



ESTADO LIBRE ASOCIADO DE
PUERTO RICO
Departamento de Salud

Unmet Need for HIV Primary Medical Care Estimate, 2012

HIV/AIDS Surveillance Division



Estado Libre Asociado de Puerto Rico
Departamento de Salud

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BACKGROUND

The 2000 Amendments to the CARE Act required that each Part A and B grantees (formerly known as Title I and Title II) provide estimates of the size and demographics of the population living with HIV disease (PLWHA), aware of their HIV status but are not receiving HIV primary medical care. This information is essential for guiding strategies aimed to address and reduce disparities and gaps in medical access and utilization.

To this end, the HIV Surveillance Program has partnered with RW grantees to estimate the number and demographics of PLWHA, aware of their HIV status who had an unmet need for primary medical care in 2012.

METHODS

The framework developed by the University of California at San Francisco (UCSF) for measuring Unmet Need for HIV primary medical care was used to determine patients in care and out of care during calendar year 2012. The first step of the unmet need calculation is to determine the total number of PLWHA in Puerto Rico as of December 31, 2012, aware of their HIV status. The second step is to determine the number of people who are in care during the calendar year 2012. A person is defined as in care if there is documentation on record of any of the following: a viral load test, CD4 test (count or percentage), ART and/or ≥ 1 claim on Puerto Rico Health Insurance during calendar year 2012. By subtracting those in care from the total number of PLWHA we obtained the estimated number of persons with an Unmet Need for primary medical care in 2012.

UNMET NEED FOR HIV MEDICAL CARE DEFINITION

We defined having an unmet need for primary medical care as having no evidence of any of the four following components:

1. Viral Load test on RW client database or eHARS, or
2. CD4 count on RW client database or eHARS, or
3. Antiretroviral therapy through ADAP or Puerto Rico Health Insurance, or
4. ≥ 1 claim on Puerto Rico Health Insurance with the following ICD9 codes: 042, 043, 079.53, 795.71, V65.44 or V08.

DATA SOURCES USED TO DEVELOP THE UNMET NEED ESTIMATE

Population size

The 2012 unmet needs estimate used persons living with HIV not AIDS and persons living with AIDS as of December 31, 2012 reported in eHARS as the population size input. The cutoff date of report was July 1, 2014, providing adequate time to receive most deaths records from those individuals whose cause of death was not related to the HIV infection. Persons whose current city of residency is no longer in Puerto Rico were excluded from analysis.

Care Patterns

The care pattern inputs came from three major data sources:

- (1) Puerto Rico Health Insurance of services provided during 2012 with one of the following ICD9 codes: 042, 043 (HIV infection), 079.53 (HIV, type 2), 795.71 or V08 (asymptomatic HIV status).
- (2) Ryan White Part A, B, C & D health care providers, including ADAP (Hospital Ryder Memorial, Iniciativa Comunitaria, Ararat, Centro de Epidemiología de Bayamón, PR CONCRA, Ponce TGA, Programa SIDA San Juan, SIVIF, CDT

Playa de Ponce (Med Centro), CDT Lares, CDT Arroyo, CDT Juana Diaz, CPTET Mayagüez, CLETS, CPTET Bayamón, CPTET Arecibo, CPTET Caguas, CPTET Fajardo, CPTET Ponce and CPTET Carolina, among others).

(3) HIV/AIDS surveillance data.

RECORD LINKAGE

On August 2014, the HIV/AIDS Surveillance Program received four datasets containing information of services provided to PLWH by the Ryan White grantees and Puerto Rico Health Insurance during the calendar year 2012 (Table 1). These datasets are considered the largest sources of HIV primary medical in Puerto Rico. Since all four datasets contained identifiable information we were able to combine and exclude duplicated persons across datasets that had the same date of birth and complete name.

Table 1. Data Sources for Care Patterns, 2012

Datasets	Total number of observations in dataset	Unduplicated client data by complete name and date of birth ¹
Part A, B, C, D grantees (including ADAP)	79,805	11,201
Puerto Rico Health Insurance medical services	257,191	13,257
ART through Puerto Rico Health Insurance	756,803	2,801

To conduct the record linkage with eHARS data we used Link Plus, which is a probabilistic record linkage program developed at CDC's Division of Cancer Prevention and Control in support of CDC's National Program of Cancer Registries (NPCR). This

¹ Only those records with the same complete name and date of birth were excluded.

program calculates a linkage score based on the likelihood that they refer to the same person. The cutoff value for accepting and rejecting a potential link for this analysis was 5. This value allowed for the maximum number of linked records. A visual review of linked records was carried out to exclude false matches.

