Differences Among U.S. States in Estimating the Number of People Living with HIV/AIDS: Impact on Allocation of Federal Ryan White Funding

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SYNOPSIS

Objective. We assessed the impact of differing laboratory reporting scenarios on the completeness of estimates of people living with human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) (PLWHA) in the U.S., which are used to guide allocation of federal Ryan White funds.

Methods. We conducted a four-year simulation study using clinical and laboratory data on 1,337 HIV-positive women, including 477 (36%) who did not have AIDS at baseline. We estimated the completeness of HIV (non-AIDS) case ascertainment for three laboratory reporting scenarios: CD4<200 cells/μL and detectable viral load (Scenario A); CD4<500 cells/μL and no viral load reporting (Scenario B); and CD4<500 cells/μL and detectable viral load (Scenario C).

Results. Each scenario resulted in an increasing proportion of HIV (non-AIDS) cases being ascertained over time, with Scenario C yielding the highest by Year 4 (Year 1: 69.0%, Year 4: 88.1%), followed by Scenario A (Year 1: 63.3%, Year 4: 84.5%), and Scenario B (Year 1: 43.0%, Year 4: 67.7%). Overall completeness of PLWHA ascertainment after four years was highest for Scenario C (95.8%), followed by Scenario A (94.5%), and Scenario B (88.5%).

Conclusions. Differences in laboratory reporting regulations lead to substantial variations in the completeness of PLWHA estimates, and may penalize jurisdictions that are most successful at treating HIV/AIDS patients or those with weak or incomplete HIV/AIDS surveillance systems.

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In addition to monitoring trends in disease transmission, and planning and evaluating the impact of prevention programs, human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) surveillance data are used for care and treatment funding and resource allocation. In the case of HIV/AIDS in the U.S., allocation of programmatic resources for prevention, care, and treatment are closely linked to disease burden, and resource allocation has therefore historically relied heavily on surveillance data.

The Federal Ryan White CARE Act (RWCA), enacted in 1990 to provide care and treatment for people with HIV/AIDS, authorizes disbursement of more than $2 billion to states and eligible metropolitan areas (EMAs) annually, and has historically used surveillance data on the number of people living with AIDS (PLWA) from each state as a guide for its Title I and Title II resource allocation.[1] However, the success of new highly active antiretroviral therapy (HAART) at slowing progression from HIV (non-AIDS) to AIDS has substantially changed the dynamics of the AIDS epidemic in the U.S.,[2–5] making the number of PLWA less reflective of the relative burden of HIV infection on health-care systems.[6] Because the care and treatment burden of HIV/AIDS is driven by all people diagnosed with HIV, not just those with AIDS, there was much discussion of incorporating HIV surveillance data into the RWCA allocation formula prior to reauthorization in late 2006.[7]

AIDS ONLY VS. HIV/AIDS SURVEILLANCE

All 50 U.S. states have laws that require reporting of people with AIDS,[7] and as of July 2006, 50 U.S. jurisdictions (45 states and five territories) required named reporting of people with HIV (non-AIDS).[8] However, the equitable distribution of federal RWCA funds will likely depend substantially on having surveillance systems capable of estimating the number of HIV (non-AIDS) cases and total number of people living with HIV/AIDS (PLWHA) with comparable accuracy across U.S. states.

Disease reporting regulations and requirements are determined at the state level, based on recommendations from the Centers for Disease Control and Prevention (CDC) and the Council of State and Territorial Epidemiologists.[7] However, unlike AIDS, only case reporting—in which all 50 states and the District of Columbia require both providers and laboratories to report cases and reportable laboratory events, respectively, by name using standard case definitions, data collection, reporting forms, and computer software[9]—the completeness of HIV (non-AIDS) case ascertainment varies greatly from state to state due to differences in regulations and approaches to implementation.[1] Further, while it may be reasonable to assume that ascertainment of newly diagnosed HIV (non-AIDS) cases will be nearly complete in many instances, there is concern about the completeness of ascertainment of prevalent HIV (non-AIDS) cases diagnosed before new reporting systems go into effect.[6]

State and local health departments in most jurisdictions have chosen to rely on a combination of provider and laboratory reporting for both AIDS and HIV (non-AIDS) case finding.[8] As of January 2005, 20 U.S. states required reporting of CD4 counts under 200 cells/μL along with HIV viral load tests, 12 required reporting of all CD4 counts and HIV viral loads, while others required reporting of only one or neither laboratory test.[10] Because the HIV/AIDS reporting requirements for providers are usually based on clinical events (i.e., HIV or AIDS diagnoses) and those for laboratories are based on serologic, virologic, and immunologic outcomes (i.e., HIV western blot, HIV viral load tests, and CD4 counts), the degree to which information from each of these complementary sources drives the overall completeness of ascertainment of HIV (non-AIDS) cases diagnosed prior to the implementation of HIV surveillance may be different.

On the order of the U.S. Congress, the Institute of Medicine (IOM) convened a workgroup to evaluate the feasibility of using available HIV (non-AIDS) data in the determinations of PLWHA estimates for RWCA allocations.[11] HIV (non-AIDS) reporting regulations have only recently been implemented in many areas, and because of the varying degree of maturity of these systems from state to state, the IOM commission determined that unreliability and inaccuracy in estimating the number of people living with HIV (non-AIDS) as well as AIDS might result in a lack of comparability across states, ultimately undermining the equity of RWCA resource allocation. Specifically, the IOM recommended in 2003 that:

> ". . . for at least the next four years, HRSA [Health Resources and Services Administration] should continue to use estimated living AIDS cases in the RWCA Titles I and II formulas. During that period, concerted effort should be devoted to improving the consistency, quality, and comparability of HIV case reporting . . . ."[1]

Reauthorized in late 2006, the RWCA includes strict requirements that funding recipients adhere to recent CDC recommendations for name-based HIV case reporting, promulgated in 2005.

