

# HIV



# Specialist

**SPECIAL  
ISSUE**

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THE AMERICAN ACADEMY OF HIV MEDICINE

**HIV**Specialist

Patient Care, Practice Management & Professional Development Information for HIV Care Providers

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G-Net Strategic Communications  
bob@gattyedits.com

#### PUBLICATION DESIGN AND ART DIRECTION

BonoTom Studio, Inc.

703-276-0612, info@bonotom.com

#### ADVERTISING

Jane Dees Richardson

AAHIVM Advertising Sales  
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703-243-9046 ext. 102, Fax: 856-219-8957  
jrichardson@admarketinggroup.com

#### PUBLISHER

The American Academy of HIV Medicine

1705 DeSales St., NW, Suite 700  
Washington, D.C. 20036  
202-659-0699 • 202-659-0976  
info@aaahivm.org • www.aahivm.org

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BY JAMES M. FRIEDMAN, MHA  
EXECUTIVE DIRECTOR, AAHIVM

## A Special Report

**T**he Academy is both pleased and honored that the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA) has selected *HIV Specialist* to publish the two major articles reporting on their HIV Workforce Study. Because of the importance of the study, we are publishing a special edition of the magazine to correspond with the National Ryan White Conference on HIV Care & Treatment, a meeting that reiterates the continued need for a strong, well-funded Ryan White Program.

There is a long history to the HIV Workforce Study. Shortly after HAB selected the contractor, they held a meeting with outside individuals and organizations who had an ongoing interest in advancing the HIV workforce. At that meeting, which I attended, we agreed to work with HRSA to provide guidance, support and access to HIV care providers as needed.

While the study provides an extensive look at the future of the HIV workforce, the main takeaway is there is and will continue to be a shortage of practitioners that can adequately treat HIV. We find ourselves within a perfect storm and no shelter in sight. More and more patients know their status and can access insurance for the first time thanks to the Affordable Care Act. Concurrently, the workforce is aging and many of our providers are retiring without a new generation to take their place.

There is good news on the prevention and treatment fronts, however. Widespread utilization of PrEP and PEP will help with prevention. The coming of long-term treatment regimens, such as injectables and single-dose therapy, will improve adherence and outcomes. And one day, we hope

and pray, a vaccine *and* a cure will finally eliminate the need for most HIV practitioners. But until then, we need to produce a workforce that is passionate, educated and dedicated to providing the best care possible for HIV patients.



James M. Friedman

AAHIVM has been working in these areas for some time. For several years, we have offered free dues for medical school students in hopes of supporting their desire to go into HIV care. Our webinar program developed with Medscape provides the basics of HIV care to primary care practitioners. Our *Fundamentals of HIV Medicine* will be published through Oxford University Press this summer and will have a broader

reach than in the past. In addition our HIV-Age.org blog provides the HIV practitioner support with respect to the care of older HIV patients.

I urge you to read these articles carefully and give us your thoughts on their conclusions and especially additional ideas for solutions. I would like to express my thanks to AAHIVM Communications Director Amber McCracken for overseeing this special issue and, again, a sincere thank you to HAB for the opportunity to report on this important study.

**HIV**

**While the study provides an extensive look at the future of the HIV workforce, the main takeaway is there is and will continue to be a shortage of practitioners that can adequately treat HIV.**

A close-up portrait of a Black female healthcare worker, likely a nurse or clinician, smiling warmly at the camera. She has short, dark, curly hair and is wearing red-rimmed glasses. A black stethoscope is draped around her neck, resting on her light blue scrubs. The background is softly blurred, showing other people in a clinical or hospital setting. The title text is overlaid on the left side of the image.

# The HIV Clinician Workforce in the United States

**I**N THE UNITED STATES, APPROXIMATELY 1.1 MILLION ADULTS AND ADOLESCENTS ARE LIVING WITH HIV, and each year another estimated 50,000 become infected.<sup>1</sup> Because of advances in HIV care, people are living longer with the disease than they previously did.<sup>1</sup> Moreover, at the end of 2008, an estimated 20% of the people living with HIV were undiagnosed.<sup>1</sup> Only 77% of HIV-diagnosed people are linked to care within four months after diagnosis, and only about 51% of those with an HIV diagnosis are engaged in long-term care.<sup>1</sup> Should universal routine HIV testing for people ages 13 through 64 be adopted, as is recommended by the Centers for Disease Control and Prevention (CDC), and improvements in linkages with and engagement in care be achieved, the demand for HIV care will increase rapidly and create significant new challenges for the health care system.<sup>2</sup> The 2010 Patient Protection and Affordable Care Act should also result in increased access to care for people with HIV who have not previously seen a provider. Under the law, people who are living with HIV but not diagnosed or who are at increased risk for HIV will be more likely to be screened for HIV infection and, among those newly diagnosed, to receive services that strengthen their ability to adhere to treatment.

Evidence suggests that the supply of HIV clinicians might not be keeping pace with the growth in the demand for HIV health care services. In a 2008 survey, the American Academy of HIV Medicine (AAHIVM) found that one third of its members plan to retire within the next 10 years.<sup>3</sup> Another study found that nearly 70% of all practices funded for early intervention services under the Ryan White HIV/AIDS Program have a difficult or very difficult time recruiting

primary care providers.<sup>4</sup> A recent qualitative assessment of the HIV workforce conducted by the federal government concluded that “the Nation faces severe workforce capacity challenges to effectively treat people living with HIV/AIDS (PLWHA). The demand for HIV and primary health care services, in particular, continues to increase as treating PLWHA becomes more complicated and new cases arise. Exacerbating workforce demands are the many experienced

# Supply and Demand Projections from 2010 to 2015

**Boyd Gilman, Ph.D.**  
(corresponding author)  
Mathematica Policy Research  
**Ellen Bouchery, M.S.**  
Mathematica Policy Research

**Paul Hogan, M.S.**  
The Lewin Group  
**Sebastian Negrusa, Ph.D.**  
The Lewin Group

**Sylvia Trent-Adams, Ph.D.**  
Office of the Surgeon General  
U.S. Department of Health  
and Human Services

**Laura Cheever, M.D.**  
Health Resources and  
Services Administration  
U.S. Department of Health  
and Human Services

**DISCLAIMER:** The views expressed in this article are those of the authors. No official endorsement by the U.S. Department of Health and Human Services is intended or should be inferred.



health professionals retiring from practice while young providers choose medical fields outside of HIV and primary health care.”<sup>5</sup> Reflecting this view, the two medical societies for HIV care and treatment in the United States—AAHIVM and the HIV Medicine Association—released a joint statement: “With the growing number of people living with HIV, a failure to promptly address HIV medical workforce issues could lead to the collapse of the HIV care system—risking lives and the public health of communities across the country.”<sup>6</sup>

In September 2010, amid growing concern about the potential shortage of HIV clinicians, the Health Resources and Services Administration within the U.S. Department of Health and Human Services (HHS) sponsored the first national study to quantify the number of clinicians providing HIV medical care in the United States and to forecast the magnitude of the HIV clinician shortage or surplus.<sup>7</sup> HHS initiated the study to assess whether there were sufficient providers available to address the goals of the National HIV/AIDS Strategy, launched by the White House Office of National AIDS Policy in 2010 to reduce new HIV infections, increase access to care and improve health outcomes for people with HIV, and reduce disparities in access to care among individuals living with HIV.<sup>8</sup> The results from that national HIV clinician workforce study are summarized in this article.

The health profession workforce issues addressed in this study are unique and require special attention for several reasons. First, HIV is a

communicable disease and, unlike most chronic conditions, failure to deal with shortages in care will have long term adverse consequences for public health in this country. Second, the expansion of health care coverage under the Affordable Care Act has the potential to bring a large proportion of the population currently living with HIV but not yet diagnosed, or those diagnosed but not yet linked to care, into the health care system. In 2012, over 62% of individuals diagnosed with HIV received medical and support services funded by the Ryan White HIV/AIDS Program<sup>9</sup> and 78% of these clients had income below 200% of the federal poverty level, making them potentially eligible for subsidized coverage under the Affordable Care Act.<sup>10</sup> Efforts must be made now to prepare for the opportunity that health reform brings to identify and engage in care those who are currently not receiving optimal treatment or not effectively managing their HIV disease. Finally, unlike other chronic conditions, HIV care in this country has historically been managed by clinicians from multiple health care professions and medical specialties, many of whom spend only a part of their clinical time treating patients with HIV. The diversity of the HIV workforce means that the administrative records of medical specialty societies cannot be used to identify HIV clinicians. Instead, we used medical and prescription drug claims to create the first national census of providers who manage HIV care in the United States today and conducted a survey to characterize their HIV practice behavior.

## METHODS AND DATA

### Defining and Characterizing the HIV Clinician Workforce

Given the lack of an established credentialing requirement for physicians and nonphysician clinicians providing HIV services, we identified (in consultation with a technical expert panel of HIV clinicians and practice administrators) potential HIV clinicians based on the services they provided as reported in a national pharmacy and medical claims database obtained from SDI Health containing claims from all payers (including managed care plans), billing providers, and geographic regions. We pulled the data in October 2011 and identified HIV clinicians based on claims from 2010. We identified 572,952 patients with at least one HIV-related claim, representing two thirds of all diagnosed cases, and an even higher proportion of those in care. Clinicians with HIV-related visits or prescription claims for 10 or more patients who were physicians, nurse practitioners, and physician assistants in internal or family medicine, general practice, and infectious disease were deemed potential HIV clinicians. We excluded clinicians who treated fewer than 10 patients with HIV because these clinicians are less likely to manage HIV care on an ongoing basis. Based on these parameters, we identified 9,145 potential high-volume HIV clinicians in the claims database.