RESULTS

Of the 19,295 people living with HIV infection in Puerto Rico as of December 31, 2012, a total of 13,892 (72.00%) received HIV primary medical care during the specified time period, while 5,403 (or 28.00%) demonstrated unmet need for HIV primary medical care.

- Among 10,926 people living with AIDS, 7,769 (71.11%) received primary medical care, while 3,157 (or 28.89%) had an unmet need for HIV primary medical care in 2012.
- Of 8,369 persons reported living with HIV (non-AIDS) as of 2012, a total of 6,123 (73.16%) received appropriate primary medical care, while 2,246 (26.84%) had unmet need for HIV primary medical care (see below).

Table 2: Unmet Needs for primary medical care in Puerto Rico, December 2012

Input	Value	Data Source
<i>Population size</i>		
A. Number of PLWA as of 12/31/2012	10,926	PR HIV/AIDS Reporting System.
B. Number of HIV+/non-AIDS/aware, as of 12/31/2012	8,369	PR HIV/AIDS Reporting System
<i>Care patterns</i>		
C. # of PLWA who received the specified primary medical care services in 12-month period	7,769	Linked client data from PR Health Insurance, eHARS, and RW Part A, B, C, D including ADAP for year 2012
D. # of HIV+/non-AIDS/aware who received the specified primary medical care services in 12-month period	6,123	Linked client data from PR Health Insurance, eHARS, and RW Part A, B, C, D including ADAP for 2012

<i>Calculated results</i>	<i>Value</i>	<i>Calculation</i>
E. Number of PLWA who did not receive specified primary medical care services	3,157 (28.89%)	= 10,926 – 7,769
F. Number of HIV+/non-AIDS/aware who did not receive specified primary medical care services	2,246 (26.84%)	= 8,369 – 6,123
G. Total persons not receiving specified primary medical care services	5,403 (28.00%)	= 3,157 + 2,246

Table 3 illustrates the demographic characteristics and exposure category of adolescents and adults living with HIV infection classified as out of care in Puerto Rico. Extreme caution should be placed when interpreting these data since patients accessing primary medical care through private health care providers, Medicare and other sources of treatments such as clinical trials are not incorporated.

Characteristics of persons with unmet need for primary medical care

The distribution of people living with HIV infection in Puerto Rico with an unmet need for primary medical show variations depending the stage of HIV disease.

- The proportion of males living with AIDS who are out of care is slightly higher compared to males living with HIV not AIDS, 73.36% and 72.71%, respectively.
- A much higher proportion is of PLWA out of care are aged over 55 years compared to PLWH, 46.18% and 18.34%, respectively. This may be due to the fact that a higher proportion of persons might be receiving medical care through Medicare, data not incorporated in this estimate.
- Forty-seven percent of patients living with HIV infection classified as out of care are injecting drug users, though a higher percentage of AIDS cases are classified as out of care among IDUs compared to HIV not AIDS cases, 53.14% and 38.59% respectively.

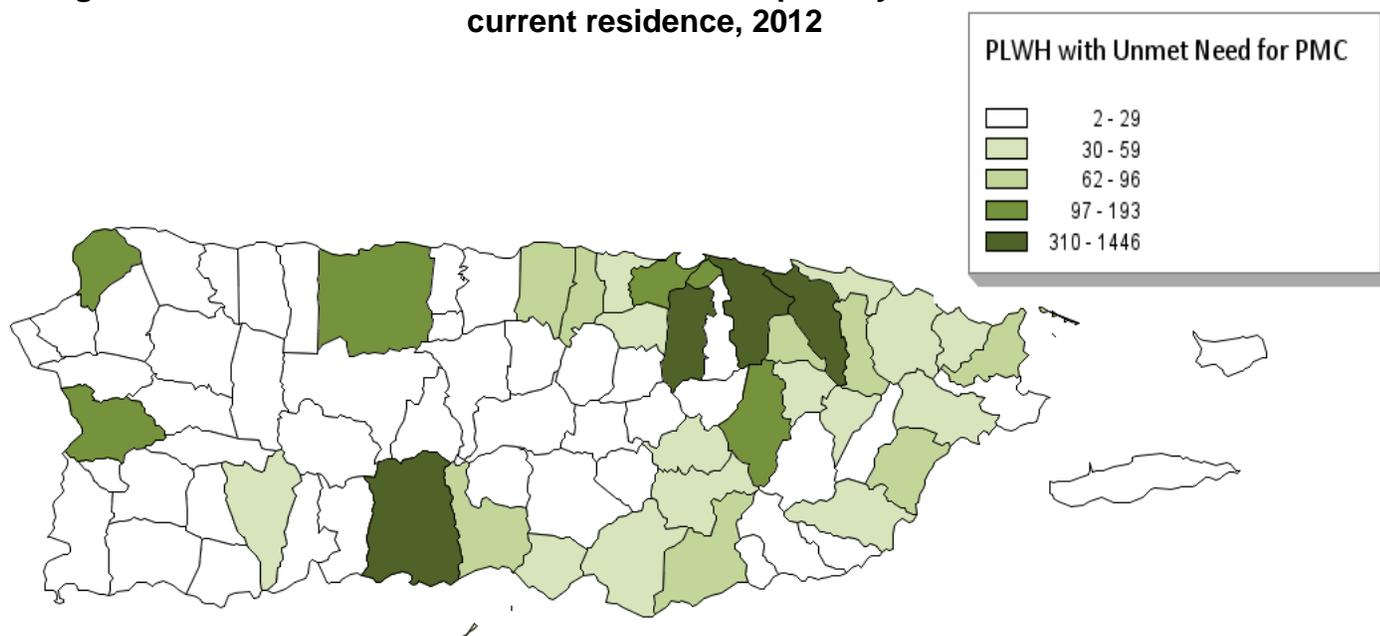
- Unprotected heterosexual contact identified as the risk factor for acquiring HIV infection accounts for 27.83% of patients out of care.
- MSM and MSM & IDU have the lowest percentages of individuals classified as out of care (13.90%).
- The Metropolitan Health Region has the highest percentage of PLWHA out of care (38.65%), followed by Bayamón (16.75%) and Ponce Health Region (16.69%).

