

Persons Living with HIV and AIDS with Unmet Need in Los Angeles County

Division of HIV and STD Programs
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EXECUTIVE SUMMARY

This report represents the first ever comprehensive analysis of persons living with HIV and AIDS (PLWHA) in Los Angeles County (LAC) with unmet service needs. The Health Resources and Services Administration (HRSA) defines PLWHA with unmet medical need as those who are aware of their HIV infection and who have not received any HIV-related primary care within the past 12 months.¹ Jurisdictions receiving Ryan White grants are asked to develop strategic plans to better identify and serve PLWHA with unmet medical need. This report pools data from multiple sources to characterize the population in LAC with unmet need and identifies barriers to medical care and ancillary service gaps. The major data sources include HIV surveillance data, demonstration project data on PLWHA who are out of care from Project Engage and the Navigation Program, Medical Care Coordination (MCC) program data and Ryan White client level data. The analyses presented here will be used to inform program planning and allocation activities to better serve PLWHA in LAC with unmet need. Key findings of this report include:

- Over a quarter (28.9%; n=13,395) of PLWHA in LAC at the end of 2013 met the HRSA definition of unmet medical need based on HIV surveillance data;
- African Americans were more likely than whites and persons ages 18-29 and 30-49 were more likely than those 50 and older to have experienced unmet medical need in 2013 based on multivariate modeling for PLWHA using HIV surveillance data;
- Among the marginalized out of care persons identified in the Project Engage demonstration project, a disproportionate percent were homeless, sex workers, and recently and ever incarcerated. The greatest self-reported service needs were for medical care (84%), case management (75%), oral health care (71%), mental health counseling (66%) and medication support services (60%). The major barriers to receipt of services were that the client reported not knowing where to go or whom to call for services, felt too sick, or reported substance use.
- Among the out of care HIV clinic patients who were recruited into the Navigation Program demonstration project, a high percent were uninsured and had a lifetime history of incarceration. Oral health, benefits assistance and pharmacy/medication services were reported as the most frequently needed services and major service barriers included other life priorities (31.9%) and lack of money (11.1%).
- MCC Program participants with unmet medical need at time of enrollment had worse outcomes for psychosocial factors that included mental health and quality of life compared to those with met need;
- While not all projects used the same criteria, no differences in demographic factors (gender, age and race/ethnicity) were found between those meeting the HRSA definition of unmet need and those meeting the LACDPH DHSP out of care definition used to determine eligibility for demonstration projects;
- This analysis underscores the importance of continued targeted programs to reduce unmet need in PLWHA in LAC by supporting timely linkage, re-engagement and retention in care for young persons, African Americans, American Indian/Alaskan Natives, transgender persons, homeless individuals, formerly incarcerated persons, those engaged in sex work, and persons with poor quality of life and mental health challenges.

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I. Background

a. Purpose of report

The purpose of this report is to pool data from multiple sources to characterize the population with unmet need among persons living with HIV and AIDS (PLWHA) in Los Angeles County (LAC). PLWHA with unmet need are defined by the Health Resources and Services Administration (HRSA) as individuals who are aware of their HIV infection and need HIV-related primary health care but have not received HIV care within the past 12 months.^{1,2} The report will focus on the LAC population with unmet medical need but will also include information on PLWHA with unmet need for non-medical ancillary services and barriers to the receipt of all needed HIV services. Results from the findings and recommendations presented here may be used to support the Commission on HIV (COH) with long-term strategic planning and resource allocation to address the LAC population with unmet need.³

LAC, with over 10 million residents, is the most populous county in the United States.⁴ As of December 31, 2014 there were an estimated 59,660 PLWHA in LAC, the second highest number of any urban jurisdiction in the US.^{5,6} Among the total PLWHA in LAC, it is estimated that 8,352(14%) are unaware of their HIV infection.⁵ According to the 2013 DHSP HIV Surveillance report, among the 47,148 persons diagnosed and living with HIV at the end of 2013, the majority were male (89%), aged 40 and older (75%), Latino (41%) or White (33%) and were infected through male-male sexual (MSM) contact (77%) or were MSM who were also injection drug users (6%).^{5,7} While no region of the county is unaffected, the greatest disease burdens can be found in the Metro Service Planning Area (SPA 4) that includes the downtown metro area, the Hollywood region and the city of West Hollywood (38%); the southern region encompassing the city of Long Beach, SPA 8 (17%); and the San Fernando Valley, SPA 3 (14%).^{5,7}

According to DHSP, in FY2012 approximately 45%, or 20,236 PLWHA, received at least one RW-funded service during the previous year.⁸ The majority of RW clients were male (86%), Latino (48%) or white (25%) and ages 40 and older (67%). Approximately 82% of these RW clients received at least one medical visit during that time.⁸ While RW clients may be similar to PLWHA in LAC generally, the majority are low income (68% living at or below the federal poverty guideline), uninsured (60%) or on public assistance (34%).⁸ Additionally, many have histories of substance abuse and incarceration, as well as other socioeconomic stressors such as housing insecurity and diagnosed mental health conditions.⁸ All of these factors highlight the need for a full evaluation of PLWHA in LAC with unmet need.

To characterize the local population with unmet need, a series of secondary analyses was conducted from a variety of sources including data from local HIV surveillance, research and demonstration projects, and DPH DHSP-funded programs. All of these projects were either designed to identify various subgroups of PLWHA with unmet need, or captured this population as part of their normal data collection cycle. Results will be used to create a profile of persons with unmet need; identify psychosocial factors that impede access to medical and ancillary services; and provide recommendations for providers and policymakers to reduce HIV unmet medical need in LAC.

b. Unmet Need Definition

HRSA defines persons with unmet medical need as those who have not received primary HIV care within the past 12 months.¹ Lack of HIV primary care within 12 months or unmet medical need in LAC will be defined as no reported HIV viral load, CD4 or genotype test in the previous 12 months. In LAC, there is limited population-based data on antiretroviral therapy use. For purposes of this report, the proxy definition for unmet need using HIV surveillance data was no reported viral load value, CD4 or genotype test in the previous 12 months. This same measure is often referred to as “engagement” in care in the surveillance-based CDC and LAC HIV cascades.

Retention in care, defined as at least two reported HIV laboratory tests at least 90 days apart, was also used as a measure of adequate care.

Two DHSP demonstration projects, Project Engage and the Navigation Program, utilized an expanded unmet need definition that considers an HIV positive person as out of care if they:

- a. have had no primary HIV care visits for 6-12 months and last viral load was less than 200 copies/ml;
- b. have had no primary HIV care visits for more than 12 months;
- c. are newly-diagnosed and never in care;
- d. have had less than 2 HIV primary care visits at the same provider in the previous 6 months; or
- e. are recently released from jail, prison or other institutionalized setting with no regular HIV care provider.

Details on which unmet need definition was used for each project is presented below.

c. HIV care continuum

Timely linkage to, and retention in, HIV primary care are critical for reducing disease morbidity and mortality among PLWHA.⁹ Consistent HIV care has been shown to facilitate viral load suppression, decrease secondary HIV transmission and slow HIV disease progression⁹⁻¹² An estimated 86% of PLWHA in the US in 2011 were aware of their HIV infection.¹³ Despite this high proportion, only 80% were linked to care in a timely manner (within 3 months of diagnosis), only 40% were retained in HIV primary care, and only 30% were virally suppressed in 2011.¹³

The 2013 HIV Cascade for LAC is shown below in Figure 1 and is based on data from the LAC HIV surveillance system.¹⁴ In 2013, an estimated 86% of PLWHA in LAC were aware of their HIV infection. In spite of relatively high HIV diagnosis rates, gaps in LAC continuum are similar to national estimates: 78% linked to care within 3 months, 61% engaged in care, 51% were retained in care and 50% achieved viral suppression. As shown in the unadjusted 2013 LAC HIV cascade stratified by gender in Figure 2, there were smaller percentages of females and transgender persons linking to care and achieving viral suppression but a higher percentage of transgender persons engaged and retained in care. Similar disparities can be seen for young persons (Figure 3) and African Americans and American Indians and Alaskan Natives (Figure 4).¹⁴ The unadjusted cascades should be interpreted with caution however since some of the disparities disappear in the multivariate modeling results that control for confounding shown below in Table 1. Factors that are statistically significant in the multivariate models and associated with linkage, engagement, retention and viral load suppression are highlighted in bold font in Table 1.