To obtain more information about the HIV care provided by these clinicians and to develop supply-side inputs that reflect the behavior of HIV clinicians, in 2012 we surveyed a nationally representative probability sample of 5,000 of these potential HIV clinicians. Only 55.1% of the original sample was eligible for the survey. Most of those deemed ineligible indicated that they did not provide HIV treatment to 10 or more patients diagnosed with HIV. Among those eligible for the survey, 42.9% responded. The number of completed eligibles enabled us to estimate national supply-side input parameters for selected age, gender, and health profession groups with statistical precision. We weighted the analyses to adjust for survey sampling and for differential nonresponse patterns.<sup>11</sup>

### Calculating the Demand for HIV-Related Medical Care

We defined demand as the total number of HIV-related medical visits provided under market conditions in 2008. We calculated the total number of visits provided based on (1) the number of individuals diagnosed and living with HIV/AIDS as identified in CDC and state and local surveillance data and (2) the number of HIV-related medical visits per diagnosed person. We calculated visit rates per diagnosed person in the base year as the ratio between the total number of HIV-related visits used and the total number of diagnosed persons in each age and gender group. We identified HIV-related visits and inpatient stays from various sources, including two National Center for Health Statistics (NCHS) provider surveys and the Health Care

Cost and Utilization Project's National Inpatient Sample (HCUP-NIS).<sup>12</sup> We excluded visits related to HIV testing and counseling because our analysis focused on clinicians who manage HIV care longitudinally. We included visits for which HIV was a secondary diagnosis because the presence of HIV as a secondary diagnosis can complicate treatment, implying that optimal treatment of the primary diagnosis might require the knowledge of an HIV specialist.

### Forecasting the Supply and Demand of HIV Clinicians

We projected the supply and demand of HIV clinicians from 2011 to 2015 using a Markov model. We calculated the number of HIV clinicians in each year as the number of HIV clinicians in the prior year plus entrants into the HIV workforce and minus losses from retirement and mortality. We estimated entry into and retirement from the HIV clinician workforce from survey responses. To estimate the total number of visits supplied by the workforce, we multiplied the supply of HIV clinicians in each year by survey-based estimates of the average number of hours worked per year, the proportion of time spent in HIV care, and the number of visits provided per hour. We assumed these parameters remained constant for each age, gender, and health profession category throughout the projection period.

**The projections reflect a real and growing shortage of HIV clinicians as current providers reach retirement age and the number of people living with HIV continues to grow.**

We calculated the number of individuals diagnosed with HIV in each projection year as the number of individuals diagnosed with HIV in the prior year plus newly diagnosed cases minus mortality, based on CDC and state and local surveillance data. We assumed utilization rates per diagnosed person by age, gender, and race remained constant throughout the projection period. We multiplied the average utilization rates per diagnosed person by the forecasted number of diagnosed cases in each age and gender category to obtain the total number of HIV visits demanded in each forecasted year. We converted forecasted visits supplied and demanded to full-time equivalent (FTE) clinician values based on the average number of HIV-related visits supplied per full-time clinician in the base year.

## RESULTS

Table 1 shows the distribution of the estimated 4,937 HIV clinicians practicing in 2010 identified in this study. Of these, an estimated 54.5% were primary care physicians, 37.2% were infectious disease specialists, and 8.3% were nurse practitioners or physician assistants. An estimated 65.8% of the HIV clinicians were male and 16.5% were age 65 and older. The majority of the HIV clinicians were white non-Hispanic (68.0%), and the largest share (39.7%)

practiced in the South. Overall, 13.2% of the HIV physicians were trained outside of the United States.

Table 2 provides an estimate of the number of HIV-related medical visits supplied in 2010. Primary care physicians reported spending on average 1,872 hours per year in patient care, with 30.4% of their clinical care time spent treating patients with HIV. Infectious disease specialists reported spending a similar amount of time in patient care (1,871 hours per year) but devoted nearly 30% more of their time to treating patients with HIV (39.3%) than did primary care physicians. Nonphysician clinicians reported spending more time in clinical care (1,993 hours) and a higher share of their time treating patients with HIV (66.9%) than their physician

counterparts. Physicians reported conducting on average 1.5 HIV-related clinician visits per hour, compared with 1.4 visits per hour for nonphysician clinicians. In total, we estimate that the HIV clinicians identified in this study provided 5.1 million HIV-related medical visits nationally in 2010.

Table 3 displays the total number of HIV-related visits demanded and received in 2008. This total includes visits in ambulatory settings (on average, 5.1 visits per diagnosed person annually), as well as visits provided to hospital inpatients (on average, 0.92 visits per diagnosed person annually). These averages include people with HIV who were engaged in care, as well as those who received treatment sporadically. Overall, we estimate 5.1 million HIV-related medical visits were demanded in 2008. An estimated 62.8% of all HIV-related visits demanded were for individuals ages 35 to 54. A total of 15.4 percent of all visits in 2008 were for people 55 and older, a proportion that is likely to increase as the HIV population ages. Approximately two thirds of total visits were for males (67.1%) and one third for females (32.9%). Black non-Hispanics accounted for the highest share of visits (45.0%), followed by white non-Hispanics (34.1%). Hispanic individuals represented 18.2% of all visits demanded. The South represented the highest proportion of visits (42.5%), followed by the Northeast (28.4%).

Table 4 shows the forecasted number of HIV clinicians and visits supplied from 2010 to 2015. Our model forecasts a

**Table 1. Number and Percentage of High-Volume HIV Clinicians, by Clinician Type, Demographic Group, and Region**

	<b>Number of HIV Clinicians</b>	<b>Percentage of HIV Clinicians</b>
<b>Number of Clinicians</b>	<b>4,937</b>	<b>100.0</b>
<b>Clinician Type</b>		
Primary care physicians	2,691	54.5
Infectious disease specialists	1,836	37.2
Nurse practitioners and physician assistants	410	8.3
<b>Gender</b>		
Male	3,249	65.8
Female	1,688	34.2
<b>Age Group</b>		
Younger than 45 years	1,570	31.8
45 to 64 years	2,552	51.7
65 years and older	815	16.5
<b>Race/Ethnicity</b>		
White, non-Hispanic	3,362	68.0
Black, non-Hispanic	410	8.3
Hispanic	360	7.3
Other/multiple race, non-Hispanic	805	16.3
<b>Census Region</b>		
Northeast	1,387	28.1
South	1,960	39.7
Midwest	746	15.0
West	844	17.1
<b>Country of Highest Clinical Degree</b>		
United States	4,285	86.8
International	652	13.2

Source: HIV Clinician Workforce Survey 2012.

Note: The results are weighted to account for the probability of selection and for differential survey nonresponse patterns. Percentages might not sum to 100% because of rounding. High-volume providers are those who treated 10 or more patients with HIV in 2010.



**Table 2. Number of HIV Clinician Visits Supplied in 2010, by Clinician Type**

Type of Clinician	(Column A) Number of HIV Clinicians	(Column B) Number of Hours Worked per Year	(Column C) Proportion of Time Spent in HIV Care (%)	(Column D) Number of HIV Visits per Hour	(Column E) Total Number of HIV Visits Supplied
<b>PCP</b>	2,693	1,872	30.4	1.5	2,297,165
<b>IDS</b>	1,836	1,871	39.3	1.5	2,023,814
<b>NP/PA</b>	408	1,993	66.9	1.4	762,238
<b>All Clinicians</b>	4,937	1,882	36.7	1.5	5,083,217

IDS = infectious disease specialist; NP = nurse practitioner; PA = physician assistant; PCP = primary care physician.

Source: HIV Clinician Workforce Survey 2012.

Notes: The results shown in Columns B, C, and D were derived from the model using statistically significant subgroup means only. The results are weighted to account for the probability of selection and for differential survey nonresponse patterns.

decline in the number of primary care and infectious disease physicians managing HIV care by 2015 of about 400 and 200 clinicians, respectively. The number of nurse practitioners and physician assistants supplying HIV care is expected to increase from 408 clinicians in 2010 to 511 clinicians in 2015. The total number of visits supplied is expected to decline 6.1%, from 5.1 million in 2010 to 4.8 million in 2015, with nonphysician clinicians providing an increasing share of HIV care. The decline in visits supplied is largely because the number of clinicians entering the HIV workforce over the next few years is not sufficient to fill the gap left by clinicians leaving the HIV workforce because of retirement and mortality. The decline in supply is also due to the demographic shift in the

HIV workforce toward female clinicians. A disproportionate number of new entrants is female and, on average, female clinicians in HIV medicine work 11.2% fewer hours per week than their male counterparts (40.3 hours for women versus 45.4 hours for men).

**Table 3. Number and Percentage of HIV Visits Demanded, by Demographic Group and Region, 2008**

Demographic Group	Number of Visits Demanded (in thousands)	Percentage of Visits Demanded
<b>Total</b>	<b>5,148</b>	<b>100.0</b>
<b>Age Group</b>		
Younger than 13 years	28	0.5
13 to 24 years	293	5.7
25 to 34 years	800	15.5
35 to 44 years	1,623	31.5
45 to 54 years	1,614	31.3
55 to 64 years	658	12.8
65 years or older	132	2.6
<b>Gender</b>		
Male	3,455	67.1
Female	1,693	32.9
<b>Race/Ethnicity</b>		
White, non-Hispanic	1,758	34.1
Black, non-Hispanic	2,317	45.0
Other/multiple race, non-Hispanic	138	2.7
Hispanic only	935	18.2
<b>Region</b>		
Northeast	1,463	28.4
South	2,190	42.5
Midwest	604	11.7
West	891	17.3

Source: National Ambulatory Medical Care Survey (NAMCS) (2009) and National Hospital Ambulatory Medical Care Survey (NHAMCS) (2008), HCUP-NIS data (2002–2009), and federal and state HIV surveillance data (2008).

Note: Percentages might not sum to 100% because of rounding.



SHUTTERSTOCK

**Table 4. Forecasted Supply and Demand of HIV Visits, 2010–2015**

	2010	2011	2012	2013	2014	2015
<b>HIV Clinicians</b>						
PCP	2,693	2,602	2,524	2,445	2,369	2,292
IDS	1,836	1,789	1,748	1,707	1,666	1,625
NP/PA	408	431	453	473	493	511
<b>Total</b>	<b>4,937</b>	<b>4,823</b>	<b>4,724</b>	<b>4,625</b>	<b>4,527</b>	<b>4,429</b>
<b>HIV Visits Supplied</b>						
PCP	2,297,165	2,237,539	2,179,493	2,120,860	2,061,589	2,000,908
IDS	2,023,814	1,978,503	1,936,158	1,893,450	1,849,754	1,806,565
NP/PA	762,238	805,993	848,868	889,285	927,861	964,288
<b>Total</b>	<b>5,083,217</b>	<b>5,022,035</b>	<b>4,964,519</b>	<b>4,903,595</b>	<b>4,839,204</b>	<b>4,771,762</b>
<b>HIV Cases</b>						
Male	678,556	700,272	722,026	743,841	765,683	787,529
Female	231,122	237,799	244,474	251,156	257,832	264,505
<b>Total</b>	<b>909,678</b>	<b>938,071</b>	<b>966,500</b>	<b>994,997</b>	<b>1,023,515</b>	<b>1,052,034</b>
<b>HIV Visits Demanded</b>						
<b>Gender</b>						
Male	3,666,900	3,772,103	3,877,386	3,982,853	4,088,411	4,193,953
Female	1,784,157	1,829,765	1,875,314	1,920,866	1,966,349	2,011,784
<b>Age Group</b>						
Younger than 35 years	1,322,415	1,422,861	1,523,329	1,623,921	1,724,197	1,824,070
35 to 44 years	1,713,726	1,757,475	1,800,314	1,842,454	1,884,195	1,925,491
5 to 54 years	1,638,418	1,650,483	1,662,237	1,673,572	1,684,499	1,695,083
55 years or older	776,498	771,050	766,820	763,771	761,869	761,094
<b>Total</b>	<b>5,451,057</b>	<b>5,601,868</b>	<b>5,752,700</b>	<b>5,903,719</b>	<b>6,054,760</b>	<b>6,205,738</b>

IDS = infectious disease specialist; NP = nurse practitioners; PA = physician assistant; PCP = primary care physicians.

