



Published in final edited form as:

Sex Transm Dis. 2014 January ; 41(1): 35–40. doi:10.1097/OLQ.0000000000000072.

Migration Distorts Surveillance Estimates of Engagement in Care: Results of Public Health Investigations of Persons Who Appear to be Out of HIV Care

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Abstract

Background—Prevention and clinical efforts are increasingly focused on improving the HIV care cascade, the sequential steps from diagnosis to engagement in care and viral suppression. Monitoring of this cascade is largely dependent on HIV laboratory surveillance data. However, little is known about the completeness of these data or the true care status of individuals for whom no data are reported.

Methods—We investigated people presumed to be living with HIV/AIDS in King County, WA, who had no laboratory results reported to HIV surveillance for at least 1 year between 2006 and 2010. We determined whether each person had relocated, died, or remained in the county.

Results—Of 7379 HIV-infected people presumed living in King County, 2545 (35%) had 1 or more 12-month gap in laboratory reporting. Among these individuals, 47% had relocated, 7% died, and 38% remained in King County; we were unable to determine the status of 8%. Of individuals remaining in the area, 91% had evidence of returning to or being in HIV care. Case investigations reduced the proportion of individuals thought to be out of care in 2011 from 27% to 16%.

Conclusions—Investigations of individuals without laboratory results reported to HIV surveillance identified large numbers of people who are no longer living in the area. Our findings suggest that current estimates of the HIV care cascade may be too pessimistic and that individual case investigations are required to accurately define the size and composition of the population of people living with HIV in local areas.

The US national HIV/AIDS reporting system (HARS) started in the 1980s to monitor the characteristics and number of AIDS cases occurring nationally. The Centers for Disease Control and Prevention subsequently expanded HARS to monitor HIV diagnoses, and for 3

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The authors have no conflicts of interest to report.

decades, the system has described the size of the HIV/AIDS epidemic and identified the populations most impacted by the virus.¹ However, the purpose of HIV surveillance is now changing. The advent of increasingly effective and well-tolerated antiretroviral therapy (ART) and growing evidence supporting early initiation of ART as both a clinical and prevention intervention have prompted greater emphasis on case finding and expanded use of antiretroviral treatment as a means to control the HIV epidemic.²⁻⁵

Many health departments now seek to monitor the HIV care cascade, to use laboratory reporting data on CD4⁺ T lymphocyte (CD4) counts and plasma HIV RNA viral load (VL) levels to define the proportion of persons living with HIV/AIDS who are linked to care, engaged in continuous care, and effectively treated.^{3,6} Some departments have gone further still and are using surveillance data to identify people who are out of care or off ART and contact those individuals, with the goal of increasing their engagement with care and treatment.^{7,8} These new uses of surveillance require data that go beyond case counting and descriptions of HIV-infected populations. They require that health departments know which people living with HIV/AIDS (PLWHA) reside in an area.

The average American moves 11.7 times over the course of their lifetime.⁹ The 2010 US census reported that more than one-third of individuals relocated in the prior 5 years, including 39% who moved out of their county of origin.¹⁰ Ignoring the population's pattern of frequent migration leads to inaccurate estimates of engagement in care and hampers efforts to use surveillance to direct interventions.¹¹

Starting in 2007, our health department initiated a series of surveillance activities through which we investigated cases of HIV for which we had no laboratory evidence of ongoing HIV care. This effort was initially developed as a means to identify and provide care referrals to people who were out of care, but subsequently evolved into an effort that also sought to accurately define the size of the population of PLWHA residing in King County, WA. By conducting this investigation, we were also able to more accurately estimate the proportion of individuals not engaged in medical care. Here we present data collected for 5 years that establish the magnitude of in- and out-migration among PLWHA in 1 US metropolitan area and the impact of those demographic shifts on the size of the county's HIV-infected population.