A modified Poisson regression model was used to model the adjusted Prevalence Ratio (PR) for linkage to care since the log binomial distribution did not converge.¹⁵ Among the factors measured in HIV surveillance data, the main factor associated with poor linkage to care in the multivariate model was African American race/ethnicity for persons diagnosed with HIV in 2013.

A generalized linear regression model with a log binomial distribution was used to model the adjusted PR for engagement, retention and viral load suppression due to the distribution of these outcomes. The engagement in care measure shown below which is defined as at least one HIV laboratory test in a given year is the closest population-based measure available in LAC to the HRSA definition of engagement in care. Factors associated with sub-optimal engagement in care included African American race/ethnicity and younger age (18-29 and 30-39 vs. ≥ 50). Factors associated with improved engagement in care included female gender, and Latino, Asian/Pacific Islander and mixed race/ethnicity.

In the multivariate model, younger age (18-29 and 30-49 vs ≥ 50) was associated with poorer retention in care which was defined as at least two HIV laboratory tests at least 90 days apart in 12 months. Female gender and Latino, Asian Pacific Islander and mixed race/ethnicity was associated with better retention in care.

Finally, in the multivariate model, transgender persons, African Americans, American Indian/Alaskan Natives and younger persons (ages 18-29 and 30-49) living with HIV were less likely to be virally suppressed and Asian/Pacific Islanders were more likely to be virally suppressed.

Although HIV care retention and viral suppression percentages are higher in LAC when compared to national data, there is room for improvement in linkage, engagement, retention and viral load suppression in LAC. The subgroups of LAC residents identified in the generalized linear regression models highlighted above continue to have unmet need for HIV medical care and sub-optimal linkage, retention and viral load suppression.

Figure 1: Los Angeles County HIV Care Continuum, 2013

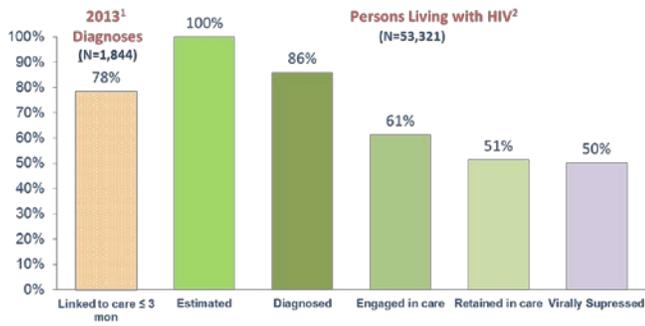


Figure 2. HIV Care Continuum by Gender, LAC 2013

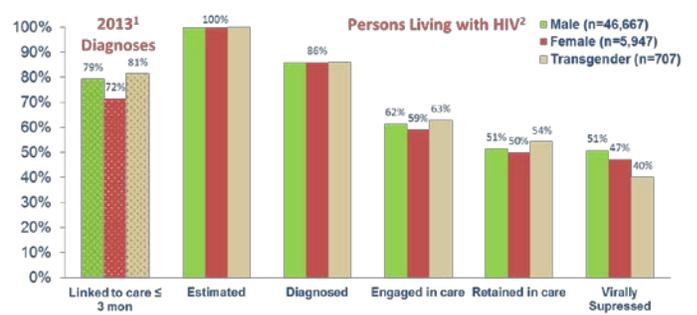


Figure 3. HIV Care Continuum by Age, LAC 2013

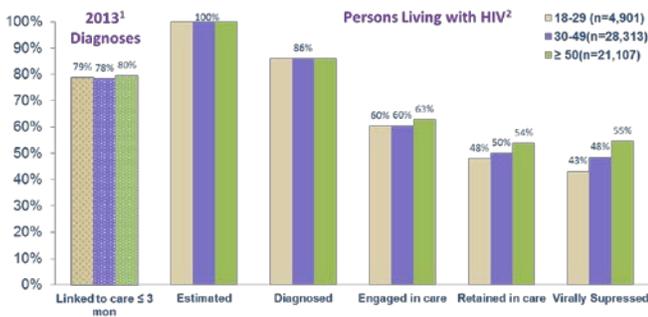


Figure 4. HIV Care Continuum by Race/Ethnicity, LAC 2013

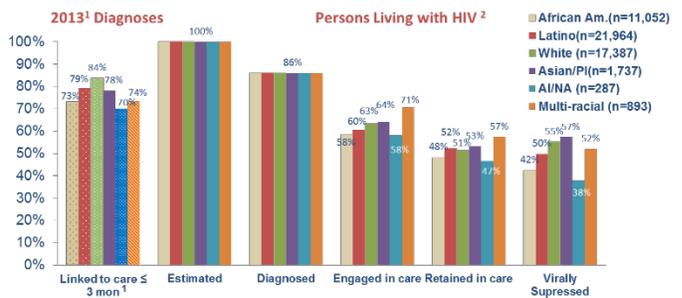


Table 1. Generalized linear regression models for factors associated with linkage, engagement, retention and viral load suppression for LAC, 2013

Characteristics	Linkage ^{2,7} PR ⁸ (95% CI)	Engagement ^{1,3,6} PR (95% CI)	Retention ^{1,4,7} PR (95% CI)	VL Suppression ^{1,5,7} PR (95% CI)
Gender				
Male	Reference	Reference	Reference	Reference
Female	1.08 (.097, 1.20)	1.05 (1.03, 1.08)	1.08 (1.04, 1.12)	1.04 (1.00, 1.08)
Transgender	1.04 (0.87, 1.23)	1.00 (0.96, 1.05)	1.04 (0.98, 1.10)	0.85 (0.78, 0.92)
Race/Ethnicity				
White	Reference	Reference	Reference	Reference
African American	0.90 (0.84, 0.96)	0.97 (0.95, 0.99)	0.99 (0.97, 1.01)	0.85 (0.83, 0.87)
Latino	0.96 (0.90, 1.01)	1.04 (1.03, 1.06)	1.10 (1.08, 1.12)	1.00 (0.98, 1.02)
Asian/Pacific Islanders	0.95 (0.85, 1.07)	1.08 (1.05, 1.11)	1.09 (1.05, 1.14)	1.10 (1.06, 1.15)
American/Alaskan Native	0.90 (0.63, 1.30)	0.94 (0.87, 1.03)	0.93 (0.83, 1.04)	0.77 (0.67, 0.88)
Mixed/Others/Unknown	0.94 (0.78, 1.15)	1.12 (1.08, 1.15)	1.14 (1.09, 1.20)	1.01 (0.96, 1.07)
Age				
18-29	0.96 (0.90, 1.03)	0.92 (0.90, 0.94)	0.85 (0.82, 0.88)	0.77 (0.75, 0.80)
30-49	0.96 (0.90, 1.03)	0.94 (0.93, 0.96)	0.90 (0.89, 0.92)	0.87 (0.86, 0.89)
≥50	Reference	Reference	Reference	Reference

¹Includes 53,321 persons diagnosed through 2012 and living in LAC as of 12/31/2013 based on most recent residence and an additional 14% that CDC estimates are unaware of HIV infection; 4,511 persons who no longer live in LAC are not included and 5,667 persons who moved to LAC were included

²Denominator includes 1,617 men, 200 women, and 27 transgender persons who were reported with a new HIV diagnosis in 2013 and were living in LAC as of 12/31/2013; 2013 data are provisional

³Engaged in care: ≥1 CD4, viral load or genotype test in 2013;

⁴Retained in care: ≥2 CD4, viral load or genotype test at least 3 months apart in 2013

⁵Viral suppression defined as last viral load ≤200 copies/ml in 2013

⁶Model adjusted for age, race, gender, HIV transmission category, county of birth, type of diagnostic facility (public, federal or private) and number of years living with HIV

⁷Model adjusted for age, race, gender, HIV transmission category, county of birth, type of diagnostic facility (public, federal or private), lifetime homelessness and number of years living with HIV

⁸Prevalence Ratio

I. Goals and Objectives

To address unmet need and the gaps noted above in the LAC HIV cascade, DHSP researched, developed, implemented and evaluated several evidence-based demonstration projects and Ryan White-funded programs to improve the identification of HIV infected persons who are out of care, improve timely linkage to care, promote re-engagement in care and support long term retention in care. Secondary data analyses were conducted on data on the unmet need population identified in the demonstration projects, program data, and surveillance data to develop a coherent profile of the HIV unmet need population in LAC.

