

## CHAPTER 2: DATA SOURCES

Surveillance data are collected to describe the demographic and geographic determinants of the HIV/AIDS epidemic in terms of incidence, prevalence, and mortality. Active surveillance not only identifies the magnitude of the medical, economic, and social impacts of the HIV/AIDS epidemic, but it also helps in the process of describing the community's needs, and then developing, targeting, and evaluating both prevention and treatment programs based on those needs. Surveillance and epidemiologic data also serve to guide decisions about policy development and planning for services and resource allocation.

### AIDS Case Reporting System

The Maryland Department of Health and Mental Hygiene (DHMH), AIDS Administration maintains the HIV/AIDS Reporting System (HARS), a confidential, name-based registry of all AIDS cases who have ever lived in or received care within Maryland. Primary case reporting is conducted by health care providers and facilities. Secondary case reporting is performed by the state and local health departments through reviews of death records, hospital discharge summaries, tuberculosis registries, cancer registries, Medicaid claims files, AIDS drug assistance program records, and laboratory reporting of low CD4+ cell counts.

All AIDS cases are reported to the AIDS Administration using a uniform surveillance case definition and case report form provided by the CDC. There are two types of AIDS case definitions and AIDS case report forms: one for adult and adolescent cases (13 years of age or older at time of diagnosis) and another for pediatric cases (less than 13 years of age at time of diagnosis). The fol-

lowing information is collected on the case report forms:

- a) Patient name, address, and social security number;
- b) Patient demographics (i.e. gender, race/ethnicity, birth date, death date when applicable);
- c) Facility of diagnosis (i.e. name, location, type);
- d) Patient history (i.e. mode of exposure);
- e) Maternal history (pediatric cases only);
- f) Laboratory data (i.e. testing methods and results);
- g) Clinical status (i.e. AIDS indicator diseases);
- h) Birth history (pediatric cases only); and
- i) Treatment and services referrals.

The AIDS case report forms are reviewed for completeness, and if necessary the provider is contacted for any additional information. Determination of Maryland residence at the time of initial AIDS diagnosis is done in conjunction with other states and the CDC. State and national death databases are routinely searched to confirm the vital status of all previously reported cases.

The HARS database includes all AIDS cases that have been reported to the Maryland state health department. In addition, HARS includes (up until December 2001) HIV (non-AIDS) infected cases with symptomatic conditions. This report describes HIV and AIDS patients who were residents of Maryland at the time of diagnosis.

## HIV Case Reporting System

Though AIDS data remain useful for health care and service planning, they do not provide sufficient information for guiding future HIV prevention efforts. Before 1996, the median time from HIV infection to AIDS was about ten years. Since 1996, the median time from HIV infection to AIDS has increased due to the availability of antiretroviral therapy and improved prophylaxis against opportunistic infections. As improvements in treatment have occurred and the time from HIV infection to AIDS diagnosis has increased, the surveillance of HIV cases has become increasingly important. To understand the full spectrum of HIV disease, it is important to continue obtaining accurate surveillance information about the incidence and prevalence of HIV infections as well as AIDS cases.

In addition to HARS, the Maryland DHMH AIDS Administration maintains a registry of all HIV positive non-AIDS cases, by Unique Identifier (UI), who have lived in Maryland and have received a positive HIV test in Maryland since June 1, 1994. The code-based reporting system provides an anonymous registry of HIV infected individuals in Maryland. The UI is a 14 digit number consisting of the last four digits of the individual's Social Security number, eight digits of the individual's date of birth, one digit representing the individual's race/ethnicity, and one digit representing the individual's gender.

The UI elements were selected to ensure anonymity while enabling the health department to describe the pattern of disease. The UI number, when complete, is 99.987% unique (Solomon, 1999). Therefore, it is unlikely that a single, complete UI number would refer to more than one individual.

