

Unmet Needs for HIV Primary Medical Care Estimate, 2016

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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 Ryan White (RW) grantees to estimate the number and demographics of persons diagnosed with HIV infection who had an unmet need for primary medical care in 2016.

# **M**ETHODS

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 2016. The first step of the unmet need calculation was to determine the total number of people diagnosed with HIV infection living in Puerto Rico by the end of 2016. The second step was to determine the number of people who are in care during the calendar year 2016. 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), receiving antiretroviral therapy through ADAP,  $\geq$ 1 claim on Puerto Rico Health Insurance or  $\geq$ 1 claims on Private Health Insurance during calendar year 2016. By subtracting those in care from the number of people diagnosed with HIV infection living in Puerto Rico we obtained the estimated number of persons with an Unmet Need for primary medical care in 2016.

# 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 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 a Private Health Insurance with the following ICD codes:

ICD-9: 042 – 044, V08, 079.53, 795.71;

ICD-10: B20 – B24, Z21, B97.35, R75, Z20.6, O98.7, O98.711, O98.712, O98.713, O98.719, O98.72, O98.73.

 ≥1 claim on Puerto Rico Health Insurance with the following codes: 042-044, 079.53, 795.71, V65.44, V08.

ICD-9: 042 – 044, V08, 079.53, 795.71;

ICD-10: B20 – B24, Z21, B97.35, R75, Z20.6, O98.7, O98.711, O98.712, O98.713, O98.719, O98.72, O98.73.

# DATA SOURCES USED TO DEVELOP THE UNMET NEED ESTIMATE

#### **Population size**

The 2016 unmet needs estimate used persons living with diagnosed HIV infection as of December 31, 2016, reported to the HIV/AIDS Surveillance System as the population size input. We used the most current database to determine population size, providing adequate time to receive most deaths records from those individuals whose cause of death was not related to the HIV infection. Additionally, persons whose city of residency by December 2016 is no longer in Puerto Rico, were excluded from this analysis.

#### **Care Patterns**

The care pattern inputs came from four data sources:

(1) Puerto Rico Health Insurance of services provided during 2016 with one of the following ICD codes:

ICD-9: 042 – 044, V08, 079.53, 795.71;

ICD-10: B20 – B24, Z21, B97.35, R75, Z20.6, O98.7, O98.711, O98.712, O98.713, O98.719, O98.72, O98.73.

- (2) Ryan White Part A, B, C & D health care providers, including ADAP (Hospital Ryder Memorial, Iniciativa Comunitaria, Ararat, CEMI, Centro de Epidemiología de Bayamón, PR CONCRA, Programa VIDA San Juan, Neomed (SIVIF), CDT Playa de Ponce (Med Centro), CDT Lares, CDT Arroyo, Migrants Health Center, CPTET Mayagüez, CLETS, CPTET Bayamón, CPTET Arecibo, CPTET Caguas, CPTET Fajardo, CPTET Ponce and CPTET Carolina, among others).
- (3) Private Health Insurance of services provided during 2016 with one of the following ICD codes:

ICD-9: 042 – 044, V08, 079.53, 795.71;

ICD-10 : B20 – B24, Z21, B97.35, R75, Z20.6, O98.7, O98.711, O98.712, O98.713, O98.719, O98.72, O98.73.

(4) HIV/AIDS surveillance data.

## **RECORD LINKAGE**

The HIV/AIDS Surveillance Program received three datasets containing information of services provided to PLWH by the Ryan White grantees, Puerto Rico Health Insurance and Private Health Insurance during the calendar year 2016. These datasets are the largest sources of HIV primary medical in Puerto Rico.

To conduct the record linkage with eHARS data we used Link Plus, 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 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

As of December 31, 2016, 18,489 people living with diagnosed HIV infection were residing in Puerto Rico. Seventy-one percent of PLWH in Puerto Rico received primary medical care during in 2016, while 5,413 (29.3%) demonstrated unmet need for HIV primary medical care.

- Among 10,417 people living with AIDS, 7,546 (72.4%) received primary medical care, while 2,871 (or 27.6%) had an unmet need for HIV primary medical care in 2016.
- Of 8,072 persons living with HIV (non-AIDS) as of 2016, a total of 5,530 (68.5%) received primary medical care, while 2,542 (31.5%) had unmet need for HIV primary medical care (see below).

