
# NATIONAL ASSESSMENT OF HIV/AIDS SURVEILLANCE CAPACITY

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## INTRODUCTION

### National Assessment of HIV Surveillance Capacity

Advances in medical therapies have contributed to longer lives for people with HIV. With HIV surveillance systems monitoring the progression of disease from diagnosis through death, HIV surveillance programs might receive data for many years on any one case and people in whom HIV infection is newly diagnosed are added to the system continuously. Despite increases each year in the number of individuals in the surveillance system, funding for HIV case reporting activities (e.g., identifying new cases, tracking disease status and indicators, de-duplicating cases, ascertaining death status) has not. During 2003–2007, total Centers for Disease Control and Prevention (CDC) funding to states, territories, and large cities for HIV case finding—referred to here as "core surveillance"—remained unchanged. CDC initiated a new cooperative agreement in 2008 and provided total funding of $35 million; however, states, cities, and territories requested $49 million.

To better describe the current resources, needs, infrastructure, and practices of U.S. HIV surveillance programs, the HIV Surveillance Coordinators and the Council of State and Territorial Epidemiologists (CSTE) conducted the National Assessment of HIV Surveillance Capacity in 2007. This report presents the findings from 47 of the 206 survey questions. These questions were selected because they address basic information about program functioning, including funding sources and amounts, level of morbidity (number of cases and rates), staffing, training needs, operations, and interactions with other programs in an agency.

### Overview of HIV Surveillance in the United States

Public health surveillance for HIV disease began in 1981 when CDC received early reports of clusters of cases of *Pneumocystis carinii* pneumonia and Kaposi sarcoma among gay men. Since then, state and local health departments have conducted HIV/AIDS surveillance in the United States in partnership with CDC. HIV surveillance in the United States now comprises different ongoing activities and limited supplemental surveillance projects in selected jurisdictions.

HIV case reporting is the principle component of HIV surveillance. All 50 states conduct core surveillance by requiring health-care providers and/or laboratories to report newly diagnosed cases of HIV/AIDS.

Since 1985, local and state health departments have collected and stored HIV case reports in a secure, computerized information system designed by CDC and known as the HIV/AIDS Reporting System (HARS). In 2005, CDC developed and began implementing a replacement system, the enhanced HIV/AIDS Reporting System (eHARS). CDC expects to complete replacement of HARS with eHARS in all 50 states and large independent city health departments by August 31, 2009 (CDC staff, personal communication). eHARS is a secure, relational database accessed by a Web browser that facilitates monitoring, review, and analysis of discrete events over time, appropriate to surveillance for the chronic infectious disease that HIV infection has become. CDC calls this new-style information system "document-based surveillance." eHARS is expected to facilitate periodic systematic surveillance evaluation. During 2007, when the National Assessment of HIV Surveillance Capacity was conducted, several states already were using eHARS, some were in the midst of conversion, and others continued to use HARS.

CDC supplements core HIV surveillance activities under separate cooperative agreements with some state and local health departments for HIV incidence, resistance, and clinical surveillance, as well as evaluation and behavioral surveillance studies. This report explores the number and distribution of these supplemental activities

and their impact on core surveillance in jurisdictions where they are ongoing. The contemporaneous, additional surveillance programs explored in this survey include HIV Incidence Surveillance, also know as Serologic Testing Algorithm for Recent HIV Seroconversion (STARHS); Variant, Atypical, and Resistant HIV Surveillance (VARHS) system; Capacity Building for Epidemiologic and Program Evaluation Activities; Enhanced Perinatal Surveillance; National HIV Behavioral Surveillance System; Medical Monitoring Project, Never in Care Project; and Evaluating Integration of HIV/AIDS Surveillance Data with Geographic Information Systems (GIS) (Appendix 1).

**Distinguishing Characteristics of HIV Surveillance**

Several characteristics distinguish HIV surveillance from surveillance for other reportable diseases. After the recognition of AIDS in 1981 and discovery in 1983 of HIV as its causative agent, all states required reporting of AIDS (an advanced stage of HIV infection), but not HIV infection itself. This period was followed by a prolonged transition to nationwide mandatory name-based reporting of all stages of HIV infection that was completed only in 2008. During this time, HIV infection became a chronic illness, necessitating HIV surveillance efforts to address HIV disease at multiple clinical stages.

When people with HIV move across state lines and their cases are reported in the destination states, surveillance programs from each state coordinate interstate efforts to identify these cases and avoid counting them as additional new cases in national prevalence estimates. Many state and local HIV surveillance programs collect additional clinical or laboratory reports on established, reported cases of HIV/AIDS, most commonly CD4 and viral load counts. Typically these programs continuously match and process many of these data to ensure incoming reports are correctly linked to existing cases or are identified as potential new cases. The additional laboratory data are also used to evaluate unmet need for adequate medical care of HIV-infected persons.

**Uses of HIV/AIDS Surveillance Data**

Public health practitioners and HIV planning groups use HIV/AIDS surveillance data to monitor disease prevalence and epidemiologic trends, identify opportunities to prevent new infections, and evaluate the impact of population-based HIV prevention. Because approximately 1.25 million U.S. residents live with HIV/AIDS and because HIV care and treatment and HIV prevention can be costly, the United States spends billions of dollars a year for these programs and services. Many of these dollars are apportioned on the basis of number of newly reported and prevalent cases recorded in a jurisdiction's HIV surveillance system. Naturally, the imperative to spend these dollars wisely magnifies the importance of accuracy and completeness of HIV surveillance in the United States.

## ASSESSMENT METHODS

In May 2007, CSTE convened a workgroup to develop an assessment instrument that would provide raw data for the National Assessment of HIV Surveillance Capacity. The workgroup consisted of HIV/AIDS Surveillance Coordinators, a State Epidemiologist, technical staff from CSTE, staff from CDC's HIV Incidence and Case Surveillance Branch, and staff from the National Alliance of State and Territorial AIDS Directors (NASTAD). The survey comprised 206 questions that covered 12 major domains: level of morbidity, level of funding, funded projects, staff capacity, surveillance practices, data linking, security and confidentiality, technical capacity, program structure, program collaboration and integration, dissemination of data, and technical guidance.