To assess the potential impact of variations in laboratory reporting requirements on the completeness of

ascertainment of previously diagnosed HIV (non-AIDS) cases and allocation of RWCA funding, and to inform efforts aimed at improving the consistency, quality, and comparability of HIV (non-AIDS) case reporting, we conducted a simulation study using routinely collected self-report, clinical, and laboratory data on HIV-positive women from the Women's Interagency HIV Study (WIHS).

METHODS

WIHS is a multicenter study (six sites, 23 clinics) of 2,058 urban women with HIV and 568 urban women without HIV recruited in 1994 and 1995.[12] Follow-up visits with interviews and laboratory testing (CD4 and HIV viral load) were conducted every six months following the baseline recruitment visit. The WIHS questionnaires included questions on provider visits, antiretroviral therapy (ART), AIDS diagnoses, as well as sociodemographic characteristics. HIV-positive women in the WIHS cohort have been shown to be similar to female reported AIDS cases with regard to demographics and transmission risk factor.[12] A study of retention among WIHS participants reported an 82% follow-up rate during the five-year period 1994–1999 (10 visits).[13]

This analysis included all HIV-positive women from WIHS who were diagnosed and alive as of January 1, 2000, with at least one subsequent follow-up (n=1,337). Most of our analyses focused on the 477 women who were AIDS-free on January 1, 2000 (beginning of Year 1).

Reportable events

Events considered reportable in this simulation included: (*1*) death due to HIV/AIDS or an unknown cause, (*2*) self-report of an AIDS or opportunistic illness (OI) diagnosis, (*3*) an HIV viral load test result (detectable or undetectable), or (*4*) CD4 count (at various cutoff levels). For the purposes of this analysis, participant self-reports of an AIDS diagnosis or a diagnosis of one of 23 OIs or a CD4 laboratory report of <200 cells/μL were considered AIDS-defining events. The validity of self-reported AIDS diagnoses has been evaluated in a subset of WIHS participants and found to be reasonably accurate.[13]

To simulate HIV reporting under diverse conditions, we examined three different laboratory reporting scenarios, each in combination with AIDS case reporting and death surveillance, that have been implemented commonly throughout the U.S.,[1] but which we hypothesized would result in incomplete HIV/AIDS case ascertainment:

- Scenario A: CD4<200 cells/μL, and detectable viral load tests reportable
- Scenario B: CD4<500 cells/μL reportable (no viral load test reporting)
- Scenario C: CD4<500 cells/μL, and detectable viral load tests reportable

These three scenarios were also compared with more common scenarios felt to result in more complete case ascertainment, due to an inclusive list of reportable laboratory tests and results.

Women were counted as having experienced a reportable event under a given laboratory reporting scenario if the specific events were documented to have occurred. To simulate laboratory reporting in the real world, we required that laboratory results could only be counted as reportable if subjects saw a provider for HIV care since their previous study visit. For people with multiple viral load and CD4 results for a given period, the highest viral load and lowest CD4 were used in this analysis. This analysis assumed that all laboratory results subsequent to a provider visit would have been reported by the testing laboratories to health authorities.

Women with HIV (non-AIDS) on January 1, 2000, were considered to have progressed to AIDS if there was a subsequent self-report of an AIDS or OI diagnosis, or a CD4<200 cells/μL preceded by a provider visit in the months prior to the CD4 result. The timing of AIDS onset was estimated using the midpoint of the time interval between the last AIDS-free interview and the interview in which an AIDS-defining event occurred.

Estimating the completeness of HIV (non-AIDS) case ascertainment and PLWHA estimation

The year-specific cumulative completeness of ascertainment of prevalent HIV (non-AIDS) cases was defined as the proportion of HIV (non-AIDS) cases that experienced a reportable event under each scenario during the follow-up period. To examine the cumulative completeness of HIV (non-AIDS) case ascertainment over time, we estimated year-specific completeness levels for each laboratory reporting scenario for the four-year simulation period. To examine the representativeness of case ascertainment, we estimated completeness of HIV (non-AIDS) case ascertainment by sociodemographics, exposure category, and treatment status at baseline (HAART vs. no HAART). Overall, year-specific cumulative completeness of PLWHA estimation was defined as the number of women with AIDS at baseline plus the number of people experiencing a reportable event under a given scenario, divided by the total number of women with HIV at baseline (n=1,337).

Age was defined as the age on January 1, 2000. Race/ethnicity was categorized as non-Hispanic white, non-Hispanic black, Hispanic, or other. Exposure categories examined were non-drug user, drug-user (non-injecting drug user [IDU]), and IDU based on self-reported drug use history.

Use of ART was ascertained at the first visit after January 1, 2000, or, if not available, then the visit immediately prior to January 1, 2000. Participants were asked about any antiretroviral medications they had used since their last visit. Based on participant responses, therapy regimens were classified either as no therapy, monotherapy, combination therapy, or HAART, as defined in prior WIHS cohort publications and informed by national guidelines.[14]

All statistical analyses were carried out using SAS Version 8.[15]

RESULTS

As of January 1, 2000, there were 1,337 women living with HIV/AIDS in the WIHS cohort, 477 (36%) of whom had HIV infection that had not yet progressed to AIDS (Table 1). Under an AIDS-only case reporting model, these cases would not be reported to state and local health departments until they developed AIDS, according to clinical and laboratory guidelines. HIV (non-AIDS) cases were more likely to be younger, unemployed, non-IDU, have a higher household income, be diagnosed more recently (all p-values ≤ 0.001), and uninsured ($p=0.01$) when compared to people with AIDS.

Sixty-two of the 477 women (13%) who were AIDS-free at baseline progressed to AIDS by December 31, 2003, defined as a self-reported AIDS diagnosis or OI, a CD4<200 cells/μL, or death (Table 2), and therefore would have been detected by AIDS-only case reporting. Women who were older, employed, IDUs, and with lower income were more likely to have experienced an AIDS-defining event (all p-values ≤ 0.05).