MATERIALS AND METHODS

King County surveillance efforts to investigate people without laboratory evidence of receipt of HIV care (CD4 or VL) were organized as part of a project called Not in Care Evaluation (NOTICE). Once each year, between 2007 and 2011, we created lists of and investigated dispositions for individuals reported to HARS with no evidence of CD4 or VL testing in the past 12 months or longer. As of March 2006, Washington State mandated the laboratory reporting of all CD4 tests in the setting of HIV infection and all HIV VL tests, regardless of whether the VL results were undetectable or not. The population from which NOTICE defined individuals who were potentially out of care varied over the course of the project. The initial NOTICE pilot in 2007 was limited to King County residents diagnosed as having HIV/AIDS 2004 through 2006.¹² In 2008, the population was expanded to King County

residents diagnosed as having HIV/AIDS 2003 through 2007. In 2009, all individuals who were King County residents at the time of an HIV/AIDS diagnosis (1982 through 2008) were included. The 2010 population was drawn following the same method as 2009 and including individuals diagnosed through 2009. In 2011, all individuals in the King County HARS database were included, regardless of residence at time of HIV/AIDS diagnosis.

Before and during NOTICE, deaths and relocations were also found during standard surveillance investigations and supplementary surveillance projects. These investigations include local and national de-duplication efforts and periodic linkage to death databases including the Social Security Death Index. Supplementary surveillance projects included the Medical Monitoring Project^{13,14} and local HIV quality assurance activities conducted as part of the Ryan White Care Act and care needs assessments conducted by the local HIV planning council. The present analysis included data received through August 2012.

NOTICE investigations sought to identify individuals who relocated or died, and also to define other explanations for potential gaps in HIV medical care. Investigations continued until a disposition explaining the lack of CD4/VL testing was found, or until staff determined that they had exhausted all reasonable avenues for further investigation. We used 2 main sources to investigate each case (unless a clear disposition was found through other means): Accurint (LexisNexis <http://www.lexisnexis.com/government/solutions/investigative/accurint.aspx>) and medical record review of a large public health hospital (MRR-PH) electronic medical record system that includes the largest HIV clinic in Washington State. Accurint is a for-profit warehouse of disaggregated residence information available to government entities.¹⁵ If MRR-PH and Accurint reviews did not clearly indicate that a patient continued to reside in the area, had left the area, or died, we contacted the patient's last known medical provider to confirm the patient's care engagement, residence, and vital status. We did not contact medical providers at facilities not providing primary HIV care, such as HIV testing facilities. Finally, we attempted to contact individuals who seemed to be out of care and reside in the area to refer them for medical care.

After eliminating individuals found to be in the HARS database in error (e.g., duplicate cases) and individuals who had never lived in King County, we categorized individuals into 4 outcomes: (1) relocations, (2) continued local residence, (3) deaths, and (4) unknown status. Each is discussed in more depth below.

1. *Relocations.* Relocations describe individuals who moved out of King County. We defined people as having relocated if they met any of the following criteria: laboratory evidence of care indicating a non-King County address; presence of a medical record or record release from a non-King County provider indicating the patient lived outside the area, HARS data from another jurisdiction, patient self-report or medical provider report of relocation, or evidence in Accurint of residence outside King County. To define a person as relocated based only on Accurint data, investigators required that at least 2 unique identifiers correctly match between cases in HARS and Accurint.
2. *Continued residence in King County.* This category includes individuals with and without evidence of engagement in medical care. We defined people as

continuing to reside in King County if we obtained CD4 or VL test results from a King County medical provider subsequent to inclusion of the person on a NOTICE list or if a medical provider, auxiliary database (e.g., Accurint), or the person being investigated reported that they resided in King County. This category included the following groups: (1) individuals who were in care but did not have their laboratories reported, either due to failure of the surveillance system to capture laboratory results or because the HIV-infected individual was receiving care under a different name or through an IRB-approved research project, which are exempt from CD4 and VL reporting requirements in Washington State; (2) individuals were out of care for 1 or more years over the course of the project, but subsequently reengaged in care and underwent laboratory testing that defined them as continuing to reside in King County; and (3) people who left King County, received care elsewhere, and then returned to King County.