After members of the CSTE Executive Committee reviewed the draft instrument, the assessment was piloted in four jurisdictions (Connecticut, Kentucky, Minnesota, and Puerto Rico) during July 2007. Comments from the pilot states were incorporated, and CSTE leadership approved the final version of the survey instrument (Appendix 2).

On August 7, 2007, CSTE distributed electronic (Web-based) and paper copies of the assessment to State Epidemiologists, Deputy State Epidemiologists, and HIV Surveillance Coordinators for all 64 jurisdictions funded separately by CDC to conduct case surveillance for HIV/AIDS. These jurisdictions were 50 state health departments, seven large-city health departments (District of Columbia, Chicago, Houston, Los Angeles, New York City, Philadelphia, and San Francisco), and eight U.S. territories (Puerto Rico, U.S. Virgin Islands, American Samoa, Guam, Federal States of Micronesia, Marshall Islands, Northern Mariana Islands, and Palau).

CSTE requested that the assessment be completed by the jurisdiction's HIV Surveillance Coordinator, with assistance as needed from fiscal and technical staff. Data from the assessment were collected during August and September 2007. Emails were sent and follow-up calls were made to remind jurisdictions that did not respond before the deadline. Throughout the data-collection period, a CSTE staff member and a workgroup member were available to answer questions and clarify use of the Web-based assessment.

Data were analyzed using Microsoft Excel and SAS version 9.1 software. Because the purpose of this report is to describe the status of aggregate U.S. HIV surveillance programs, breakdowns by states, large cities, and territories are not included.

To investigate whether morbidity and/or funding were related to the structure, methods, and needs of the HIV surveillance programs, survey responses were cross-tabulated along two different categorical dimensions for ranking the programs. The cross-tabulation categories were based on (1) calendar year 2006 level of CDC core funding for the HIV surveillance program and (2) average annual number of new HIV diagnoses for 2004–2006.

For these analyses, respondents were ranked from 1 to 57 according to their responses to survey questions about population size, funding level, and number of new HIV diagnoses. The rankings were the basis for assigning jurisdictions to one of five quintiles. The quintile assignment of a jurisdiction varied from one category to another; for example, state X might be in quintile 3 for the ranking for funding level and in quintile 4 for the ranking for average annual HIV diagnoses. The cross-tabulated tables display only items for which quintiles appeared to differ.

For computations of morbidity, where both a large city and the state in which it is located (e.g., the city of Houston and the state of Texas) responded, the state's morbidity was recalculated by subtracting the city's morbidity from the state's morbidity.

## SURVEY RESULTS

Fifty-seven (89%) of 64 jurisdictions responded to the assessment. Five of seven nonresponders were jurisdictions with very low HIV morbidity. This report presents responses from 48 states, all seven large cities, and two territories.

## I. Program Support: Level of Funding and Funded Projects

For calendar year 2006, awards for HIV core surveillance cooperative agreements ranged from $61,619 to $2,959,773 (Figure 1). Ten jurisdictions were each awarded ≥$1,000,000. The HIV core surveillance cooperative agreement was the source of 92% of funding for the programs (Table 1).

Sixty-five percent of respondents reported receiving funds for other surveillance projects in addition to core activities. The most commonly funded surveillance activities other than core surveillance were HIV incidence surveillance (58% of programs) and the Medical Monitoring Project (44%) (Table 2).

**Figure 1:**
**Core HIV Surveillance Funding Level in CY 2006 for 57 Jurisdictions**

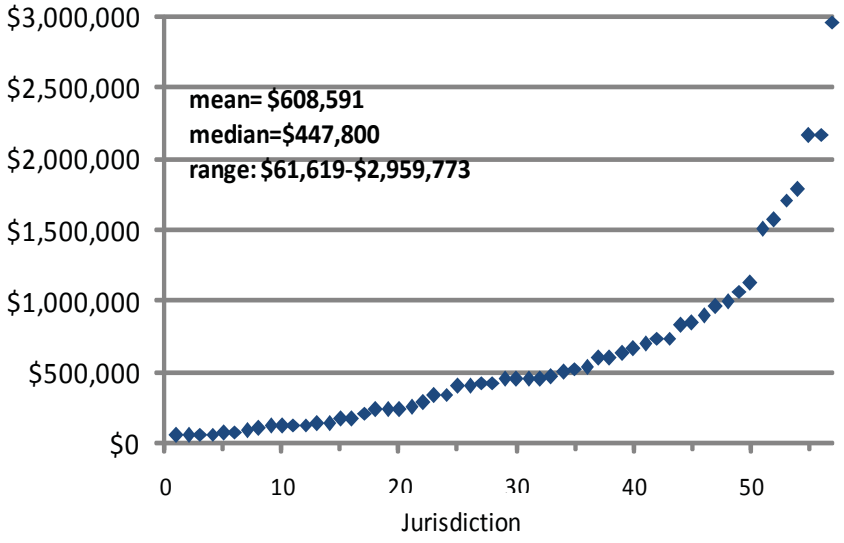



Table 1 (Q5). Mean percentage of HIV core surveillance budget by funding source - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57)

| Funding source | Percentage ( ±SD †) |
|---|---|
| Federal funds | |
| HRSA (HIV Treatment) | 1.4 (±4.7) |
| CDC HIV Prevention | 2.5 (±8.3) |
| CDC HIV Surveillance | 91.7 (±14.0) |
| State funds | 2.8 (±10.0) |
| Other | 1.6 (±10.3) |

*For each program, percentages totaled 100%, but because the data are for all 57 programs combined, the percentages do not sum to 100%.
†SD, standard deviation; HRSA, Health Resources and Services Administration; CDC, Centers for Disease Control and Prevention.

