is differentiated by a unique identifier. Data are entered by a third-party administrator who provides a monthly data file to HCS in the Ohio Department of Health.

**Population:** Persons who are HIV-infected who are receiving case management and persons who are HIV-infected and are eligible to receive financial assistance in the State of Ohio.

**Strengths:** The data contained by the database allow comparison between those that are receiving only case management services versus those that are receiving emergency financial assistance. It also contains service utilization information for those using emergency financial assistance and home health services.

**Limitations:** Data are limited to those who are HIV-infected and are receiving case management services, financial assistance or home health services. It is a challenge to unduplicate clients when there are data entry errors because of the anonymity of the data. If updates on clients are not sent by case management agencies, the status of the client in the program may be inaccurate; therefore the number of people in the various programs may not be accurate.

## **Sexually Transmitted Disease Case Reporting**

**Overview:** Surveillance activities are conducted to monitor the levels of syphilis, gonorrhea and chlamydia to establish prevention programs, develop and revise treatment guidelines and identify populations at risk for STDs. Case report forms include information on patient demographics, type of infection and source of report (private or public sector).

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

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

**Limitations:** STDs are reportable, but requirements for reporting vary across states. 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.

## **U.S. Bureau of the Census (Census Bureau)**

**Overview:** The Census Bureau collects and provides timely information about the people and economy of the United States. The Web site for the Census Bureau includes data on the 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:** U.S. population.

**Strengths:** A wide range of online statistical data on the U.S. population are 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 take longer to download.

## Vital Records-Death Data

**Overview:** In the United States, state laws require death certificates to be completed for all deaths and federal law mandates national collection and publication of deaths. A standard certificate of death is used to record death information on each decedent.

**Population:** All deaths occurring within Ohio.

**Strengths:** Reporting of deaths is 100 percent complete. The data are widely available and can be used to determine the impact of deaths related to HIV infection 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 under reported on the death certificate. Clinical information related to HIV or AIDS may be missing. Death records are less timely than AIDS case reports.

## Youth Risk Behavior Surveillance System

**Overview:** The Youth Risk Behavior Surveillance System (YRBSS) was established to monitor six priority high-risk behaviors that contribute to 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. Using a self-administered questionnaire, YRBSS collects information on six categories of behaviors, of which sexual behaviors that contribute to unintended pregnancy and STDs, including HIV, is one. Questions are also asked about transmission to HIV prevention education materials, sexual activity (age of onset, number of partners, condom use, preceding drug or alcohol use), contraceptive use and pregnancy history.

**Population:** YRBSS is a representative sample of ninth through 12<sup>th</sup> grade students.

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

**Limitations:** The YRBSS projects rely on upon self-reported information; reporting of sensitive behavioral information may not be accurate (under-or over-reporting may occur). Because the YRBSS questionnaires are administered in high schools, the data are representative only of adolescents who are enrolled in school and cannot be generalized to all young people. Questions that ask 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. In addition, the questionnaire does not ask about homosexual or bisexual behavior or experiences.

## Appendix B: Glossary of Terms

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**Adjustments:** Statistical calculations that allow the comparison of different groups (when the difference may affect what you are studying) as though they are alike. Differences in populations or subgroups make it difficult to make comparisons; adjustments remove the influence of a specific factor (e.g., age, gender, race or disease status) from the analysis.

**AIDS (Acquired Immune Deficiency Syndrome):** The condition that results from HIV infection and is marked by the presence of opportunistic infections that do not affect persons with healthy immune systems.

**Behavioral data:** Data collected from studies of human behavior that are relevant to disease risk. Relevant behaviors for HIV risk may include sexual activity, substance use, sharing of drug paraphernalia, condom use or responses to primary and secondary prevention messages.

**CARE Act (Ryan White Comprehensive AIDS Resources Emergency Act):** The primary federal legislation created to address the needs for health and support services among persons living with HIV/AIDS and their families in the United States; enacted in 1990 and reauthorized in 1996.

**Case:** A condition, such as HIV infection (e.g., an HIV case) or AIDS (e.g., an AIDS case) diagnosed according to a standard case definition.

