Striving Toward Comprehensive HIV/AIDS Surveillance: The View from New York City

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On June 1, 2005, New York State issued regulations requiring laboratories to report all CD4 and viral load (VL) values and nucleotide sequences obtained for genotypic analyses, continuing eight years of steady progress toward comprehensive surveillance of HIV/AIDS.[1] Since 2000, confidential named reporting of HIV diagnoses, CD4<500, and detectable HIV VL has been mandatory in New York State, and 36,985 people with HIV (non-AIDS) have been reported to the New York City surveillance system. As of June 30, 2006, 189,770 people had been diagnosed and reported with HIV or AIDS in the city's 25-year surveillance history.

New York has an increasingly comprehensive HIV surveillance system by virtue of its state law, citywide behavioral risk factor surveys, and supplemental surveillance systems supported by the Centers for Disease Control and Prevention (CDC). In contrast, many states, including some with very large epidemics, did not adopt named HIV reporting until 2006, and only 14 states currently require the reporting of all CD4 and VL values. Of these 14 states, only two have more than 50,000 people living with HIV and AIDS (Florida and New York).

HIV reporting and recent laboratory reporting requirements allow virtually complete surveillance of diagnoses of HIV non-AIDS, concurrent HIV/AIDS, and people diagnosed and presumed to be living with HIV. Using CD4 and VL test ordering as a proxy measure for initiating HIV primary care after the first positive Western Blot test allows for calculation of the time between diagnosis and initiation of care. Frequency of visits, regularity of U.S. Department of Health and Human Services (DHHS)-recommended laboratory monitoring,[2] and estimates of the proportion of cases eligible for antiretroviral therapy are now possible with CD4 and VL result reports. These laboratory indicators also allow estimates of the number and characteristics of cases not in care. Clusters of highly resistant HIV will be detectable when the genotype reporting system becomes operational.

Because comprehensive clinical and behavioral information is collected only at the two sentinel diagnostic events—diagnosis of HIV and diagnosis of AIDS—and

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at death, the case surveillance system relies on many other data sources to paint a fuller picture of the HIV epidemic and the city's behavioral risk profile. The New York City Health Department's annual population-level Community Health Survey (CHS) collects data on a variety of health issues including behavioral risk for HIV. For example, in 2002 the CHS determined that only one-third of adults who had had three or more sex partners in the preceding year (and only half of men who had sex with men [MSM] who had three or more partners) had been tested for HIV in the previous 18 months.[3] An expanded Youth Risk Behavior Survey in New York City high schools follows trends in sexual behaviors and condom use among teens, oversampling communities at highest risk for HIV.

The surveillance registry is matched quarterly with other disease registries and the vital registry, and annually with the Social Security Death Master File and the National Death Index. In addition, anonymized hospitalization databases are analyzed on a regular basis. Various CDC-sponsored supplemental surveillance systems provide data that fill in a number of important epidemiologic gaps. For example, although the laboratory and case reporting system is a powerful surveillance tool, it does not provide data on variables such as treatment regimen, adherence, risk behavior, comorbid conditions, need for and use of allied support services (e.g., housing, mental health, and substance abuse), and social and economic issues that may impede prevention behavior and access to and continuity of care.

The Medical Monitoring Project (MMP) follows clinical course and behavior in a representative sample of people in care and estimates proportions on antiretroviral therapy, thereby allowing us to more accurately interpret the longitudinal CD4 and VL data and to better understand the behaviors of HIV-positive people that put them and their partners at risk. MMP's future supplemental Never in Care (NIC) project will allow us to collect far more comprehensive data than are currently available through surveillance on risk factors for failure to initiate care.[4] The National HIV Behavioral Surveillance System (NHBS), already in its third year, provides valuable information on prevalence, incidence, testing history, treatment, attitudes, and risk behaviors among venue-based samples of MSM, injecting drug users (IDUs), and, in the next cycle, people at risk for heterosexual transmission (high-risk heterosexuals, or HRH). Because each of these groups has a different epidemic growth pattern,[5] the behavioral detail provided by NHBS is especially important. For example, new HIV diagnoses among MSM have grown slowly but steadily since HIV reporting began; in contrast, new diagnoses among IDUs have plunged. NHBS that incorporate a behavioral interview *and* HIV testing help us understand the factors that underlie these trends and the issues facing the known positives vs. the positives newly detected by the studies. Because more than one-quarter of new AIDS diagnoses in New York City are concurrent with initial HIV diagnosis, understanding the relationship between testing behavior and late diagnosis can help us develop interventions to reduce delayed diagnosis.