### Table 1: Unmet Needs for Primary Medical Care in Puerto Rico, December 2016

Input	Value	Data Source					
Population size							
A. Number of PLWA as of 12/31/2016	10,417	PR HIV/AIDS Surveillance System.					
B. Number of PLWH, as of 12/31/2016	8,072	PR HIV/AIDS Surveillance System					
Care patterns							
C. Number of PLWA who received the specified medical care services in 12-month period	7,546	Linked client data from PR Health Insurance, Private Health Insurance, eHARS and RW Part A, B, C, D including ADAP for year 2016					
D. Number of PLWH who received the specified medical care services in 12-month period	5,530	Linked client data from PR Health Insurance, Private Health Insurance, eHARS and RW Part A, B, C, D including ADAP for year 2016					
Calculated results	Value	Calculation					
E. Number of PLWA who did not receive specified primary medical care services	2,871 (27.6%)	= 10,417 – 7,546					
F. Number of PLWH who did not receive specified primary medical care services	2,542 (31.5%)	= 8,072 – 5,530					
G. Total persons not receiving specified primary medical care services	5,413 (29.3%)	= 2,871 + 2,542					

Table 2 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 original Medicare Part A or B (some Medicare Advantage plans were included) 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, 73.0% and 70.9%, respectively.
- A higher proportion of PLWA out of care are aged over 55 years compared to PLWH, 57.7% and 27.9%, respectively.
- Forty-five percent of persons living with HIV infection classified as out of care are persons who inject drugs, though a higher percentage of PLWA are classified as out of care among PWIDs compared to PLWH, 50.5% and 37.8% respectively.
- Unprotected heterosexual contact identified as the risk factor for acquiring HIV infection accounts for 31.5% of persons out of care.
- MSM and MSM & IDU have the lowest percentages of individuals classified as out of care (19.6%).
- Over one-third of PLWHA who are not in care were residing in the Metropolitan Health Region by December 2016.

Demographic Group/	<i>PLWH</i> n = 2,542		<i>PLWA</i> n = 2,871		<i>PLWH/PLWA</i> n = 5,413	
Exposure Category						
Gender	Number	%	Number	%	Number	%
Male	1,802	70.9	2,095	73.0	3,897	72.0
Female	740	29.1	776	27.0	1,516	28.0
Total	2,542	100.0	2,871	100.0	5,413	100.0
Age as of December 2016						
0 - 12	1	0.0	0	0.0	1	0.0
13 - 24	24	0.9	10	0.4	34	0.6
25 - 34	279	11.0	91	3.2	370	6.8
35 - 44	718	28.3	278	9.7	996	18.4
45 - 54	812	31.9	837	29.2	1,649	30.5
55 - 64	478	18.8	1,053	36.7	1,531	28.3
≥ 65	230	9.1	602	21.0	832	15.4
Total	2,542	100.0	2,871	100.0	5,413	100.0
Adult/Adolescent Exposure Category						
MSM	412	16.4	387	13.8	799	15.0
IDU	951	37.8	1417	50.5	2,368	44.5
MSM & IDU	75	3.0	170	6.1	245	4.6
Heterosexual Contact	877	34.8	798	28.4	1,675	31.5
Other/Hemophilia/ blood transfusion	4	0.2	9	0.3	13	0.2
NRR/NIR	200	7.9	25	0.9	225	4.2
Total	2,519	100.0	2,806	100.0	5,325	100.0
Pediatric Exposure Categories						
Perinatal exposure	17	73.9	60	92.3	77	87.5
Child NRR/NIR/OTHER	6	26.1	5	7.7	11	12.5
Total	23	100.0	65	100.0	88	100.0
Health Region						
Aguadilla	84	3.3	88	3.1	172	3.2
Arecibo	166	6.5	187	6.5	353	6.5
Bayamón	459	18.1	455	15.9	914	16.9
Caguas	291	11.5	297	10.3	588	10.9
Fajardo	96	3.8	98	3.4	194	3.6
Mayagüez	115	4.5	124	4.3	239	4.4
Metropolitana	991	39.0	1095	38.1	2,086	38.5
Ponce	340	13.4	526	18.3	866	16.0
Unknown	0	0.0	1	0.0	1	0.0
Total	2,542	100.0	2,871	100.0	5,413	100.0

### Table 2. Characteristics of PLWH who did not received primary medical care, Puerto Rico 2016

## LIMITATIONS OF THIS REPORT

The limitations of the Unmet Needs for Primary Medical Care in 2016 report include lack of information regarding patients with access to primary health care covered by 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 might 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.