

Council of State and Territorial Epidemiologists  
Position Statement

**04-ID-05**

**Committee:**     **Infectious Disease**

**Title:**           **Development of population-based HIV/AIDS clinical surveillance**

**Statement of the Problem:**

Surveillance of HIV infection in the United States began in 1981 as surveillance for cases of *Pneumocystis carinii* pneumonia and Kaposi's Sarcoma, and rapidly developed into surveillance for AIDS cases as defined by a wider range of opportunistic illnesses. The HIV/AIDS surveillance system evolved over the next two decades, resulting in several refinements of the case definition; these refinements were in response to diverse factors including improved diagnostic and prognostic tests, increased recognition of the spectrum of HIV-related disease, improving therapies, and changes in funding for both surveillance for AIDS and treatment of HIV-related disease. The data from the HIV/AIDS surveillance system have been used for varied purposes including planning of prevention and treatment activities, development of treatment guidelines, resource advocacy, responding to Ryan White CARE Act (RWCA) reporting requirements, and allocation and prioritization of available resources within communities.

Supplementary HIV/AIDS surveillance systems have been implemented in many states and large city health departments since the early 1990s. Two of these are the Adult and Adolescent Spectrum of HIV Disease Project (ASD) and the Supplement to HIV/AIDS Surveillance (SHAS). ASD is a facility-based observational cohort study implemented in 10 US cities in 1990 as a supplemental surveillance system to study the natural history of HIV disease, and to collect information on clinical outcomes (e.g., AIDS-OIs, other illnesses, and prescribed therapeutic regimens) of people with HIV infection who were in care. SHAS is a cross-sectional interview project for persons living with HIV infection initiated in 1990 and currently conducted in 19 US states.

The ASD and SHAS projects are ending as of June 30, 2004. A replacement clinical outcomes project for ASD and SHAS has been developed by CDC, considering the strengths and limitations of the previous study designs and their reach. The new project, called the Morbidity Monitoring Project, is meant to make clinical outcomes surveillance data available in more project areas; to improve the representativeness of supplemental surveillance data on the local and national levels; to allow collection of both interview and chart abstraction data on the same persons, in order to address new high-priority questions about quality of care and prevention; and to include persons known to be HIV infected but not in care in supplemental surveillance projects.

ASD and SHAS have provided information useful for understanding the epidemic in its various stages in many states and cities. However, increasing numbers of cities and states have become heavily impacted by the epidemic and need data that represent their own jurisdictions. Data from the large cities historically funded for supplemental surveillance projects no longer credibly represent an epidemic which has spread so widely.

All sites in the ASD project and many SHAS sites also have a significant limitation in that their data are from a convenience sample of facilities or patients. This limits the generalizability of the data collected, and may introduce significant biases to analyses of quality of care.

Additionally, new issues have emerged as critical elements of understanding prevention and care for people living with HIV infection. To understand these emerging issues, such as quality of HIV-related ambulatory care, adherence to antiretroviral medications, and the need for HIV-related prevention, care and support services, both chart abstraction and interview data from the same persons are needed.

Finally, both ASD and SHAS are focused on obtaining information from persons already receiving care for HIV. It is estimated that half of the persons diagnosed with HIV in the United States are not receiving medical care for their HIV disease. For persons not in care for HIV infection, data are needed on demographics, risk behaviors, and resource needs, as well as reasons for not seeking care.

Council of State and Territorial Epidemiologists  
Position Statement

The proposed design for the Morbidity Monitoring Project is a probability sample of persons in care for HIV infection, based on a 3-stage sampling technique. A similar sample of persons not in care for HIV infection will be drawn using a 2-stage sampling method. The nature of the probability sample design is that all US states were given a chance for inclusion in the project, with the probability of selection proportional to number of prevalent AIDS cases in the state. The proposed design for the Morbidity Monitoring Project is a probability sample of persons in care for HIV infection, based on a 3-stage sampling technique. A similar sample of persons not in care for HIV infection will be drawn using a 2-stage sampling method. The nature of the probability sample design is that all US states were given a chance for inclusion in the project, with the probability of selection proportional to number of prevalent AIDS cases in the state. To optimize the integrity of the national sample, it is important that all states selected in the random sample of states participate in the project.

This proposed design for monitoring morbidity among HIV infected persons will provide more representative data at the state and national level. These data will provide an overall understanding of the HIV/AIDS epidemic at the state and national levels by providing information about co-morbid conditions, treatment and adherence to antiretroviral medications, access to and utilization of health care services, and social and behavioral factors. At the state level, these data can be used by HIV/AIDS care planning groups to assess met and unmet needs for care and to respond to RWCA reporting requirements, and by prevention program staff to deliver more targeted prevention activities

**Statement of desired action(s) to be taken:**

**CSTE recommends**

1. CDC should continue to move towards development and implementation of a nationally representative morbidity monitoring system in as many states as possible and sampling in such a way that all US states have a chance of inclusion in the project. CDC should coordinate development closely with HRSA, to ensure that data from the project may be maximally useful for RWCA reporting requirements. The project should include surveillance of people in care and not in care for HIV, to improve the availability and quality of data used for local prevention and care planning and national evaluation and resource advocacy.
2. CDC and HRSA should ensure that selected states have annual funding at levels sufficient to maintain collection of data that can be used for meaningful analysis at the local level. Funding levels should be high enough that the number of patients enrolled will allow both estimates of key parameters for the entire population in the state, as well as estimates of key parameters for important sub-populations, e.g., RWCA Title I eligible metropolitan areas. CSTE encourages states selected as part of the national sample of states for the new nationally representative Morbidity Monitoring Project to participate in the project, because non-participation of states will compromise the integrity of national estimates which will be used for resource advocacy at the national level.
3. CDC and HRSA should provide technical assistance, if requested, to participating states so that they can use the process of planning their local clinical outcomes project to engage with their local Ryan White and community planning programs. This will ensure that the new project will serve multiple planning and reporting needs in participating communities.
4. CDC and participating states should develop and implement methods to improve our understanding of the characteristics of persons not in care for HIV infection, in order to document unmet needs for care and treatment, and to understand barriers to accessing care for HIV infection.
5. States who are not selected for the Morbidity Monitoring Project but who wish to participate in the project to obtain clinical outcomes data for their state may consider using RWCA evaluation or administrative funds to support local activities. CDC should provide technical assistance to any state that wishes to participate in the project using local funding.

**Fiscal and Impact Statement:**

Fiscal impact — The additional costs for selected states for implementing the new program will be provided by cooperative agreement with CDC.

Impact on Public Health—The impact on the public's health by establishment of a national population-based HIV/AIDS clinical surveillance system will be positive. Accurate population-based data can be used to appropriately prioritize HIV prevention and treatment activities at both the local and national levels. Assessment of compliance with treatment recommendations will benefit patient outcomes and highlight areas for improvement. Risk assessment can help in developing effective and focused

Council of State and Territorial Epidemiologists  
Position Statement

prevention interventions. Accurate information on the population of persons infected with HIV who are not in care can inform decisions on service needs and reducing barriers to care. The overall impact will be to provide accurate data for informing decisions on increasing the number of persons with HIV who receive medical care, ensuring that care is of the highest standard, reducing the number of new HIV infections, and maximizing efficient use of resources.

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Council of State and Territorial Epidemiologists  
Position Statement

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