Table 3 shows the characteristics of women with HIV (non-AIDS), classified by laboratory outcomes (highest viral load and lowest CD4) and clinical outcomes (AIDS diagnosis or death) experienced during the four-year period 2000–2003. Seventy-three (16%) of the 471 women who had a viral load test and reported seeing a health-care provider since their previous study visit did not have a detectable viral load during the entire four-year period. Similarly, the CD4 count of 143 (30%) women did not fall below 500 cells/μL. Forty-nine (10%) of the 477 women reported having had an AIDS diagnosis, and 13 of 477 (3%) died during the study period.

People whose highest viral load during the study period was detectable were less likely to be on HAART (42% vs. 77%, $p<0.001$) and more likely to be IDUs (7% vs. 12%, $p=0.0066$). People whose lowest CD4 count was 500 cells/μL or more were more likely to be on ART, and particularly more likely to be on HAART than people with lower CD4 counts (56% vs. 30%, $p=0.04$). Among those with clinical outcomes during the study period (i.e., AIDS diagnosis or death), people who died were more likely not to be on HAART than those with an AIDS diagnosis (69% vs. 51%, $p=0.53$), and more likely to be IDUs (62% vs. 17%, $p=0.006$).

In Scenario A (CD4<200 cells/μL and detectable viral loads reportable), only 63% of the 477 women with previously diagnosed HIV (non-AIDS) experienced a reportable event in Year 1 of the study period, and 84.5% of women with HIV (non-AIDS) experienced a reportable event by the end of Year 4. Women who were on HAART at baseline and non-IDUs were less likely to experience a reportable event.

In Scenario B (CD4 counts<500 cells/μL reportable, no viral load reporting), only 43% of the 477 women with HIV (non-AIDS) at the beginning of the study period experienced a reportable event by the end of Year 1, and only 68% had experienced a reportable event by the end of Year 4. Again, women who were on HAART at baseline and non-IDUs were less likely to experience a reportable event under this scenario.

In Scenario C (CD4<500 cells/μL and detectable viral load reportable), only 69% of women with HIV (non-AIDS) in the beginning of the study period experienced a reportable event in Year 1. By the end of Year 4, 88% of women had experienced a reportable event. In this scenario, women who were on HAART at baseline, younger women, and non-IDU respondents were less likely to experience a reportable event during the four-year study period.

Figure 1 compares the completeness of ascertainment of HIV (non-AIDS) cases for the three highlighted scenarios from this study to that of other possible reporting scenarios over time. In addition to Scenarios A, B, and C, this graph includes AIDS-only case reporting and all laboratory events (all CD4 and detectable and undetectable viral loads). All scenarios resulted in an increasingly higher proportion of women with HIV (non-AIDS) experiencing a reportable event over time. The scenario with the highest completeness of HIV (non-AIDS) case reporting was the one reporting all CD4 and viral load tests (99% by Year 4).

Finally, Figure 2 shows the impact of each reporting scenario on the completeness of overall PLWHA (HIV and AIDS) estimates. While all laboratory reporting scenarios resulted in a high level of completeness

Table 1. Descriptive characteristics of HIV-positive women from the WIHS who were diagnosed and alive as of January 1, 2000, by baseline clinical status

			Clinical status on January 1, 2000[a]				
	Total		*AIDS*		*HIV (non-AIDS)*		
	N	*Percent*	N	*Percent*	N	*Percent*	P-*value*
Total	1,337	100	860	100	477	100	
Receipt of medical care for HIV							
Never							
Not on HAART at baseline	6	0.4	2	0.2	4	0.8	1.0
On HAART	2	0.1	1	0.1	1	0.2	
Sometimes							
Not on HAART at baseline	209	15.6	110	12.8	99	20.8	0.34
On HAART	142	10.6	82	9.5	60	12.6	
Routinely							
Not on HAART at baseline	435	32.5	285	33.1	150	31.4	0.137
On HAART	543	40.6	380	44.2	163	34.2	
Age (years)							
20–29	71	5.3	32	3.7	39	8.2	<0.0001
30–39	496	37.1	295	34.3	201	42.1	
40–49	601	45.0	424	49.3	177	37.1	
50+	169	12.6	109	12.7	60	12.6	
	860						
Race/ethnicity							
Non-Hispanic black	748	55.9	480	55.8	268	56.2	0.6826
Non-Hispanic white	228	17.1	141	16.4	87	18.2	
Hispanic	327	24.5	218	25.3	109	22.9	
Other	34	2.5	21	2.4	13	2.7	
Health insurance							
Yes	1,228	91.8	802	93.3	426	89.3	0.0115
No	109	8.2	58	6.7	51	10.7	
Employed							
Yes	888	66.4	627	72.9	261	54.7	<0.0001
No	449	33.6	233	27.1	216	45.3	
Household income							
≤$6,000	243	18.2	160	18.6	83	17.4	<0.001
$6,001–$12,000	494	36.9	347	40.3	147	30.8	
$12,001–$18,000	199	14.9	127	14.8	72	15.1	
$18,001–$24,000	109	8.2	72	8.4	37	7.8	
≥$24,001	292	21.8	154	17.9	138	28.9	
Exposure category							
Sexual (non-IDU)	445	33.3	269	31.3	176	36.9	0.0038
Sexual (drug user, non-IDU)	679	50.8	434	50.5	245	51.4	
IDU	213	15.9	157	18.3	56	11.7	
Year of HIV diagnosis							
Unknown	28	2.1	17	2.0	11	2.3	0.0004
Prior to 1990	476	35.6	335	39.0	141	29.6	
1991	203	15.2	135	15.7	68	14.3	
1992	182	13.6	115	13.4	67	14.0	
1993	200	15.0	122	14.2	78	16.4	
1994	171	12.8	102	11.9	69	14.5	
1995	77	5.8	34	4.0	43	9.0	