3. *Deaths.* Deaths were confirmed by review of a death record, clinician report, the Social Security Death Index (a database used to find deaths of HIV-infected individuals), Accurint, a report from another jurisdiction, or a newspaper or other obituary.
4. *Unknown status.* This category includes individuals defined as lost to follow-up and/or of unknown status. To be classified as lost to follow-up, all investigations yielded no alternative disposition, and at least 5 years had passed since the person's last CD4 or VL measurement in surveillance or a clinical encounter as identified through investigations with medical providers. Unknown status describes individuals for whom we could not verify residence or medical care status and who had a last laboratory test, including an HIV diagnosis, in the past 5 years. Unknown status thus was assigned when no other disposition could be found through Accurint, MRR, contacts with last known medical provider, or attempts to contact patients by telephone and mail (telephone numbers were disconnected, calls not returned, and/or US mail to the last known residence was returned as undeliverable).

We calculated the proportion of PLWHA who received medical care in King County in 2011, based on reported CD4/VL in 2011 for individuals dispositioned by NOTICE as residing in King County and PLWHA as of December 31, 2010, under 4 different surveillance definitions. These 4 definitions are as follows: (a) PLWHA who resided in King County at the time of HIV/AIDS diagnosis, (b) those in the prior category plus in-migrants, (c) those in the prior category minus out-migrants found through routine surveillance activities, and (d) those in the prior category minus relocations found by NOTICE.

Demographic (age, sex, residence, birthplace) and HIV risk categories were compared—by χ^2 testing—for those who were investigated under the NOTICE protocol and all others presumed alive at any period during the 5 catchment years of 2006 through 2010. This comparison category of PLWHA included individuals living in King County at the time of HIV diagnosis, at the time of AIDS diagnosis, or at their most recent address (including residence at the time of death). HIV risk categories included men who had sex with men

(MSM), injection drug users (IDUs), MSM-IDU, heterosexual transmission (heterosexual partner with a known HIV infection or a known HIV risk factor, such as IDU or being a bisexual man; presumed heterosexual transmission—women who reported sex with men and denied IDU—were also included), other (blood and perinatal exposures), and unknown.

This work was conducted as a public health activity, specifically for the purpose of ensuring that HIV-infected residents had access to HIV care and, as such, did not require human subjects review.

RESULTS

As of December 31, 2010, there were 13,327 cumulative PLWHA who were King County residents at the time of HIV diagnosis or subsequent to that diagnosis based on a reported AIDS diagnosis, CD4 or VL test, or other investigation reported to surveillance. This group included 11,509 people diagnosed as having HIV or AIDS in King County (86%) and 1818 people who migrated into the area after their diagnosis (14%). Before the NOTICE catchment time (2006 through 2010), routine HARS investigations identified 4655 deaths and 188 relocations, leaving 8484 PLWHA thought to be still alive and residing in King County at the time we began NOTICE investigations (Fig. 1). Over the 5 NOTICE catchment years, an additional 435 deaths and 670 relocations were ascertained by standard core surveillance activities. Of the remaining 7379 individuals, 2573 (35%) were eligible for NOTICE investigations based on 1 or more 12-month gap in laboratory reports. A total of 28 individuals were investigated in error, including 10 duplicate cases, 16 cases presumptively diagnosed with HIV anonymously, and 2 individuals who did not have HIV infection. We excluded the erroneous cases from further analysis.

Table 1 compares the demographic characteristics of PLWHA in King County 2006 through 2010 by NOTICE eligibility. The only factors that varied more than 2% between individuals with and without identified 12-month lapses in care were residence in King County at the time of HIV diagnosis and longer time since HIV diagnosis ($P < 0.01$).