Sources: HIV clinician workforce survey, 2012.

Table 4 also shows forecasts of the number of HIV patients and visits demanded and received from 2010 to 2015. The number of diagnosed cases is expected to increase by about 140,000 (from 0.9 million in 2010 to slightly more than 1.0 million by 2015) and the total number of visits demanded is expected to increase 13.8% (from 5.4 million in 2010 to 6.2 million in 2015). The growth in the number of visits demanded is due primarily to the continued number of newly diagnosed cases each year and the low mortality rate among the currently diagnosed population. The increase in demand is also due to the aging of the diagnosed population and the higher rate of HIV-related visits among individuals ages 45 to 54.

Figure 1 expresses demand and supply projections in FTE HIV clinicians per year over the five-year forecasting period, adjusted to reflect that high-volume HIV clinicians spend, on average, less than 40% of their time treating patients with HIV. The total number of FTE HIV clinicians supplied in the United States is expected to decline 5.5% over this period, from 1,812 FTE HIV clinicians in 2010 to 1,713 in 2015. During the same period, the total number of FTE HIV clinicians demanded in the United States is expected to increase 13.9%, from the base-year value of 1,945 to 2,215 by 2015. The net result is an estimated shortage of 133 FTE clinicians in 2010, growing to a shortage of 502 FTE HIV clinicians in 2015. Because few clinicians work full time in HIV care, the number

of providers needed to fill this gap will be substantially higher than the number of FTEs required.

If expanded HIV testing efforts are successful in identifying and linking to care 5% of the estimated 240,000 living but undiagnosed cases of HIV annually over the forecasted period, the shortfall of FTE clinicians will increase to 36% of supply. A 5% increase in the proportion of time clinicians spend treating patients with HIV would reduce the deficit to 24.8% of supply, while a 10% increase in the number of visits per hour would reduce the shortage to 17.6% of supply.

Physicians providing a low-volume of services are not included in the estimate of HIV physicians in this model. Low-volume providers can address some of this excess demand. However, the projections reflect a real and growing shortage of HIV clinicians as current providers reach retirement age and the number of people living with HIV continues to grow.

## DISCUSSION

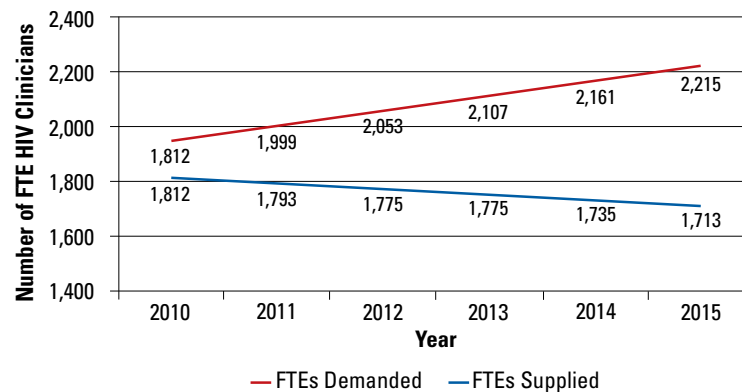
The study offers several important insights into the HIV clinician workforce. HIV clinicians represent a range of medical specialties and health professions. Nurse practitioners and physician assistants are likely to become an increasingly important component of the HIV workforce. Effective workforce

strategies will need to be tailored to differences in training and scope of practice across the range of HIV practitioners. Another important feature of the HIV workforce is that most HIV clinicians spend only a portion of their time treating patients with HIV. The capacity of the HIV clinician workforce might be expanded by increasing the proportion of time that clinicians currently treating patients with HIV spend in HIV care. Our analysis also identified many clinicians who treat a low volume of HIV patients and who do not manage the HIV treatment of these patients on an ongoing basis. The HIV workforce might be

expanded by providing training or professional support, such as comanaging care with HIV specialists, to low-volume clinicians.

The study has several limitations. First, there are gaps in the data sources supporting our supply and demand estimates. The supply estimates include only providers identified on claims, which likely results in an undercount of HIV clinicians who treat a large proportion of uninsured patients, federally employed providers, and nurse practitioners and physician assistants who do not bill under their own name. Our demand estimates also underestimate services provided by nurse practitioners and physician assistants because these providers are underrepresented on the NCHS ambulatory medical care survey. Second, the HIV clinician survey's response rate was below the desired level. Although the nonresponse bias analysis showed that respondents differed from nonrespondents in several observable characteristics, our weighting procedures were effective at mitigating that bias, assuming the characteristics we used in the weighting process are correlated with the survey outcome measures. Finally, the findings reflect current market-based supply and demand. They do not take into account unmet needs, such as people living with HIV but not yet

**Figure 1. Forecasted Supply and Demand of FTE HIV Clinicians, 2010–2015**



FTE = full-time equivalent.

Sources: HIV Clinician Workforce Survey 2012, NAMCS (2009), NHAMCS (2008), HCUP-NIS (2002–2009), and federal and state HIV surveillance data (2008).

diagnosed, people diagnosed with HIV but not yet in care, and people in care but not yet receiving the optimal level of care. Nor do they take into account potential changes in market conditions, such as expanded health insurance coverage likely to occur after the full implementation of the Affordable Care Act in 2014.

Overall, the study shows a small but rapidly expanding shortage of HIV providers. Our forecasting model predicts that by 2015 the supply of HIV clinicians will be sufficient to meet only three quarters of total demand for HIV-related medical services under current market-based

assumptions. Expanded HIV testing and diagnosis and improvements in linkages, engagement, and adherence to care—without an increase in the number of health care providers willing to treat people with HIV or improvements in the productivity of the HIV workforce—will only make the forecasted deficit of HIV providers worse.

## Acknowledgements

Dr. Boyd Gilman and Ms. Ellen Bouchery from Mathematica Policy Research conducted and are responsible for the analysis using the survey data collected for this study. Both authors had full access to all of the original data used in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. The research was conducted under contract to the Health Resources and Services Administration in the U.S. Department of Health and Human Services (Contract No. HHS25020100122G). Staff from the HIV/AIDS Bureau within the Health Resources and Services Administration helped to design the study and reviewed and provided substantive comment on the findings and conclusions presented in this manuscript.

**HIV**

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- HIV physician visits associated with inpatient stays were calculated assuming that one HIV specialist visit was provided during each day of an inpatient stay for patients with a primary diagnosis of HIV. For patients with a secondary diagnosis of HIV, we assumed that one HIV specialist consultation was provided for each discharge.

# Characteristics of the Ryan White HIV/AIDS Program Provider Network

## Implications for Access to Care Under the Affordable Care Act

**Ellen Bouchery, M.S.**  
(corresponding author)  
Mathematica Policy Research

**Boyd Gilman, Ph.D.**  
Mathematica Policy Research

**Sylvia Trent-Adams, Ph.D.**  
Office of the Surgeon General  
U.S. Department of Health and Human Services

**Laura Cheever, M.D.**  
Health Resources and Services Administration  
U.S. Department of Health and Human Services

**T**HIS STUDY PROVIDES a baseline view of the HIV care system prior to implementation of the Patient Protection and Affordable Care Act (ACA). Prior to ACA implementation, approximately 30 percent of individuals who received Ryan White HIV/AIDS Program (RWHAP) funded services were uninsured. For the remainder, RWHAP provided services not covered by their insurance (HRSA 2010). Even though RWHAP represented only 16 percent of federal funding for HIV/AIDS care (KFF 2013), it provided a critical source of supplemental funding that reached broadly across the HIV care system. In 2012, among the approximately 850,000 individuals diagnosed with HIV, more than 529,000 (over 62 percent) received RWHAP-funded medical or support services (HRSA 2012). Among physicians specializing in HIV care, 42 percent reported that their primary practice setting received RWHAP funding.

The ACA provided new sources of funding for and is likely to have increased the demand for HIV care. Insurers, providers, and policy makers need to be proactive in ensuring that the increased availability of insurance coverage has a positive impact on care access. Many individuals receiving



RWHAP-funded services are likely to have been affected by the provisions of the ACA that enhanced access to insurance coverage. Of those receiving a service funded by RWHAP in 2010, about 59 percent had income below 100 percent of the federal poverty level (FPL), and an additional 19 percent reported income between 101 and 200 percent of the FPL (HRSA 2010).

Under the ACA, many such individuals are eligible for Medicaid if they live in a state that has expanded Medicaid coverage, or they might be eligible for subsidized insurance through a health insurance exchange. As these individuals gain insurance coverage, their care choices are determined by specific features of their health plan's provider network and service coverage. Health plan limitations might result in disruptions to existing provider-patient relationships.

For example, a health plan's provider network might not include an individual's current HIV care provider or might not accept that provider as a primary care physician (Hargreaves et al. 2011). In California in 2011, after the state implemented its Medicaid expansion, thousands of patients living with HIV/AIDS transitioned from RWHAP-funded providers to managed care plans and then experienced difficulty accessing HIV providers and pharmacies that were not part of their managed care organization's network (Donnelly and Mulhern-Pearson 2012). Access issues might be more pronounced as

several states plan to implement new or significant expansions of their Medicaid managed care programs<sup>7</sup> that include high-need disabled individuals (Smith et al 2011).

