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Dear Colleagues,

On behalf of HIV-positive consumers and HIV public health, health policy, and clinical professionals everywhere, we are pleased to introduce the Medical Monitoring Project (MMP). MMP is a new HIV surveillance initiative sponsored by the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), the Health Resources and Services Administration (HRSA), and your state and local health department, and is broadly endorsed by a wide array of national organizations. Select HIV health care providers and their patients across the United States are being invited to take part in MMP.

More than twenty-five years after the first reported AIDS cases, public health continues to partner with communities to answer increasingly complex questions about better ways to curb—and eventually end—HIV transmission. The knowledge we hold represents the shared experiences of millions of people affected by the epidemic, and the HIV/AIDS case surveillance system is an example of how our collective effort can be harnessed to forecast risk, propose prevention interventions, and allocate resources. To date, however, HIV/AIDS case surveillance has not provided sufficiently detailed, representative information to guide the public health response, and many vital questions remain unanswered. Unanswered questions about unmet medical and social needs, access to medical care and services, clinical outcomes, and the impact of prevention counseling appear as missing pieces of a puzzle; filling in these gaps will help further our collective effort to decrease preventable HIV transmission, disability, and death among the HIV-infected population.

MMP uniquely advances the puzzle's completion by providing comprehensive clinical and behavioral information from a patient sample carefully selected to represent everyone receiving medical care for HIV in the U.S. Because MMP's national estimates will be scientifically representative, the answers provided may be used by prevention planning groups, Ryan White consortia, policy leaders, and clinicians to highlight disparities in care and services and advocate for new interventions and additional resources.

A surveillance system of this scope has never before been undertaken, but it is a project whose time has come. While support is broad, MMP's true success depends upon the endorsement of HIV-positive persons and HIV health care providers like you. We invite you to visit CDC's website at http://www.cdc.gov/hiv/topics/treatment/mmp/index.htm for additional details about participating. MMP data are collected under the same Federal security and confidentiality guidelines that govern HIV/AIDS surveillance activities and are protected under CDC's Federal Assurance of Confidentiality.

Together, we can answer the most challenging questions that remain and advocate in the best interest of our communities and one another.

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ASSURANCE OF CONFIDENTIALITY FOR SURVEILLANCE OF ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) AND INFECTION WITH HUMAN IMMUNODEFICIENCY VIRUS (HIV) AND SURVEILLANCE-RELATED DATA (INCLUDING SURVEILLANCE INFORMATION, CASE INVESTIGATIONS AND SUPPLEMENTAL SURVEILLANCE PROJECTS, RESEARCH ACTIVITIES, AND EVALUATIONS)

The national surveillance program for HIV/AIDS is being coordinated by the HIV Incidence and Case Surveillance Branch (HICSB) and the Behavioral and Clinical Surveillance Branch (BCSB) of the Division of HIV/AIDS Prevention - Surveillance and Epidemiology (DHAP - SE), the National Center for HIV/STD/TB Prevention, a component of the Centers for Disease Control and Prevention (CDC), an agency of the United States Department of Health and Human Services. The surveillance information requested by CDC consists of reports of persons with suspected or confirmed AIDS or HIV infection, including children born to mothers infected with HIV, and reports of persons enrolled in studies designed to evaluate the surveillance program. The information collected by CDC is abstracted from laboratory, clinical, and other medical or public health records of suspected or confirmed HIV/AIDS cases; and from surveys that interview persons in recognized HIV risk groups or known to have a diagnosis of HIV/AIDS.

Surveillance data collection is conducted by State and Territorial health departments which forward information to CDC after deleting patient and physician names and other identifying or locating information. Records maintained by CDC are identified by computer-generated codes, patient date of birth, and a state/city assigned patient identification number. The data are used for statistical summaries and research by CDC scientists and cooperating state and local health officials to understand and control the spread of HIV/AIDS. In rare instances, expert CDC staff, at the invitation of state or local health departments, may participate in research or case investigations of unusual transmission circumstances or cases of potential threat to the public health. In these instances, CDC staff may collect and maintain information that could directly identify individuals.

Information collected by CDC under Section 306 of the Public Health Service Act (42 U.S.C. 242k) as part of the HIV/AIDS surveillance system that would permit direct or indirect identification of any individual or institution on whom a record is maintained, and any identifiable information collected during the course of an investigation on either persons supplying the information or persons described in it, is collected with a guarantee that it will be held in confidence, will be used only for the purposes stated in this Assurance, and will not otherwise be disclosed or released without the consent of the individual or institution in accordance with Section 308 (d) of the Public Health Service Act (42 U.S.C. 242m(d)). This protection lasts forever, even after death.

Information that could be used to identify any individual or institution on whom a record is maintained by CDC will be kept confidential. Full names, addresses, social security numbers, and telephone numbers will not be reported to this national HIV/AIDS surveillance system. Medical, personal, and lifestyle information about the individual, and a computer-generated patient code will be collected.

Surveillance information reported to CDC will be used without identifiers primarily for statistical and analytic summaries and for evaluations of the surveillance program in which no individual or institution on whom a record is maintained can be identified, and secondarily, for special research investigations of the characteristics of populations suspected or confirmed to be at increased risk for infection with HIV and of the natural history and epidemiology of HIV/AIDS. When necessary for confirming surveillance information or in the interest of public health and disease prevention, CDC may confirm information contained in case reports or may notify other medical personnel or health officials of such information; in each instance, only the minimum information necessary will be disclosed.

No CDC HIV/AIDS surveillance or research information that could be used to identify any individual or institution on whom a record is maintained, either directly or indirectly, will be made available to anyone for non-public health purposes. In particular, such information will not be disclosed to the public; to family members; to parties involved in civil, criminal, or administrative litigation, or for commercial purposes; to agencies of the federal, state, or local government. Data will only be released to the public, to other components of CDC, or to agencies of the federal, state, or local government for public health purposes in accordance with the policies for data release established by the Council of State and Territorial Epidemiologists.

Information in this surveillance system will be kept confidential. Only authorized employees of DHAP - SE in HICSB, BCSB, and in the Statistics and Data Management Branch (SDMB), their contractors, guest researchers, fellows, visiting scientists, research interns and graduate students who participate in activities jointly approved by CDC and the sponsoring academic institution, and the like, will have access to the information. Authorized individuals are required to handle the information in accordance with procedures outlined in the Confidentiality Security Statement for Surveillance of Acquired Immunodeficiency Syndrome (AIDS) and Infection with Human Immunodeficiency Virus (HIV) and Surveillance-Related Data (Including Surveillance Information, Case Investigations and Supplemental Surveillance Projects, Research Activities, and Evaluations.