Of the 2545 eligible individuals investigated through NOTICE, 47% had relocated, 38% continued to reside in King County, 7% had died, and 8% were dispositioned as unknown. Among the 959 individuals dispositioned as living in King County, 91% had evidence of receiving medical care after the initiation of their NOTICE investigation, based on subsequent reporting of CD4/VL, medical record review, provider report, or self-report. This included 65 PLWHA receiving medical care under a research protocol and thus exempt from reporting requirements. Of the 91% with evidence of medical care after the initiation of a NOTICE investigation, 70% had laboratory results reported to HARS in 2011.

We defined dispositions on 400 individuals through investigations of medical records, 907 through Accurant searches, 265 through contact with medical providers, and 177 through contact with surveillance staff in other jurisdictions. Project staff initiated efforts to contact a total of 282 PLWHA, of whom 63 were successfully contacted. Twenty-three (36%) of the 63 PLWHA contacted reported that they were not receiving medical care, 16 of whom agreed to meet with project staff and 13 of whom sought medical care after a brief

intervention. Among the 7 people who declined to meet with staff, 2 had subsequent laboratory results reported to HIV surveillance.

Our estimates of the size of the population of PLWHA, as well as the percentage of people who seem to be out of care, varied substantially based on the extent to which we accounted for in- and out-migration. Figure 2A and B presents the number of individuals living in King County with HIV/AIDS as of December 31, 2010, and the percentage who were out of care in 2011 (i.e., no laboratory results reported) under different surveillance definitions. All estimates excluded confirmed deaths through 2010. Restricting the population to people residing in King County at the time of HIV/AIDS diagnosis and neglecting out-migration resulted in an estimated population of 6767 PLWHA with 31% having no reported laboratory results in 2011. Including people who migrated into King County after an HIV/AIDS diagnosis increased the estimated size of the population 20% to 8120, with roughly the same proportion having no laboratory results reported to surveillance in 2011. Further modifying this estimate to include out-migration based on routine surveillance activities, but without including the results of NOTICE identified out-migrations, decreased the number of PLWHA by 12% and decreased the proportion without reported laboratory results in 2011 from 31% to 27%. Finally, accounting for out-migrations ascertained through NOTICE decreased the number of PLWHA an additional 16% and reduced the estimated out-of-care proportion to 16%. Of the 6018 PLWHA whom our investigations indicated resided in King County at the end of 2010, 1153 (19%) had in-migrated after an HIV/AIDS diagnosis in another jurisdiction. Assuming that PLWHA without laboratory results reported to surveillance for 5 or more years had out-migrated decreases the number of PLWHA by 4% ($n = 5748$), among whom 12% had no laboratory monitoring in 2011.

DISCUSSION

Our findings demonstrate that migration is common among PLWHA and that HIV surveillance procedures routinely used to date—which fail to accurately account for migration—result in overestimation of both the size of the HIV-infected population and in the proportion of PLWHA who are out of care. At the same time, we found that intensive investigations were feasible and can improve surveillance data, laying the groundwork for outreach efforts to improve engagement in care and monitor the HIV care cascade.

We also found that individuals with a gap in laboratory reporting of 12 or more months were demographically similar to other PLWHA (Table 1), suggesting that there were few discernible characteristics differentiating individuals with and without annual laboratory monitoring in King County. Two exceptions were factors potentially associated with an increased likelihood of relocation: length of time since HIV diagnosis and King County residence at the time of HIV diagnosis.

In-migration and out-migration were both important contributors to the size the composition of the HIV-infected population of King County. Among the 6018 PLWHA in King County at the end of 2010, nearly 1 in 5 were diagnosed in another area. On the other side, based on our NOTICE investigation findings, failure to account for out-migration that was not ascertained through routine surveillance activities led to a 19% overestimate of the number

of PLWHA in the area and a 69% overestimate (27% vs. 16%) of the number of PLWHA who were out of care in 2011.

