

Jurisdiction Level Differences in HIV Diagnosis, Retention in Care, and Viral Suppression in the United States

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Abstract: Using data from the National HIV Surveillance System, we determined the number of persons diagnosed with HIV and the percentages of persons linked to care, retained in care, and virally suppressed across 19 jurisdictions with complete reporting of CD4 and viral load test results. Reports from these jurisdictions represent 37% of persons diagnosed with HIV infection in the United States in 2011. Although 80% of persons diagnosed in 2011 were linked to HIV medical care within 3 months of diagnosis, half of all persons living with HIV in the 19 jurisdictions were not receiving ongoing care in 2010. In addition, 43% of persons living with HIV by year-end 2009 and alive at year-end 2010 did not have a suppressed viral load, with substantial variability across the 19 jurisdictions. These data highlight the need for improved outcomes along each step of the HIV continuum of care.

Key Words: HIV continuum of care, HIV surveillance

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INTRODUCTION

Viral suppression among HIV-positive persons is a critical component of HIV treatment and prevention programs because it leads to improved individual health outcomes and reduced transmission.^{1,2} To achieve these outcomes and ultimately achieve viral suppression, persons with HIV must engage in a continuum of services, including HIV diagnosis, linkage to care and ongoing HIV care, and appropriately timed and consistent antiretroviral therapy (ART).

Attaining a high level of engagement at each step of the continuum of care is essential in a comprehensive strategy to address HIV in the United States. A 2011 review concluded that better testing strategies and more adequate engagement in each step of the continuum improve the care of persons living with HIV (PLWH) and decrease incident infections.³ Data from this review indicated that ~75% of individuals newly

diagnosed with HIV successfully linked to HIV care within 6–12 months after diagnosis, 80%–90% linked within 3–5 years, and ~50% of PLWH were not engaged in regular HIV care. More recently, analyses based on HIV surveillance data from 14 jurisdictions indicated that optimal levels of engagement have still not been achieved. According to these data, 80% of persons diagnosed with HIV had at least 1 HIV care visit within 3 months after diagnosis. However, only 43% of all diagnosed persons received regular HIV care and 36% achieved viral suppression.⁴ The low level of viral suppression reinforces the well-documented view that individuals who do not receive regular medical care, also do not receive consistent ART and do not achieve optimal outcomes.

The U.S. Department of Health and Human Services and the Institute of Medicine have developed national indicators for monitoring HIV clinical care and services for PLWH.^{5,6} The National HIV/AIDS Strategy (NHAS) has also set specific targets to achieve by 2015.⁷ Some of the objectives outlined in NHAS include increasing (1) linkage to clinical care among newly diagnosed patients from 65% to 85%, (2) receipt of continuous care among PLWH from 73% to 80%, and (3) viral suppression among HIV-diagnosed gay and bisexual men, blacks, and Hispanics by 20%. In response to NHAS, the Division of HIV/AIDS Prevention (DHAP) within the Centers for Disease Control and Prevention (CDC) developed a strategic plan that outlines 15 objectives for strengthening DHAP programming and operations.⁸

HIV surveillance data can be used to measure the linkage to care, retention in care, and viral suppression goals outlined by NHAS, Institute of Medicine, and the DHAP Strategic Plan. Our objective was to examine differences at the state level for each step in the continuum of care using updated surveillance data, which now has data available from 19 jurisdictions.

METHODS

Data from the National HIV Surveillance System (NHSS) reported to CDC through December 2012 were used to determine the number of persons diagnosed with HIV and the percentages of persons linked to care, in care, retained in continuous care, and virally suppressed. As of December 2012, 19 jurisdictions had met the following criteria for the collection and reporting of CD4⁺ T-lymphocyte (CD4) and viral load (VL) test results: (1) the jurisdiction's laws or regulations required the reporting of all CD4 and VL results to the state or local health department; (2) ≥95% of all

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laboratory test results were reported by laboratories that conduct HIV-related testing for each jurisdiction; and (3) the jurisdiction had reported to CDC all CD4 and VL results received since at least January 2010. The 19 areas include 18 states [Delaware, California (Los Angeles County and San Francisco only), Georgia, Hawaii, Illinois, Indiana, Iowa, Louisiana, Michigan, Minnesota, Missouri, Nebraska, New Hampshire, New York, North Dakota, South Carolina, West Virginia, and Wyoming] and the District of Columbia.