[a]Data obtained by patient self-report or CD4<200 cells/μL

HIV = human immunodeficiency virus

WIHS = Women's Interagency HIV Study

AIDS = acquired immunodeficiency syndrome

HAART = highly active antiretroviral therapy

IDU = injection drug user

Table 2. Clinical status at the end of four years of follow-up of 477 women from the WIHS who were AIDS-free on January 1, 2000

	Clinical status on January 1, 2000		*Clinical status on December 31, 2003*				
	HIV (non-AIDS)		*Remained AIDS-free*		*Progressed to AIDS[a] or died[b]*		
	N	*Percent*	N	*Percent*	N	*Percent*	P-*value*
Total	477	100	415	100	62	100	
Receipt of medical care for HIV							
Never							
Not on HAART at baseline	4	0.8	3	0.7	1	1.6	1.0
On HAART	1	0.2	1	0.2	0	0.0	
Sometimes							
Not on ART at baseline	99	20.8	89	21.4	10	16.1	
On HAART	60	12.6	54	13.0	6	9.7	0.98
Routinely							
Not on ART at baseline	150	31.4	123	29.6	27	43.5	0.08
On HAART	163	34.2	145	34.9	18	29.0	
Age (years)							
20–29	39	8.2	36	8.7	3	4.8	0.0407
30–39	201	42.1	180	43.4	21	33.9	
40–49	177	37.1	144	34.7	33	53.2	
50+	60	12.6	55	13.3	5	8.1	
Race/ethnicity							
Non-Hispanic black	268	56.2	229	55.2	39	62.9	0.3402
Non-Hispanic white	87	18.2	74	17.8	13	21.0	
Hispanic	109	22.9	100	24.1	9	14.5	
Other	13	2.7	12	2.9	1	1.6	
Health insurance							
Yes	426	89.3	370	89.2	56	90.3	0.7817
No	51	10.7	45	10.8	6	9.7	
Employed							
Yes	261	54.7	219	52.8	42	67.7	0.0272
No	216	45.3	196	47.2	20	32.3	
Household income							
≤$6,000	83	17.4	65	15.7	18	29.0	0.0174
$6,001–$12,000	147	30.8	125	30.1	22	35.5	
$12,001–$18,000	72	15.1	62	14.9	10	16.1	
$18,001–$24,000	37	7.8	34	8.2	3	4.8	
≥$24,001	138	28.9	129	31.1	9	14.5	
Exposure category							
Sexual (non-IDU)	176	36.9	162	39.0	14	22.6	0.0003
Sexual (drug user, non-IDU)	245	51.4	213	51.3	32	51.6	
IDU	56	11.7	40	9.6	16	25.8	
Year of HIV diagnosis							
Unknown	11	2.3	9	2.2	2	3.2	0.9325
Prior to 1990	141	29.6	119	28.7	22	35.5	
1991	68	14.3	60	14.5	8	12.9	
1992	67	14.0	59	14.2	8	12.9	
1993	78	16.4	70	16.9	8	12.9	
1994	69	14.5	60	14.5	9	14.5	
1995	43	9.0	38	9.2	5	8.1	

[a]Self-report of one or more of 23 AIDS-defining opportunistic illnesses or death by any cause during the follow-up period

[b]Death due to any cause; self-report AIDS or CD4<200 cells/μL

AIDS = acquired immunodeficiency syndrome

HIV = human immunodeficiency virus

WIHS = Women's Interagency HIV study

ART = antiretroviral therapy

HAART = highly active antiretroviral therapy

IDU = injection drug user

Table 3. Number and proportion of HIV-positive women from the WIHS who had an HIV-related outcome during 2000–2003