| Table 2 (Q10). Number and percentage of funded surveillance activities - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57) | |
|---|---|
| Activity | No. (%) |
| HIV/AIDS core surveillance | 57 (100) |
| HIV incidence surveillance (i.e., Serologic Testing Algorithm for Recent HIV Seroconversion [STARHS]) | 33 (58) |
| Medical monitoring project | 25 (44) |
| National HIV behavorial surveillance | 23 (40) |
| Capacity Building for Epidemiologic and Program Evaluation Activities | 20 (35) |
| Enhanced Perinatal Surveillance | 14 (25) |
| Variant, Atypical, and Resistant HIV Surveillance (VARHS) system | 13 (23) |
| Never in Care Project | 5 (9) |
| Evaluating integration of HIV/AIDS Surveillance Data with Geographic Information Systems | 3 (5) |

## II. Level of Morbidity

The average annual number of newly diagnosed HIV cases identified by individual surveillance programs varied considerably, from 11.3 to 5,683 (Figure 2). Six jurisdictions identified >2,000 cases per year, and 39 jurisdictions identified <1,000 cases per year. The correlation coefficient of funding level with average annual number of new HIV diagnoses was 0.62[1] ($p<0.05$). The association between funding and case counts appeared strongest at lower levels of funding (<$1,000,000) and morbidity (<1,000 cases per year or <30.0 cases per 100,000 per year) than at higher levels (Figure 3).

[1] The correlation coefficient is a number between 0 and 1 that describes the association between the predicted value (in this case, that jurisdictions with more HIV diagnoses received more funding) and the real data. A very low coefficient of correlation indicates a nonexistent or very weak association. As the strength of the association increases, so does the coefficient of correlation.

**Figure 2:**
**Average Annual Number of New HIV Diagnoses 2004-2006 for 57 Jurisdictions**

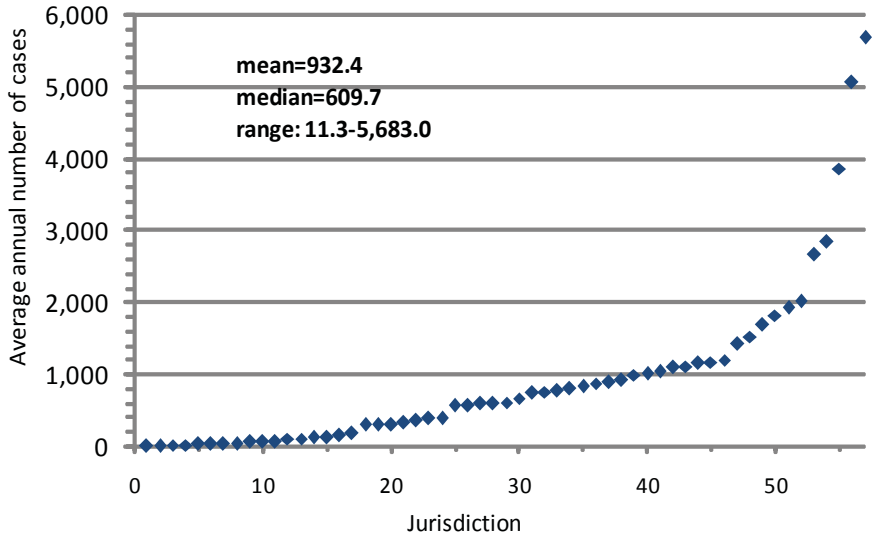
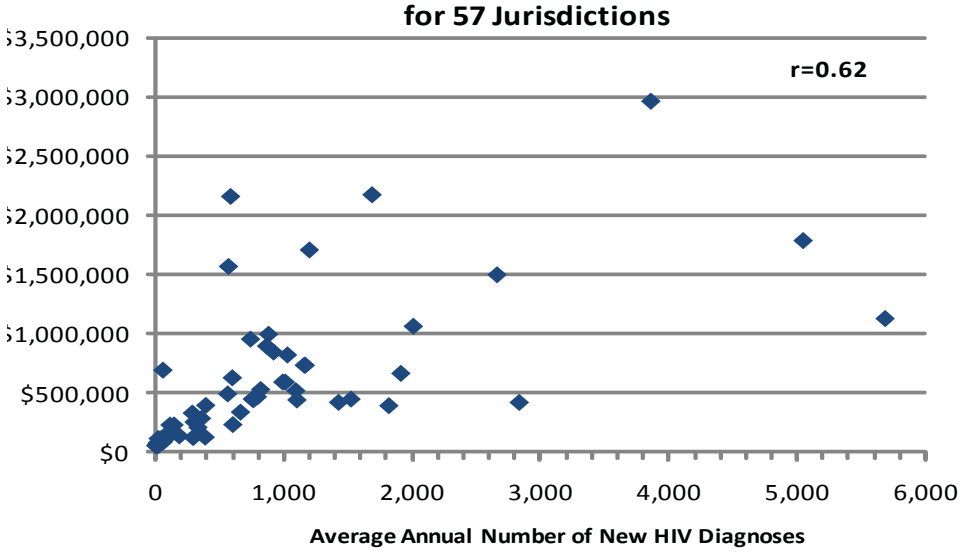



**Figure 3:**
**Correlation of Core HIV Surveillance Funding Level to Average Annual Number of New HIV Diagnoses for 57 Jurisdictions**




III. Program Capacity: Staff Capacity, and Technical Capacity

The CDC core HIV surveillance cooperative agreement funded full-time equivalents (FTEs) for various staff positions within HIV surveillance programs. Jurisdictions reported the greatest number of FTEs are engaged in field investigation (Table 3).

Respondents reported needing additional FTEs to accomplish all core surveillance objectives. Categories with the greatest median need (1.0 FTE each) were epidemiology, data management, data entry, and field investigation (Table 4).

Table 3 (Q12). CDC core surveillance funding for current FTEs* conducting surveillance, by surveillance activity - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57)

| Activity | Mean (±SD) | Median |
|---|---|---|
| Field investigation | 3.2 (±3.5) | 2.0 |
| Data entry | 1.4 (±1.3) | 1.0 |
| Epidemiology | 0.9 (±1.0) | 0.5 |
| Data management | 0.9 (±0.8) | 1.0 |
| Data analysis | 0.8 (±0.8) | 0.5 |
| Surveillance coordination | 0.8 (±0.5) | 1.0 |
| Administrative support | 0.8 (±0.9) | 0.5 |
| Out-of-state record searches | 0.5 (±0.4) | 0.5 |
| Information technology | 0.4 (±0.6) | 0.0 |

*FTE, full-time equivalent; SD, standard deviation.