Two other CDC supplemental systems provide additional data of public health importance—HIV Incidence Surveillance, which uses the Serologic Testing Algorithm for Recent HIV Seroconversion (STARHS), and Variant and Resistant Strains of HIV Surveillance (VARHS). Since June 1, 2000, New York City has used a sensitive/less sensitive enzyme immunoassay algorithm on all remnant WB+ serum tested at public laboratories to ascertain whether a new diagnosis represents an incident or prevalent infection and to estimate HIV incidence among testers.[6,7] With CDC support, we were able to expand specimen salvage in 2005 to include proprietary laboratories and thus now have virtually complete surveillance of diagnosed incident infections citywide. Using STARHS, we can estimate the size and characteristics of the leading edge of the epidemic because we can distinguish between likely new diagnoses representing recently infected people and new diagnoses representing previously undetected prevalent infections. The data allow us to evaluate the city's "Know Your Status" campaign and routinization of HIV testing in large medical centers—both aimed at reducing the number of concurrent HIV/AIDS diagnoses and the associated morbidity and mortality.[8,9]

CDC's support for VARHS, now in the early stage of implementation, adds further value. Although resistance reporting is mandatory in New York State, software systems for VARHS provide ready access to interpretive technology and ease the process of analyzing and reporting the results. The VARHS system will allow us to track community-acquired resistance in newly infected and newly diagnosed individuals. These data may one day provide an early warning system suggesting the possibility of increasing transmission within treatment-experienced communities or increasing fitness of resistant strains.

CDC's supplemental studies and surveillance initiatives have the advantage of generating standardized data that can be used by CDC for national and regional monitoring, as well as for comparative analysis of epidemic trajectory across sites. However, all epidemics are local and are therefore driven by local demographics, behavior, exposure, and prevalence pools. The

standardized methods, instrumentation, and data needed for national trends analysis sometimes limit their local relevance. Moreover, the process of creating and implementing the protocols can be so lengthy that the data are outdated before they can be used to respond to local needs to improve diagnosis, treatment, or access to care. Instrumentation can be unwieldy and repetitive. While the standardized protocols make possible the cross-site comparisons that are so valuable on a national level, the local cost can be high.

New York's increasingly comprehensive HIV reporting, laboratory, and behavioral surveillance systems provide data needed to formulate, pursue, and evaluate initiatives to control the epidemic. The strength of the surveillance system is that it is population-based, and laboratory reporting is fully electronic. The CDC supplemental systems, with their focus on specific populations and issues, address many of the questions arising from but not answered by surveillance. As New York City enters the second quarter-century of the epidemic, with more than 100,000 people living with HIV and AIDS, it faces many new challenges. Confidentiality laws currently prohibit use of surveillance data to provide historical information to treating physicians to link people with HIV to housing, medication, or other support systems, or to offer assistance to doctors, case managers, and even, as a last resort, to patients. Developing disease registries and using surveillance data to help doctors and patients with linkage and return to care are several ways that the increasingly comprehensive information now available could be directly translated into reductions in morbidity and mortality. This is a critical area for future work. Finally, ensuring that the surveillance systems are flexible enough to respond to new diagnostic, clinical monitoring, and treatment technologies as well as new developments in incidence, prevalence, and prognosis will allow them to play an increasingly key role in ongoing local prevention and control efforts.

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