In addition to concerns about maintaining existing relationships with HIV specialists, the shifts in insurance coverage induced by the ACA raise concerns about access to medical and support services funded by RWHAP that might not be covered by health plans, including, for example, treatment adherence counseling and support services such as nonmedical case management and health education/risk reduction (Hargreaves et al. 2011). Patients obtaining health insurance under the ACA and directed to a non-RWHAP-funded provider might find that, based on the terms of their insurance coverage, the support services they have been receiving at their RWHAP-funded provider are no longer available under their new plan. Providers might be required to address the needs of patients new to their care without access to resources such as peer counselors and case managers that might have been available at the patient's RWHAP-funded provider. Similarly, a newly insured patient might find that their insurance plan does not cover some services they were previously receiving through a RWHAP-funded provider.

In addition to potentially creating access issues for individuals currently receiving care from RWHAP-funded providers, the ACA is also expected to affect individuals



with HIV who were not previously engaged in care. Many individuals with HIV who were previously uninsured or had limited insurance coverage may have increased access to care and thereby an increased likelihood of diagnosis or re-entry into treatment. At the end of 2008, approximately 20 percent of people living with HIV had an undiagnosed infection<sup>10</sup> and only about 51 percent of those with an HIV diagnosis were engaged in long-term care (CDC 2010).

The availability of case management, behavioral health, and ancillary services such as transportation and childcare that are funded through RWHAP grants is likely to improve linkage to and retention in care among the newly diagnosed and those re-entering the care system if these individuals are referred to care at RWHAP-funded providers (Giordano 2011).

Drawing on results from a national survey of HIV clinicians conducted in 2012 prior to ACA implementation, this study compares the characteristic of clinicians whose primary practice setting received RWHAP funding with those whose primary practice setting did not receive RWHAP funding. RWHAP-funded providers play a unique and important role in the HIV care system. They deliver HIV-related medical and support services to individuals living with HIV who are uninsured or underinsured. Accordingly, we expect the

observed characteristics of RWHAP-funded practices and their associated clients and providers to differ substantially from those of practices that did not receive RWHAP funding. Thus, in this article, we present descriptive statistics on provider characteristics and test for statistically significant differences based on whether a physician's primary practice received RWHAP funds.

## STUDY DATA AND METHODS

The data source for the analysis is the HIV Clinician Survey conducted for the Health Resources and Services Administration by Mathematica Policy Research between August 9, 2012, and October 31, 2012. In this section, we briefly describe the survey methods.<sup>1</sup> The clinician instrument consisted of the following categories of questions: eligibility screener, background, hours in patient care, patient load, practice setting, practice management, future plans, perceptions about workforce capacity, and demographic characteristics.

Given the lack of an established credentialing requirement for physicians providing HIV services, we identified HIV clinicians and thus the survey frame based on the

level of HIV services reflected in a clinician's billing records. We used a national, all-payer proprietary claims database from SDI Health, a national health care data warehouse and analytics organization. SDI Health collects and maintains a warehouse of both pharmacy (RX) and medical (DX) claims from all payer sources, including managed care plans, billing providers, and geographic regions. The RX database includes electronic final-action claims submitted primarily by retail pharmacies.

The RX file captures approximately 50 percent of all electronically transmitted pharmaceutical records in the country and includes from 120 to 130 million covered lives. The DX file includes medical claims transmitted electronically between providers and payers via third-party transaction houses or medical practice management companies.

The DX database captures approximately two-thirds of all electronically filed medical claims, includes roughly 1.1 billion records per year, and represents about 157 million covered lives. We extracted the data in October 2011 and identified our list of HIV clinicians based on all claims from calendar year 2010. The 2010 claims identified 572,952 patients with at least one HIV-related claim (based on diagnosis and prescription national drug codes), representing approximately two-thirds of all diagnosed cases in the United States and an even higher proportion of those in care.

We limited the survey to clinicians with HIV-related claims for 10 or more patients and to physicians, nurse practitioners (NP), and physician's assistants (PA) who specialize in internal or family medicine, general practice, or infectious disease. We identified 9,145 primary care physicians, infectious disease specialists, NPs, and PAs who, based on an examination of medical and pharmacy claims, treated 10 or more patients with HIV in 2010.

Using the census of 9,145 HIV clinicians as our sampling frame, we drew a nationally representative probability sample of 5,000 clinicians for the survey and defined the explicit strata by professional degree (physicians versus nonphysician clinicians), medical specialization (primary care physicians versus specialists), and urbanicity (metropolitan versus nonmetropolitan practice location).<sup>2</sup> We implicitly stratified within these strata by U.S. Census region and specialization (for nonphysician clinicians) and gender (for physicians).

Clinicians responded to the questionnaire either by web or mail. Only 55.1 percent of the original sample was eligible for the survey. Most of those deemed ineligible indicated that they did not provide HIV treatment to 10 or more patients diagnosed with HIV. Among those eligible for the survey, 42.9 percent responded. We weighted the analyses to account for the probability of selection of each provider and for differential nonresponse patterns. We cleaned the survey data based on face validity and internal consistency checks. We logically imputed reported values that fell outside a realistic range or set them to missing. Excluding 31 respondents who did not

identify whether their primary practice received RWHAP funding, the final sample for this analysis was 1,002.

The data for this study have four major limitations: the potential underrepresentation of HIV clinicians on claims data, the low rate of survey response, the large number of ineligible sample members among those who did respond, and the high number of internally inconsistent or implausible item responses. First, claims data underrepresent HIV clinicians who treat a large proportion of uninsured patients. Because the survey frame is based on billing data, it failed to capture clinicians who treat patients with HIV but either do not submit a claim for third-party reimbursement or submit a claim under a name other than their own. To address this limitation, we used a low threshold, ten HIV patients in 2010, to identify potential HIV clinicians.

Second, the survey's 42.9 percent response rate was below the desired level. However, response rates for provider surveys are historically low and, in many cases, lower than the rate we achieved. Our nonresponse bias analysis showed that, even though respondents differed from nonrespondents in terms of observable characteristics, our weighting procedures were effective in mitigating nonresponse bias, assuming that the characteristics we used in the weighting process correlate with the key survey outcome measures.

Third, among those responding to our screener questions, about 45 percent of sample members turned out to be ineligible to participate in the survey, highlighting the difficulty of using billing data to identify high-volume providers. The high degree of ineligible sample members might reflect the fact that, despite having at least 10 HIV-related claims associated with their provider ID, these clinicians treat a small number of patients with HIV, do not manage their patients' HIV disease, and do not view themselves as HIV providers.

Finally, although item nonresponse was relatively low, the number of responses with internally inconsistent values or in an implausible range was high. Among groups of responses that were inconsistent or fell in an implausible range, we were generally able to identify a logical source for the inconsistent or out-of-range values and to edit the reported values to address misinterpretation of questions or other reporting errors.

## STUDY RESULTS

In this section, we report findings from the HIV Clinician Survey. First, we discuss patient characteristics, followed by practice characteristics, and physician characteristics. As noted, we disaggregate our findings based on receipt of RWHAP funds. Physicians were deemed RWHAP-funded if they indicated in the survey that their primary practice setting received RWHAP funding. Even though the survey included NPs and PAs, the findings in this article are for physicians only because NPs and PAs who do not bill under their own name were not represented in the survey.

**Exhibit 1: Average Share of Patients with Listed Characteristic**

Patient Characteristic	All Physicians	RWHAP-funded Physicians	Non-RWHAP-funded Physicians
<b>AIDS status</b>			
HIV only	65.7	61.4**	69.6
AIDS diagnosis	34.3	38.6**	30.4
<b>Established in care</b>			
Diagnosed with HIV/AIDS in the past 12 months	12.4	11.5**	12.9
Not newly diagnosed but new to provider's care within the past 12 months	18.9	16.0**	20.9
Established in care for the last 12 months	68.9	72.5**	66.5
<b>Patient comorbidities</b>			
Serious mental illness	27.3	33.3**	22.7
Substance abuse disorder	21.8	26.9**	17.4
Hepatitis A or B	21.9	25.4**	19.1
Other significant comorbidities	33.0	39.3**	27.9
Number of observations	1,002	466	536

SOURCE: Analysis of HIV Clinician Workforce Survey, 2012.

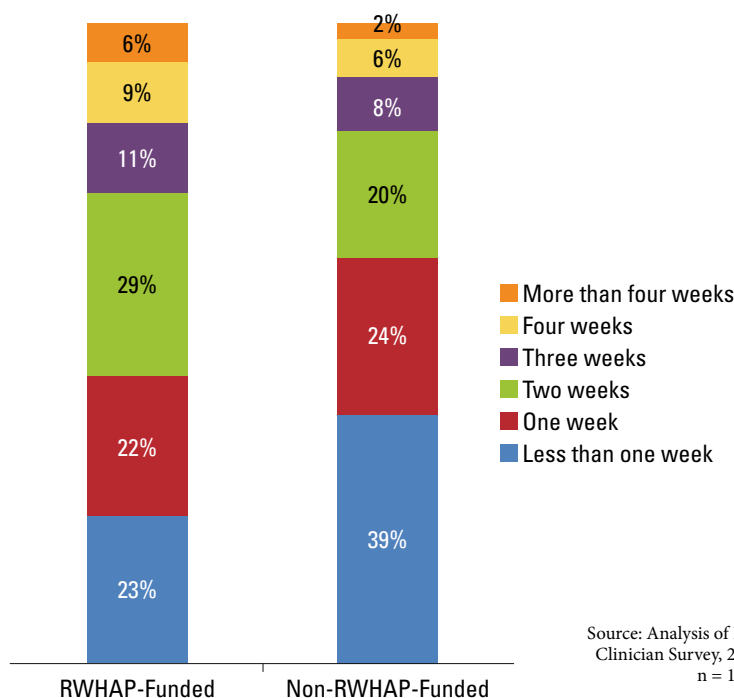
NOTES: Estimates are weighted to account for the probability of selection of each provider and for differential nonresponse patterns. We tested for statistical significance of differences between RWHAP and non-RWHAP providers. \*\* Differences are significant at the 1 percent level using an F-test.

### Patient Characteristics

HIV patients have a range of care needs related to their HIV diagnosis, as well as to other comorbidities. In Exhibit 1, we display the average share of an HIV physician's patients with each characteristic. Relative to their non-RWHAP-funded

counterparts, RWHAP-funded physicians reported more complex patient caseloads. A higher share of their patients had AIDS (39 versus 30 percent), a serious mental illness (33 versus 23 percent), a substance use disorder (27 versus 17 percent), hepatitis A or B (25 versus 19 percent), or another significant comorbidity (39 versus 28 percent).