II. Methods

Bivariate analyses were calculated to examine unadjusted associations between demographic and other factors and unmet need. Risk ratios (RR) and 95% confidence intervals were calculated when these associations were examined for population-based data and odds ratios (OR) and 95% confidence intervals were calculated for non-representative smaller sample groups. Results from multivariate regression analyses that control for

confounding are only presented for HIV surveillance data in which associations were examined between socio-demographic and behavioral factors and linkage, engagement, retention and viral load suppression.

a. Data Sources

Data from several diverse sources were utilized to characterize the LAC unmet need population for this report and are described below.

1. LAC HIV/AIDS Reporting System (HARS) surveillance database – 2013

Data used from the LAC HIV/AIDS Reporting System (HARS) includes all PLWHA diagnosed and living with HIV in LAC as of December 31, 2013. For purposes of this report, PLWHA with unmet need were defined according to the HRSA definition. In LAC and California, any indication of an HIV infection and care is reportable by law including HIV test results, CD4 counts, viral load measures and genotype tests. Thus, the HIV surveillance database is the most complete source for infection and care status for HIV infected persons.

2. LAC Ryan White (Casewatch) database – 2013-2014

Patient-level information on all Ryan White services are maintained in the DHSP Casewatch Millennium system to support contract management, billing, key elements of care and other mandated reporting requirements. In FY 2013 18,119 PLWHA received at least one Ryan White funded service in LAC, representing 34% of all HIV-infected persons in LAC. Unmet need for patients receiving Ryan White services was defined according to the HRSA unmet need definition of at least 1 medical care visit or HIV-related laboratory test (viral load, CD4 or genotype) within the previous 12 months.

3. Project Engage (PE) – 2013-2015

The goal of Project Engage (PE) is to use two innovative methods to identify hard-to-find, “hidden” HIV infected persons who are out of care and link them to care. PE participants were identified and enrolled using either social network referrals (snowball sampling) or direct recruitment (street outreach, flyers) methods. PE participants were recruited from 2013 to 2015 based on the expanded definition of unmet need described above. The PE database includes data on hard-to-reach, marginalized PLWHA who are not in consistent HIV care.

4. Navigation Program (NAV) – 2013-2015

The goal of the DHSP/APLA Navigation Program was to work with 7 LAC HIV clinics to re-engage lost clinic patients using enhanced locator techniques and a modified Antiretroviral Treatment Access to Services (ARTAS) strengths-based case management intervention. Out of care clinic patients were identified using clinic medical records and verified using HARS. This project used the expanded definition of unmet need detailed above for PE and the NAV program.

5. Medical Care Coordination Program (MCC) – 2013

The MCC program is a RW-funded core medical service that uses multidisciplinary teams co-located at HIV medical facilities to improve patient outcomes, increase retention in care, reduce viral load and prevent forward transmission. Unmet need or inadequate retention in HIV care was defined as fewer than 2 HIV-related laboratory tests (viral load, CD4 or genotype) at least 90 days apart within the past 12 months.

III. Results

a. LAC HARS surveillance database – 2013

Data on all PLWHA in LAC with met (in HIV care) and unmet (not in HIV care) need is presented in Table 2. There were 46,413 PLWHA residing in LAC at the end of 2013. Among this population, 33,018 (71.1%) were engaged in care according to the HRSA “met need” definition with at least one HIV laboratory test in the previous 12 months. In addition, 13,395 or 28.9% had unmet need or did not have any HIV laboratory tests in the previous 12 months.

Table 2. Demographic characteristics of PLWHA in LAC at the end of 2013 by HIV primary care retention status: HARS surveillance

Characteristic	Total		Retained (met need)		Unmet Need ¹	
	N	%	n	%	n	%
Total	46,413	100	33,018	71.1	13,395	28.9
Gender						
Male	40,596	87.5	28,994	87.8	11,602	86.6
Female	5,216	11.2	3,586	10.9	1,630	12.2
Transgender	601	1.3	438	1.3	163	1.2
Unknown	--	--	--	--	--	--
Race/Ethnicity						
White	15,097	32.5	11,121	33.7	3,976	29.7
African American	9,616	20.7	6,529	19.8	3,087	23.0
Latino	19,032	41.0	13,357	40.5	5,675	42.4
Asian/Pacific Islanders	1,466	3.2	1,091	3.3	375	2.8
Am Indian/Alaskan Native	95	0.2	52	0.2	43	0.3
Mixed/Others/Unknown	1,107	2.4	868	2.6	239	1.8
Age						
<18	113	0.2	95	0.3	18	0.1
18-24	1,338	2.9	949	2.9	389	2.9
25-49	27,435	59.1	19,223	58.2	8,212	61.3
50-64	15,381	33.1	11,252	34.1	4,129	30.8
≥65	2,146	4.6	1,499	4.5	647	4.8
Viral Suppression						
Virally suppressed ²	27,019	58.2	27,019	83.4	--	--
Transmission Category						
IDU	1,827	3.9	1,167	3.5	660	4.9
MSM	31,024	66.8	22,855	69.2	8,169	61.0
MSM & IDU	2,755	5.9	2,077	6.3	678	5.1
Heterosexual	2,918	6.3	2,160	6.5	758	5.7

¹Unmet need is defined as no HIV laboratory test (VL, CD4, genotype) indicative of HIV care in the last 12 months

²Viral suppression is defined as last reported viral load ≤200 copies/ml

Figure 5 includes data on the proportion of PLWHA reporting unmet need within individual socio-demographic groups. Thus, while Table 2 illustrates that the majority of PLWHA with unmet need were male (86.6%), Latino, etc., Figure 5 shows that approximately 28.9% of all males living with HIV have unmet need. Among all gender groups, women have the largest proportion of unmet need (31.3%). When the distribution of PLWHA with unmet need is stratified by racial/ethnic group, American Indian/Alaskan Natives (AI/AN) had the largest percentage with unmet need (45.3%), followed by African Americans (32.1%) and Latinos (29.8%). Proportions of PLWHA with unmet need were similar within age categories, with all groups except those under 18 years old reporting levels of unmet need ranging from 27-30%.

Figure 5. Proportion of PLWHA reporting unmet medical need within specific socio-demographic groups, LAC HIV surveillance data, as of December 31, 2013 (n=13,395)