Table 4 (Q16). Additional FTEs* needed for conducting various surveillance activities - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57)

| Activity | Mean (±std) deviation | Median |
|---|---|---|
| Field investigation | 2.5 (±4.3) | 1.0 |
| Data entry | 1.0 (±1.1) | 1.0 |
| Epidemiology | 0.9 (±1.0) | 1.0 |
| Data management | 0.7 (±0.6) | 1.0 |
| Data analysis | 0.6 (±0.7) | 0.5 |
| Administrative support | 0.6 (±0.8) | 0.3 |
| Information technology | 0.6 (±0.5) | 0.5 |
| Out-of-state record searches | 0.4 (±0.5) | 0.0 |
| Surveillance coordination | 0.3 (±0.4) | 0.0 |

*FTE, full-time equivalent; SD, standard deviation.

Programs in jurisdictions with higher morbidity had a greater average number of FTEs in field investigation (Table 5); these jurisdictions also indicated needing more FTEs to perform field investigation, data entry, data management, and data analysis. Jurisdictions with more funding generally had more FTEs in field investigation and data entry, as well as a greater need for FTEs in data entry and data analysis (Table 6).

Table 5.Average annual number of newly diagnosed HIV cases during 2004-2006 by quintile - National Assessment of HIV Surveillance Capacity, August-September 2007 (N = 57)

| No. states | n = 12 | n = 11 | n = 11 | n = 11 | n = 12 |
|---|---|---|---|---|---|
| Range | 11-109 | 112 - 395 | 399 - 801 | 827 - 1,174 | 1,205 - 5,683 |
| Mean no. FTEs* currently conducting surveillance activities in field investigation | 1.9 | 0.9 | 3.6 | 3.6 | 5.1 |
| Mean no. FTEs needed in field investigation | 1.8 | 0.5 | 4.1 | 1.6 | 3.8 |
| Mean no. FTEs needed in data entry | 0.6 | 0.4 | 1.5 | 0.9 | 1.7 |
| Mean no. FTEs needed in data management | 0.5 | 0.3 | 0.7 | 0.9 | 1.0 |
| Mean no. FTEs needed in data analysis | 0.3 | 0.1 | 0.4 | 0.6 | 1.1 |

*FTE, full-time equivalent.

Table 6. Funding levels for core HIV surveillance in Program Announcement 04017* (calendar year 2006), by quintile - National Assessment of HIV Surveillance Capacity, August-September 2007. (N = 57)

| Number of states | n = 12 | n = 11 | n = 11 | n = 11 | n = 12 |
|---|---|---|---|---|---|
| Range | $61,619 - $134,414 | $142,517 - $336,994 | $344,718 - $498,359 | $524,888- $850,151 | $900,851- $2,959,773 |
| Mean no. of FTEs† currently conducting surveillance activities in field investigation | 1.9 | 0.9 | 3.6 | 3.6 | 5.1 |
| Mean number of FTEs needed in field investigation | 1.8 | 0.5 | 4.1 | 1.6 | 3.8 |
| Mean number of FTEs needed in data entry | 0.6 | 0.4 | 1.5 | 0.9 | 1.7 |
| Mean number of FTEs needed in data management | 0.5 | 0.3 | 0.7 | 0.9 | 1.0 |
| Mean number of FTEs needed in data analysis | 0.3 | 0.1 | 0.4 | 0.6 | 1.1 |

*See http://edocket.access.gpo.gov/2003/03-26837.htm
† FTE, full-time equivalent.

Jurisdictions selected the average salary ranges of staff performing different surveillance activities (Table 7). Using median values for the job classifications (and using entry-level epidemiologists for that job category) listed in both Tables 3 and 4, a typical program reported needing an additional 3.5 FTEs with a total additional salary cost of $140,000–$174,996.

Jurisdictions most often stated Microsoft Access, SAS, and eHARS/HARS as their training priorities (Table 8).

Table 7 (Q24). Median annual salary range for major job classifications in HIV surveillance programs - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57)

| Job Classification | Median | Mode |
|---|---|---|
| Data entry staff | $30,000-$39,999 | $20,000-$29,999 |
| Field staff | $40,000-$49,999 | $30,000-$39,999 |
| Entry-level epidemiologist | $40,000-$49,999 | $30,000-$39,999 |
| Senior-level epidemiologist | $60,000-$69,999 | > $70,000 |
| Surveillance coordinator | $60,000-$69,999 | > $70,000 |
| Information technology staff | $60,000-$69,999 | NA |

Table 8 (Q20). Number and percentage of jurisdictions selecting areas for training need by staff, in descending order - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57)

| Training subject | No. (%) |
|---|---|
| Microsoft Access | 47 (83) |
| SAS | 44 (77) |
| eHARS/HARS* | 38 (67) |
| Database management/ manipulation | 30 (63) |
| Linking/ database matching | 27 (47) |
| Geographic information systems | 15 (26) |
| Microsoft Excel | 8 (14) |
| Statistics | 4 (7) |
| Medical Record Abstraction | 4 (7) |

*HARS, HIV/AIDS Reporting System; eHARS, Enhanced HIV/AIDS Reporting System.

## IV. Program Collaboration/Integration

Structures and reporting relationships varied across the 57 jurisdictions. Thirty-seven percent of HIV surveillance coordinators report to the AIDS Director (the person who oversees the health department's HIV prevention and care program and is a member of NASTAD); 28%, to both the AIDS Director and the State Epidemiologist (generally the person who oversees the health department's communicable disease activities); 20%, to the State Epidemiologist (and not the NASTAD member); and 15%, to neither.

Regardless of the organizational position of the HIV surveillance program, surveillance staff need to have ongoing interaction with other epidemiology and prevention programs within an agency (Tables 9 and 10).