Table 3. Characteristics of PLWH who did not received primary medical care, Puerto Rico 2012

Demographic Group/ Exposure Category	PLWH n = 2,246		PLWA n = 3,157		PLWH/PLWA n = 5,403	
	Number	%	Number	%	Number	%
Gender						
Male	1,633	72.71	2,316	73.36	3,949	73.09
Female	613	27.29	841	26.64	1,454	26.91
Total	2,246	100.00	3,157	100.00	5,403	100.00
Age as of December 2012						
0 - 12						
13 - 24	42	1.87	24	0.76	66	1.22
25 - 34	366	16.3	68	2.15	434	8.03
35 - 44	710	31.61	327	10.36	1,037	19.19
45 - 54	716	31.88	1280	40.54	1,996	36.94
55 - 64	290	12.91	1005	31.83	1,295	23.97
≥ 65	122	5.43	453	14.35	575	10.64
Total	2,246	100.00	3,157	100.00	5,403	100.00
Adult/Adolescent Exposure Category						
MSM	314	14.06	426	13.80	740	13.90
IDU	862	38.59	1,641	53.14	2,503	47.03
MSM & IDU	62	2.78	190	6.15	252	4.74
Heterosexual Contact	691	30.93	790	25.58	1,481	27.83
Other/Hemophilia/ blood transfusion	1	0.04	16	0.52	17	0.32
NRR/NIR	304	13.61	25	0.81	329	6.18
Total	2,234	100.00	3,088	100.00	5,322	100.00
Pediatric Exposure						

Demographic Group/ Exposure Category	PLWH		PLWA		PLWH/PLWA	
	n = 2,246		n = 3,157		n = 5,403	
Categories						
Perinatal exposure	9	75.00	66	95.65	75	92.59
Child NRR/NIR	3	25.00	3	4.35	6	7.41
Total	12	100.00	69	100.00	81	100.00
Health Region						
Aguadilla	87	3.87	99	3.14	186	3.44
Arecibo	135	6.01	179	5.67	314	5.81
Bayamón	383	17.05	522	16.53	905	16.75
Caguas	265	11.80	322	10.20	587	10.86
Fajardo	80	3.56	112	3.55	192	3.55
Mayagüez	104	4.63	125	3.96	229	4.24
Metropolitan	897	39.94	1,191	37.73	2,088	38.65
Ponce	295	13.13	607	19.23	902	16.69
Total	2,246	100.00	3,157	100.00	5,403	100.00

Figure 1. Number of PLWH with Unmet Need for primary medical care by city of current residence, 2012



LIMITATIONS OF THIS REPORT

The limitations of the Unmet Needs for Primary Medical Care in 2012 report include lack of information regarding patients with access to primary health care covered by private health insurance, Medicare and clinical trials in pediatric and adult populations. Another limitation that should be noted is that persons who moved out of Puerto Rico will automatically be counted as having unmet need. Currently, the Puerto Rico HIV Surveillance Program participates in Routine Interstate Duplicate Review (RIDR) with other states to assess and resolve potential matches and is the process of determining the current city of residency of persons diagnosed with HIV. These limitations contribute to an overestimate of patients having an unmet need for primary medical care. Further adjustments are needed to provide a better estimate of unmet need for primary medical care in Puerto Rico. As new behavioral and prevalence data become available they will be incorporated into future estimates.