

PROGRESS TOWARD IMPLEMENTATION OF INTEGRATED SYSTEMS FOR SURVEILLANCE OF HIV INFECTION AND MORBIDITY IN THE UNITED STATES

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Public health surveillance is the basis for evidence-based action. Case surveillance for AIDS was critical in the early 1980s to understand the scope and impact of the epidemic, and multiple systems to monitor the epidemic have evolved during the past 25 years.¹ The changes in surveillance systems and practices have occurred in response to improved understanding of the pathogenesis and treatment of HIV infection, and to emerging needs for data to monitor the epidemic and to direct prevention, care, and research programs.

In 2000, the Centers for Disease Control and Prevention (CDC) described a strategy for the development of an integrated approach to HIV surveillance, to respond to changes in the epidemic and associated data needs.² This approach envisioned a basic platform of HIV case surveillance in all U.S. states, with supplemental surveillance projects in states and cities more heavily impacted by the HIV epidemic. In this issue of *Public Health Reports*, a series of reports describes progress toward the implementation of multiple new surveillance approaches that will provide information on the leading edge of the epidemic. These new systems focus on earlier events in the natural history of HIV; recognize the critical contributions of therapy, both for the health of the individual and as part of an integrated prevention approach; and relate to new prevention initiatives being conducted by CDC's prevention partners.

New HIV surveillance systems focus on earlier events in the natural history of HIV than historical systems. AIDS case surveillance was implemented by all U.S. states by the early 1980s,³ before the availability of highly active antiretroviral therapy (HAART), AIDS diagnosis bore a predictable, though distant, relationship to earlier HIV infection.⁴ The broad availability of HAART has fortunately resulted in a disruption of the predictable progression from early HIV infection to AIDS by vastly increasing the interval between these

two stages of the disease for those who enter care and receive therapy.⁵ Thus, HIV public health surveillance systems must collect information on earlier events in the course of an HIV infection: behaviors that put uninfected people at risk for HIV infection, incident HIV infections, first diagnoses of HIV infection, and entry into medical care. In response to these needs, new systems for monitoring behaviors⁶ and HIV incidence⁷ are currently underway, and CDC has recently recommended that all states collect data on first HIV diagnoses by use of named identifiers.^{8,9}

Effective therapy for HIV infection has changed the characteristics of the epidemic in the United States. As HAART has become broadly available, the number of persons living with HIV infection in the U.S. has increased steadily.¹⁰ Benefits of appropriate therapy accrue to people living with HIV infection, and also the greater community, because risk of transmission of HIV infection is greatly lowered in the setting of undetectable viral load.¹¹ Accordingly, effective surveillance systems require data on access to and quality of care and prevention services for the increasing number of people living with HIV infection. In response, CDC and state surveillance partners are deploying a new system—the Medical Monitoring Project (MMP)—to describe needs for and use of care and prevention services for people who are in care for HIV infection.¹² This system builds on the history of population-based clinical outcomes evaluation established by the Health Care Services and Utilization Survey (HCSUS),^{13,14} and on pilot studies of population-based approaches to clinical outcomes surveillance conducted by CDC and the Health Resources and Services Administration (HRSA).¹⁵ A complementary surveillance system will help provide an understanding of the characteristics of those HIV-infected people who have never received care for their HIV infection, and barriers to entry into care.¹⁶ A new surveillance system for drug resistance will provide information about prevalent resistance patterns that may threaten the long-term benefits of antiretroviral therapy in the population.¹⁷

Finally, CDC has launched new prevention approaches, and has developed new surveillance systems to help determine the impact of these approaches in communities. For example, the Advancing HIV Prevention (AHP) initiative calls for increased access to and use of HIV testing.¹⁸ The National HIV Behavioral Surveillance System will provide a means to describe HIV testing behaviors among the highest-risk populations

in major U.S. cities,^{19,20} and a new post-marketing surveillance system has provided data on the uptake of rapid HIV tests by HIV prevention providers, and on field performance of rapid HIV tests.²¹ AHP also brings focus to the provision of prevention services as part of medical care to people living with HIV infection. MMP will collect data on the needs and receipt of prevention services for people living with HIV infection.¹² Finally, CDC continues to focus on the dissemination of prevention interventions of proven efficacy.^{22,23} It is critical to determine whether these proven effective interventions are reaching those at highest risk for HIV infection. The National HIV Behavioral Surveillance System allows state public health officials to understand the extent to which effective prevention interventions are reaching those people with the greatest behavioral risks.²⁰

The collection and use of public health surveillance data is a public trust. For HIV and AIDS case surveillance, the collection of data for the purposes of disease control does not require consent, and the Health Insurance Portability and Privacy Act specifically allows for the collection of such data.²⁴ For other supplemental surveillance projects, such as interview studies, consent is obtained, and mechanisms to assure ethics oversight and the protection of human subject are in place.²⁵ In either case, it is incumbent on those who work in these diverse HIV surveillance activities to protect the confidentiality of data collected; to ensure that data collected are most relevant for use in local prevention planning and resource planning; to ensure that the data are available to the community for these purposes; and to ensure that personally identifiable data are protected, and used only for public health purposes.²⁶

The surveillance systems described in this special issue of *Public Health Reports* will be the systems that inform prevention and care planning into the fourth decade of the AIDS epidemic in the U.S. CDC continues to work with public health partners to implement systems that will paint a picture of the cutting edge of the epidemic, and that honor the public trust to use these data to achieve greater control of the HIV epidemic.

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