Table 9 (Q60). Level of integration* of the HIV surveillance program with other programs within the agency - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57)

| Program | No. | Not at all integrated | Somewhat or moderately integrated | Mostly or completely integrated |
|---|---|---|---|---|
| HIV prevention | 56 | 14% | 32% | 54% |
| HIV care (Ryan White) | 57 | 18% | 32% | 51% |
| STD program | 56 | 28% | 33% | 38% |
| Partner counseling & referral services | 56 | 16% | 38% | 45% |
| STD surveillance | 57 | 23% | 37% | 40% |
| Tuberculosis | 57 | 46% | 39% | 16% |
| Hepatitis | 54 | 33% | 43% | 24% |

*Defined as proximity on an organizational chart and shared supervisory oversight.

Table 10 (Q61). Level of collaboration* of the HIV surveillance program with other programs within the agency - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57)

| Program | No. | Collaborate poorly | Collaborate somewhat or moderately | Collaborate mostly or completely |
|---|---|---|---|---|
| HIV prevention | 56 | 0% | 11% | 89% |
| HIV care (Ryan White) | 57 | 0% | 16% | 84% |
| STD program | 57 | 2% | 28% | 70% |
| Partner counseling & referral services | 53 | 4% | 25% | 72% |
| STD surveillance | 57 | 2% | 34% | 64% |
| Tuberculosis | 56 | 5% | 36% | 59% |
| Hepatitis | 46 | 9% | 46% | 46% |

*Defined as degree to which programs share resources, conduct joint planning or projects, and provide mutual program support.

## V. HIV Surveillance Practices and Data Linking

Ninety-five percent of jurisdictions reported using laboratory records to ascertain HIV cases (Table 11), and a median of 75% of programs reported *initially* identifying cases by laboratory reports. Approximately two thirds of programs monitor morbidity using laboratory reports, usually CD4 levels at diagnosis and frequency of CD4 and viral load testing. One fourth of HIV cases are identified through direct provider reporting and a small percentage through partner counseling and referral services.

| Table 11 (Q82, Q83, Q105). Types of surveillance activities and practices conducted by jurisdictions - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57) | | |
|---|---|---|
| Programs that use laboratory records for | | |
| Ascertaining cases | 95% | |
| Updating HARS/eHARS | 91& | |
| Monitoring proportion in-care | 81% | |
| Monitoring morbidity | 65% | |
| Cases initially identified through | Mean | Median |
| Laboratory reporting | 67% | 75% |
| Direct provider reporting | 24% | 15% |
| Other | 15% | 12% |
| Partner counseling and referral services | 6% | 2% |
| Priority (1 to 5, where 1 = lowest, 5 = highest) for actively looking for AIDS-defining opportunistic infection in an HIV-infected patient | Mean = 2.7 ($\pm$SD)<br>Median = 3<br>Mode = 3 | |

A high percentage of jurisdictions indicated they directly receive laboratory reports of HIV viral loads, CD4 counts, and positive antibody tests (96%, 95%, and 98% respectively) (Table 12); 32% reported receiving direct reports of electronic HIV genotyping sequence data. The proportion of jurisdictions with mandatory reporting of these laboratory tests was smaller than the proportion receiving results directly (Table 13). Requirements for reporting of viral loads and CD4 results differed among states, and in some jurisdictions, even though reporting of certain levels of CD4 or viral load test results is mandatory, labs often report all results. Thirty percent of jurisdictions require reporting pregnancy in HIV-infected women. This survey did not explore the association between such reporting and receipt of antiretroviral therapy by the mother and infant.

| Table 12 (Q69, Q70, Q72, Q75, Q76). Receipt of HIV laboratory results by surveillance programs - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57) | | | |
|---|---|---|---|
| Question | Response | | |
| Does your program receive direct reports of | | | |
| • Confirmed positive antibody tests? | Yes = 98% | No = 2% | |
| If yes, by what method does the program receive reports? [n = 54] | Mail = 73% | Electronic = 60% | Other = 16% |
| • HIV viral loads? | Yes = 96% | No = 4% | |
| If yes, by what method does the program receive reports? [n = 55] | Mail = 75% | Electronic = 60% | Other = 23% |
| • CD4 counts? | Yes = 95% | No = 5% | |
| If yes, by what method does the program receive reports? [n = 54] | Mail = 78% | Electronic = 60% | Other = 18% |
| • Electronic sequencing data from HIV genotyping results? | Yes = 32% | No = 68% | |
| If yes, by what method does the program receive reports?* [n = 18] | Mail = 0% | Electronic = 100% | Other = 0% |

*Median response displayed; percentages do not total 100% because respondents could choose multiple answers.

| Table 13 (Q85, Q86, Q87, Q88, Q89, Q90). Mandatory* reporting requirements for selected types of surveillance data - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57) | |
|---|---|
| Type of report | Mandatory reporting of all results |
| HIV viral loads | 70% |
| HIV antibody tests | 61% |
| CD4 counts | 49% |
| Pregnancy in known HIV+ women | 30% |
| Electronic sequence data from HIV genotyping results | 18% |
| Other | 4.7 (±10.3) |

*Required by law or regulation.

Jurisdictions reported on all methods by which HIV-related test results were received. Results were most often received by mail (with a large percentage of results also being received electronically). The only exception was electronic sequence data from HIV genotyping results, which were always received electronically.

HIV surveillance programs used various methods to gather data beyond routine laboratory or provider reporting (Table 14). Many surveillance programs record in their surveillance system individuals receiving HIV services in the jurisdiction, even if these patients' HIV infection was not diagnosed there, as well as laboratory results over time after initial diagnosis. Even though 20% of jurisdictions allowed reporting of HIV without patient names, this did not necessarily indicate that names were not used at time of report of disease to the health department; often names are required to initiate HIV care.