		Laboratory outcomes[a]								*Clinical outcomes*				
		Highest viral load			*Lowest CD4*					*AIDS diagnosis*[b]	*Death*			
		n=*471 (percent)*			n=*471 (percent)*					N=*49 (percent)*	N=*13 (percent)*			
	All women	*Detect-able*	*Unde-tectable*	P-*value*[c]	*<200*	*200–350*	*351–500*	*>500*	P-*value*[d]		*Any*	*HIV/AIDS-related*	*Other/unknown*	P-*value*[d]
Total	477 (100)	398 (100)	73 (100)		73 (100)	137 (100)	118 (100)	143 (100)		49 (100)	13 (100)	8 (100)	5 (100)	
Therapy														
Not on ART	201 (42.1)	185 (46.5)	11 (15.1)	<0.0001	44 (60.3)	63 (46.0)	44 (37.3)	46 (32.2)	0.0386	25 (51.0)	9 (69.2)	6 (75.0)	3 (60)	0.53
Monotherapy	2 (0.4)	2 (0.5)	0 (0)		1 (1.4)	0 (0)	0 (0)	1 (0.7)		0 (0)	0 (0)	0 (0)	0 (0)	
Combination therapy	50 (10.6)	44 (11.1)	6 (8.2)		6 (8.2)	14 (10.2)	14 (11.9)	16 (11.2)		4 (8.2)	0 (0)	0 (0)	0 (0)	
HAART	224 (47)	167 (42.0)	56 (76.7)		22 (30.1)	60 (43.8)	60 (50.8)	80 (55.9)		21 (40.8)	4 (30.8)	2 (25.0)	2 (40)	
Age (years)														
20–29	39 (8.2)	30 (7.5)	8 (11.0)	0.4837	5 (6.8)	10 (7.3)	9 (7.6)	13 (9.1)	0.7257	3 (6.1)	0 (0)	0 (0)	0 (0)	0.99
30–39	201 (42.1)	170 (42.7)	28 (38.4)		37 (50.7)	50 (36.5)	48 (40.7)	64 (44.8)		16 (32.7)	5 (38.5)	3 (37.5)	2 (40)	
40–49	177 (37.1)	151 (37.9)	25 (34.2)		26 (35.6)	54 (39.4)	46 (39.0)	50 (35)		26 (53.1)	7 (53.8)	4 (50.0)	3 (60)	
50+	60 (12.6)	47 (11.8)	12 (16.4)		5 (6.8)	23 (16.8)	15 (12.7)	16 (11.2)		4 (8.2)	1 (7.7)	1 (12.5)	0 (0)	
Race/ethnicity														
Non-Hispanic black	268 (56.2)	229 (57.5)	37 (50.7)	0.1082	45 (61.6)	89 (65.0)	59 (50.0)	73 (51.0)	0.1748	31 (63.3)	8 (61.5)	3 (37.5)	5 (100)	0.73
Non-Hispanic white	87 (18.2)	70 (17.6)	15 (20.5)		6 (8.2)	22 (16.1)	24 (20.3)	34 (23.8)		11 (22.5)	2 (15.4)	2 (25.0)	0 (0)	
Hispanic	109 (22.6)	91 (22.9)	16 (21.9)		21 (28.8)	23 (16.8)	31 (26.3)	31 (21.7)		6 (12.2)	3 (23.1)	3 (37.5)	0 (0)	
Other	13 (2.7)	8 (2.0)	5 (6.8)		1 (1.4)	3 (2.2)	4 (3.4)	5 (3.5)		1 (2.0)	0 (0)	0 (0)	0 (0)	
Exposure category														
Sexual (non-IDU)	176 (36.9)	136 (34.2)	39 (53.4)	0.0066	20 (27.4)	50 (36.5)	42 (35.6)	62 (43.4)	0.1586	13 (26.5)	1 (7.7)	0 (0)	1 (20)	0.006
Sexual (drug user, non-IDU)	242 (51.4)	213 (53.5)	29 (39.7)		45 (61.6)	66 (48.2)	65 (55.1)	67 (46.9)		28 (57.1)	4 (30.8)	3 (37.5)	1 (20)	
IDU	56 (11.7)	49 (12.3)	5 (6.8)		8 (11.0)	21 (15.3)	11 (9.3)	14 (9.8)		8 (16.3)	8 (61.5)	5 (62.5)	3 (60)	

[a]To be counted in this analysis, laboratory events must have been preceded by a doctor/clinic visit since their last visit.

[b]Obtained by patient self-report

[c]Chi-square test for comparing distributions among those with detectable vs. undetectable viral load

[d]Chi-square test for comparing distributions among those with CD4≥500 cells/μL to those with CD4<500 cells/μL

HIV = human immunodeficiency virus

WIHS = Women's Interagency HIV Study

AIDS = acquired immunodeficiency syndrome

ART = antiretroviral therapy

HAART = highly active antiretroviral therapy

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(>85%) by Year 4, Scenario B (CD4 counts<500 cells/μL reportable, no viral load reporting) had the lowest completeness by Year 4 (88.5%).

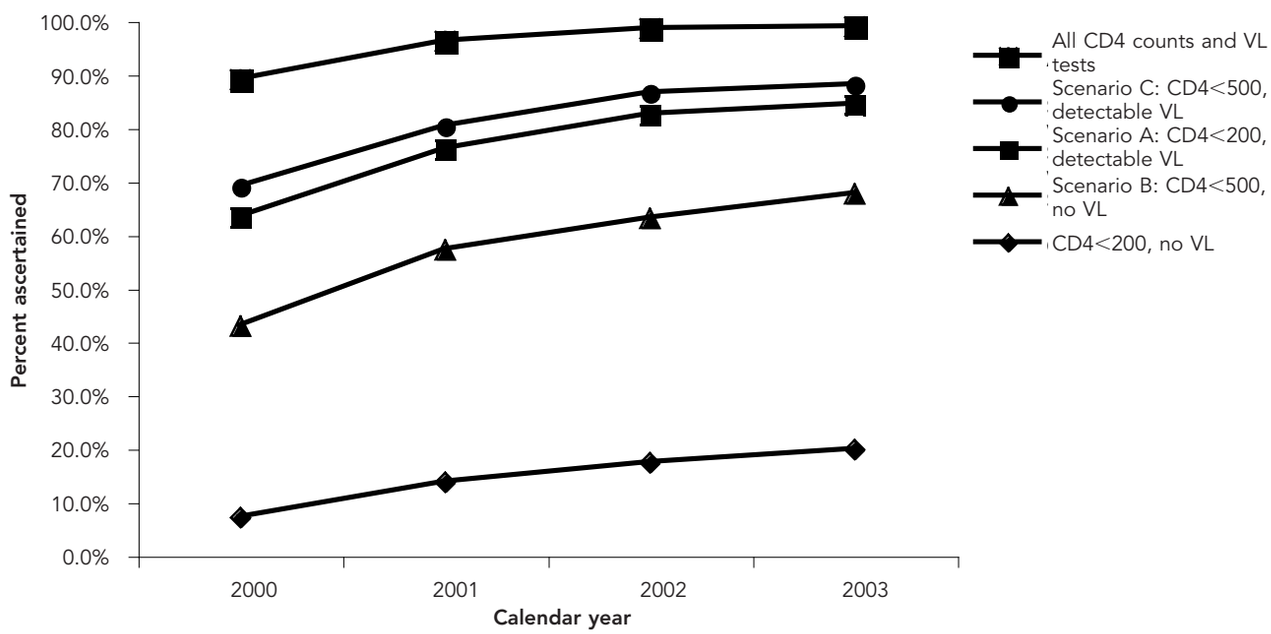
DISCUSSION

Our simulation of various HIV reporting scenarios found substantial differences in the proportion of HIV (non-AIDS) cases ascertained during a four-year period, which will likely have practical implications on overall PLWHA estimates, depending on how states choose to implement HIV reporting. It may take years following the implementation of HIV (non-AIDS) reporting for PLWHA estimates to stabilize and reach acceptable levels of completeness (>85%). Reporting systems in which only some HIV-related laboratory outcomes are reportable may considerably underestimate the number of PLWHA both initially and over time, compared with a system in which all laboratory events are reportable. Other means of ascertainment of prevalent cases, such as provider reporting or active field surveillance, would likely improve completeness. People who are not on HAART and IDUs are likely overrepresented in the three reporting scenarios highlighted in this analysis.