Linkage to care was based on data for persons newly diagnosed with HIV during 2011 and was defined as having ≥ 1 CD4 (count or percentage) or VL test performed within 3 months after HIV diagnosis, including those performed during the same month as diagnosis. A minimum of 9 months was allowed for delays in reporting of case reports and laboratory data to NHSS.

Receiving any HIV medical care (“in care”), retention in continuous care, and viral suppression were based on data for all persons diagnosed with HIV by December 31, 2009, who resided in any of the 19 jurisdictions at the time of diagnosis and were alive at year-end 2010 (ie, persons living

with diagnosed HIV; PLWH). A minimum of 18 months delay was allowed for the reporting of deaths to NHSS. In care was defined as having ≥ 1 CD4 and/or VL result during 2010. Retention in continuous care was defined as having ≥ 2 CD4 or VL results at least 3 months apart during 2010.

Viral suppression was defined as having a VL result ≤ 200 copies per milliliter at the most recent VL test during 2010. The cutoff value of ≤ 200 copies per milliliter was based on the U.S. Department of Health and Human Services–recommended definition of virological failure.⁹ If multiple VL tests occurred in the same month that could qualify as “most recent,” the highest VL was selected. If the numerical result was missing or the result was a logarithmic value, the result interpretation (eg, below limit) was used to determine viral suppression.

RESULTS

Linkage to Care

In the 19 jurisdictions, 15,449 persons were diagnosed with HIV during 2011 (Table 1), representing 37% of persons

TABLE 1. Linkage to Care, Retention in Care, and Viral Suppression Among Persons With Diagnosed HIV Infection Aged 13 Years and Older, by Area of Residence—19 US Jurisdictions

Area	Linkage to Care			Retention in Continuous Care and Viral Suppression										
	Total Diagnoses During 2011	≥ 1 CD4 or VL Test*		Total†	In HIV Care‡		Retained in Continuous HIV Care§		Persons With a VL Test		VL ≤ 200			
		No.	No.		%	No.	%	No.	%	No.	%	Among Overall Population	Among Persons With ≥ 1 CD4 or VL Test	Among Persons With a VL Test
California	2374	1911	80.5	54,728	39,198	71.6	31,892	58.3	37,824	69.1	30,458	55.7	77.7	80.5
Delaware	114	91	79.8	2914	1285	44.1	816	28.0	830	28.5	417	14.3	32.5	50.2
District of Columbia	733	601	82.0	13,811	8205	59.4	6112	44.3	7841	56.8	5485	39.7	66.8	70.0
Georgia	1834	1314	71.6	33,584	19,279	57.4	14,636	43.6	16,429	48.9	10,584	31.5	54.9	64.4
Hawaii	72	63	87.5	2220	1190	53.6	768	34.6	937	42.2	731	32.9	61.4	78.0
Illinois	1669	1232	73.8	30,895	12,724	41.2	7615	24.6	10,656	34.5	7575	24.5	59.5	71.1
Indiana	485	379	78.1	8207	5619	68.5	4335	52.8	5433	66.2	3913	47.7	69.6	72.0
Iowa	120	106	88.3	1628	1213	74.5	957	58.8	1132	69.5	869	53.4	71.6	76.8
Louisiana	1249	940	75.3	16,301	10,453	64.1	8102	49.7	9679	59.4	6404	39.3	61.3	66.2
Michigan	794	651	82.0	13,351	9268	69.4	6837	51.2	8407	63.0	5905	44.2	63.7	70.2
Minnesota	302	240	79.5	6276	2985	47.6	1882	30.0	2837	45.2	2243	35.7	75.1	79.1
Missouri	531	406	76.5	10,597	6714	63.4	5020	47.4	6305	59.5	4597	43.4	68.5	72.9
Nebraska	77	67	87.0	1607	1118	69.6	921	57.3	1079	67.1	799	49.7	71.5	74.1
New Hampshire	40	34	85.0	1061	616	58.1	511	48.2	578	54.5	475	44.8	77.1	82.2
New York	4149	3477	83.8	126,377	84,731	67.0	73,631	58.3	82,526	65.3	59,474	47.1	70.2	72.1
North Dakota	13	13	100.0	174	107	61.5	73	42.0	99	56.9	87	50.0	81.3	87.9
South Carolina	778	715	91.9	13,575	9116	67.2	7676	56.5	8656	63.8	6349	46.8	69.6	73.3
West Virginia	100	79	79.0	1430	772	54.0	476	33.3	726	50.8	550	38.5	71.2	75.8
Wyoming	15	14	93.3	223	141	63.2	111	49.8	136	61.0	100	44.8	70.9	73.5
Total	15,449	12,333	79.8	338,959	214,734	63.4	172,371	50.9	202,110	59.6	147,015	43.4	68.5	72.7

CD4, CD4+ T-lymphocyte count (cells/ μ L) or percentage.

Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis.

*One or more CD4 or VL tests within 3 months after HIV diagnosis.

†Persons diagnosed by year-end 2009 and alive at year-end 2010.

‡One or more CD4 or VL tests performed during 2010.

§Two or more CD4 or VL tests performed at least 3 months apart during 2010.

||Includes data from LA County and San Francisco only.

diagnosed in the United States. Of these, 79.8% were linked to HIV medical care within 3 months after diagnosis. By jurisdiction, the percentage linked to care ranged from 71.6% in Georgia to 100% in North Dakota.

In Care/Retention in Continuous Care

A total of 338,959 persons were living with diagnosed HIV at year-end 2010 in the 19 jurisdictions (Table 1). Of these, 214,734 (63.4%) were in care during 2010. By jurisdiction, the percentages ranged from 41.2% in Illinois to 74.5% in Iowa (Fig. 1). Meanwhile, 172,371 (50.9%) of PLWH were retained in continuous care during 2010. The percentages, by jurisdiction, ranged from 24.6% in Illinois to 58.8% in Iowa. Overall, there was a 12.5% difference between the percentages of persons in care (63.4%) and those retained in care (50.9%). The largest difference by jurisdiction was in West Virginia (54.0%–33.3%), followed by North Dakota (61.5%–42.0%), and Michigan (69.4%–51.2%).

Viral Suppression

Of the 338,959 PLWH at year-end 2010, a total of 147,015 (43.4%) persons had suppressed VL during 2010 (Table 1). By jurisdiction, the percentages ranged from 14.3% in Delaware to 55.7% in California. Of persons with a VL test, 72.7% had suppressed VL with a range from 50.2% in Delaware to 87.9% in North Dakota. Overall, there was a 7.5% difference between the percentages of persons retained in care (50.9%) and those with suppressed VLs (43.4%). The largest difference by jurisdiction was in Delaware (28.0%–14.3%), followed by Georgia (43.6%–31.5%), and New York (58.3%–47.1%).

DISCUSSION

Our findings indicate that 80% of newly diagnosed persons were linked to care within 3 months after HIV diagnosis. Although this estimate is lower than the NHAS target for linkage to care, 7 jurisdictions have met or

surpassed the 2015 goal of 85%, and several others are within 5% of the goal. Across most jurisdictions, the percentage linked to care was generally higher than what has been reported in other studies.^{3,10,11}

A large percentage of PLWH in the 19 jurisdictions were not receiving ongoing care. Only 63.4% had 1 care visit in 2010, and 50.9% were retained in care in 2010. Care utilization varied substantially across the 19 jurisdictions, but across many jurisdictions, the percentages retained in continuous care were lower than findings from other studies.^{3,4,10,11} All areas fell well below the NHAS goal of 80% of persons receiving continuous care necessitating substantial improvement to meet the 2015 goal. Across all jurisdictions, the percentage of persons who had suppressed VL was higher (43.4%) than an earlier estimate (36.2%).⁴

In all jurisdictions except New York, there were large differences between the percentages of persons who were in care and those retained in continuous care, and somewhat smaller differences between the percentages retained in care and virally suppressed. In 3 jurisdictions (Minnesota, North Dakota, and West Virginia), the percentage of persons with suppressed VL was higher than that for persons retained in care indicating that persons may be in care but do not meet the retention in care definition of having ≥ 2 CD4 or VL tests at least 3 months apart in a given year. To monitor disease status and the response to treatment, CD4 and VL testing is recommended every 3–4 months, after the initial care visit. However, among those who are clinically stable, CD4 may be monitored less frequently.^{9,12}

Several factors may impact success at each step of the continuum. For example, social and economic barriers can affect access to and retention in care, including lack of health insurance,^{13,14} poverty, unemployment, homelessness, food insecurity, lack of transportation, lack of social support, mental health, substance abuse, and lower education.^{15–18} Our analysis is one of the first explorations of state-level data to identify gaps in the continuum of care; additional analyses are needed at the state-level that further investigate the continuum