**Exhibit 2: Proportion of HIV Physicians Reporting Given Average Wait Time for an Initial Visit**



### Practice Characteristics

Physicians who receive RWHAP funding practice in markedly different environments from those who do not. Physicians whose primary practice did not receive RWHAP funding were more likely to identify their primary practice setting as a private clinic or office (68 versus 11 percent). In contrast, physicians whose primary practice received RWHAP funds were more likely to identify their primary practice setting as a hospital or university-based outpatient clinic (49 versus 16 percent).

HIV physicians reported that the duration of initial and follow-up visits at their primary practice averaged 47 and 22 minutes, respectively. Average visit length was comparable for physicians whose primary practice did and did not receive RWHAP funding. However, reported wait times for appointments were longer for physicians in RWHAP-funded primary practices than for those in non-RWHAP-funded practices (Exhibit 2). Twenty-seven percent of physicians in RWHAP-funded primary practices reported a wait time of three or more weeks for an initial appointment. In contrast, only 16 percent of physicians in practices that did not receive RWHAP funds reported a wait time of three or more weeks. The observed pattern of wait times was similar for follow-up visits.

### Exhibit 3: Percentage of HIV Physicians Using Electronic Health Records For Listed Purpose Or Using Listed Management Technique

EMR use or management practices	All Physicians	RWHAP-funded Physicians	Non-RWHAP-funded Physicians
<b>HIV physician's primary practice uses HER</b>			
To review patient records	78.4	81.9	76.4
To increase clinician's adherence to clinical guidelines	43.9	45.2	42.7
To share clinical information with providers internal to practice	72.1	79.5**	66.9
To share clinical information with providers external to practice	35.9	34.9	37.8
To share clinical information with patients	43.5	47.5*	41.0
To write and/or order prescriptions (i.e, e-prescribing)	77.3	81.7	74.2
To order laboratory, radiology, or other diagnostic tests	67.6	71.8	64.5
To receive laboratory, radiology, or other diagnostic test results	77.1	82.6	73.0
To make referrals for specialty care	56.2	62.5**	51.5
To track patient enrollment, appointments, and/or referrals	63.0	71.5**	56.7
To monitor quality of care	54.4	63.8**	47.8
Primary practice does not use a computerized or EMR system	12.4	8.8	15.3
<b>HIV physician's primary practice uses the following management technique</b>			
Expediting intake procedures so new patients can be seen more quickly	54.0	62.8**	46.6
Contacting patients to remind them of their appointments	87.8	90.7	85.8
Double-booking appointments	43.4	55.1**	33.8
Maintaining open appointments for walk-ins	47.0	53.1**	42.4
Maintaining cancellation lists	34.1	37.1*	32.7
Offering group appointments	8.7	10.1**	7.8
Using medical case managers to help patients navigate the health care system	46.3	77.8**	21.6
Using peer counselors to help patients understand and adhere to treatment	23.5	42.7**	7.7
Coordinating appointments so that patients see multiple clinicians during one visit	32.4	50.5**	17.9
Providing HIV-related care for patients for whom the physician are not the primary care provider	63.3	66.6	61.9
Devoting time and resources to delegating clinical tasks to NPs, PAs, RNs, or others	54.7	79.6**	34.9
Devoting time and resources to promoting long-term self-management of care	70.3	91.8**	52.7
Devoting time and resources to building integrated teams to provide previsit, postvisit, and between-visit contacts	53.9	79.5**	32.5
Number of observations	1,002	466	536

SOURCE: Analysis of HIV Clinician Workforce Survey, 2012.

NOTES: Estimates are weighted to account for the probability of selection of each provider and for differential nonresponse patterns. We tested for statistical significance of differences between RWHAP and non-RWHAP providers. \* Differences are significance at 5 percent level and \*\* differences are significant at the 1 percent level using chi-squared test. EMR= Electronic medical records; NP = nurse practitioners; PA = physician's assistant; RN = registered nurse.

The survey asked respondents to indicate (1) whether their primary practice location used electronic medical record (EMR) systems for each of a list of purposes and (2) whether their primary practice used each of a list of scheduling and practice management techniques (Exhibit 3). Physicians whose primary practice received RWHAP funds were significantly more likely than non-RWHAP-funded physicians to report that their primary practice used

EMR systems to share clinical information among providers internally (80 versus 67 percent), to share information with patients (48 versus 41 percent), to make referrals for specialty care (63 versus 52 percent), to track specialty care referrals (72 versus 57 percent), and to monitor care quality (64 versus 48 percent).

The survey also disclosed substantial differences in the use of practice management techniques based on receipt of

RWHAP funds. Providers whose primary practice received RWHAP funds were significantly more likely to indicate the use of care coordination services, including medical case managers (78 versus 22 percent), peer counselors (43 versus 8 percent), coordination of appointments so that patients see more than one clinician during one visit (51 versus 18 percent), promoting long-term self-management (92 versus 53 percent), and devoting time and resources to building integrated teams (80 versus 33 percent). RWHAP-funded providers were also more likely than their non-RWHAP-funded counterparts to use practice management techniques associated with greater efficiency, including expedited intake procedures (63 versus 47 percent) and the delegation of clinical tasks to NPs, PAs, registered nurses, or other clinical and nonclinical staff (80 versus 35 percent).

### HIV Physician Characteristics

The characteristics of HIV physicians varied. Overall, 46 percent were infectious disease specialists; the other physicians in the sample were primary care physicians. Thirty-one percent were age 45 or under, and 17 percent were age 60 or older. Distributions by specialty and age did not vary substantially based on a physician's receipt of RWHAP funds. In contrast, HIV physicians whose primary practice was RWHAP-funded were significantly more likely to report that they spent 50 percent or more of their time caring for patients with HIV than non-RWHAP-funded providers (55 versus 22 percent).

HIV physicians whose primary practice was RWHAP-funded were also more likely to report lower annual income than their counterparts whose primary practices were not RWHAP-funded (Exhibit 4). Seventy-five percent of HIV physicians with an RWHAP-funded primary practice had an annual income under \$200,000, in contrast to only 48 percent of HIV physicians whose primary practices were

not RWHAP-funded. One explanation for the difference in income might be related to differences in hours worked by the two groups of physicians. Physicians whose primary practice received RWHAP funds reported a median of 40 hours worked per week; those whose primary practice did not receive RWHAP funds reported a median of 50 hours worked per week.

The survey asked HIV physicians how they expected their HIV caseload to change over the next five years. Fifty-six percent of physicians whose practice received RWHAP funds and 46 percent of physicians whose practice did not receive RWHAP funds expected an increase in their HIV caseload. Thirty-four percent of physicians whose practice received RWHAP funds and 46 percent of physicians whose practice did not receive RWHAP funds expected their caseload to remain the same.

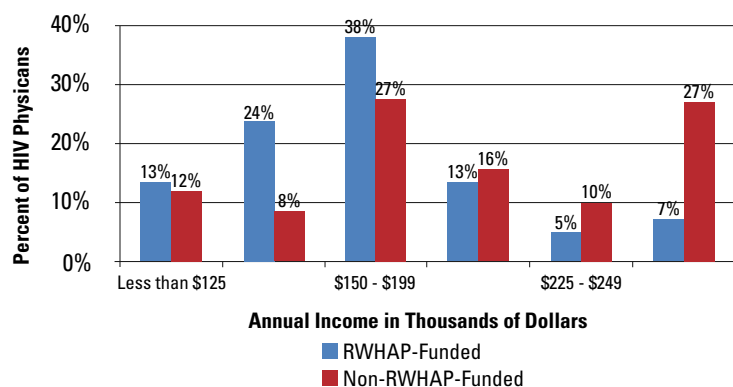
### Discussion

The survey results indicate that RWHAP-funded providers tend to serve HIV patients with disproportionately greater health care needs, including a high proportion of patients with an AIDS diagnosis and significant comorbidities such as serious mental illness, substance use disorders, and hepatitis A and B. Even though they reported a patient population with greater care needs, RWHAP-funded providers indicated that patients' visit lengths were similar to those of their counterparts. The availability of enhanced care coordination services, such as medical case managers and peer counselors, in RWHAP-funded practices is likely to be instrumental in addressing patient needs outside the physician visit.

Also, the available evidence suggests that these services are associated with greater retention in treatment (Giordano 2011). Physicians in practices that did not receive RWHAP funds were less likely to report the provision of care coordination services in their primary practice setting. With the implementation of the ACA and the shift in insurance coverage, it will be important to consider whether people living with HIV have access to the care coordination and other medical and support services they have been receiving through RWHAP but that are not traditionally covered by Medicaid and private insurance plans. Our research indicates that these services are less likely to be available in practices that do not receive RWHAP funding.

RWHAP-funded providers were significantly more likely to report that they spent 50 percent or more of their practice time caring for patients with HIV than non-RWHAP-funded providers. This difference in time providing care to HIV patients is likely to influence the quality of care provided. A recently published review of research on the effects of outpatient care provider training and experience on outcomes for people living with HIV found that receiving treatment from a provider with more training and expertise

**Exhibit 4: Annual Income of HIV Physicians**



Source: Analysis of HIV Clinician Survey, 2012, n = 1,002

was associated with improved outcomes (Rackal, Tynan and Handford 2011). Thus, changes in insurance coverage resulting from the ACA that shift patients toward lower volume or less experienced HIV care providers might have an adverse effect on care quality.

The ACA is likely to lead to an increase in demand for HIV care. Many HIV physicians in practices that do and do not receive RWHAP funds expect to see an increase in the number of HIV patients in their care over the next several years. While more detailed information on access to care might be gathered from clients seeking treatment, the HIV Clinician Survey offered some insights into the available capacity within the treatment system. More than 11 percent of HIV physicians indicated that their practice had a wait time of four weeks or more for an initial appointment, indicating limited capacity to serve additional patients. Further, the current physician workforce and newly trained HIV physicians will have to compensate for the 9 percent of HIV physicians who plan to reduce their caseload or retire from HIV care. RWHAP-funded providers were more likely to indicate appointment wait times of four weeks or more, suggesting that these physicians are less likely to have available capacity to address increased demand resulting from the implementation of the ACA.