Although data on migration and its effects on surveillance estimates are limited, previously published findings suggest that our observations are unlikely to be unique to King County. A study of 325 HIV-infected individuals in North Carolina conducted in the early 1990s found that 20% of participants had been diagnosed as having HIV out of state.¹⁶ Berk et al.¹⁷ reported that 17% of a probability sample of HIV clinic patient in 1996 had moved to another state or noncontiguous county after testing HIV positive, whereas a study of Alabama and Mississippi HIV clinic patients conducted in 1995 to 1997 found that 25% of patients moved to a new state after testing HIV positive.¹⁸ Lieb et al.¹⁹ reported a similar level of in-migration among Florida HIV clinic patients surveyed in 2004. More recently, investigators in Colorado found that surveillance-based estimates of the proportion of individuals with viral suppression 60 months after diagnosis rose from 36% to 48% after censoring deaths and out-migrants.²⁰

Our findings also highlight that receipt of care is highly dynamic. Relatively few people whom we contacted reported that they were out of care. At the same time, about 20% of all PLWHA in King County seemed to have at least one 12-month period during which they had no laboratory tests reported to surveillance between 2006 and 2010. Although some of these people may have been receiving care and our surveillance system failed to capture their test results, this finding highlights that episodic engagement in care is common. Indeed, in a place like King County, transient disengagement with care seems to be much more common than being out of care for years at a time. Low levels of engagement with care are associated with the absence of viral suppression,^{5,21,22} and efforts to improve engagement in care among PLWHA who intermittently receive care are a clinical and public health priority.

In addition to the inherent problem of summarizing dynamic events (care engagement and migration over a 5-year interval) at specific periods, our investigations had several other limitations. Some medical providers may have overestimated their patients' care engagement and the patients themselves may have inaccurately self-reported engagement in care because of social desirability or other biases. (Under NOTICE, the disposition of being in care did not have a specific definition; in our current care engagement outreach activities, we describe individuals in care as those with visits within 6 months or a visit scheduled in the next 2 months.) Investigating cases with no laboratory results reported in a year excluded some individuals not fully engaged in care and included others whose laboratory results were not reported or matched correctly to the right person. Despite completion of this project, there likely will be some remaining misclassification of residence and care status among individuals included and excluded by our HIV surveillance system. Furthermore, the low proportions of individuals contacted and who agreed to be interviewed highlight the difficulty of reaching individuals truly not engaged in care. On the basis of the outcomes of successful investigations, many individuals with "unknown" dispositions may have been in care or relocated. An unknown proportion of the death and relocation outcomes attributed to NOTICE would have been eventually discovered with routine surveillance activities. Finally, owing to the dynamic nature of surveillance data, newly reported (or newly linked) CD4 and VL test reports changed some individuals' eligibility for NOTICE over the period of

investigation. For example, an individual selected for NOTICE in 2008 because of not having reported laboratory tests in 2007 may later have laboratory results reported for 2007 or may have died in 2007 and, in retrospect, should not have been eligible for NOTICE.

A standard definition for cases that are lost to follow up is necessary if this work will be interpreted—or repeated—by other jurisdictions. Some cases now seem to be “out of care” for more than 20 years. Our use of 5 years without reported laboratory results was a somewhat arbitrary length of time. However, after these NOTICE investigations were completed, in 2012, the Washington State HIV laboratory tracking system added thousands of CD4 and VL tests for 2011 the first half of 2012; none of the individuals we classified as being lost to follow up had new laboratory results reported with this increase in available laboratory data. Using this definition of lost to follow-up—no laboratory results reported over a 5-year period—as a method of estimating our jurisdictions’ PLWHA resulted in an estimation similar to that found after extensive NOTICE investigations (5748 vs. 6018), with an even greater proportion with laboratory monitoring in 2011 (88% vs. 84%). Future projects would benefit by deriving methods to categorize individuals’ actual care status (in medical care, marginally in care, or not receiving medical care) during a period without receipt of laboratory results to better describe whether individuals without reported laboratory results actually were not receiving medical care.