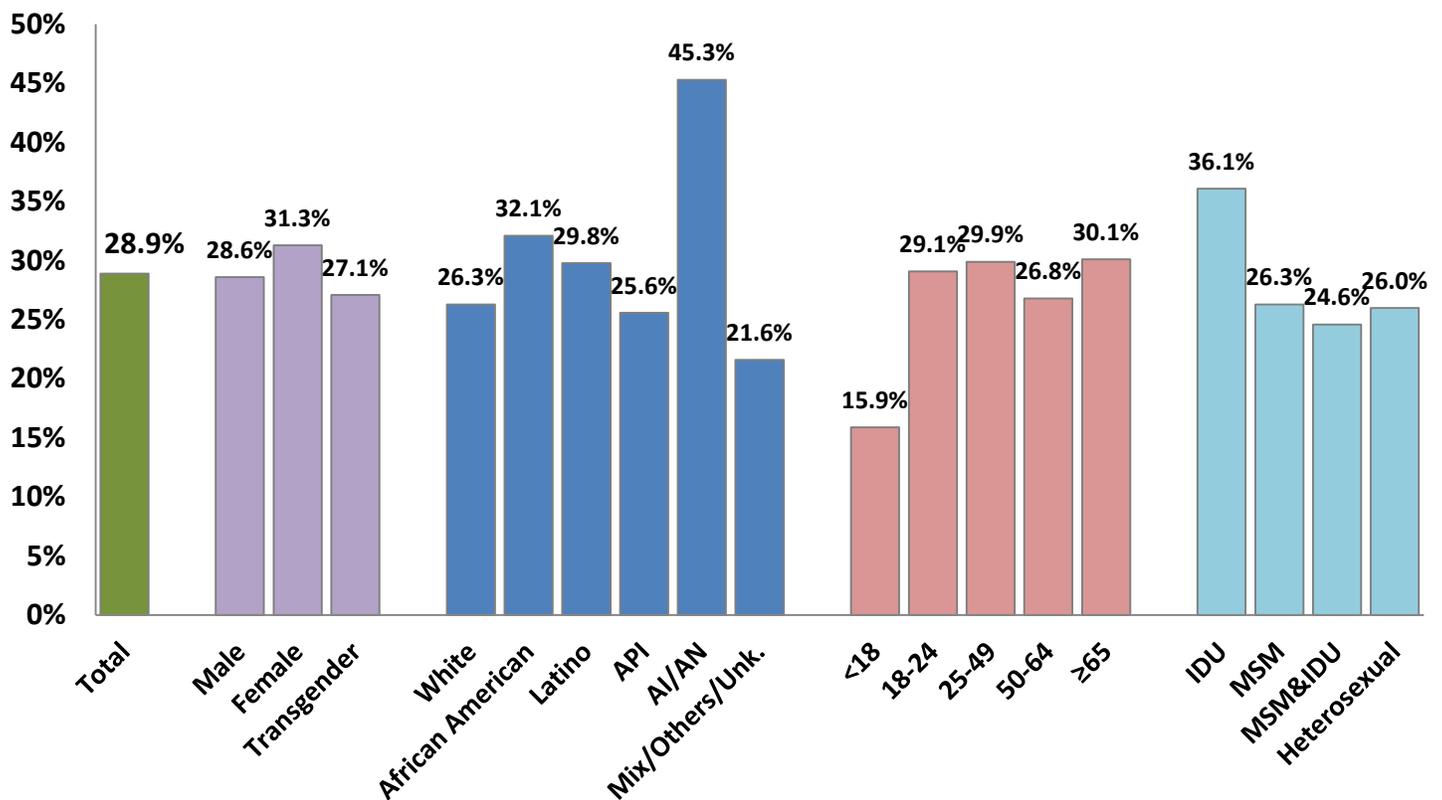


Figure 5 above includes the unmet need percentages for HIV transmission category and IDUs (36.1%) represented the largest percentage with unmet need. Taken together, these data show that although certain groups may contain the largest number of persons with unmet need, these groups don't always represent the largest proportion. For example, while the majority of persons with unmet need are male, females are proportionately more likely to report having unmet need compared to males. Also, while AI/AN make up less than 1% of persons with unmet need, 45.3% of AI/AN with HIV report unmet need.

b. LAC Ryan White Casewatch Data: March 2013-February 2014

Table 3 includes a comparison of demographic characteristics for persons with met and unmet need among persons who received any Ryan White-funded services between March 2013 and February 2014. As mentioned previously, unmet need in the analysis of the Ryan White data is defined as no evidence of any HIV laboratory test in the previous 12 months.

Table 3. Demographic characteristics of PLWHA enrolled in Ryan White by HIV primary care need status, March 2013-February 2014 (n=18,119)

Characteristics	Total		Unmet need		Retained (met need)		RR(95% CI) ¹
	n	%	n	%	n	%	
Total	18,119	100	828	4.6	17,291	95.4	
Gender							
Male	15,698	86.6	698	84.3	15,000	86.8	Reference
Female	2,116	11.7	105	12.7	2,011	11.6	1.12 (0.91-1.38)
Transgender	305	1.7	25	3.0	280	1.6	1.92 (1.27-2.91)
Unknown	--	--	--	--	--	--	--
Race/Ethnicity							
White	4,361	24.1	240	29.0	4,121	23.8	Reference
African American	3,990	22.0	245	29.6	3,745	21.7	1.12 (0.94-1.35)
Latino	9,017	49.8	308	37.2	8,709	50.4	0.61 (0.51-0.72)
Asian/Pacific Islanders	672	3.7	26	3.1	646	3.7	0.69 (0.46-1.04)
Am Indian/Alaskan Native	56	0.3	6	0.7	50	0.3	2.06 (0.87-4.85)
Mixed/Others/Unknown	23	0.1	3	0.4	20	0.1	2.58 (0.76-8.73)
Age							
<18	28	0.2	8	1.0	20	0.1	9.95 (4.36-22.70)
18-24	741	4.1	54	6.5	687	4.0	1.95 (1.45-2.62)
25-49	11,509	63.5	445	53.7	11,064	64.0	Reference
50-64	5,324	29.4	281	33.9	5,043	29.2	1.39 (1.19-1.61)
≥65	517	2.9	40	4.8	477	2.8	2.08 (1.49-2.92)

¹Risk of having unmet need for primary HIV medical care

-- Not applicable, not reported

Among Casewatch clients, transgender persons were almost twice as likely (OR=1.92: 95% CI=1.27-2.91) to have unmet need compared to males. Latinos were less likely to have unmet need compared to whites. Among Ryan White recipients, younger persons under 24 and older persons 50 and above were more likely to experience unmet need. Youth under 18 were at greatest risk for unmet need (OR=9.95: 95% CI=4.36-22.70), however the estimate is unstable due to small numbers and should be interpreted with caution.

Table 4 includes the frequency distribution on risk behaviors, insurance and other factors for Ryan White clients with met and unmet need. In addition, odds ratios and 95% confidence intervals were calculated to compare characteristics of persons with met need versus unmet need. No significant differences by risk groups (MSM, IDU, MSM/IDU and Heterosexual) were observed. The majority of clients with unmet need had public insurance (51.2%). When stratified by care status, uninsured persons were less likely to report unmet need

(OR=0.65: 95% CI=0.56-0.76) compared to persons with insurance. Also, persons with either private (OR=1.54: 95% CI=1.22-1.96) or other insurance types (OR=3.19: 95% CI=1.99-5.12) were at elevated odds of having unmet need compared to those with public insurance. While this may seem counterintuitive, results suggest that uninsured persons (and persons on public assistance) are still able to receive medical care and may be better able to navigate these complex health systems.

Table 4. Factors associated with unmet service need for Ryan White-funded patients, March 2013-February 2014 (n=18,119)

Characteristic	Total		Unmet need		Retained (met need)		RR (95% CI) ¹
	n	%	n	%	n	%	
Total	18,119	100	828	4.6	17,291	95.4	
Risk behavior¹							
MSM	8,968	49.5	468	56.5	8,500	49.2	Reference
IDU	457	2.5	30	3.6	427	2.5	1.28 (0.87-1.87)
MSM&IDU	450	2.5	25	3.0	425	2.5	1.07 (0.71-1.62)
Heterosexual	3,445	19.0	177	21.4	3,268	18.9	0.98 (0.82-1.17)
Primary Insurance							
No Insurance	8,633	47.6	296	35.7	8,337	48.2	0.65 (0.56-0.76)
Public	8,221	45.4	424	51.2	7,797	45.1	Reference
Private	1,123	6.2	87	10.5	1,036	6.0	1.54 (1.22-1.96)
Other/Unknown	142	0.8	21	2.5	121	0.7	3.19 (1.99-5.12)
Federal Poverty Level							
At or below FPL	12,163	67.1	587	70.9	11,576	66.9	1.71 (1.21-2.41)
101-200% FPL	4,151	22.9	182	22.0	3,969	23.0	1.54 (1.07-2.23)
≥201% FPL	1,508	10.0	59	7.1	1,746	10.1	Reference
Socio-Demographic Factors							
Homeless (past 12 months)	1,114	6.1	83	10.0	1,031	6.0	1.76 (1.39-2.22)
Incarceration (past 2 years)	2,303	12.7	155	18.7	2,148	12.4	1.62 (1.36-1.94)

¹Appropriate reference group for OR unavailable or missing

-- Not applicable or not reported

There was an increased odds for unmet need among persons with lower federal poverty level (FPL) and a reported history of homelessness and incarceration. FPL incorporates income and household size as a gauge of socioeconomic status. When compared to persons of higher FPL, an inverse relationship was observed, with persons living at or below FPL more likely to have unmet need (95% CI=1.21-2.41) and persons living at 101% to 200% of FPL were at increased odds for unmet need relative to persons more than 200% of FPL. Finally, persons reporting recent homelessness and incarceration were also more likely to experience unmet need (OR=1.76: 95%CI=1.39-2.22 and OR=1.62: 95%CI=1.36-1.94, respectively) compared to their non-homeless and non-incarcerated counterparts.