**CDC:** The Centers for Disease Control and Prevention (CDC), within the U.S. Department of Health and Human Services, is the lead federal agency for protecting the health and safety of the people of the United States. CDC accomplishes its mission through developing and applying disease prevention and control, environmental health and health promotion and education activities designed to improve public health in the United States. The CDC provides majority of funding for HIV prevention and HIV surveillance activities in Ohio.

**Community Planning Group:** A group of persons who represent, or have interests in, a given community and who work in partnership with health departments to design local prevention plans to meet the needs of persons at risk for, or infected with, HIV.

**Co-morbidity:** The co-existence of a disease or illness and HIV infection in one person (e.g., an HIV-infected person who also has TB).

**Confidentiality:** The treatment of information that an individual or institution has disclosed in a relationship of trust, with the expectation that the information will not be divulged to others in ways that are inconsistent with the individual's or institution's understanding when the individual or institution provided the information. It encompasses access to and disclosure of, information in accordance with requirements of state law or official policy. For HIV/AIDS surveillance data, confidentiality refers to the protection of private information collected by the HIV/AIDS surveillance system.

**Eligible Metropolitan Area (EMA):** A metropolitan statistical area that qualifies for Title I funding by reaching a certain threshold of AIDS cases. EMAs may cover one city, several cities or counties or more than one state.

**Epidemiology:** The study of the distribution and the determinants of health-related states or events in specified populations and the application of this study to the control of health problems.

**Epidemiologic profile:** A document that describes the HIV/AIDS epidemic in various populations and identifies characteristics both of HIV-infected and HIV-negative persons in defined geographic areas. It is composed of information gathered to describe the effect of HIV/AIDS on an area in terms of sociodemographic, geographic, behavioral and clinical characteristics. The epidemiologic profile serves as the scientific basis from which HIV prevention and care needs are identified and prioritized for a jurisdiction.

**Estimate:** In situations in which precise data are not available, an estimate may be made on the basis of available data and an understanding of how the data can be generalized to larger populations. In some instances, national or state data may be statistically adjusted to estimate local conditions. Good estimates are accompanied by statistical estimates of error (a confidence interval), which describes the limitations of the estimate.

**Federal Poverty Level (FPL):** Families and persons are classified as below poverty if their total family income or unrelated individual income was less than the poverty threshold specified for the applicable family size, age of householder and number of related children under 18 present.

**HIV (Human Immunodeficiency Virus):** The virus that causes AIDS. Persons with HIV in their immune system are referred to as HIV-infected.

**HIV Care Consortia:** An association of public and private nonprofit providers of health support services and community-based organizations that plans, develops and delivers services for people living with HIV. The CARE Act authorizes states to use Title II funds to establish consortia in “areas most affected by HIV disease.”

**HIV primary medical care:** Medical evaluation and clinical care that is consistent with U.S. Public Health Service guidelines for the treatment of HIV/AIDS.

**HIV/AIDS Surveillance:** The systematic collection, analysis, interpretation, dissemination and evaluation of population-based information about persons with a diagnosis of HIV infection and persons with a diagnosis of AIDS.

**Incidence:** The number of new cases in a defined population during a specific period, often a year, which can be used to measure disease frequency. It is important to understand the difference between HIV incidence and reported HIV diagnoses. Because the results of anonymous tests are not included and therefore not all diagnoses of HIV infection are included, HIV surveillance data do not represent incident cases.

**Incidence rate:** The number of new cases in a specific area during a specific period among persons at risk in the same area and during the same period. Incidence rate provides a measure of the effect of illness relative to the size of the population. Incidence rate is calculated by dividing in the specified period by the population in which cases occurred. A multiplier is used to convert the resulting fraction to a number over a common denominator (often 100,000).

**Interpretation:** The explanation of the meaning of the data. For example, interpreting a trend in the number of HIV cases diagnosed during a five-year period enables a planning group to

assess whether the number of cases has increased or decreased. However, groups should use caution in interpreting trends that are based upon small increases or decreases.

**Line graph:** A type of figure used to display the changes in a particular variable over time. Values are recorded periodically as points on the graph and then connected as a line to show a trend.

**Mean:** The sum of individual values in a data set divided by the total number of values. The mean is what many people refer to as an average.

**Median:** The middle value in a data set. Typically, approximately half the values will be higher and half will be lower. The median is useful when a data set has unusually high or unusually low values, which can affect the mean. It is also useful where data are skewed, meaning that most of the values are at one extreme or the other.