We observed that physicians in RWHAP-funded practices tended to work fewer hours than those in practices that do not receive RWHAP funds. One approach to addressing increased demand for HIV care might be to increase the hours worked for the RWHAP-funded group to the level of their counterparts in practices that do not receive RWHAP funds. Given that RWHAP-funded physicians tend to work in settings in which they are likely to be employees, the structure and incentives in these settings might induce a standard 40-hour work week. Restructured incentives might encourage these physicians to expand the time they spend

in HIV care. Alternatively, the physicians working in these settings might have opted for settings with shorter work hours and thus might not respond to restructured incentives.

Overall, we find notable differences between physicians according to whether their primary practice is RWHAP-funded. Differences extend to the patients served, practice characteristics, and characteristics of the physicians themselves. Although this study did not assess the extent to which individuals might change providers as a result of obtaining insurance coverage with a limited network of providers, it is expected that as individuals gain insurance coverage under the ACA, they might find that their new insurance plan network does not include their current RWHAP-funded provider. Although we cannot assess the potential magnitude of the potential shift the findings from this study suggest that patients who transition from a RWHAP-funded provider to a non-RWHAP funded provider might be shifting to a provider who is less experienced in handling HIV patients with complex needs and has fewer resources available to address HIV patient care needs and to support retention in care. As they consider how to meet the increasing demand for HIV care, policymakers, providers, and insurers need to recognize the current differences between practices that do versus do not receive RWHAP funds and consider how these differences might affect patient care.

**HIV**

## Endnotes

1. A complete description of the survey methods can be found in the following report: Stalley S, Gilman B, Bouchery E, Barrett K, Lepidus Carlson B, McCauley M (Mathematica Policy Research, Cambridge, MA). *HIV Clinician Workforce Survey: survey report*. Rockville (MD): Health Resources and Services Administration, HIV/AIDS Bureau; 22 Feb 2013.
2. We obtained limited demographic, specialty, and contact information on our survey frame from various sources, including the Ingenix Provider360™ database, the National Plan and Provider Enumeration System (NPPES), and the SK&A health care provider database. We used this information to stratify the frame before selecting the sample.

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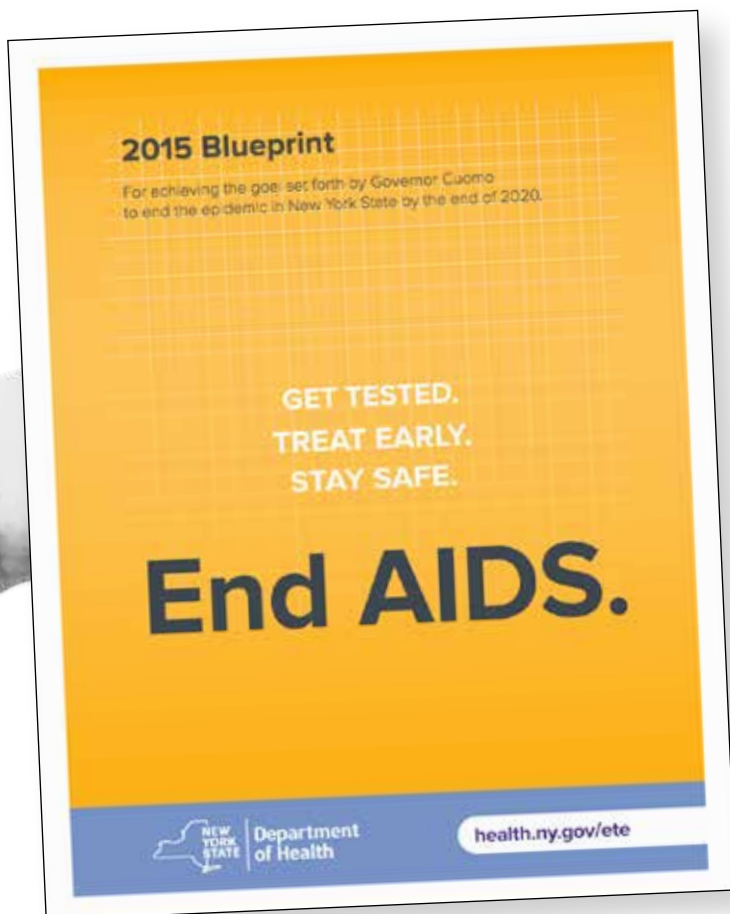
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# Ending the



# HIV Epidemic

## The New York State Plan



**O**N JUNE 29, 2014, New York Governor Andrew Cuomo detailed a three-point plan to end the HIV epidemic in New York State. The goal is to reduce the number of new HIV infections from the current 3,000 to 750 per year by 2020 resulting in the first ever statewide decrease in HIV prevalence to sub-epidemic levels.

**The three points for the End the Epidemic by 2020 (EtE 2020) initiative are:**

- 1. Identify persons with HIV who remain undiagnosed and link them to health care.**
- 2. Retain those diagnosed with HIV to health care to maximize viral suppression so they remain healthy and prevent further transmission.**
- 3. Facilitate access to Pre-Exposure Prophylaxis (PrEP) for high-risk persons to keep them HIV negative.**

In October 2014, Governor Cuomo appointed 66 members to the EtE 2020 Task Force. Members represented community, academic and managed care health providers; service agencies; patients; community advocates; health departments; and educators. The Task Force's charge was to develop and synthesize several hundred recommendations, and develop a "Blueprint" to end the epidemic.

The group's high energy and tightly-focused dynamics produced this pivotal Blueprint document in a series of 5 meetings from October 2014 to January 2015. Four Task Force committees (Care, Prevention, Housing & Supportive Services and Data) reviewed nearly 300 recommendations submitted online and received during regional Listening Forums held across the state and used this information to develop a Blueprint containing 44 committee recommendations (CRs), including supplemental recommendations that move beyond the goal of 750 to zero new infections.

## THE BLUEPRINT

In April 2015, the governor accepted the final Blueprint with 44 recommendations grouped into several major themes that address both the medical and social determinants of HIV care.<sup>1-3</sup> These themes include recommendations for:

- Enforcing and expansion of routine HIV testing
- Improved recognition of acute HIV infection
- Options for linkage to care and retention in treatment
- New sites for delivery of non-occupational post-exposure prophylaxis (nPEP) and pre-exposure prophylaxis (PrEP) and associated quality measures
- Integration of behavioral health into HIV care
- Use of health department patient-level data to identify patients lost to care
- Improving rates of viral suppression
- Improved treatment adherence strategies
- Expanded use of a peer workforce
- Supportive services including nutrition, housing, health insurance under the Affordable Care Act, employment and transportation
- Linkage to care for patients leaving the corrections system, use of phylogenetic data for surveillance and prevention
- Eliminating health disparities for key subpopulations including youth, injection drug users, transgender people and young men of color who have sex with men
- An anti-stigma media campaign
- Hepatitis C screening and treatment
- Strategies for updating the Blueprint

Also, the Blueprint conforms to Federal Guidance relative to achieving a more coordinated response to the HIV epidemic through the use of an Integrated Plan.<sup>4</sup>

## Who Will Pay for EtE 2020?

Justification for this initiative was driven by a published estimate of \$357,498 as the lifetime HIV-related medical care costs (in 2013 dollars).<sup>5</sup> The goal of reducing new HIV infections from 3,000 in 2013 to 750 per year by the end of 2020 would result in medical cost savings of \$804.5 million by averting 2,250 HIV infections. While cost aversion supported the rationale for EtE 2020, the Task Force recognized thinned for new funding to implement the Blueprint's CRs. A Task Force workgroup estimated that an additional \$70 million would be needed in the 2016-7 state budget in addition to New York's current overall HIV expenditures of \$2.5 billion.<sup>6</sup> The initial budget item for EtE 2020 was \$10 million in new program money to the state health department's HIV programming arms, the AIDS Institute. More recently, another monies for housing and supportive services were allocated.

## Can It Be Done?

While some say it is impossible, the EtE 2020 initiative has galvanized health care and service providers, patients, advocates and local health departments (LHD) to end the epidemic. Built on more than 30 years of accumulated science, activism and the benefit of sound public health policy in New York State, EtE 2020 is a call to action that has put HIV back into the public consciousness. My answer is that if we don't reduce new infections to 750 by 2020, we will come very close.

## A Brief Timeline of Activities Since the Blueprint's Introduction

Activities in support of EtE 2020 include changes in statute and statewide treatment and other guidance for providers and payers. When taken collectively, these efforts continue to break down barriers to care to support EtE 2020. Examples of this ongoing process include:

**September 2015:** The AIDS Institute's best practice Treatment Guidelines Committee revised statewide recommendation for HIV treatment initiation to start treatment at the time of diagnosis, based on evidence that patients with established HIV infection benefit from antiretrovirals at all stages of infection and the science of HIV treatment as prevention.<sup>7</sup>

**May 2016:** Governor Cuomo announced legislation, to be introduced in the 2016-7 session, which allows teens to receive treatment without requiring parental consent.

**June 2016:** Since the first announcement of EtE 2020, the State has had some early success in expanding treatment. As of June 2016, prescriptions for PrEP have more than tripled among Medicaid enrollees and the state has committed another \$3 million to continue expanding access through a PrEP Drug Assistance Program (PrEP-AP) for uninsured/underinsured patients.<sup>8</sup>

**June 2016:** In New York City, benefits for housing, transportation and nutrition have been restricted to individuals on public assistance pursuant to obsolete terms such as

“symptomatic HIV” or AIDS, and those who are receiving New York City HIV/ AIDS Services Administration (HASA) services. New AIDS Institute guidance simplifies the terms “clinical/symptomatic HIV illness or AIDS”, “AIDS or HIV-related illness”, and similar terms to mean “laboratory-confirmed HIV diagnosis.”

**June 2016:** New York State Department of Health Policy redefined eligibility for HIV care and treatment statewide based on infection status, thus making any person with an HIV diagnosis eligible for care.

## Translating EtE 2020 Recommendations into Programming

EtE 2020 challenges the status quo and has resulted in a reevaluation of HIV programs statewide to ensure that our activities are coordinated and aligned with the goals of EtE 2020. The AIDS Institute has made significant investments in programs statewide to expand services to align with the Blueprint's recommendations and to encourage internal and external program linkages that are patient centered and goal-oriented.