Our findings underscore the need to address the differences in the accuracy of PLWHA estimates that will likely result when they are derived from HIV/AIDS surveillance systems from multiple states with different laboratory reporting requirements, particularly as the 2007 deadline for incorporating HIV (non-AIDS) surveillance data into RWCA formulas approaches.

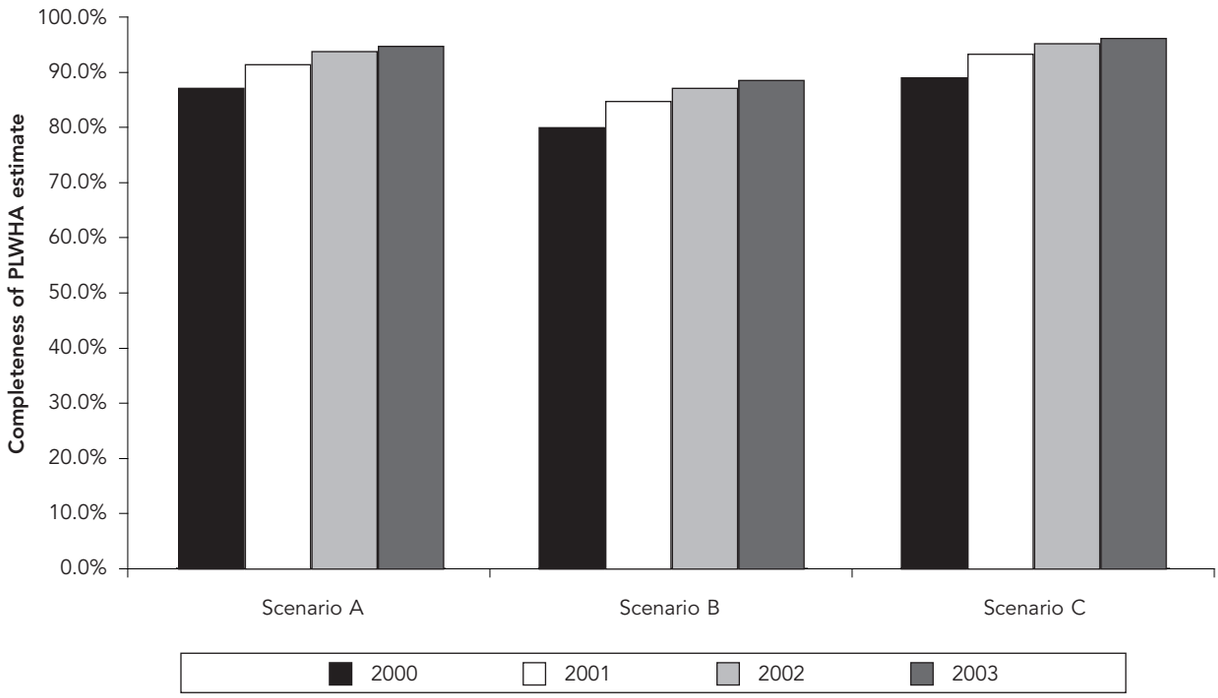
The decision to incorporate data on HIV (non-AIDS) into the RWCA formulas is justified as there are many reasons why relying on AIDS-only case reporting alone may not result in an equitable distribution of RWCA Title 1 and Title 2 funds to affected regions. First, the number of reported PLWA is not an accurate reflection of the number of people receiving care and treatment for HIV or those in need of treatment (i.e., diagnosed PLWHA). Some jurisdictions may have a lower AIDS to HIV (non-AIDS) case ratio, either because their HIV epidemics are only recently emerging and less mature than others, or because they may have a more successful treatment program that is slowing disease progression. Additionally, there may be some regional differences in rates of screening, diagnosis, and time to enrollment into care for HIV-positive individuals, which would affect care and treatment burdens. Finally, there is likely variation in the degree to which states and local jurisdictions supplement surveillance systems

Figure 1. Completeness of HIV (non-AIDS) case ascertainment under various laboratory reporting scenarios



HIV = human immunodeficiency virus
AIDS = acquired immunodeficiency syndrome
VL = viral load

Figure 2. Overall completeness of PLWHA estimates for three HIV/AIDS reporting scenarios



PLWHA = people living with HIV/AIDS
HIV = human immunodeficiency virus
AIDS = acquired immunodeficiency syndrome

with additional staff and resources, and as a result, some variation in the completeness of AIDS-only case reporting may already exist.

A useful step toward improving the comparability of PLWHA estimates across states would be to standardize the laboratory reporting requirements for all states as much as possible, as was done for AIDS-only case reporting. Although all states have some form of HIV (non-AIDS) case reporting, there is considerable variation in the way that reporting and surveillance systems are implemented. For example, some states require laboratories to report all HIV-related laboratory tests, such as HIV antibody tests, RNA or DNA viral load assays, and CD4 counts. Others require reporting of selected laboratory tests, or no laboratory reporting at all. We have shown that the completeness of case ascertainment and therefore states' estimates of the number of diagnosed PLWHAs will vary greatly depending on the laboratory reporting scenario in place in a given state. Making all HIV-related laboratory tests reportable, regardless of the result, would maximize the likelihood that those diagnosed with HIV/AIDS will be reported to the surveillance system, and is likely the best way to ensure the comparability of PLWHA estimates from surveillance data across states.

