AIDS (Acquired Immunodeficiency Syndrome) was first recognized in the United States as a new disease in the early 1980s. By the mid-1980s researchers had established HIV (Human Immunodeficiency Virus) as the cause of AIDS. Diagnoses increased steadily through the mid-1990s. The introduction of antiretroviral therapy (ART) in 1996 substantially reduced AIDS-related morbidity and mortality. Since the beginning of the U.S. epidemic, 1.7 million people have been infected with HIV and an estimated 600,000 have died. Today, 1.1 million are estimated to be living with HIV (called HIV prevalence). About 50,000 people become newly infected each year (called HIV incidence), a number that has remained steady for over a decade.¹

The continuum of HIV care, or the “treatment cascade” as some call it, starts with HIV testing and diagnosis, followed by linkage to care for those who test positive, retention in care, provision of ART, and achievement of viral suppression. The Centers for Disease Control and Prevention (CDC) within the U.S. Department of Health and Human Services estimates that 82 percent of the 1.1 million people living with HIV in the United States are aware of their status, yet only 37 percent are retained in care and 25 percent are virally suppressed.² People with HIV who are not virally suppressed progress in their disease, leading to early death, and they are also able to spread HIV to others.

Research has shown that ART not only reduces HIV-related morbidity and mortality, but also significantly reduces the risk of transmission from an HIV-positive to an HIV-negative partner by up to 96 percent.³ Recently, federal HIV treatment guidelines⁴ have been revised to recommend immediate initiation of ART after HIV diagnosis as more studies appear to demonstrate the
clinical benefits for patients of starting treatment as soon as possible after infection. This complements a novel prevention strategy being evaluated in the United States—“test and treat”—that seeks to prevent HIV transmission by aggressively identifying cases of HIV infection and putting people on treatment as soon as possible after diagnosis.

A widely cited estimate of the lifetime treatment cost for HIV care is $370,000. Medicare is the largest federal payer for HIV care in the United States; most people with HIV/AIDS on Medicare qualify because they meet the disability definition of the Social Security Administration (SSA) and have earned enough work credits to receive Social Security Disability Insurance (SSDI) payments, not because they are age 65 or older. When counting only federal dollars, not state dollars as well, Medicaid is the second largest federal payer for HIV care and the Ryan White HIV/AIDS program is third largest. Unlike Medicaid and Medicare, Ryan White does not provide health insurance; rather, grant dollars are awarded to cities, states, and community-based organizations to pay for core medical services and ART for uninsured and underinsured people. The authorization for the Ryan White HIV/AIDS program, a discretionary program, expires September 30, 2013, although the statute does not include a sunset provision so the program continues as long as funds are appropriated.

The Patient Protection and Affordable Care Act of 2010 (ACA) includes a number of provisions that affect people with HIV. Prior to the ACA, HIV was considered a pre-existing condition and people without employer-sponsored insurance applying for coverage on the individual insurance market could be denied. Starting in January 2014, the law requires health insurers to offer coverage to everyone regardless of health status (known as guaranteed issue). The ACA, modified by a June 2012 Supreme Court decision, authorizes a 100 percent federal match for three years (phased down to 90 percent thereafter) to states for the expansion of their Medicaid programs to all nonelderly adults with incomes up to 133 percent of the federal poverty level beginning in January 2014. Prior to the ACA, people with HIV only qualified for Medicaid if they met much stricter income eligibility standards and were categorically eligible. For most, the main route to being categorically eligible was their disability status. However, qualification as “disabled” necessitated becoming quite sick, effectively requiring individuals to meet the criteria for an AIDS diagnosis, even though early ART can prevent disability and disease transmission.
In addition to expanded and simplified Medicaid eligibility, health insurance coverage and subsidies offered through private health insurance marketplaces authorized in the ACA will also help many people with HIV. All health plans offered in the marketplaces and the Medicaid benchmark plan offered to Medicaid expansion populations must include ten essential health benefits: ambulatory services, emergency services, hospitalization, maternity and newborn care, mental health and substance use disorder services, prescription drugs, rehabilitative and habilitative services and devices, laboratory services, preventive and wellness services and chronic disease management, and pediatric services, including oral and vision care. The ACA also requires new health insurance plans and Medicare to cover all Grade A and B screening recommendations from the U.S. Preventive Services Task Force (USPSTF) at no cost to the patient. And it provides financial incentives to state Medicaid programs to do the same. In April 2013, the USPSTF released a Grade A recommendation for routine HIV screening for everyone ages 15 to 65, younger adolescents and those older than 65 at increased risk for infection, and all pregnant women.