Table 5. Comparison of demographic characteristics of PLWHA in LAC compared to Project Engage participants, 2013-2015

Characteristics	HARS		Project Engage ¹	
	N	%	n	%
Total	46,413	100	88	100.0
Gender				
Male	40,596	87.5	71	80.7
Female	5,216	11.2	--	--
Transgender	601	1.3	13	14.8
Race/Ethnicity				
White	15,097	32.5	22	25.0
African American	9,616	20.7	31	35.2
Latino	19,032	41.0	20	22.7
Asian/Pacific Islanders	1,466	3.2	--	--
Am Indian/Alaskan Native	95	0.2	--	--
Mixed/Others/Unknown	1,107	2.4	12	13.6
Age				
<18	113	0.2	--	--
18-24	1,338	2.9	5	5.7
25-49	27,435	59.1	68	77.3
50-64	15,381	33.1	15	17.1
≥65	2,146	4.6	--	--

¹PLWHA included in these databases had other, broader than HRSA's, definition of "out of care".

-- Not applicable, not reported or too few to report (n<5)

c. Project Engage (PE) – 2013-2015

Demographic Comparison

Table 5 includes a comparison of the demographic characteristics of out of care persons enrolled into Project Engage (PE) versus the general population of persons living with HIV reported in HIV surveillance. This analysis will highlight the differences in a sample of out of care persons compared to all persons with HIV in LAC. As previously described, PE used an expanded definition of unmet need that captures both individuals with unmet need, as defined by HRSA, and persons with additional types of unmet need. No statistical comparisons were made between the HIV surveillance population and the PE population since the sample size for PE is small and somewhat unstable. In addition, the PE sample was partially identified through social network referrals and may not be representative of the overall LAC out of care population.

As seen in Table 5, a larger percentage of out of care PE participants are transgender compared to all persons diagnosed and living with HIV in LAC (14.8% versus 1.3%, respectively). In addition, when compared to HIV surveillance data, a larger percentage of PE participants were African American (35.2%) and a lower percentage were white (25.0%) and Latino (22.7%). PE participants were also younger compared to the overall HIV infected population in LAC.

Differences by Unmet Need Status

Among the 88 PE participants, 31 (35.2%) met the HRSA definition of unmet need and 57 (64.8%) met the expanded out of care definition described above suggesting that PE was successful at finding a larger

proportion of PLWHA with unmet need compared to the general LAC PLWHA population. Table 6 shows differences in demographic characteristics between the above-mentioned groups. Although sample sizes were small, few observed differences can be found. One exception to note is that respondents meeting the HRSA definition for unmet need (as opposed to PE’s expanded criteria) tended to be white (45.2% versus 14.0%).

Table 6. Project Engage demographic characteristics by unmet need, 2013-2015

Characteristics	Total		Unmet need (HRSA)		Out of Care (expanded definition ¹)	
	n	%	n	%	n	%
Total	88	100.0	31	35.2	57	64.8
Gender						
Male	71	80.7	24	77.4	47	82.5
Female	--	--	--	--	--	--
Transgender	13	14.8	5	16.1	8	14.0
Race						
White	22	25.0	14	45.2	8	14.0
African American	31	35.2	12	38.7	19	33.3
Latino	20	22.7	--	--	16	28.1
Asian/Pacific Islanders	--	--	--	--	--	--
Am Indian/Alaskan Native	--	--	--	--	--	--
Mixed/Others/Unknown	12	13.6	--	--	11	19.3
Age						
18-24	5	5.7	--	--	--	--
25-49	68	77.3	24	77.4	44	77.2
50-64	15	17.1	5	16.1	10	17.5
≥65	--	--	--	--	--	--

¹expanded definition included individuals meeting HRSA definition of unmet need as well as those newly diagnosed but never in care, <2 primary care visits at the same provider in the previous six months and those recently released from jail, prison or other institutional setting.

-- Not applicable, not reported, or too few to report (n<5)

Factors Affecting Care

PE respondents were also asked a series of questions at time of project enrollment related to service utilization, risk behaviors, barriers to care, substance use and HIV stigma which are presented in Table 7. Participants reported being infected with HIV for an average of 10 years at time of project enrollment, attended an average of 2.2 HIV clinics and were out of care for 14 months on average prior to enrollment.

Although no data were available on the following factors for the general LAC HIV population, a large percentage of the out of care PE study group reported homelessness in the previous 6 months (76%), being uninsured (45%), lifetime exchange sex (26%), lifetime incarceration (85%), and incarceration in the previous 12 months (50%). In addition, the average number of service needs reported was 5.1.

Figure 6 includes the top five services needs reported by the out of care PE participants and the largest service needs were for medical care (84%), case management (75%), oral health (71%), mental health counseling (66%) and medication support services (60%). The distribution of barrier type for each service category also is shown within each bar and as shown, the main barrier type was related to individual factors.

Figure 7 includes the distribution of barrier type across all service categories combined and individual factors were reported as the major barrier to receiving the service. Individual barriers included that the participant did not know where to go for services or who to call, felt too sick or reported substance use as a barrier to receiving services.

Table 7. Baseline characteristics of Project Engage participants, 2013-2015 (n=88)

Baseline Characteristics	n	%
Homeless (past 6 months)	67	76.1
Ever engaged in sex work	25	28.4
Lifetime incarceration	75	85.2
Recent incarceration (past 12 months)	44	50.0
Viral suppression at linkage	37	45.7
Uninsured	39	45.3 ¹
Risk Behaviors		
MSM	47	53.4
IDU (past 3 months)	--	--
MSM&IDU	14	15.9
HIV Testing and Treatment History		
	mean	SD
Years infected	10.0	8.5
Number of clinics attended	2.2	2.4
Months out of care	13.9	19.6
Service Needs		
Number of service gaps	5.1	4.6

-- too few to report (n<5)

¹ two participants did not report their insurance status and were not included in the denominator

Figure 6. Top 5 service needs and barrier type for each service category: Project Engage, 2013-2015 (n=88)

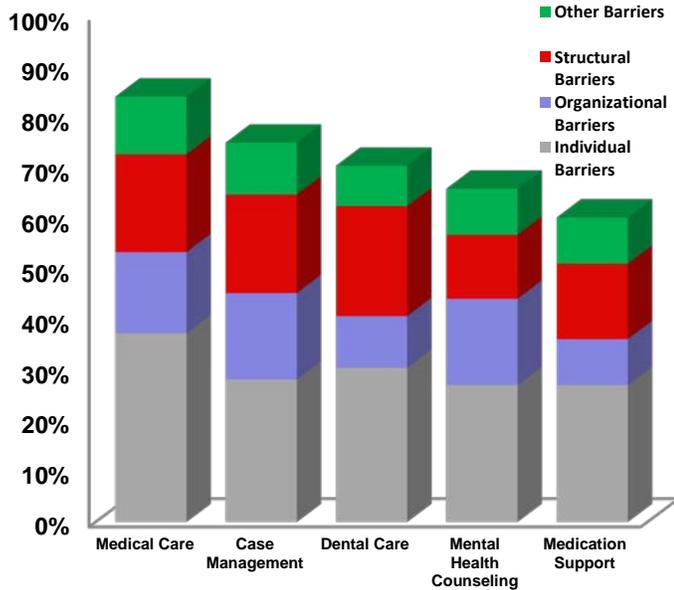
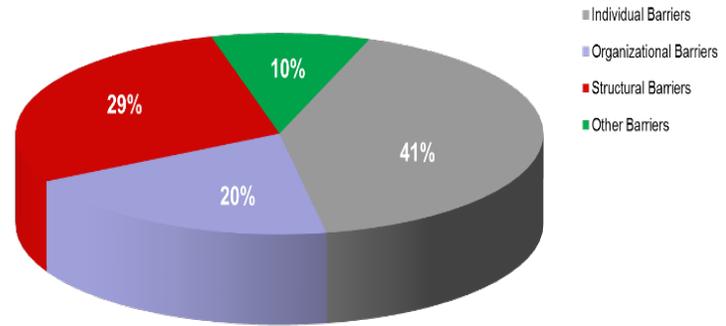