Jurisdictions reported that HIV surveillance programs are responsible for obtaining information about the death status of HIV-infected persons in their surveillance systems. Because these individuals may move out of state during their illness, programs need to be able to match their case records with national-level death records. Sixty-one percent of programs use the Social Security Death Index to obtain death status for persons with reported HIV/AIDS, and a smaller percentage use the National Death Index or the National Death Index Plus (Appendix 1) (Table 15). The most common reason given for not using the National Death Index or the National Death Index Plus was insufficient funds.

| Table 14 (Q91, Q93, Q94, Q95, Q96, Q97, Q98). HIV surveillance methods and anonymous testing and reporting - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57) | |
|---|---|
| Question | Percentage responding Yes |
| • Does your program have a method for systematically identifying and tracking: | |
| HIV/AIDS diagnosed outside your jurisdiction but living in/receiving care in your jurisdiction? | 86% |
| Multiple CD4 counts over time in persons with previously reported HIV infection? | 72% |
| Incident cases of HIV infection as determined by the Serologic Testing Algorithm for Recent HIV Seroconversion (STARHS)? | 58% |
| Incident opportunistic infections in persons with previously reported HIV infection? | 46% |
| Antiretroviral HIV drug resistance? | 29% |
| • Does your jurisdiction have a legal requirement to offer anonymous HIV testing? | 55% |
| • Is it permissible in your jurisdiction for a provider or laboratory to report a new HIV/AIDS case without name or other personal identifiers? | 20% |

| Table 15 (Q126). Program use of national death data sources for HIV surveillance - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57) | | | | |
|---|---|---|---|---|
| Source | Yes | No, because do not collect SSN or missing SSN for > 30% | No, because not a high priority | No, because of insufficient funds |
| Social Security Death Index (n = 57) | 61% | 14% | 13% | 13% |
| National Death Index (n = 54) | 24% | 9% | 26% | 41% |
| National Death Index Plus (n = 50) | 10% | 10% | 32% | 48% |

Seventy-four percent of programs maintain a database separate from eHARS/HARS to collect data about reported cases (Table 16). The data maintained separately are most often laboratory test results.

Table 16 (Q 33, Q34, Q190). Types of surveillance practices reported by jurisdictions - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57)

| Surveillance Practice | No. (%) |
|---|---|
| • Program maintains a database separate from eHARS/HARS* to collect surveillance data | 42 (74) |
| • The data collected in separate database(s) are | |
| Laboratory test results | 35 (83) |
| Perinatal exposure | 15 (36) |
| Co-infections (i.e., hepatitis, tuberculosis, STDs) | 13 (31) |
| HIV (not AIDS) | 9 (21) |
| Residential street address | 6 (14) |
| Anonymous cases | 4 (10) |

*eHARS, Enhanced HIV/AIDS Reporting System; HARS, /HIV/AIDS Reporting System.

All programs link to state and/or local death certificate databases (Table 17). This linkage is performed electronically by 53% of programs and manually by 47% (Table 18). The next most commonly linked databases are the tuberculosis (84%) and sexually transmitted diseases (75%) case reporting databases, AIDS Drug Assistance Program (73%) databases, and electronic laboratory report databases (67%). For these databases, 40%–67% of jurisdictions perform matches manually. Electronic matches not using eHARS were reported more frequently than electronic matches using eHARS for every database except the birth defects databases.

Table 17 (Q108). HIV surveillance program linkage with local databases - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57)

| Does the program link to the following local databases? | No. (%) responding Yes |
|---|---|
| State/local death certificates | 57 (100) |
| Tuberculosis | 48 (84) |
| Sexually transmitted diseases | 43 (75) |
| AIDS drug assistance program | 42 (73) |
| Electronic lab reports | 38 (67) |
| HIV counseling and testing | 30 (53) |
| Client services | 27 (47) |
| State/local birth records | 26 (46) |
| Medicaid | 21 (37) |
| Hepatitis C | 19 (33) |
| Cancer | 19 (33) |
| Hospital discharge | 17 (30) |
| Enhanced perinatal surveillance | 14 (25) |
| Hepatitis B | 14 (25) |
| Incidence testing history forms | 10 (18) |
| Birth defects | 5 (9) |

| Table 18 (Q109). Method of linking HIV surveillance program with local databases - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57) | | | |
|---|---|---|---|
| Of the programs that perform linkage, the method of linkage is | No. (%) manual | No. (%) electronic (not eHARS*) | No. (%) electronic (eHARS) |
| State/local death certificates | 27 (47) | 26 (46) | 4 (7) |
| Tuberculosis | 32 (59) | 14 (14) | 2 (2) |
| Sexually transmitted diseases | 22 (51) | 19 (44) | 2 (5) |
| AIDS drug assistance program | 21 (50) | 19 (45) | 2 (5) |
| Electronic lab reports | 15 (40) | 17 (45) | 6 (16) |
| HIV counseling and testing | 16 (53) | 11 (37) | 3 (10) |
| Client services | 9 (33) | 16 (59) | 2 (7) |
| State/local birth records | 6 (23) | 17 (65) | 3 (12) |
| Medicaid | 7 (33) | 12 (57) | 2 (10) |
| Hepatitis C | 8 (42) | 10 (53) | 1 (5) |
| Cancer | 6 (32) | 11 (58) | 2 (11) |
| Hospital discharge | 8 (47) | 8 (47) | 1 (6) |
| Enhanced perinatal surveillance | 7 (50) | 6 (43) | 1 (7) |
| Hepatitis B | 5 (36) | 9 (64) | 0 (0) |
| Incidence testing history forms | 6 (60) | 3 (30) | 1 (10) |
| Birth defects | 1 (20) | 2 (40) | 2 (40) |

*eHARS, Enhanced HIV/AIDS Reporting System; HARS, /HIV/AIDS Reporting System.

In response to questions about GIS, more than half of jurisdictions reported mapping their data. Most programs would like to use GIS more, especially if technology and training were available.

| Table 19 (Q40, Q41, Q42). Use of GIS* by HIV surveillance programs - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57) | |
|---|---|
| Assessment question | Percentage responding Yes |
| • Does your program map its HIV/AIDS surveillance data? | 58% |
| • GIS should play a larger role in routine HIV surveillance in your jurisdiction? | 70% |
| • If GIS technology and training were available, would your surveillance program use it? | 81% |

*GIS, geographic information systems.