In summary, our findings highlight how limitations in the existing HIV surveillance system may be inflating local estimates of the number of PLWHA and the percentage of people who are out of care or not virally suppressed. Ongoing national efforts to improve communication between health departments should diminish this problem over time. However, at least for the time being, we believe that accurate assessment of the HIV care cascade requires health departments to investigate people for whom no laboratory data are reported to surveillance. Such efforts can also be designed to increase individuals’ engagement with care, encourage antiretroviral treatment, improve surveillance monitoring, and identify populations at increased risk for inadequate engagement with care.

Acknowledgments

Sources of support: Centers for Disease Control and Prevention HIV/AIDS Surveillance and Category C Grants (CDC-RFA-PS08-80205CONT12 and PS12-1201, respectively); Ryan White HIV Emergency Relief Project Grants, Part A (H89HA00022); Demonstration Projects to Implement and Evaluate Innovative, High-Impact HIV Prevention Interventions and Strategies (1U62PS003666-01); the National Institutes of Mental Health (K23MH090923; to J.C.D.); and the University of Washington Center for AIDS Research, a National Institutes of Health–funded program (P30 AI027757) which is supported by the following National Institutes of Health institutes and centers: National Institute of Allergy and Infectious Diseases; National Cancer Institute; National Institute of Mental Health; National Institute on Drug Abuse; National Institute of Child Health and Human Development; National Heart, Lung, and Blood Institute; and National Institute on Aging.

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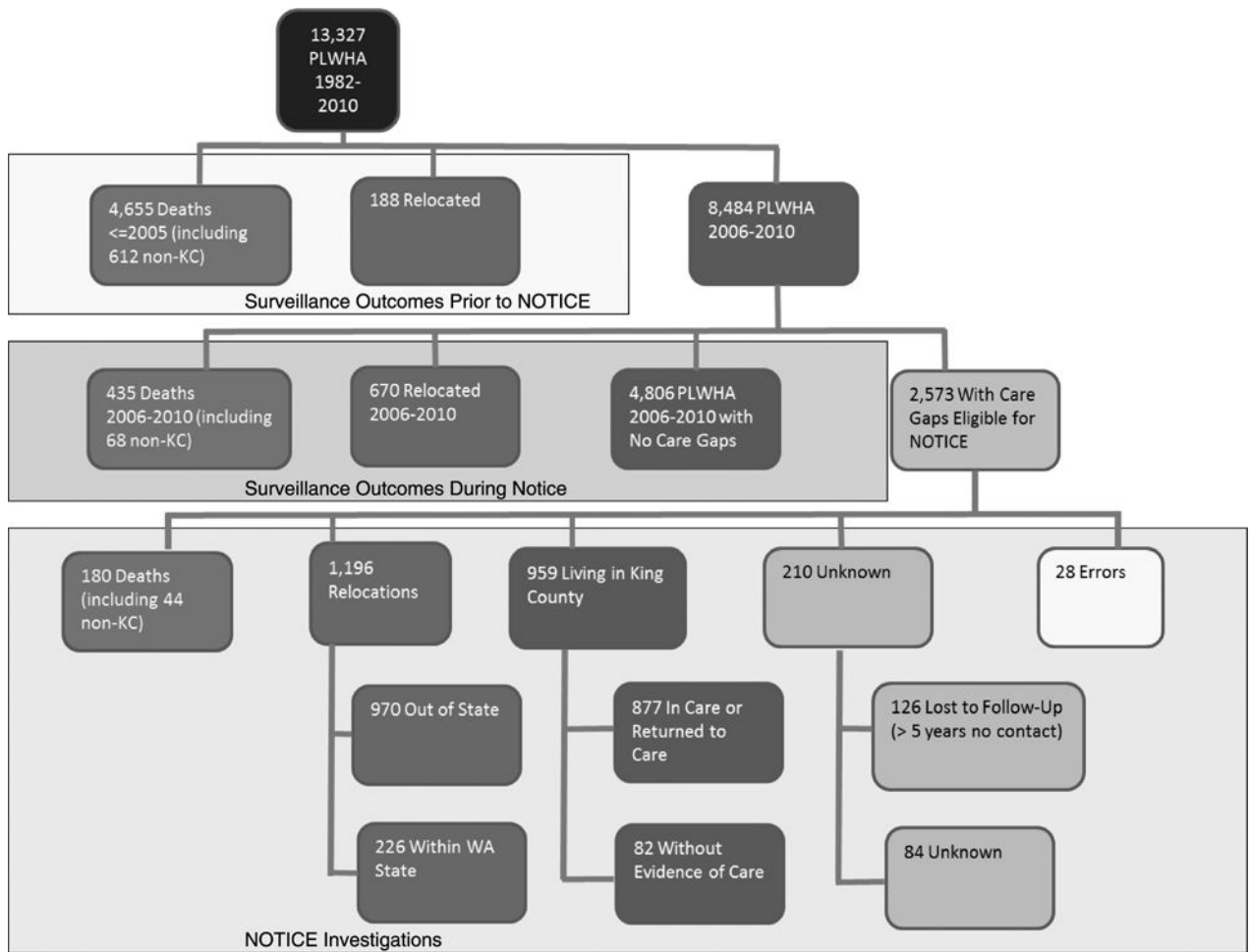


