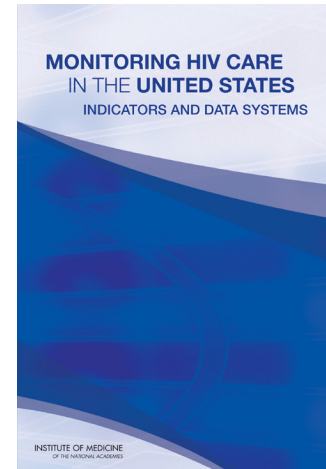


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# Monitoring HIV Care in the United States

## Indicators and Data Systems



**Advances in medical treatment** in the last two decades have made it possible for people infected with the human immunodeficiency virus (HIV) to live longer, healthier lives. The Centers for Disease Control and Prevention estimates that 1.2 million people live with HIV in the United States—more than ever before. In addition, approximately 50,000 people are newly infected each year.

In order to achieve optimal health, people with HIV require continuous access to quality care and treatment for HIV as well as for their other health conditions. Many people with HIV also need supportive services, such as housing, transportation, and food assistance. When these needs go unmet, people with HIV can find it difficult to remain in care and continue taking their medicines—therefore exacerbating their health problems. Limited access to and inconsistent use of medicines by infected individuals also increases their risk of transmitting the virus to others.

In July 2010, the White House Office of National AIDS Policy (ONAP) released its National HIV/AIDS Strategy (NHAS), which includes goals to increase access to care and optimize health outcomes for people with HIV, and to reduce HIV-related health disparities. The NHAS is intended to complement implementation of the Patient Protection and Affordable Care Act (ACA), which is poised to bring millions of uninsured people—including many people with HIV—into the health care system. In order to gauge the effect of the new strategy and law on HIV care, it is necessary to identify core measures that are aligned with the NHAS goals.

To that end, ONAP asked the Institute of Medicine (IOM) to convene an expert committee to identify core indicators related to continuous HIV clini-

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cal care and access to supportive services, and to monitor the effect of both the NHAS and ACA on improving HIV care. The IOM expert committee also was asked to identify the best sources of data to calculate the core indicators, as well as to describe potential barriers to data collection and the role of health information technology (IT) in data collection.

## Indicators and Data Systems

In its report, *Monitoring HIV Care in the United States: Indicators and Data Systems*, the IOM committee outlines a number of obstacles that prevent people with HIV from experiencing optimal health, including late diagnosis, delayed access to care, breaks in care, delayed prescription and intermittent use of life-saving antiretroviral therapy (ART), untreated mental health and substance use disorders, and unmet basic needs. Based on these challenges, the committee identifies core indicators for use by the Department of Health and Human Services (HHS) to evaluate the effect of the NHAS and ACA on improvements in HIV care and access to supportive services for people with HIV.

The core indicators include measures of clinical HIV care, access to treatment for substance abuse and mental health disorders, and access to supportive services, such as housing, transportation, and food assistance, all of which have been shown to influence the overall health of people with HIV (see Detailed Information). All of the indicators identified by the committee can be applied to subpopulations of people with HIV—such as certain age, racial, or ethnic groups—to monitor HIV-related health disparities.

The committee identifies 12 data collection systems that could be used to monitor the effect of the NHAS and ACA. These systems include epidemiologic studies of people with HIV, claims databases (such as Medicare and Medicaid claims systems), HIV program and surveillance systems, and clinical care electronic health record (EHR)

systems. The committee acknowledges that each system has limitations. Key facets of mental health, substance abuse, supportive services, and homelessness data, for example, are lacking in most data systems the committee reviewed. Clinically based EHRs collect most of the desired clinical care data but contain little of the data needed to estimate supportive service indicators. And systems that do collect mental health, substance abuse, and supportive services data frequently lack clinical data. Data systems should evaluate the scope of data that they collect and, where relevant, make changes in order to permit calculation of the core indicators, the committee recommends. Improving the completeness and quality of data will increase the accuracy of calculations based on those systems.

## Potential Barriers to Collecting Indicator Data

Many of the indicators identified by the committee require counts of the total number of people with diagnosed HIV infection in the United States as well as dates and values of CD4+ T cell counts and HIV viral load levels, both of which measure disease severity. These data are reported by health care providers to public health authorities to monitor the HIV epidemic. The committee finds that incomplete HIV/AIDS case reporting, variation across reporting areas for the threshold at which CD4 counts and viral load results become reportable, and barriers to sharing data for people with HIV across jurisdictions may influence the comprehensiveness and accuracy of reported data.

Reimbursement policies and practices also can complicate data collection. For example, health plan reimbursement policies may parse services for clinical care, behavioral health, transportation, and other benefits across separate organizations, making it challenging to combine data at the patient level for research and monitoring purposes.

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Providers of HIV care and supportive services must contend with numerous federal and state privacy laws on proper use and disclosure of patient information. Although such laws are vital to protect patient privacy, they often are subject to different interpretations that could result in discrepancies in data reporting. The committee recommends that HHS issue guidance to the HIV care community to clarify which patient information is permissible to share.