In general, programs with more cases and/or more funding have more ability to perform database linkages, more ability to use electronic methods to link databases, and more interest in obtaining training and using GIS (Tables 20 and 21).

| Table 20 (Q41, Q42, Q91, Q109). Average annual number of newly diagnosed HIV cases during 2004–-2006, by quintile - National Assessment of HIV Surveillance Capacity, August-September 2007 (N = 57) | | | | | |
|---|---|---|---|---|---|
| No. states | n = 12 | n = 11 | n = 11 | n = 11 | n = 12 |
| Range | 11-109 | 112 - 395 | 399 - 801 | 827 - 1,174 | 1,205 - 5,683 |
| | Percentage responding Yes | | | | |
| Do you link to state/local birth records? | 27% | 36% | 45% | 64% | 58% |
| Do you currently link electronically to AIDS Drug Assistance Program database? | 17% | 27% | 45% | 45% | 50% |
| Do you currently link electronically to electronic lab reports? | 25% | 18% | 55% | 5% | 50% |
| Do you currently link electronically to state/local death certificates? | 17% | 55% | 73% | 64% | 58% |
| Should GIS* play a larger role in routine HIV surveillance? | 27% | 82% | 73% | 91% | 83% |
| If GIS training were available, would your surveillance program use it? | 42% | 82% | 82% | 100% | 100% |
| Program has a method for systematically tracking anti-retroviral HIV drug resistance | 13% | 6% | 25% | 19% | 38% |

*GIS, geographic information systems.

| Table 21 (Q33, Q42, Q109). Core surveillance funding level in Program Announcement 04017* (calendar year 2006), by quintile - National Assessment of HIV Surveillance Capacity, August-September 2007. (N = 57) | | | | | |
|---|---|---|---|---|---|
| Number of states | n = 12 | n = 11 | n = 11 | n = 11 | n = 12 |
| Range | $61,619 - $134,414 | $142,517 - $336,994 | $344,718 - $498,359 | $524,888- $850,151 | $900,851- $2,959,773 |
| Question | Percentage responding Yes | | | | |
| Do you currently link electronically to state/local | 33% | 36% | 64% | 45% | 83% |
| Do you maintain a database separate from HARS to collect any surveillance data? | 58% | 64% | 73% | 91% | 83% |
| If GIS training were available, would your surveillance program use it? | 58% | 73% | 82% | 91% | 100% |

*See http://edocket.access.gpo.gov/2003/03-26837.htm
†HARS, HIV/AIDS Reporting System; GIS, geographic information systems.

## VI. Dissemination of Data and Technical Guidance

Jurisdictions identified programmatic barriers to developing surveillance dissemination products. Lack of time (65%), lack of staff (63%), and lack of funding (44%) were most commonly reported (Table 22). Smaller programs with less funding were more likely to report lacking expertise in developing dissemination products (Table 23).

Most jurisdictions reported using the CDC/HRSA *Integrated Guidelines for Developing Epidemiologic Profiles* (http://www.cdc.gov/hiv/topics/surveillance/resources/guidelines/epi-guideline/pdf/epi_guidelines.pdf) (Table 24).

Table 22 (Q190). Programmatic barriers to developing surveillance dissemination products (i.e., lack of, insufficient amount of) - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57)

| Programmatic barrier | No. (%) |
|---|---|
| Time | 37 (65) |
| Staff | 36 (63) |
| Funding | 25 (44) |
| Technical expertise to program SAS | 21 (37) |
| Modifiable SAS programs provided by CDC | 20 (35) |
| Expertise for data management | 10 (18) |
| No barriers | 9 (16) |
| Technical expertise to analyze HARS data | 8 (14) |

Table 23 (Q190). Core surveillance funding level in Program Announcement 04017* (calendar year 2006), by quintile - National Assessment of HIV Surveillance Capacity, August-September 2007. (N = 57)

| Number of states | n = 12 | n = 11 | n = 11 | n = 11 | n = 12 |
|---|---|---|---|---|---|
| Range | $61,619 - $134,414 | $142,517 - $336,994 | $344,718 - $498,359 | $524,888- $850,151 | $900,851- $2,959,773 |
| Question | Percentage responding Yes | | | | |
| Lack of technical expertise is a barrier to developing dissemination products. | 42% | 55% | 36% | 27% | 25% |

*See http://edocket.access.gpo.gov/2003/03-26837.htm

| Table 24 (Q67). HIV surveillance programs' use of CDC/HRSA* Integrated Guidelines by Developing Epidemiologic Profiles[†‡] - National Assessment of HIV Surveillance Capacity, August-September 2007. (N=57) | |
|---|---|
| • Do you use CDC/HRSA Integrated Guidelines for Developing Epidemiologic Profiles?* | n= 54 |
| Mostly/completely | 70% |
| Somewhat/moderately | 20% |
| Not at all | 9% |

*CDC, Centers for Disease Control and Prevention; *HRSA, Human Resources and Services Administration

[†]See http://www.cdc.gov/hiv/topics/surveillance/resources/guidelines/epi-guideline/pdf/epi_guidelines.pdf.

[‡]An epidemiologic profile is a document produced using data, including surveillance data, to describe the HIV epidemic in a local jurisdiction and used for decision-making by health service planners.

## CONCLUSION

Principal findings of the assessment are as follows:

- Funding level and number of new HIV diagnoses are generally correlated.
- Programs receive most of their funding from one source: the CDC HIV core surveillance cooperative agreement. Although other HIV-related programs (e.g., HIV prevention, disbursement programs, money for HIV care services) rely on HIV surveillance staff and data for planning of services and disbursement of funds, few surveillance programs receive support from these programs.
- Many jurisdictions are funded for supplemental surveillance projects in addition to core surveillance. Because many of these projects rely on information collected through core surveillance and staff often work across projects, supplemental surveillance projects often enhance core surveillance. When jurisdictions lose supplemental funding, this enhancement is difficult to maintain.
- CDC funds support a median of seven FTEs to conduct core surveillance; these staff include the program coordinator, field investigators, and data entry and analysis personnel. Jurisdictions stated needing an additional 5.3 FTEs (median).
- Jurisdictions need additional training for data management and analysis personnel.
- Although HIV surveillance programs may not be integrated with sexually transmitted diseases, tuberculosis, and hepatitis programs under a common supervisory structure, these programs appear to collaborate.
- Many programs continue to receive laboratory results by mail and maintain ancillary databases to HARS/eHARS to store surveillance information. Additional work is needed to streamline management of electronic surveillance information.
- Equitable distribution of federal funds relies on accurate case counts. This reliance on case counts increases focus on accurately reflecting the death status of individuals reported to the surveillance system. The reasons most often cited for not linking with national death registries are that the activity is not a high priority locally or that funds are insufficient to perform linkages.