Other factors such as the number of staff dedicated to HIV/AIDS surveillance programs may further hinder comparability in the accuracy of PLWHA estimates across states, even with similar laboratory reporting schemes. Therefore, while states can adapt laws that maximize the likelihood that people diagnosed with HIV/AIDS will be reported (e.g., all laboratory and clinical events reportable), this may not translate into improved completeness in the surveillance system if there is inadequate staff or information systems to properly investigate all of the cases.

Although name-based reporting is common in communicable disease programs because of the public health urgency of disease control and prevention activities, in the case of HIV/AIDS, discrimination and privacy issues have added a particularly heightened political layer to the discussion. All 50 U.S. states now have laws that require named reporting of people with AIDS[7] and, as of July 2006, 50 U.S. jurisdictions (45

Table 4. Number and proportion of HIV-positive women from the WIHS who were in care and had one or more HIV-related outcomes in the context of AIDS and OI case reporting.[a] Laboratory reporting scenario A: CD4<200 cells/μL or detectable viral loads reportable[b]

		Year event occurred								*No event*		
		2000		*2000–2001*		*2000–2002*		*2000–2003*		*2000–2003*		
	Total N	N	*Percent with event*	N	*Percent with event*	N	*Percent with event*	N	*Percent with event*	N	*Percent without event*	P-*value*[c]
Total	477	203	42.6	363	76.1	394	82.6	403	84.5	74	15.5	
ART status at baseline												
Not on ART	202	93	46.0	176	87.1	185	91.6	186	92.1	16	7.9	<0.0001
On ART	275	110	40.0	187	68.0	209	76.0	217	78.9	58	21.1	
Age (years)												
20–29	39	23	59.0	27	69.2	31	79.5	31	79.5	8	20.5	
30–39	201	135	67.2	154	76.6	168	83.6	170	84.6	31	15.4	0.4771
40–49	177	111	62.7	139	78.5	148	83.6	154	87.0	23	13.0	
50+	60	33	55.0	43	71.7	47	78.3	48	80.0	12	20.0	
Race/ethnicity												
Non-Hispanic black	268	184	68.7	220	82.1	227	84.7	231	86.2	37	13.8	
Non-Hispanic white	87	48	55.2	58	66.7	69	79.3	72	82.8	15	17.2	0.3638
Hispanic	109	63	57.8	77	70.6	89	81.7	91	83.5	18	16.5	
Other	13	7	53.8	8	61.5	9	69.2	9	69.2	4	30.8	
Exposure category												
Non-drug users	176	102	58.0	122	69.3	138	78.4	139	79.0	37	21.0	
Non-IDUs	245	167	68.2	195	79.6	208	84.9	214	87.3	31	12.7	0.0371
IDUs	56	33	58.9	46	82.1	48	85.7	50	89.3	6	10.7	

[a]Obtained by patient self-report

[b]To be counted in this analysis, laboratory events must have been preceded by a doctor/clinic visit within two months of the WIHS visit.

[c]*p*-value for highly active ART use (yes/no) vs. any event (yes/no)

HIV = human immunodeficiency virus

WIHS = Women's Interagency HIV Study

AIDS = acquired immunodeficiency syndrome

OI = opportunistic illness

ART = antiretroviral therapy

IDU = injection drug user

states and five territories) require named reporting of people with HIV (non-AIDS),[8] and among these systems there is inevitably some variability in how the surveillance systems are implemented. The remaining states are currently transitioning from code-based to named-based systems, as name-based reporting is likely to maximize the accuracy of HIV prevalence and incidence statistics.[16,17]

Limitations

The approach used in this investigation has some limitations. First, this is a simulation study, and as such represents a simplification of a very complex process of disease occurrence, health care-seeking patterns, and disease surveillance. There are likely many aspects of our simulation that are not representative of what happens in the real world or at least outside the research setting.

First, our study included women only; our findings may not apply equally to men. Second, data on OI diagnoses in the WIHS are based on participant self-report, and these events may be over- or underrepresented in our simulation. We also relied on self-report to ascertain whether study participants saw a health-care provider for HIV care during the interim since their previous study visit to determine whether their result would have been reported. Again, the degree to which HIV-positive women over- or underreport their health-care utilization for HIV care is not known and may have influenced our results in an unforeseen way. It is also unclear how

Table 5. Number and proportion of HIV-positive women from the WIHS who were in care and had one or more HIV-related outcomes in the context of AIDS/OI case reporting.[a] Laboratory reporting scenario B: CD4<500 cells/μL reportable[b]

		Year event occurred								*No event*		
		2000		*2000–2001*		*2000–2002*		*2000–2003*		*2000–2003*		
	Total N	N	*Percent with event*	N	*Percent with event*	N	*Percent with event*	N	*Percent with event*	N	*Percent without event*	P-*value*[c]
Total	477	205	43.0	273	57.2	301	63.1	323	67.7	153	32.1	
ART status at baseline												
Not on ART	202	103	51.0	131	64.9	143	70.8	151	74.8	50	24.8	0.0128
On ART at baseline	275	102	37.1	142	51.6	158	57.5	172	62.5	103	37.5	
Age (years)												
20–29	39	13	33.3	20	51.3	24	61.5	25	64.1	14	35.9	
30–39	201	88	43.8	115	57.2	124	61.7	133	66.2	68	33.8	0.6525
40–49	177	78	44.1	105	59.3	115	65.0	126	71.2	51	28.8	
50+	60	26	43.3	33	55.0	38	63.3	39	65.0	21	35.0	
Race/ethnicity												
Non-Hispanic black	268	125	46.6	169	63.1	182	67.9	191	71.3	77	28.7	
Non-Hispanic white	87	30	34.5	42	48.3	52	59.8	55	63.2	32	36.8	0.0556
Hispanic	109	46	42.2	58	53.2	62	56.9	72	66.1	37	33.9	
Other	13	4	30.8	4	30.8	5	38.5	5	38.5	8	61.5	
Exposure category												
Non-drug users	176	73	41.5	93	52.8	102	58.0	109	61.9	67	38.1	
Non-IDUs	245	103	42.0	142	58.0	159	64.9	172	70.2	73	29.8	0.0932
IDUs	56	29	51.8	38	67.9	40	71.4	42	75.0	14	25.0	

[a]Obtained by patient self-report

[b]To be counted in this analysis, laboratory events must have been preceded by a doctor/clinic visit within two months of the WIHS visit.