Figure 7. Reported barriers to receiving needed services: Project Engage, 2013-2015 (n=88)



- **Individual Barriers:** I didn't know where to go or who to call; substance abuse; too sick
- **Organizational Barriers:** didn't complete the application/paperwork; financial difficulties; language barrier; disrespect/mistreatment by staff
- **Structural Barriers:** The system is too confusing; wait times for service are too long; not available in my area; transportation problems; not eligible/denied service; immigration status concerns

d. Navigation Program – 2013-2015

As described above, the Navigation Program was a collaborative project between DHSP, APLA and 7 LAC HIV clinics to identify, locate and re-engage lost HIV clinic patients. The demographic characteristics for the 78 lost HIV clinic patients enrolled into the Navigation Program are shown in Table 8. As a reminder, an expanded definition of out of care was used to recruit participants into the Navigation Program. Demographic data on PLWHA in LAC from HIV surveillance data are presented to illustrate differences between the out of care Navigation Program population and the general population of HIV-infected persons living with HIV in LAC. No statistical comparisons were made between the surveillance population and the Navigation Program population since the cell sizes for the Navigation Program are small and somewhat unstable.

As shown in Table 8, the majority of participants in the Navigation Program and in the general population of persons living with HIV in LAC are male (Navigation: 78.2%, HIV Surveillance: 87.5%), Latino (Navigation: 73.1%, HIV Surveillance: 41.0%) and ages 25-49 years (Navigation: 71.8%, HIV Surveillance: 59.1%). The major differences were that there was slightly more representation of females in the Navigation Program (18.0%) compared to PLWHA in LAC (11.2%). Also, there was a smaller representation of whites in the Navigation Program (3.9%) when compared to PLWHA in LAC (32.5%). The Navigation Program did not enroll any participants under 18 years of age although the age distribution in the Navigation Program was slightly younger when compared to PLWHA in LAC.

Table 8. Comparison of demographic characteristics of PLWHA in LAC compared to Navigation Program participants, 2013-2015

Characteristics	HARS		NAV ¹	
	N	%	n	%
Total	46,413	100	78	100.0
Gender				
Male	40,596	87.5	61	78.2
Female	5,216	11.2	14	18.0
Transgender	601	1.3	--	--
Unknown	--	--	--	--
Race/Ethnicity				
White	15,097	32.5	--	--
African American	9,616	20.7	14	18.0
Latino	19,032	41.0	57	73.1
Asian/Pacific Islanders	1,466	3.2	--	--
Am Indian/Alaskan Native	95	0.2	--	--
Mixed/Others/Unknown	1,107	2.4	--	--
Age				
<18	113	0.2	--	--
18-24	1,338	2.9	--	--
25-49	27,435	59.1	56	71.8
50-64	15,381	33.1	18	23.1
≥65	2,146	4.6	--	--

¹PLWHA included in these databases had other, broader than HRSA's, definition of "out of care".

-- Not applicable, not reported, or too few to report (n<5)

Differences by Unmet Need Status

An expanded definition of unmet need was used to recruit the Navigation Program participants. Among the 78 enrolled participants, 25 (32%) met the HRSA definition of unmet need and 53 (68%) were enrolled using the expanded out of care definition. The demographic characteristics of the above-mentioned groups are presented in Table 9. Although sample sizes were small, few observed differences can be found between these groups. One exception to note is that more African American and male Navigation Program participants met the HRSA definition (24% versus 15% and 84% versus 76%, respectively).

Table 9. Navigation Program sample demographic characteristics, barriers to care, testing and care history by subpopulation, 2013-2015 (n=78)

Characteristics	Total		Unmet need (HRSA)		Out of Care (expanded definition ¹)	
	n	%	n	%	n	%
Total	78	100.0	25	32.1	53	67.9
Gender						
Male	61	78.2	21	84.0	40	75.5
Female	14	18.0	--	--	10	18.9
Transgender	--	--	--	--	--	--
Unknown	--	--	--	--	--	--
Race						
White	--	--	--	--	--	--
African American	14	18.0	6	24.0	8	15.1
Latino	57	73.1	17	68.0	40	75.5
Asian/Pacific Islanders	--	--	--	--	--	--
Am Indian/Alaskan Native	--	--	--	--	--	--
Mixed/Others/Unknown	--	--	--	--	--	--
Age						
18-24	--	--	--	--	--	--
25-49	56	71.8	18	72.0	38	71.7
50-64	18	23.1	6	24.0	12	22.6
≥65	--	--	--	--	--	--

¹expanded definition included individuals meeting HRSA definition of unmet need as well as those newly diagnosed but never in care, <2 primary care visits at the same provider in the previous six months and those recently released from jail, prison or other institutional setting.

-- Not applicable, not reported or too few to report (n<5)

Participants were also asked about service needs and barriers they experienced while trying to obtain HIV care. Similar to the barriers to HIV care reported for participants in PE, the majority of Navigation Program participants (59%) reported individual barriers as being the primary reason for being unable to obtain HIV care, followed by structural barriers (24%; Figure 8). Table 11 provides a detailed breakdown of reported barriers and service needs. Oral health care, benefits assistance and pharmacy/medication services were reported as the most frequently needed support service. Participants were also asked to report all barriers they experienced in trying to obtain HIV care and identify what they perceived to be the main barrier. Most participants reported that other life priorities (31.9%) and lack of money (11.1%) were the main barriers to obtaining timely HIV care. It can be also noted these two lists (all barriers and most main barrier) are consistent in their rankings.

Table 10. Baseline characteristics of lost HIV clinic patients enrolled in the Navigation Program, 2013-2015 (n=78)

Baseline Characteristics	n	%
Homeless (past 6 months)	7	9.0
Lifetime incarceration	19	24.4
Incarceration (past 12 months)	6	7.7
Viral suppression at linkage	38	52.1
Risk Behaviors		
IDU (past 6 months)	--	--
MSM	42	53.9
MSM&IDU	--	--
Uninsured	43	56.6
HIV Testing and Treatment History		
	mean	sd
Years with HIV	10.1	6.9
Months out of care	14.8	18.0
Service Needs		
Number of service gaps	3.0	1.8

-- too few to report (n<5)

Figure 8. Reported Barriers to receiving needed services: Navigation Program, 2013-2015 (n=78)

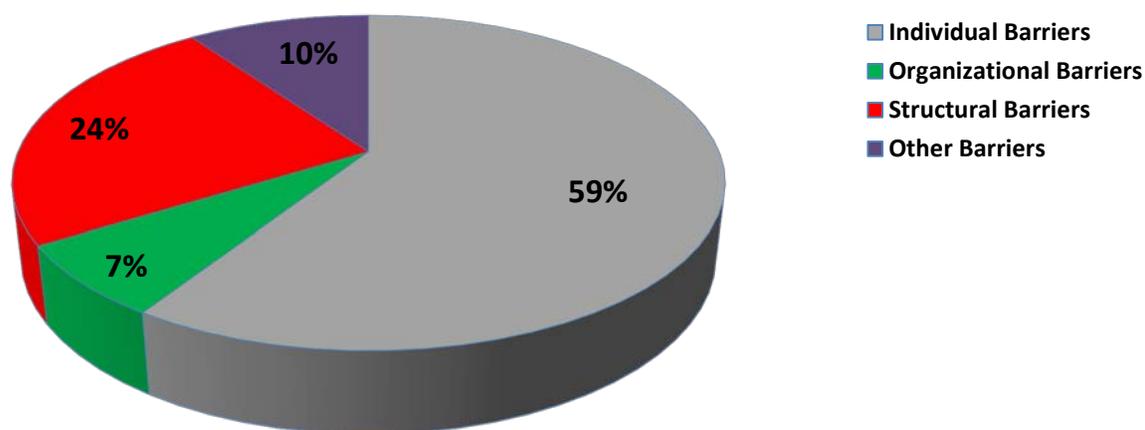


Table 11. Top 10 reported support service needs and barriers to HIV care (n=78): Navigation Program, 2013-2015 (n=78)