As health reform implementation unfolds in the coming months and years, policymakers and advocates alike will closely monitor the interplay of Medicaid, health insurance marketplace plans, and Ryan White. A number of key issues have already emerged. The role of Ryan White in the context of expanded health insurance coverage, for example, is already under discussion, with most agreeing that the program’s activities will likely differ in states that expand Medicaid versus those that do not. Provisions that require Ryan White to be the payer of last resort and that require most grantees to spend 75 percent of funds on core medical services and 25 percent on support services are also being reconsidered. Finally, Ryan White grantees are essential community providers (ECP) according to the ACA, but concerns exist about the adequacy of federal requirements for inclusion of ECPs in qualified health plan networks and the impact they will have on access to care and existing provider relationships.

SESSION

This Forum session explored the opportunities and challenges the ACA presents for providing insurance coverage and care to people with HIV. Jeffrey S. Crowley, MPH, is program director, National HIV/AIDS Initiative and distinguished scholar at the O’Neill Institute for National and Global Health Law at the Georgetown University Law
Center. He directed the White House Office of National AIDS Policy from 2009 to 2011. He provided an overview of the epidemic in the United States, discussed current treatment policy and payment, and reviewed key HIV-related ACA provisions. Kevin Cranston, MDiv, is the director of the Bureau of Infectious Disease at the Massachusetts Department of Public Health. He discussed the Massachusetts experience expanding Medicaid and private insurance coverage and its effect on people with HIV, as well as changes in the way the state uses Ryan White. Michael Saag, MD, is the director of the Center for AIDS Research at the University of Alabama at Birmingham. He talked about his decades-long experience treating people with HIV and the opportunities and challenges health reform offers for people with HIV living in Alabama, a state that does not plan to expand Medicaid to nonelderly adults, but where coverage will be available through a federally facilitated marketplace.

KEY QUESTIONS

• What is the extent of HIV disease in the United States? What are the characteristics of people with HIV in terms of gender, race, age, income, and health insurance status? Is the disease prevalence growing in particular areas of the country, or among particular groups of people?

• What are the current treatment guidelines for HIV? What is the estimated cost of treating someone with HIV? What type(s) of clinicians typically treat a person with HIV?

• Who pays for HIV treatment in the United States? What roles do public payers like Medicare, Medicaid, and the Ryan White HIV/AIDS program play? How do Medicaid and Ryan White compare in terms of eligibility and services?

• What provisions of the Affordable Care Act will have the greatest effect on people with HIV? What is the predicted impact of the ACA in terms of coverage shifts for people living with HIV?

• Are there issues specific to the needs of people with HIV that states expanding Medicaid should consider?

• How might Ryan White change to be maximally effective in the new environment? In what ways would use of Ryan White funds differ in a state that expands Medicaid and one that does not? Is the program’s current design flexible enough to meet the needs of states, regardless of their Medicaid expansion decisions? Are there aspects that might need revision in the next reauthorization, such as funding formulas?
• What network adequacy, benefit, and other issues might be important to those living with HIV/AIDS who receive coverage through the health insurance marketplaces?

FOR MORE INFORMATION


ENDNOTES


2. CDC, “Today’s HIV/AIDS Epidemic.”