Figure 1. Cumulative reports of PLWHA to HIV/AIDS surveillance and disposition as of December 31, 2010, in King County, Washington State.

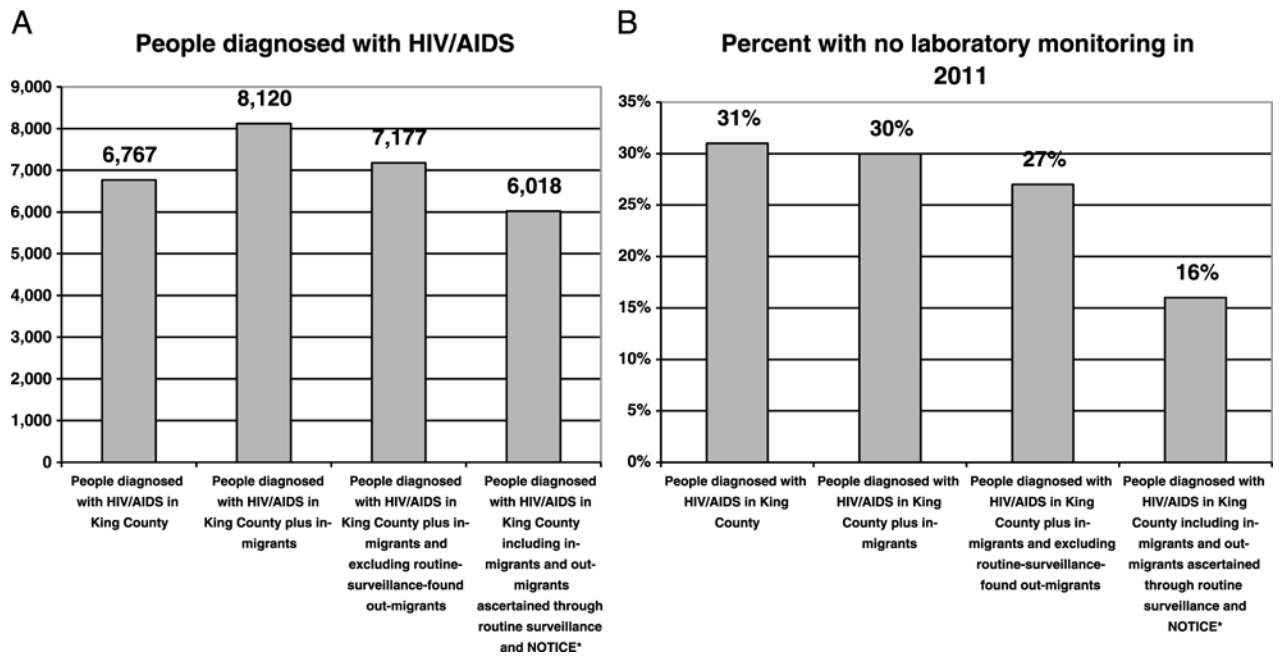


Figure 2. Number of PLWHA as of December 31, 2010, using different surveillance definitions and the proportion without reported HIV monitoring laboratory results in 2011, King County, Washington State. *NOTICE = Not In Care Evaluation where individuals with no reported CD4⁺ lymphocyte or plasma VL tests for 12 months or longer between 2006 and 2010 were investigated.

TABLE 1

Demographic Characteristics of Individuals Living With HIV in King County, Washington State, 2006 Through 2010, Without Gaps in Laboratory Monitoring Versus Individuals Selected for the NOTICE With Gaps of 12 Months or Longer

	PLWHA 2006–2010 Without Gaps in Laboratory Monitoring (n = 5911)	People Investigated Due to Lapses in Reported Laboratory Monitoring 12 mo (n = 2545)	Total (n = 8456)
Sex, n (%)			
Female	643 (11)	241 (9)	884 (10)
Male	5268 (89)	2304 (91)	7572 (90)
Birthplace, n (%)			
United States and territories	4772 (81)	2010 (79)	6782 (80)
Foreign-born	934 (16)	408 (16)	1342 (16)
Unknown	205 (3)	127 (5)	332 (4)
HIV risk category, n (%)			
MSM	3997 (68)	1747 (69)	5744 (68)
IDUs	346 (6)	129 (5)	475 (6)