Service Needs	Number (%)
Dental Services	46 (59.7)
Benefits Assistance	33 (42.9)
Pharmacy/Medication Services	32 (41.6)
Food/Other Basic Needs	27 (35.1)
HIV-related Medical Services	26 (33.8)
Housing/Shelter	20 (26.0)
Mental Health Services	21 (27.3)
Drug/Alcohol Treatment	8 (10.4)
General Medical Services (Not HIV-related)	8 (10.4)
Case Management	8 (10.4)

Barriers to HIV Care	All Reported Barriers¹ Number (%)	Main Barrier Reported^{2,3} Number (%)
Other Life Priorities (e.g., Childcare, Work)	39 (50.0)	23 (31.9)
Lack of Money	20 (25.6)	8 (11.1)
Lack of Transportation	13 (16.7)	4 (5.6)
Drinking/Using Drugs	9 (11.5)	3 (4.2)
Stigma	8 (10.3)	3 (4.2)
Homelessness	8 (10.3)	3 (4.2)
Fear Someone Would Find Out	8 (10.3)	2 (2.8)
Perceived Lack of Need for HIV Care	6 (7.7)	2 (2.8)
Living Between US and Another Country	5 (6.4)	1 (1.4)
Immigration Status	5 (6.4)	1 (1.4)

¹ Participants selected all that applied

² Participants selected the greatest barrier to HIV care

³ n=72

e. Medical Care Coordination Program (MCC) – 2013

Table 12 includes the basic demographic characteristics of patients enrolled in MCC with unmet need (at least 2 HIV laboratory tests at least 90 days apart in the past 12 months) compared to patients who were retained in care (met need). As shown in Table 12, the majority of the 1,204 MCC participants (55.4%) had unmet need at time of enrollment. The majority of enrolled participants were male, Latino or African American and ages 25-49. When stratified by care status, women were less likely to have unmet need (95% CI: 0.47-0.93) compared to men. No differences by race/ethnicity were detected. Youth 18-24 were over twice as likely (OR: 2.07; 95% CI: 1.35-3.16), and persons 50-64 years old were less likely (95% CI: 0.54-0.98) to experience unmet need compared to persons 25-49 years of age. It should be noted that these results are different from those previously reported in HIV surveillance but are consistent with literature showing an inverse relationship between age and care status nationally.

Table 12. Socio-demographic characteristics of MCC Patients by HIV primary care need status, January-December 2013

Characteristics	Total		Unmet need ¹		Retained ² (met need)		OR (95% CI) ³
	n	%	n	%	n	%	
Total	1,204	100.0	667	55.4	537	44.6	
Gender							
Male	1,022	84.9	579	86.8	442	82.3	Reference
Female	157	13.0	73	10.9	84	15.6	0.66 (0.47-0.93)
Transgender	25	2.1	15	2.2	10	1.9	1.15 (0.51-2.57)
Unknown	--	--	--	--	--	--	--
Race/Ethnicity							
White	261	21.7	154	23.1	107	19.9	Reference
African American	310	25.7	171	25.6	139	25.9	0.85 (0.61-1.19)
Latino	587	48.8	307	46.0	280	52.1	0.76 (0.57-1.02)
Asian/Pacific Islanders	38	3.2	27	4.0	11	2.0	1.70 (0.81-3.59)
Am Indian/Alaskan Native	--	--	--	--	--	--	--
Mixed/Others/Unknown	--	--	--	--	--	--	--
Age							
<18	7	0.6	7	1.0	--	--	--
18-24	118	9.8	85	12.7	33	6.1	2.07 (1.35-3.16)
25-49	845	70.2	469	70.3	376	70.0	Reference
50-64	217	18.0	103	15.4	114	21.2	0.72 (0.54-0.98)
≥65	17	1.4	--	--	14	2.6	--
Transmission Category							
MSM	710	59.0	413	61.9	297	55.3	1.31 (1.04-1.66)
IDU	38	3.2	20	3.0	18	3.4	0.89 (0.47-1.70)
MSM&IDU	49	4.1	27	4.0	22	4.1	0.99 (0.56-1.75)
Heterosexual	290	24.1	135	20.2	155	28.9	0.63 (0.48-0.82)
Socio-Demographic Factors							
Homeless (past 6 months)	163	13.5	99	14.8	64	11.9	1.29 (0.92-1.80)
Lifetime incarceration	461	38.3	249	37.3	212	39.5	0.91 (0.72-1.15)
Incarceration (past 6 months)	125	10.4	79	11.8	46	8.6	1.45 (0.99-2.13)
STD diagnosis (past 6 months)	279	23.2	183	27.4	96	17.9	1.74 (1.31-2.30)
HIV Testing and Treatment History							
Viral suppression ⁴	388	32.2	157	25.5	231	43.0	2.21 (1.72-2.83)

¹Fewer than 2 HIV laboratory tests (viral load, CD4, or genotype) at least 90 days apart in the past 12 months since MCC enrollment

²Two or more HIV laboratory tests (viral load, CD4, or genotype) at least 90 days apart in the past 12 months since MCC enrollment

³Odds of having unmet need for primary HIV medical care

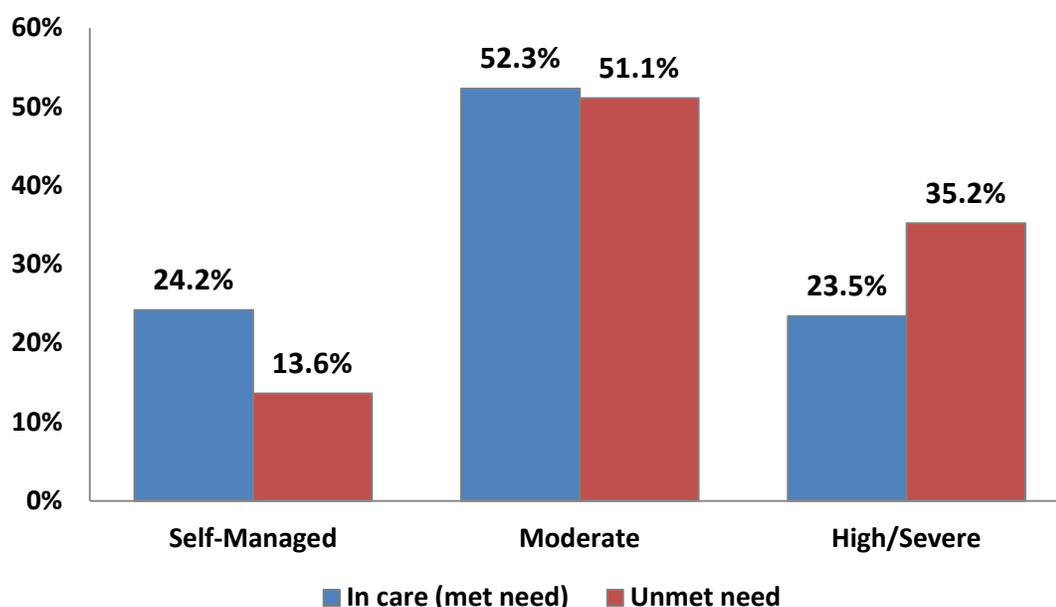
⁴From most recent viral load reported in the last 6 months of the previous year since MCC enrollment

-- Not applicable, not reported or too few to report (n<5)

Table 12 also includes socio-demographic characteristics of MCC patients stratified by care status. When stratified by self-reported transmission category, MSM were more likely to have unmet need compared to non-MSM. Conversely, those identifying as heterosexual had a reduced odds for unmet need. Among the MCC sample, approximately 15% of persons with unmet need reported recent homelessness. Also, a high proportion of MCC clients with unmet need reported both recent (11.8%) and lifetime (37.3%) incarceration histories, although no differences were found. It should be noted that a larger proportion of MCC participants with unmet need reported a recent STD infection (27.4% versus 17.9%), which translated into a 74% increased odds of having unmet need for persons who reported a recent STD. A significantly lower proportion of those with unmet need were virally suppressed compared to those retained in HIV care (25.5% versus 43.0%; OR=2.21: 95% CI=1.72-2.83) at enrollment. Finally, although not shown, MCC participants with unmet need were infected more recently (5.4 years) compared to those in regular care (9.5 years; p<0.001).