While the Task Force's work is completed, an ongoing EtE Subcommittee of the state's AIDS Advisory Council meets quarterly to oversee Blueprint implementation and progress. To support this effort, the health department maintains a dashboard to monitor and track EtE progress.<sup>9</sup> On the local level, a series of regional interagency collaborations have been formed to fulfill EtE 2020's objectives and overcome patient level barriers to Blueprint implementation.

## A Case Study

This case highlights the Care Committee's recommendation to use patient-level data to identify patients lost to care. Recently, our local health LHD notified us that one of our HIV patients has not had a viral load reported in the past 12 months. The patient has a history chronic mental illness and a series of mental health arrests. Our medical outreach team, formed in response to EtE 2020, consisting of a care manager and nurse practitioner, located the patient and made a home visit. The LHD EtE coordinator accompanied them and arranged for a home blood draw that day. Our team learned that the patient had not taken antiretrovirals for a year and remains sexually active. Viral load was 18,000 copies/mL and CD4 count, 483 (20%). Our in-house, psychiatric nurse practitioner accompanied the team on a follow-up visit to assess the patient's mental health status and is arranging for hospitalization to stabilize the patient and return him to care. The patient is now enrolled in our Health Homes Care Management Program.

This complex patient highlights the early returns on one Task Force CR. Also, several of our own systems issues need to be addressed including tighter coordination across clinic programs, more prospective monitoring and tracking of patients lost to care, and a more aggressive approach to re-engaging these patients back into to care.

## Summary

EtE 2020 moves New York from a history of having the worst HIV epidemic in the country to a future where new infections are rare and those living with HIV have normal lifespans with few complications. For all of us who are part of the HIV effort, this is an opportunity to help “finish the job.” **HIV**

# EtE 2020

**Built on more than 30 years of accumulated science, activism and the benefit of sound public health policy in New York State, EtE 2020 is a call to action that has put HIV back into the public consciousness.**

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### ABOUT THE AUTHOR:

**Bill Valenti, MD** is an infectious diseases physician who has been involved in HIV Medicine, policy and research since the beginning of the epidemic. He served on the New York State Governor's Task Force to End the Epidemic by 2020 as co-chair of the Care Committee. He is Clinical Associate Professor of Medicine at the University of Rochester School of Medicine and Senior Vice-president, Chief of Innovation and a staff physician at Trillium Health, Rochester, NY.

# The Brave New World of Life and Disability Insurance for the HIV Positive Population

BY: LARRY M. HALPERN AND JASON M. HALPERN

**L**IFE INSURANCE AND DISABILITY INSURANCE were not available to those infected with HIV until recently, due to the perceived adverse mortality risk to insurance companies. In terms, mortality risk is the actuarial calculation of life expectancy that considers chronic medical conditions, in some cases, to be a deterrent when making this calculation.

In the past, discrimination, sheer intolerance to the condition, unrecognized advancement in treatments and the uncertainty of the patient's longevity also played a role as reasoning behind insurance companies not offering coverage to those infected with the virus. Thankfully with the

advancement of medical science making highly effective antiretroviral therapies available, patients can now enjoy the same privileges healthy individuals have utilized for decades.

Major insurance carriers have now realized that living with HIV is as manageable as many of the other chronic





illnesses affecting those currently insured. The programs are available now because insurance companies have defined a set of underwriting parameters that will secure an insurable risk.

The main requirement to be insured is having been monitored and cared for by an HIV specialist for a minimum of five years. The patient must be on antiretroviral medication with no lapse or delays in treatment.

Furthermore, patients must have CD-4 cell counts greater than or equal to 350 cells/mm<sup>3</sup>. Current and prior two-year viral loads must be undetectable (< 50 copies/ml or below current detectable laboratory limits). Patients must also test negative for Hepatitis B and C antigens.

Exclusions under these parameters include

- Being newly diagnosed with HIV
- Having any AIDS defining illnesses
- Documented resistance to treatment
- History of intravenous or polysubstance drug use
- Documented alcohol use concerns
- History of coronary artery disease or diabetes
- History of ratable psychiatric conditions
- History of ratable low decreasing build, hypoalbuminemia, protein

urea, or any malignancies.

Patients infected with HIV have been provided the opportunity to now create a legacy and provide permanent protection for their loved ones and families. Individuals can obtain a multitude of products from business term life insurance and individual permanent life coverage to full-scale disability income replacement protection.

HIV specialists that keep their patients healthy in terms of strict adherence and response to ART, absence of significant immunosuppressant and comorbid conditions, and non-tobacco use allow for a favorable underwriting process.

As a result, major insurance companies have now become advocates to the HIV community by now providing the possibility for an optimal outcome in acquiring the necessary financial protection so desperately needed by many.

**HIV**



**ABOUT THE AUTHORS:**

**Larry M. Halpern** and **Jason M. Halpern** are agents with World Insurance Network. They can be reached at 800-728-7147, [info@wininsure.com](mailto:info@wininsure.com) or via their website at [www.WINinsure.com](http://www.WINinsure.com).

# PARTNER Study

## Is this enough evidence to have sex without condoms?

**S**EXUAL TRANSMISSION of Human immunodeficiency virus (HIV) occurs after exposure to bodily fluids that contain the virus, such as semen and secretions from the vagina and rectum. Recently, estimates of per-act transmission probabilities have been updated with data from cohort studies of heterosexuals and men who have sex with men (MSM). Table 1 shows the estimated per-act probability of acquiring HIV from an infected source by exposure act.<sup>1</sup> The viral load is the most important factor in determining whether an exposure will lead to infection. Studies have shown that higher viral loads increase the risk of HIV transmission. This was demonstrated by an early study conducted by Thomas C. Quinn et al in a rural district of Uganda where they examined the influence of viral load in relation to other risk factors for heterosexual transmission of HIV. They identified 415 serodiscordant couples and followed them prospectively for 30 months. The key finding was that there were no transmissions among 51 subjects with serum HIV-1 RNA levels of less than 1500 copies /ml and there was a significant dose-response relation of increased transmission with increasing viral load. This study was similar to the findings that the risk of perinatal HIV transmission was associated with maternal viral load.<sup>2</sup>

**Table 1 Estimated per-act probability of acquiring HIV from an infected source, by exposure route.<sup>1</sup>**

Type of exposure	Risk per 10,000 exposure
Parenteral	
Blood Transfusion	9,250
Needle sharing during injection drug use	663
Percutaneous (needle-stick)	23
Sexual	
Receptive anal intercourse	138
Insertive anal intercourse	11
Receptive penile-vaginal intercourse	8
Insertive penile-vaginal intercourse	4
Receptive oral intercourse	Low
Insertive oral intercourse	Low
Other*	
Biting	negligible
Spitting	negligible
Throwing body fluids (including semen or saliva)	negligible
Sharing sex toys	negligible

\*HIV transmission through these exposure routes is technically possible but unlikely and not well documented.

Over the past few years, several studies have confirmed that antiretroviral therapy (ART) not only has profound clinical benefits but also prevention benefits. The most well cited study was HPTN 052, a randomized controlled clinical trial where serodiscordant couples were randomized to early versus deferred ART and the primary endpoint was linked transmissions. The study was terminated prematurely when the investigators found that early therapy was associated with a 96% reduction in the risk of HIV transmission to the uninfected partner.<sup>3</sup> Final study results showed a 93% reduced risk of HIV transmission and no transmission events on those on suppressive ART.<sup>4</sup> There were some limitations to this study: the study included mostly heterosexual couples and therefore it was unclear if the same results can apply to MSM. The study also involved a comprehensive prevention package that included counseling on safe sex, testing and treatment for sexually transmitted infections (STIs), frequent testing for HIV, and the use of condoms, which when used can effectively prevent HIV transmission.

The PARTNER study (Partners of people on ART-A New Evaluation of the Risks) is a prospective, observational study conducted at 75 clinical sites in 14 European countries and it enrolled 1166 HIV serodiscordant couples (HIV-positive partner must be on suppressive ART) who reported condomless



sex between September 2010 to May 2014. In order to be eligible, the couples must have had condomless sex and have a HIV-1 viral load less than 200 copies/ml. Of the 1166 enrolled couples, 888 were heterosexual and 340 were MSM and they provided 1238 eligible couple-years of follow-up. There were 11 HIV-negative partners who seroconverted during the study; 8 reported condomless sex with other partners. There was no phylogenetically linked transmissions that occurred over the eligible couple-years, giving a rate of within-couple HIV transmission of zero.<sup>5</sup>

While the findings of this study are very encouraging, they must be interpreted with caution. The original study design aimed to observe 2000 couple-years of follow-up, but only 1238 couple-years were eligible for the primary analysis, so the study had limited power. The study participants who were on ART reported adherence to ART from 93 to 97% and this level of adherence may not reflect what is seen in many populations. The authors also note that while the rate for linked transmission was zero, the upper 95% confidence limit for within-couple transmission per 100 eligible couple-years of follow-up for heterosexual was 0.97 for the male HIV-positive/female HIV-negative control group, 0.88 for the female HIV-positive/male HIV-negative control group, and 0.84 for the MSM couple group. Finally, for persons engaging in receptive anal intercourse with ejaculation inside the uninfected

partner, the upper 95% confidence limit for within-couple HIV transmission was 2.7 per 100 couple-years of follow-up but due to a small sample size this estimate is inaccurate.

The message from the PARTNER study is that we should not discard condoms but we should change our understandings and beliefs about the risk of getting infected by HIV. We know that viral loads are not checked daily and they can fluctuate for many reasons. We also know that HIV exists in semen even though the patient may have an undetectable viral load in the blood. Finally, ART may protect against HIV but it does not protect against other STIs.

