Monitoring HIV Care in the United States
A Strategy for Generating National Estimates of HIV Care and Coverage

Approximately 1.2 million people in the United States currently live with HIV, and the number increases each year. Facing this public health challenge, the federal government in July 2010 released the National HIV/AIDS Strategy (NHAS), aimed at reducing HIV transmission, increasing access to care, improving health outcomes, and reducing health disparities for people living with HIV. Because the NHAS will be implemented within the context of the Patient Protection and Affordable Care Act (ACA), it is designed to build on ACA provisions that will provide health insurance to people with HIV.

A critical part of federal efforts will be to accurately monitor the scope of the HIV/AIDS epidemic and the availability and success of treatment and prevention programs. For help in structuring its plans, the White House Office of National AIDS Policy (ONAP), which coordinates federal efforts targeting HIV, asked the Institute of Medicine (IOM) to prepare two reports. Monitoring HIV Care in the United States: A Strategy for Generating National Estimates of HIV Care and Coverage is the second report from the IOM study committee.

Legislation Expands the Reach of HIV Care
The committee released its first report, Monitoring HIV Care in the United States: Indicators and Data Systems, in March 2012. The report identified 14 core indicators of clinical HIV care and other services that the Department of Health and Human Services (HHS) could use to monitor the effects of the NHAS and the ACA on HIV care. It also identified the best sources of data for use in measuring and documenting the ability of new and existing programs to help people with HIV achieve optimal health.
In this second report, the IOM committee discusses how to obtain national estimates of health care coverage, utilization, and outcomes for people living with HIV to monitor the impact of the ACA on HIV care in the United States. By expanding insurance coverage to millions of previously uninsured people, including many living with HIV, the ACA is expected to greatly increase the number of people seeking and receiving HIV care. (See Figures.)

**Backbone of a National Monitoring System**

Although there currently is no single data collection effort that can provide nationally representative estimates of health care coverage, utilization, and outcomes for people with HIV, relevant data are being collected by a number of public and private data systems. Together, these data systems provide a reasonably accurate baseline for health care coverage and utilization prior to 2014, when the ACA will be implemented fully. Looking forward, the committee concludes that the Medical Monitoring Project (MMP) is a promising resource for regularly obtaining data from a nationally representative sample of people with HIV to monitor the effect of the ACA on health care coverage and utilization.

Initiated in 2005 by the Centers for Disease Control and Prevention (CDC), the MMP is a supplemental surveillance project designed to collect data from a nationally representative sample of adults receiving care for HIV. It collects data elements central to health care reform, such as access to and sources of health coverage; unmet need for mental health, substance use, and supportive services, such as housing, food, and transportation; quality and comprehensiveness of care; and the organizational context and structure of care. The MMP also collects data on age, race and ethnicity, country of birth, sex at birth, gender, sexual orientation, and education and income levels, allowing for analyses of disparities in participants’ health care coverage and utilization. In addition, the MMP permits new questions to be added to the data collection instruments each year and could reflect the evolving information needs at different phases of ACA implementation.

The MMP data reflect the experiences of individuals who receive care in both public and private settings and that is covered by a variety of payers, including Medicaid, Medicare, the Ryan White HIV/AIDS Program, and private insurers. This makes the MMP a useful source of data to track quality of care across different organizational models and the distribution of health coverage among people with HIV during and following ACA implementation.

Despite its promise, the MMP is not designed to obtain data that are nationally representative of all people diagnosed with HIV, such as individuals who are not receiving HIV care and adolescents. In addition, the MMP has a relatively low participant response rate. The committee recommends that the CDC improve the MMP to ensure higher response rates and more representative samples. The MMP should include sufficient information on HIV-diagnosed individuals who are not in care, adolescents, and those in the criminal justice system, and it should take particular care to ensure adequate representation of vulnerable populations, including immigrants, individuals who are homeless or unstably housed, and people with mental or substance use disorders. Once the MMP is improved, the IOM committee recommends that ONAP and HHS use it to obtain nationally representative data on health care coverage and utilization for people with HIV.

**Sharpening the Focus on States**

The MMP, once improved, may be used to generate national estimates of the health care experiences of people with HIV. It cannot be used for state-by-state analysis of health care coverage and utilization because it does not include individuals from every state. States, however, are responsible
for implementing some of the most significant provisions of the ACA, such as establishing insurance exchanges and determining whether and how to expand Medicaid.

To provide information about differences in health care coverage and utilization by people with HIV within and across states, ONAP and HHS should use data from such sources as Medicaid, Medicare, the Ryan White HIV/AIDS Program, and private insurers to monitor the effect of the ACA at the state and program level.

**Monitoring Care Quality**

Although health care reform is expected to increase access to health care coverage for people living with HIV, it does not guarantee linkage to, retention in, or receipt of quality care. In addition, the movement of a large number of previously uninsured individuals with HIV into the health care system may place increased demands on the health care workforce. Health care provider shortages and delays in providing service could impair care quality.

