

*Strengths:* These data are useful in estimating the completeness of reporting of HIV-related mortality, measuring migration patterns, and changing patterns of terminal care with death certificate data from a large sample of persons with AIDS.

*Limitations:* Data collection is dependent on the delay in reporting of death certificate information of 1-2 years. Project also reflects accuracy of cause-of-death information on death certificates.

#### **4.2.3.4 Pediatric Spectrum of Disease Project**

*Stated Objectives and Overview:* Much remains to be learned about the pediatric HIV epidemic in the United States. AIDS surveillance is critical in providing information on children meeting the AIDS surveillance case definition. In states with HIV reporting, brief information is now available on all children identified as infected. Further information comes from prospective clinical studies such as those conducted by the AIDS Clinical Trials Groups. These projects, however, are capable of following only a small portion of the infected children. Thus, there is a need for a more thorough and broad-based description of HIV-related illness in children.

To address this need, CDC instituted a multi-center, active surveillance project in 1988. The goals of this project are to: 1) describe the demographic characteristics of HIV-exposed children; 2) describe the spectrum of morbidity and causes of mortality among these children; 3) assess when and why children are initially evaluated for HIV infection; and 4) describe what constitutes standard medical care.

Data are collected on a standard data collection form, entered into a CDC-designed software system at each site that allows local analyses, and forwarded to CDC without personal identifiers. Detailed instructions and intensive support help to ensure uniformity in data abstraction across sites. The information collected on each child initially and every 6 months afterward includes: demographic characteristics; mode of HIV exposure; diseases in the 1987 AIDS surveillance case definition and the Pediatric HIV Classification System; laboratory data; treatment and prophylaxis for HIV and specific related conditions; and causes of death when applicable. Documentation of immunizations is obtained from inpatient and outpatient records. Information on individual hospitalizations is collected on the follow-up forms for each 6-month period.

*Target Population:* All children under 13 years of age, who were HIV-infected or born to infected mothers and who had been seen at one of the participating institutions are eligible for inclusion. Children who are eligible for inclusion are identified by contact with key practitioners at each hospital. Project personnel visit the participating institutions on a regular basis to identify children eligible for the project.

*Funded sites:* Los Angeles County Department of Health; the New York City Department of Health; the Texas Department of Health (Houston, Dallas, and San Antonio); the Massachusetts Department of Health; Children's National Medical Center, Washington DC; and Stanford University, Palo Alto CA.

*Strengths:* The project: 1) provides a high quality and large quantity of data available on a sample of children exposed to HIV; 2) allows for active surveillance in hospitals, where 23% of 1991 pediatric AIDS cases were reported; and 3) enables the tracking of trends over time, including changes in clinical practice in response to published guidelines (e.g., PCP prophylaxis guidelines).

*Limitations:* Data are obtained by abstraction of the medical records; therefore, information not documented in the medical record is not obtained. The rural population of HIV-exposed children is not well represented.

**Note:** Due to the increase in tuberculosis among the population at risk for HIV, this project has recently added questions to the data collection form to determine the prevalence of TB skin testing and the incidence of TB diagnosis among children enrolled. Additional funding has been allocated to the New York City site to conduct further surveillance for TB disease.

#### **4.2.3.5 The Adult and Adolescent Spectrum of Disease (ASD) Project**

*Stated Objectives and Overview:* The primary objectives of the ASD Project are to enumerate and characterize persons with HIV infection at various stages of immunologic function who receive medical care at selected inpatient and outpatient facilities. Information is collected on AIDS-defining conditions, other illnesses and symptoms,