HIV

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# Emerging Syphilis Epidemic Among MSM Living with HIV

**SYPHILIS IS A COMPLEX, MULTISTAGE DISEASE** caused by the bacterium *Treponema pallidum*. Often called the “great imitator,” syphilis has a long and complex social and clinical history in the United States. It tracks closely to cultural trends that impact health beyond the arena of sexually transmitted diseases (STDs). In the most recent chapter of the domestic syphilis story, the evolving epidemic has landed in domestic populations of men who have sex with men (MSM). Recent national trends indicate that MSM account for an increasing proportion of cases of infectious syphilis. Between 2013 and 2014, the number of reported primary and secondary (P&S) cases increased by 15%. In 2014, 83% of the reported male P&S syphilis cases where gender of sex partner was known were among gay, bisexual, and other MSM.<sup>1</sup> About half of MSM diagnosed with syphilis are also infected with HIV. Although an area of ongoing clinical debate, there is some evidence that the disease course and treatment efficacy may be modified by HIV co-infection.<sup>2</sup> Recent cases of ocular syphilis among MSM living with HIV have further highlighted the potential for more severe complications in people with HIV infection.<sup>3,4</sup>

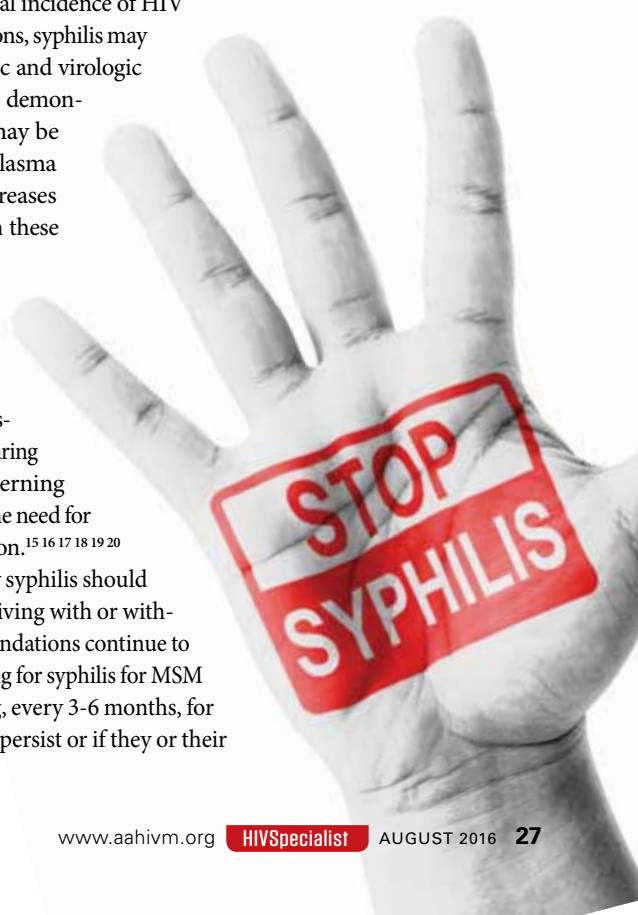
For many MSM in the United States, the sexual landscape is rapidly changing. As data emerge that HIV treatment prevents transmission, and that Pre-Exposure Prophylaxis (or PrEP) can prevent HIV in seronegative men who may not use condoms with a high level of consistency, the dogma of HIV and STD prevention has been challenged.<sup>5,6,7</sup> As treatment as prevention becomes more accepted by populations of MSM, STD prevention too needs to co-evolve to achieve a new homeostasis within the MSM population.

Among HIV-infected MSM sampled in the Centers for Disease Control and Prevention Medical Monitoring Project (MMP), approximately 30% report anal intercourse without a condom.<sup>8</sup> As more and more MSM in care achieve viral suppression and understand the impact of an “undetectable” viral load in HIV transmission, this “Treatment as Prevention” strategy is entering the calculus of condom use and sex.<sup>9</sup> These men are not wrong: Their strategy is effective in HIV prevention, but lacks the same efficacy in STD prevention, specifically syphilis. Sexual health discussions must be integrated into the care of all MSM, whether HIV negative or positive. Unfortunately, many people living with HIV do not get HIV/STD prevention interventions. In the MMP, less than half of HIV-infected persons in care received HIV/STD risk-reduction interventions from their provider and nearly 40% at highest-risk of HIV/STD did not get any risk-reduction interventions.<sup>10</sup> Caring for HIV negative or positive MSM requires frank conversations about sex and other behaviors, but this often takes time and requires providers and patients to have a high level of trust to explore deeper issues of sex, love, relationships, and HIV/STD protection.<sup>11</sup> A shared, multidisciplinary approach may be needed, and patients

should be provided sexual health resources to supplement the interactions that they have with their HIV care provider.

Syphilis has a very complex interaction with HIV disease and transmission dynamics. Several studies have reported an increase in the incidence of HIV infection related to recent syphilis infection.<sup>12,13</sup> Epidemiologic data also support that incident syphilis in an HIV-negative MSM is associated with a very high subsequent annual incidence of HIV infection.<sup>14</sup> Like other infections, syphilis may also impact the immunologic and virologic control of HIV. Studies have demonstrated that early syphilis may be associated with increased plasma viral load and transient decreases in CD4 cell count. Although these changes may be temporary and may have little impact on disease progression, the theoretical risk of HIV replication in the setting of antiretroviral therapy for resistance and HIV transmission during periods of viremia are concerning issues that further highlight the need for syphilis control and prevention.<sup>15,16,17,18,19,20</sup>

Little has changed in how syphilis should be managed in both people living with or without HIV infection. Recommendations continue to advise at least annual screening for syphilis for MSM and more frequent screening, every 3-6 months, for those MSM if risk behaviors persist or if they or their



sexual partners have multiple partners.<sup>21</sup> Some HIV providers include syphilis screening at each HIV primary care visit when CD4 or HIV parameters are evaluated. Sexually active MSM who demonstrate risk behaviors listed above, should continue syphilis screening every 3-6 months even if HIV visits decrease to twice annually, based on viral suppression and intact immunological status.<sup>22,23</sup> Early syphilis (including primary, secondary, or early latent) should be treated with a single dose of 2.4 million units of intramuscular (IM) benzathine penicillin. Late latent syphilis and later stage syphilis without neurologic involvement is treated with 3 weekly doses of 2.4 million units IM benzathine penicillin. A careful ocular and neurologic exam remains an essential part of any syphilis evaluation, especially in people living with HIV. Recent clusters of ocular syphilis highlight the need

for such evaluation.<sup>24</sup> Individuals with neurologic findings should have a cerebrospinal fluid examination to evaluate the need to treat for neurosyphilis. Ongoing screening and aggressive treatment of possible lesions are critical elements of controlling syphilis in MSM regardless of HIV status.<sup>25</sup>

### A Case from the Field

A 23-year old MSM patient—who has been in our practice for 4 years since he was diagnosed with HIV in the acute phase of infection—came to our clinic complaining of a penile ulcer. Because of his excellent HIV parameters, we had agreed that he would come to the office for HIV primary care visits every 6 months. His last visit was 4 months ago. At that time, his HIV viral load was <20, and his CD4 count was at its baseline of 1,225 cells/mm<sup>3</sup>, and syphilis testing

## CDC Prevention IS Care Resource Kit and Other Practice Resources Related to this Topic



The *Prevention IS Care* resource kit provides tools based on scientific evidence developed for HIV care providers. These materials include health care provider educational materials, exam room posters, materials to use during patient discussions, and educational materials for patients living with HIV. To order or download these free, educational brochures and in-practice tools based on scientific evidence, and to learn how health care providers can engage in small talks with patients, please visit the Prevention IS Care website at <http://www.cdc.gov/actagainstaids/campaigns/pic>.

### Other CDC resources that may help you in your practice include:

- The 2015 STD Tx Guide app**—Official CDC-developed, easy-to-use reference app combines information from the **STD Treatment Guidelines** as well as *MMWR* updates, and features a streamlined interface so providers can access treatment and diagnostic information. The free app is available for **Apple** and **Android** devices.
- Wall Chart**—Poster-sized chart provides an overview of CDC's **2015 STD Treatment Guidelines**. The wall chart is ideal for use in doctors' offices, nurse's stations, and other clinical settings. Limited quantities can be ordered through CDC-INFO on Demand Publications.
- Pocket Guide**—A printed pocket guide summary of CDC's **2015 STD Treatment Guidelines** that can fit in a lab coat, pocket, or desk drawer. Limited quantities can be ordered through CDC-INFO On-Demand Publications.
- Evidence Tables**—Background documents provide a basis for the STD screening, diagnostic, and treatment recommendations included in the **2015 STD Treatment Guidelines**.
- Taking a Sexual History Guide**—A 24-page brochure that offers parameters for discussion of sexual health issues with patients.

was negative. When interviewed, the patient reported that he has been using online and smartphone applications to find sex partners. He engages in insertive and receptive oral and anal sex. He stated that he uses condoms as often as he can and that his strategy includes:

- Condoms with HIV-negative men not on PrEP
- No condoms for other HIV-positive men and for those on PrEP based on the preference of his partner
- No condoms for oral sex.

Examination revealed a single, clean-based ulcer inside his foreskin with heaped up borders and with no pain subjectively or on examination. No oral or anal lesions were noted. He had no ocular, otic, or other neurologic complaints. Given his sexual exposure history, the patient was screened for gonorrhea and chlamydia using nucleic acid testing from his urine, throat, and anus. Syphilis testing was done using a treponemal Immunoglobulin G (Tp IgG) with reflex rapid plasma reagin (RPR) and *Treponema pallidum* particle agglutination (TPPA) tests. Given his suspicion for syphilis, the patient was treated for primary syphilis with 2.4 million units IM benzathine penicillin. He was counseled

about a Jarisch–Herxheimer reaction, and partners were elicited for reporting to the Department of Health. During the visit, the patient referred two of the partners he met on a mobile dating application to a local STD center for evaluation and treatment. His syphilis testing returned with a positive Tp IgG, an RPR titer of 1:16, and a positive TPPA. The patient was given a copy of these results, and they were released to him via the patient portal of the clinic electronic medical record. Expectations of titer decline by four fold in 6–12 months were discussed, as was the need for consistent monitoring of his titer.

Given the patient's excellent HIV indices, the decision was made with him to include interim STD screening visits to his semi-annual HIV visits. To expedite the visits, the patient was provided a standing order for blood work and for three-site STD screening. Clear instructions were provided for rectal and oral self-collection. Given his sexual history, screening every 3 months was decided as the interval of testing. The patient was also counseled about the importance of condoms in preventing STDs and the additive HIV prevention benefit of combining condoms with treatment as prevention and PrEP. **HIV**

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### ABOUT THE AUTHOR:

**Dr. Demetre Daskalakis** is an infectious disease doctor and serves as the Assistant Commissioner of the Bureau of HIV/AIDS Prevention and Control at the New York City Department of Health and Mental Hygiene. He specializes in HIV medicine with special focus on HIV prevention. Dr. Daskalakis is also an Associate Professor of Medicine at the Icahn School of Medicine at Mount Sinai Health System.

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clogged artery  
in my neck.  
Smoking with  
HIV did.**

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