HIV/AIDS programs funded by federal agencies are a vital source of HIV care and supportive services data, but they currently are overburdened by reporting obligations that must be fulfilled as a requirement of continued funding. The committee supports the effort by HHS to streamline data collection and to reduce reporting burdens for programs funded by federal grants. HHS should formalize and continue this effort, which would allow for periodic reprioritization of data needs to mirror the evolution of the HIV epidemic.

### **The Role of Health IT**

When used effectively, health IT can facilitate collection of health care data and directly improve patient care. However, the committee finds that adoption of health IT, such as EHRs, is occurring slowly in settings where people with HIV receive care. The committee concludes that educating HIV care providers on the uses and benefits of health IT for their own practices, technical assistance, and financial incentives may help to promote more widespread use.

The full benefits of health IT cannot be realized without exchange of health information across and among various health IT systems and organizations. People with HIV stand to benefit from the promise of health IT in particular because, over the course of their illness, they shift between myriad health care providers and are seen for multiple health conditions. But for these patients, health IT today is limited by disparate systems that cannot communicate with each other. The committee recommends that HHS provide technical assistance and policy guidance to state and local health departments, clinical providers, and other agencies serving people living with HIV to help to remove these barriers.

### **Conclusion**

The vision provided by the National HIV/AIDS Strategy and the changes to the U.S. health care system embodied in the ACA both have the potential to help curb the HIV epidemic and blunt its impact. The changed eligibility requirements for public and private health insurance resulting from the ACA are expected to expand access to prescription medicines and clinical care for HIV and other conditions that affect people living with HIV, including mental health and substance use disorders.

Increased focus on why people diagnosed with HIV fail to enter or remain in HIV care, as well as removing obstacles to care, such as by providing supportive services, will improve individual health and reduce transmission of HIV to



## Committee to Review Data Systems for Monitoring HIV Care

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**Paul A. Volberding** (Chair)  
Professor and Vice Chair,  
Department of Medicine,  
University of California, San  
Francisco

**Angela A. Aidala**  
Associate Research Scientist,  
Department of Sociomedical  
Sciences, Joseph L. Mailman  
School of Public Health,  
Columbia University, New York,  
New York

**David D. Celentano**  
Chair and Professor,  
Department of Epidemiology,  
Bloomberg School of Public  
Health, Johns Hopkins  
University, Baltimore, Maryland

**Moupali Das**  
Director of Research, HIV  
Prevention Section, San  
Francisco Department of Public  
Health, California

**Victor G. DeGruttola**  
Chair and Professor,  
Department of Biostatistics,  
Harvard School of Public  
Health, Boston, Massachusetts

**Marshall Forstein**  
Associate Professor of  
Psychiatry, Department of  
Psychiatry, Harvard Medical  
School, Boston, Massachusetts

**Carmine Grasso**  
Director, Care and Treatment  
Unit, New Jersey Department  
of Health and Senior Services,  
Trenton

**Shannon Houser**  
Associate Professor,  
Department of Health Services  
Administration, University of  
Alabama, Birmingham

**Jennifer Kates**  
Vice President and Director,  
Global Health and HIV Policy,  
The Henry J. Kaiser Family  
Foundation, Washington, DC

**Erika Martin**  
Assistant Professor,  
Department of Public  
Administration and Policy,  
University of Albany-State  
University of New York

**Kenneth H. Mayer**  
Lecturer in Medicine,  
Harvard University, Boston,  
Massachusetts

**Vickie M. Mays**  
Professor, Departments  
of Psychology and Health  
Services, School of Public  
Health, University of California,  
Los Angeles

**David P. Pryor**  
West Coast Medical Director,  
NBC Universal, Universal City,  
California

**Carlos del Rio**  
Chair and Professor, Hubert  
Department of Global Health,  
Emory University Rollins  
School of Public Health,  
Atlanta, Georgia

**Sten H. Vermund**  
Professor of Pediatrics, Amos  
Christie Chair in Global Health,  
Director, Institute for Global  
Health, Vanderbilt University,  
Nashville, Tennessee

**Adam Wilcox**  
Assistant Professor,  
Department of Biomedical  
Informatics, Columbia  
University, New York, New York

**Douglas Wirth**  
Chief Executive Officer,  
AmidaCare, New York, New  
York

### Study Staff

---

**Morgan A. Ford**  
Study Director

**Carol Mason Spicer**  
Associate Program  
Officer

**Colin F. Fink**  
Senior Program Assistant (from  
July 2011)


**China Dickerson**  
Senior Program Assistant  
(through July 2011)

**Rose Marie Martinez**  
Director, Board on Population  
Health and Public Health  
Practice

### Study Sponsor

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White House Office of National AIDS Policy

others. Developing reliable ways to measure and document the ability of new and existing programs to overcome the obstacles that prevent people with HIV from achieving optimal health, as the committee outlines in its report, is critical to monitoring improvements in HIV care resulting from the NHAS and ACA. 

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500 Fifth Street, NW  
Washington, DC 20001

TEL 202.334.2352

FAX 202.334.1412

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