**Morbidity:** The presence of illness in the population.

**Mortality:** The total number of persons who have died from the disease of interest. Usually expressed as a rate, mortality (total number of deaths over the total population) measures the effect of the disease on the population as a whole.

**Needs assessment:** The process of gathering and analyzing information from a variety of sources to determine the current status and the unmet needs for HIV prevention or care among a defined population or in a geographic area.

**No identified risk (NIR):** Cases in which epidemiologic follow up has been conducted, sources of data have been reviewed – which may include an interview with the patient or provider – and no mode of transmission has been identified. Any case that continues to have no reported risk 12 or more months after the report date is considered NIR.

**No reported risk (NRR):** Cases in which risk information is absent from the initial case report because the information had not been reported by the reporting source, had not been sought or had not been found by the time the case was reported. Cases may remain NRR until epidemiologic follow up has been completed and potential risks (transmissions) have been identified. If risk has not been identified within one year of being reported as NRR, the case may be considered NIR.

**Percentage:** A proportion of the whole, in which the whole is 100.

**Prevalence:** The total number of cases of a disease in persons not known to have died in a given population at a specific point in time. Prevalence does not indicate how long a person has had a disease and cannot be used to calculate rates of disease. It can provide an estimate of risk for a disease at a point in time. For HIV/AIDS surveillance, prevalence refers to living persons with HIV disease, regardless of time of infection or date of diagnosis. Note the difference between prevalence of a condition in the population and the prevalence of cases, namely, that a case must be diagnosed according to a definition.

**Proportion:** A portion of a complete population or data set, usually expressed as a fraction or percentage of the population or data set.

**Range:** The largest and smallest values in a data set.

**Rate:** A measure of the frequency of an event or disease compared with the number or persons at risk for the event or disease.

**Ratio:** A way of showing the relative size of two numbers. The first number is divided by the other number to derive the ratio. The ratio may be expressed as a fraction (e.g. 2/3), or the two numbers may be separated by a colon (X:Y).

**Reporting delay:** The time between when a diagnosis of HIV infection or AIDS and the time the report is received by the health department.

**Representative:** A sample that is similar to the population from which it is drawn and thus can be used to draw conclusions about the population.

**Sample:** A group of people selected from a total population with the expectation that studying this group will provide important information about the total population.

**Sociodemographic factors:** Background information about the population of interest (e.g., age, sex, race, educational status, income, geographic location). These factors are often thought of as explanatory because they help us to make sense of the results of our analyses.

**Socioeconomic status (SES).** A measure of social and economic factors that helps to describe a person's standing in society (e.g. income levels, relationship to national poverty line, educational achievement, neighborhood of residence, home ownership).

**Title I (CARE Act):** Provides formula and supplemental grants to EMAs that are disproportionately affected by the HIV epidemic.

**Title II (CARE Act):** Provides formula grants to states, the District of Columbia, Puerto Rico and eligible U.S. territories to improve the quality, availability and organization of health care and support services for people living with HIV and their families.

**Trend:** A long-term movement or change in frequency, usually upward or downward; may be presented as a line graph.

**Year of diagnosis:** The year in which the diagnosis of HIV infection or AIDS was made.

**Year of report:** The year in which a person with a diagnosis of HIV infection or AIDS was reported to the health department.

## Contact Information

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### **HIV CARE Services Program**

(614) 466-6374

<http://www.odh.ohio.gov/ODHPrograms/AIDS/aids1.htm>

### **HIV Counseling and Testing Systems (CTS) Data**

(614) 466-1388

### **HIV/STD Prevention Program**

(614) 644-1838

<http://www.odh.ohio.gov/ODHPrograms/HIVSTD/hivstd1.htm>

### **HIV/AIDS Surveillance Program**

(614) 466-1388

[http://www.odh.ohio.gov/Data/Inf\\_Dis/hivcov.htm](http://www.odh.ohio.gov/Data/Inf_Dis/hivcov.htm)

### **STD Surveillance Program**

(614) 466-1388

[http://www.odh.ohio.gov/Data/Inf\\_Dis/STD/Std1.htm](http://www.odh.ohio.gov/Data/Inf_Dis/STD/Std1.htm)