The findings in this report are subject to some limitations. Since 11% of jurisdictions did not participate in the assessment, it does not describe all surveillance programs. Additionally, since the report contains results for fewer than half of the assessment questions, it can be considered only an overview. However, this report is the first assessment-based report to describe how these programs conduct HIV surveillance.

Surveillance for HIV disease presents unique challenges, in part because HIV is an infectious disease that has become chronic and in part because distribution of funding for programs relies on accurate case counts of people with HIV during the years they live with disease. The assessment showed the many expectations tied to receipt of surveillance funding—case finding, data management, surveillance system evaluation, and data analysis and dissemination—and the ability of jurisdictions to meet these expectations with available resources.

As an increasing number of people live with HIV and program staff try to maintain accurate case counts and case records over time, surveillance programs will need to obtain the support they need. This support could take on a variety of forms: more efficient data management systems, including electronic laboratory reporting, that reduce the burden on surveillance staff, or receipt of resources from programs that rely on surveillance data for resource allocation and program planning. CSTE will conduct another surveillance capacity assessment in 2009–10 to learn the extent to which HIV/AIDS surveillance programs are able to obtain this support and to describe the most current surveillance policies and practices. Surveillance program staff, CDC, and CSTE have used and will continue to use findings from the assessment to guide strategies for strengthening HIV surveillance programs.

## APPENDIX 1: Definitions

**Capacity Building for Epidemiologic and Program Evaluation Activities** – Project areas use these supplemental funds to enhance their ability to use their HIV/AIDS surveillance data to describe the local epidemic and evaluate HIV prevention programs. Activities include development of an integrated HIV/AIDS epidemiologic profile and tools to communicate information to HIV prevention programs and planning groups.

**Core HIV Surveillance –** All project areas receive funds and are responsible for monitoring the number of HIV diagnoses each year, the prevalence of persons living with HIV, and HIV-related morbidity; monitoring perinatal exposure and transmission; monitoring behaviors related to HIV testing, risk for infection, and access to care among persons living with HIV; monitoring changes to trends in transmission; providing data to guide local resource allocation for prevention and services programs; providing data to inform and evaluate local prevention and services programs; and conducting ongoing efforts to ensure the completeness, timeliness, and accuracy of the jurisdiction's surveillance data to ensure the quality of the national data.

**Enhanced Surveillance for Perinatal Prevention –** Project areas use these supplemental funds to conduct comprehensive review of maternal and pediatric medical records in order to monitor the impact of efforts to reduce mother-to-child transmission of HIV, prevention failures, and the efficacy of recommended to treatments to reduce perinatal transmission to exposed children and prevent opportunistic infection among children who become infected.

**Evaluating Integration of HIV/AIDS Surveillance Data with Geographic Information Systems –** Project areas use these supplemental funds to demonstrate and evaluate methods for spatially linking existing HIV/AIDS surveillance data with other datasets to enhance epidemiologic capacity. A main goal of this project is to develop procedures and guidelines that allow the use of Geographic Information Systems in analyses while safeguarding security and confidentiality.

**HIV Incidence Surveillance (STARHS) –** Sometimes referred to as STARHS (Serologic Testing Algorithm for Recent HIV Seroconversion), HIV incidence surveillance was developed to provide reliable and scientifically valid estimates of the number of newly acquired HIV infections each year. Jurisdictions funded to conduct incidence surveillance collect testing and treatment history as a part of routine surveillance activities. In addition, sites work closely with commercial, private, public, and hospital-based laboratories to acquire remnant blood specimens to test for recent infection. The information collected through surveillance in combination with the results of additional testing allows jurisdictions and CDC to calculate population-based estimates for HIV incidence.

**HIV Resistance Surveillance (VARHS) –** Also referred to as VARHS (Variant, Atypical, and Resistant HIV Surveillance), data from this system are used to estimate trends in the prevalence of drug-resistant strains of HIV among persons in whom HIV infection is newly diagnosed. Similar to HIV Incidence Surveillance, sites work to acquire and test remnant specimens from persons with newly diagnosed HIV infection, unless such testing as been done as part of HIV care.

**Medical Monitoring Project –** The goal of this project is to collect supplemental data from a nationally representative sample of individuals receiving care for HIV in order to describe their demographic characteristics, risk behaviors, clinical characteristics and outcomes, and access to and quality of care. Data are collected via in-person interview and medical record abstraction, and are used to aid in policy planning, resource allocation, and evaluating of prevention and treatment initiatives.

**National Death Index –** This is a central computerized index of death record information on file in the State vital statistics offices. It assists surveillance programs in determining whether persons in their surveillance databases have died and, if so, provider the names of the states in which those deaths occurred and the dates for death.

**National Death Index Plus –** This index index includes the same information as the National Death Index (see above) as well as cause of death codes.

**National HIV Behavioral Surveillance –** Through this project, data are collected on a rotating basis from one of three populations at high risk for HIV – men who have sex with men, injection drug users, and high risk heterosexuals. Information is collected via anonymous interview and participants are voluntarily tested for HIV. Data are used to assess the prevalence/trends in HIV-related risk behaviors, HIV testing, and exposure to and use of HIV prevention services.

**Never In Care Project –** Project areas use these supplemental funds to identify through the HIV surveillance system individuals who have not entered care within three months of their initial HIV diagnoses. These individuals are located and recruited for voluntary interview and blood specimen collection in order to learn about barriers to initiating HIV care and the disease status and characteristics of those who delay entry into care.

**Social Security Death Index –** This index contains a listing of persons who had a Social Security number who are deceased, and whose death was reported to the Social Security Administration. It includes information about dates of death and states in which individuals died.