Therefore, it will be important to monitor trends in both care quality for individuals with HIV and enrollment among the various sources of care coverage as the ACA is implemented. Toward this aim, ONAP, working with HHS, should take steps to ensure the collection and linkage of data on the core indicators, such as those identified in the committee’s first report, to monitor quality of care for people with HIV during and after implementation of the ACA.

**Conclusion**

Developing an ongoing, dynamic strategy for monitoring HIV is important for a variety of reasons. The advent of advanced antiretroviral therapy transformed HIV into a chronic disease, allowing infected individuals to live longer, healthier lives—but only if they receive adequate treatment as early as possible. Monitoring can provide data on the numbers and demographic characteristics of people no longer receiving care at various points along the HIV care continuum, as well as track HIV-related health disparities.

More broadly, monitoring will provide an enhanced means of assessing the effect of the NHAS and the ACA on care received by people with HIV—knowledge that can inform future planning and guide potential redistribution of resources to improve the efficiency and quality of care and reduce health inequities.
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**FIGURE 1: Pathways to Coverage for People with HIV: Prior to the Affordable Care Act, 2010**

- **Start here.**
  - Is employer coverage or private insurance available?
    - Yes → Employer-based/private insurance
    - No → Is individual eligible for Medicaid in his/her state or eligible for Medicare?
      - Yes → Medicaid
      - No → Is other coverage available and affordable in individual’s state?
        - Yes → Other coverage: State high-risk pool, State-only-funded programs
        - No → Ryan White* (varies by state and depends on capacity)

*Medicaid eligibility (state-based): low-income and categorically eligible (disabled, pregnant women, children, medically needy); states may seek waivers to cover other groups (such as nondisabled, childless adults); must be a U.S. citizen or legal resident for at least 5 years. Under the Affordable Care Act (ACA), as of 2014, low-income adults up to 133 percent of the FPL (effectively 138 percent due to a 5 percent income disregard) become a new Medicaid-eligibility group. The Supreme Court has limited the authority of the federal government to enforce this provision, making it uncertain whether all states will comply. For current state eligibility requirements and information on which states have moved to expand Medicaid as permitted by the ACA, see Kaiser Family Foundation (KFF), State Health Facts, Medicaid Income Eligibility Limits for Adults as a Percent of Federal Poverty Level, http://statehealthfacts.org/comparereport.jsp?rep=130&cat=4. For more information on Medicaid, see KFF, Medicaid: A Primer, http://www.kff.org/medicaid/7334.cfm.
b Medicare eligibility (national): ≥65, disabled (Social Security Disability Insurance [SSDI]) or end-stage renal disease; must be a U.S. citizen or legal resident for at least 5 years. Currently under the ACA, Medicare beneficiaries are getting discounts on drugs while in the Medicare coverage gap and preventive services are covered without cost sharing. See KFF, Medicare: A Primer, http://www.kff.org/medicare/7615.cfm.

c State high-risk insurance pools: Prior to the ACA, health plans were permitted to deny coverage to individuals with pre-existing conditions or to charge them higher premiums. Because of this, several states operate high-risk insurance pools, which provide health insurance to residents who are considered medically uninsurable and are unable to buy coverage in the individual market. See KFF, State Health Facts, State High Risk Pool Programs and Enrollment, http://www.statehealthfacts.org/comparetable.jsp?ind=602&cat=7.

d Health insurance exchange: A key component of the ACA, exchanges are entities that will be set up in states to facilitate the purchasing of health insurance by qualified individuals and employers. All legal, non-incarcerated residents are eligible to purchase insurance through the exchanges. Additionally, all legal, non-incarcerated residents are eligible for subsidies, in the form of tax credits, if they do not have access to employer-sponsored insurance, Medicaid, or Medicare, and their incomes are between 100 and 400 percent of the FPL. In addition, if an employer plan does not cover at least 60 percent of average health expenses or the employee must pay more than 9.5 percent of his/her income for the premium, individuals, depending on income, may be eligible for a tax credit to offset premiums for coverage purchased through an exchange. Exchanges are required to be fully operational in every state by 2014. See KFF, State Health Facts, State Action Toward Creating Health Insurance Exchanges, http://www.statehealthfacts.org/comparemaptable.jsp?ind=962&cat=17.

*Ryan White: The Ryan White HIV/AIDS Program, the single largest federal program designed specifically for people with HIV in the United States, provides care and services for people with HIV who are uninsured or underinsured, serving as payer of last resort. It includes the AIDS Drug Assistance Program. Federal funding is provided to states, cities, and providers but may not match the number of people who need services or the cost of their care. See KFF, The Ryan White Program, http://www.kff.org/hiv/aids/7582.cfm.

NOTE: The ACA provides new dependent coverage for children up to age 26 for all individual and group policies and prohibits insurers from denying coverage to children with pre-existing conditions. As of 2014, the ACA prohibits health plans from being able to deny coverage to anyone with a pre-existing health condition. Individuals with pre-existing conditions will be able to obtain insurance in the exchange or non-group market.

SOURCE: Kaiser Family Foundation. 2012. How the ACA Changes Pathways to Insurance Coverage for People with HIV.