MSM-IDU	546 (9)	257 (10)	803 (9)
Heterosexual	600 (10)	217 (9)	817 (10)
Other	48 (1)	25 (1)	73 (1)
Unknown	374 (6)	170 (7)	544 (6)
Age in 2010, n (%)			
<20 y	30 (1)	10 (<1)	40 (<1)
20–29 y	426 (7)	128 (5)	554 (7)
30–39 y	1069 (18)	489 (19)	1558 (18)
40–49 y	2292 (39)	1041 (41)	3333 (39)
50–59 y	1571 (27)	656 (26)	2227 (26)
60+ y	523 (9)	221 (9)	744 (9)
Race, n (%)			
Latino/Hispanic	598 (10)	299 (12)	897 (11)
American Indian/Alaska native	67 (1)	25 (1)	92 (1)
Asian/Pacific Islander	192 (3)	74 (3)	266 (3)
Black/African American	1007 (17)	444 (17)	1451 (17)
White	3915 (66)	1659 (65)	5574 (66)
Multiple/Unknown	131 (2)	44 (2)	175 (2)
King County resident at HIV, n (%)			
Yes	4784 (81)	2232 (88)	7016 (83)
No	1127 (19)	313 (12)	1440 (17)
Year of HIV diagnosis, n (%)			
1982–1995	1823 (31)	886 (35)	2709 (32)
1996–2000	1310 (22)	611 (24)	1921 (23)
2001–2005	1308 (22)	702 (28)	2010 (24)

	PLWHA 2006–2010 Without Gaps in Laboratory Monitoring (n = 5911)	People Investigated Due to Lapses in Reported Laboratory Monitoring 12 mo (n = 2545)	Total (n = 8456)
2006–2010	1467 (25)	346 (14)	1813 (21)
Time from HIV diagnosis to 1/1/2011 (y), mean (95% confidence interval)	11.1 (10.1–11.3)	12.4 (12.2–12.7)	11.5 (11.4–11.6)

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