[c]*p*-value for highly active ART use (yes/no) vs. any event (yes/no)

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representative the HIV-positive women in WIHS are of HIV-positive women in other jurisdictions. We have attempted to address this discrepancy in a limited way by providing estimates stratified by race/ethnicity, age, and transmission risk. Also, Hessol et al. demonstrated that the demographic and risk profiles of self-reported AIDS cases among women from the WIHS study were comparable to those in the general population.[13] However, it is likely that HIV-positive women participating in the WIHS may differ in other ways from HIV-positive women in the general population, and this difference may have influenced our results.

We also could not control for completeness of reporting in our simulation even among those events deemed reportable. In the real world of disease surveillance, not all events that occur are subsequently reported to health departments by health-care providers and laboratories, or sometimes they are reported and not properly incorporated into the disease surveillance system. While HIV (non-AIDS) case reporting is becoming increasingly common, few studies have examined the proportion of people who experience a reportable event that are properly counted in surveillance systems. However, AIDS case reporting is one of the most complete disease surveillance activities in the U.S. due to the high level of funding and attention it receives relative to reporting of other diseases,[18] and the high level of completeness may likely apply to HIV (non-AIDS) case reporting as well.

Studies of completeness of AIDS case reporting

Table 6. Number and proportion of HIV-positive women from the WIHS who were in care and had one or more HIV-related outcomes in the context of AIDS/OI case reporting.[a] Laboratory reporting scenario C: CD4<500 cells/μL and detectable viral loads reportable[b]

		Year event occurred								*No event*		
		2000		*2000–2001*		*2000–2002*		*2000–2003*		*2000–2003*		
	Total N	N	*Percent with event*	N	*Percent with event*	N	*Percent with event*	N	*Percent with event*	N	*Percent without event*	P-*value*[c]
Total	477	329	69.0	383	80.3	413	86.6	420	88.1	58	12.2	
ART status at baseline												
Not on ART at baseline	202	155	76.7	176	87.1	186	92.1	188	93.1	15	7.4	<0.0001
On ART at baseline	275	174	63.3	207	75.3	227	82.5	232	84.4	43	15.6	
Age (years)												
20–29	39	26	66.7	29	74.4	31	79.5	31	79.5	7	17.9	0.3461
30–39	201	140	69.7	161	80.1	175	87.1	177	88.1	22	10.9	
40–49	177	124	70.1	146	82.5	155	87.6	159	89.8	17	9.6	
50+	60	39	65.0	47	78.3	52	86.7	53	88.3	6	10.0	
Race/ethnicity												
Non-Hispanic black	268	195	72.8	226	84.3	234	87.3	237	88.4	29	10.8	0.8989
Non-Hispanic white	87	54	62.1	62	71.3	73	83.9	75	86.2	11	12.6	
Hispanic	109	71	65.1	85	78.0	95	87.2	97	89.0	10	9.2	
Other	13	9	69.2	10	76.9	11	84.6	11	84.6	2	15.4	
Exposure category												
Non-drug users	176	116	65.9	134	76.1	146	83.0	147	83.5	28	15.9	0.0355
Non-IDUs	245	175	71.4	201	82.0	217	88.6	221	90.2	22	9.0	
IDUs	56	38	67.9	48	85.7	50	89.3	52	92.9	2	3.6	

[a]Obtained by patient self-report

[b]To be counted in this analysis, laboratory events must have been preceded by a doctor/clinic visit within two months of the WIHS visit.

[c]*p*-value for highly active ART use (yes/no) vs. any event (yes/no)

HIV = human immunodeficiency virus

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have been conducted in a variety of settings, usually by comparing the cases actually seen (identified through medical record review) at specific facilities to those reported to surveillance registries. Such estimates of the completeness of AIDS case reporting have generally been high (80% to 95%)[19] with little variation by gender, race, or risk factor. As neither provider nor laboratory reporting is likely to be complete, each type of reporting is likely complementary to the other in many instances, thereby enhancing completeness. However, because we assumed that all reportable events in our simulation would have been reported to health authorities, our estimates of completeness of case ascertainment are likely overestimates.

CONCLUSIONS

The HIV/AIDS epidemic in the U.S., with an estimated 1 million PLWHA, occurs in the context of a country with 43 million uninsured individuals. To extend HIV care and treatment to those in need, allocation of resources must consider the relative need of each jurisdiction. However, it may take years following the implementation of HIV (non-AIDS) reporting systems for PLWHA estimates to stabilize. Surveillance systems that do not include both CD4 and viral load reporting will considerably underestimate the number of PLWHA both initially and over time, compared with a system in which all laboratory events are reportable.

People who are not on HAART and IDUs are likely overrepresented in the PLWHA estimates derived from such systems, at least initially. Depending on the laboratory reporting scenario in place, states that do well in controlling HIV disease through adequte care, treatment, and testing could be penalized with lower RWCA awards. Uniform implementation of HIV (non-AIDS) reporting, particularly with regard to laboratory reporting requirements, is necessary before HIV (non-AIDS) surveillance data can be used to allocate RWCA funds to states and EMAs. In the meantime, jurisdictions should consider adjusting their surveillance-derived PLWHA estimates according to this or other local simulation studies to account for the lack of completeness of HIV/AIDS case ascertainment, which depends on both the laboratory reporting scenario and the length of time it has been in place in a given jurisdiction.

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