Maryland's HIV surveillance system is laboratory-based. The provider who orders an HIV, CD4+, or HIV viral load test is responsible for generating the UI number and sending it to the laboratory with the requisition. Medical laboratory directors both in and out of state are required to submit a Laboratory Reporting Form to the state health department to report all confirmed HIV positive infections, CD4+ lymphocyte counts less than 200 cells/ $\mu$ l, and any HIV viral load test results for Maryland residents by UI. Alternatively, labs can send Laboratory Reporting Forms to the local health departments, where the forms are then forwarded to the state health department. The Laboratory Reporting Form contains the following information:

- a) Unique Identifier (UI);
- b) ZIP code of patient's residence;
- c) Type of laboratory test and result;
- d) Name and address of the laboratory or assigned laboratory number;
- e) Health care provider's name, address, and telephone number;
- f) Date the test specimen was obtained from the patient; and
- g) Name and phone number of the person completing the form.

All low CD4+ test results reported are routinely matched by UI to the AIDS case registry. Low CD4+ tests that do not match existing cases in the registry are investigated as potential new AIDS cases. All HIV viral load tests reported are routinely matched by UI to the HIV and AIDS case registries. HIV viral load tests that do not match existing cases in the registries are investigated as potential new HIV or AIDS cases.

HIV positive test results with complete UIs or UIs missing only race and/or gender are matched to both the HIV registry and the

AIDS registry to produce unduplicated HIV incidence estimates that are then adjusted to account for tests with incomplete UI numbers. HIV positive tests that do not match existing cases in the registries are investigated to confirm HIV status and to collect information on mode of HIV exposure. Systematic collection of information on mode of HIV exposure began in 1998 and is available yet incomplete (34.6% of all new HIV cases detected in 2004 had an identified mode of exposure by June 2005).

There are three known reasons for why the data for HIV cases are not complete and may not accurately represent the demographics of the entire population of HIV cases. First, Maryland borders on four other states and the District of Columbia, and border crossing for health care and HIV testing is not captured. Second, individuals who tested positive prior to June 1994 and have not been tested since then are not included in the Maryland HIV registry until they are either re-tested or develop AIDS. Third, the CDC estimates that 25% of all HIV infected people in the U.S. are unaware that they are infected (CDC, 2003).

### **HIV Reporting System Evaluation**

The HIV reporting system was evaluated using four criteria: the uniqueness of the UI, the completeness of the UI, the completeness of reporting, and the accuracy of matching the UI from one database to another. Details of this evaluation were reported in the *Journal of AIDS* (Solomon, 1999) and are summarized here. The UI was applied to the name-based AIDS registry and duplicate UIs were investigated. Eight pairs of records with duplicate UIs were found to be the same person with two different names in the AIDS registry. Only two pairs of records were found to be different individuals sharing the same UI. Based on this, the uniqueness of the UI for AIDS cases

was found to be 99.987%. Overall completeness of the UI reported by laboratories started at 55% in 1994 and increased to 63% in 1998. Completeness of the individual components of the UI varies. In 1998, gender was reported 99% of the time, date of birth was reported 98% of the time, race/ethnicity was reported 80% of the time, and the last four digits of the Social Security number were reported 77% of the time.

Completeness of reporting was evaluated in two studies. The first examined all CD4+ less than 200 cells/ $\mu$ l tests reported to the AIDS registry through routine surveillance medical record reviews in a one-year period (1996) and verified that they were reported through laboratory reporting. Eighty-five percent of the tests in the AIDS registry were matched to laboratory reports by UI. The second evaluation examined all HIV positive individuals identified through confidential Counseling, Testing and Referral (CTR) sites in a one-year period (1997) and verified that they were reported through laboratory reporting. Eighty-eight percent of the positive tests in CTR were matched to laboratory reports by UI.

The accuracy of matching was assessed by investigating all CTR tests from one county that shared the same UI with another CTR test in the same or any other county in Maryland (201 tests). Testing consent forms were reviewed (95% located) to confirm the identity of the person testing. In all cases of multiple tests, both within the county and across different counties, the names either matched perfectly or varied with an explanation provided by clinic staff (i.e. surname change due to marriage).

More recently, the CDC provided data that permitted an overall outcome evaluation. Since not all states were performing name-based HIV case reporting, the CDC used data from the 25 states that were performing

both HIV and AIDS name-based reporting to generate estimates of HIV cases using a state's AIDS cases. The estimate released in 1999 for Maryland was 10,714 non-AIDS HIV adolescent and adult cases. At that time, the Maryland HIV surveillance system was reporting 10,749 HIV cases, an agreement of 99.7%.