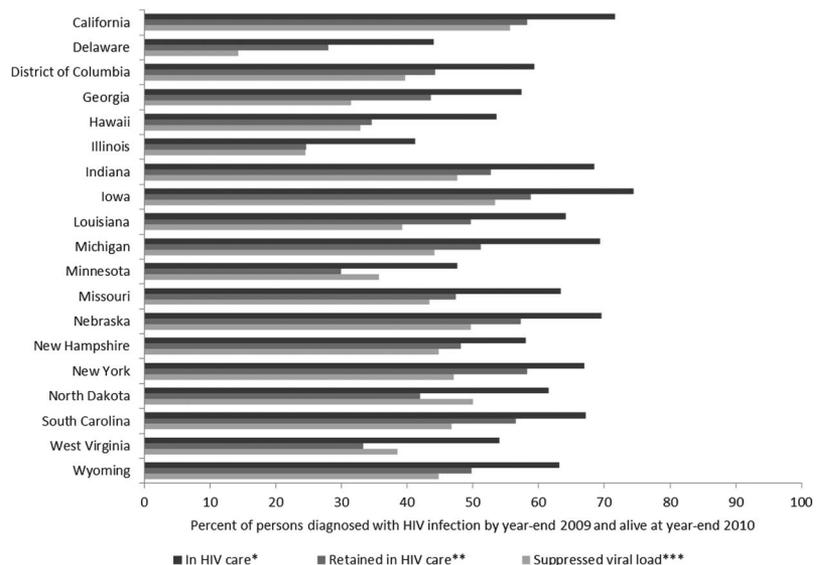


FIGURE 1. Percentage of persons aged 13 years and older diagnosed with HIV infection by year-end 2009 and alive at year-end 2010 in selected stages of the continuum of HIV care, by area of residence—19 US jurisdictions. *In care: persons with ≥ 1 CD4 or VL test during 2010. **Retained in continuous HIV care: ≥ 2 CD4 or VL tests at least 3 months apart during 2010. ***Suppressed VL: VL ≤ 200 copies per milliliter among overall population.

by demographic and behavioral characteristics, as well as social determinants of health. Such future analyses will help identify disparities in care and treatment and may assist in targeting prevention and care efforts.

Our analyses are subject to several limitations. Our estimations of linkage to care, retention in care, and viral suppression were based on data from 19 jurisdictions and therefore may not be representative of the United States. Second, we calculated the percentage linked to care based on the population of persons diagnosed during the most recent year (2011). We did not have data available to determine whether all prevalent cases had been linked to care within 3 months after diagnosis. Therefore, linkage to care estimates could not be presented as part of the continuum of care in Figure 1. Also, this analysis included PLWH in the jurisdictions based on residence at diagnosis. Laboratory reports may have been missed if PLWH moved to an area outside the 19 jurisdictions.¹⁹ Finally, treatment data are not available in NHSS, so we were not able to assess the relationship between ART and viral suppression; instead, we measured viral suppression among PLWH.

HIV surveillance programs within state and local health departments are essential for monitoring and interpreting levels of engagement across the continuum of care at the population level. The ability to measure these outcomes using surveillance data is dependent on the quality and availability of laboratory data; several additional factors also influence which jurisdictions can be evaluated. First, state regulations need to support the reporting of all CD4 and VL result values. Next, jurisdictions must have practices in place to: (1) ensure data reported by providers and laboratories are complete, timely, and follow state reporting regulations, (2) evaluate the quality of laboratory data, and (3) enter all laboratory results into the surveillance software at the local level. Improvements in laboratory reporting will allow the essential steps in the continuum to be examined across additional states and by region.

In summary, the national HIV care indicators allow care providers and public health personnel to focus efforts around key priorities and monitor and report on progress. Although 80% of persons were linked to care within 3 months of diagnosis, a large percentage of PLWH in the 19 jurisdictions were not receiving ongoing care in 2010, and this lack of regular care may have been associated with a lack of viral suppression. These data highlight the importance of analyzing data by jurisdiction to tailor interventions that are appropriate at the local level. Health care providers, state and local health departments, and government agencies can collaborate to build the infrastructure and services needed to promote linkage to and retention in care, and to re-engage persons into care who have fallen out of care.^{20–22} Services can include patient education about the benefits of HIV medical care and adherence to treatment for improving individual health outcomes and preventing HIV transmission.

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