As described earlier, the MCC program assesses patients' need for medical and support services based on an assessment of multiple health and psychosocial domains. Responses on the assessment are used to calculate an acuity level that reflects patients' level of need and drives the intensity of service delivery. As shown in Figure 9, similar proportions of participants were assessed as having "Moderate" acuity at enrollment based on care status (52% versus 51% respectively). Despite this, a much higher proportion of person with unmet need (35%) were assessed with an overall acuity score of "High" or "Severe" at enrollment, compared to "Self-Managed" (14%). This indicates that persons with unmet need are more likely to require expanded services compared to persons retained in care (met need).

Figure 9. MCC clients by HIV primary medical care need and acuity level, January-December 2013 (n=1,204)



The proportion assessed with "high" or "severe" acuity on all measured domains compared to those enrolled in MCC receiving care is shown in Table 13. Among domains assessed, persons with unmet need had significantly higher levels of identified need across multiple domains compared to those receiving care. This included a greater need for services related to overall health status (74%); ART access and adherence (74%); sexual risk behaviors (48%); medical access, linkage and retention (26%); mental health (21%) and quality of life measures (9%). Taken together, these data indicate that a significant proportion of persons with unmet need

have identified a need for expanded clinical and psychosocial services which may be affecting their ability to be retained in care.

Table 13. Patient acuity by need domain in MCC clients by HIV primary care status, January-December 2013 (n=1,204)

Domain ¹	In care (met need) (n=537)		Unmet need (n=667)	
	n	%	n	% ¹
Health status	332	61.8	495	74.2^{††}
ART access and adherence	328	61.1	492	73.8^{††}
Risk behaviors	192	35.8	319	47.8^{††}
Financial	213	39.7	297	44.5
Medical access, linkage and retention	178	33.1	175	26.2[†]
Alcohol/Drug Use and Addiction	117	21.8	168	25.2
Support system and relationships	111	20.7	166	24.9
Mental health	87	16.2	138	20.7[†]
Legal/end of life needs	66	12.3	105	15.7
Housing	68	12.7	103	15.4
Quality of life	70	13.0	57	8.5[†]

¹Patient is identified as having need for a category if they score high or severe in a specific domain

[†]p<0.05; ^{††}p<0.01

f. Project Comparisons

The variables that are common to all of the projects described above are included in Table 14 below for comparison purposes. It is important to keep in mind that the populations included in each project are different with respect to sampling methodology and eligibility criteria, however this report includes the first attempt to pool data on persons with unmet need in LAC.

The majority of the projects and databases included men (range: 78%-88%) followed by women (range: 4%-18%) and transgender individuals (range: 1%-15%). Also, in most instances the majority of participants were Latino (range: 21%-56%). The majority of persons with unmet need were between 25-49 years of age (range: 61%-77%) and reported MSM behavior (range: 52%-62%). Also of interest, projects reported varying percentages with suppressed viral load at either project enrollment or re-engagement (range: 25.5%-52.1%). Overall the sample that most closely matches HIV surveillance data is MCC. This finding isn't unexpected as the MCC sample was the largest of all reported and enrollment is more geographically diverse than many of the other projects.

Table 14. Demographic characteristics of PLWHA in LAC with unmet need by data source

Characteristics	Casewatch	PE	NAV	MCC	HARS
	(N=828)	(N=85)	(N=78)	(N=667)	(n=46,413)
	%				
Gender					
Male	84.3	81.2	78.2	86.8	87.5
Female	12.7	3.5	18.0	10.9	11.2
Transgender	3.0	15.3	3.9	2.2	1.3
Unknown	--	--	--	--	--
Race/Ethnicity					
White	29.0	24.7	3.9	23.1	32.5
African American	29.6	36.5	18.0	25.6	20.7
Latino	37.2	21.2	73.1	46.0	41.0
Asian/Pacific Islanders	3.1	3.5	2.6	4.0	3.2
Am. Indian/Alaska Native	0.7	--	--	0.6	0.2
Mixed/Others/Unknown	0.4	14.1	2.6	0.6	2.4
Age					
<18	1.0	--	--	1.0	0.2
18-24	6.5	5.9	5.1	12.7	2.9
25-49	53.7	76.5	71.8	70.3	59.1
50-64	33.9	17.7	23.1	15.4	33.1
≥65	4.8	--	--	0.4	4.6
Risk Categories					
IDU	3.6	1.3	5.1	3.0 ¹	3.9 ¹
MSM	56.5	52.0	53.9	61.9 ¹	66.8 ¹
MSM & IDU	3.0	14.3	2.6	4.0 ¹	5.9 ¹
Homelessness	10.0 ²	76.1 ³	9.0 ⁴	14.8 ⁴	--
Recent Incarceration	18.7 ²	50.0 ³	7.7 ²	11.8 ⁴	--

¹ Risk behavior most associated with HIV transmission instead of current risk behavior

² Past 12 months

³ past 2 years

⁴ past 6 months

-- Not applicable or not reported

IV. Discussion

The purpose of this report is to utilize multiple local data sources to characterize the population of PLWHA in LAC with unmet need. Results can be used by local LAC planners for resource allocations as services are rolled out to address the needs of the LAC unmet need population. LAC's unmet need population as a percent of the total persons living with HIV (28.9%) is at the low end of the range of 18-56% reported in other jurisdictions.¹⁶⁻¹⁹ These data suggest that while PLWHA in LAC are retained in care somewhat better than patients in other jurisdictions, nearly all of the jurisdictions fall short of the National HIV/AIDS Strategy that 80% of HIV-infected persons be retained in care.^{3,20}

In LAC, PLWHA most at risk for unmet need include African Americans and young persons. The findings from Project Engage and the Navigation Program that specifically target hard-to-find out of care persons, suggests that there is a subset of persons with unmet need in LAC who are severely marginalized who are disproportionately engaged in sex work, have a history of incarceration and a history of homelessness. These

findings suggest that targeted approaches designed specifically for the marginalized subgroups who are out of care are needed to more effectively identify and engage HIV-infected persons in LAC with unmet need.²¹⁻²⁶

As mentioned, although sample sizes and sampling methods varied by project, overall, persons with unmet need were generally consistent with the sample from surveillance. The proportion of patients by gender varied from surveillance for PE and Navigation as these projects enrolled a larger number of transgender persons and fewer women comparably. Also, PE enrollment was primarily African American while NAV was a largely Latino sample. Finally, only MCC collected information on persons under 18 years of age. These distinctions across the datasets are most likely due to differences in sampling methods and selection criteria, so any cross-study comparisons should be done with caution as most populations are not generalizable. Despite the differences in sampling and definitions used, it is clear that these supplemental samples are capturing important aspects of persons with unmet need that can offer deeper insights into this population as a whole.

In addition to characterizing the demographic distributions of persons with unmet need, it is also important to understand how socio-structural characteristics affect care access and retention. Research has shown that factors such as substance use, housing insecurity, incarceration history and mental health status can negatively affect HIV care retention.^{23-24,27} Project Engage and the Navigation Program results support previous findings that many persons who have challenges staying in consistent HIV care and have unmet need also have basic subsistence needs for improved housing, substance use support, and grapple with all of the safety and health issues associated with sex work and incarceration. These issues were particularly relevant for the Project Engage participants who were the most difficult to locate and reported the most incarceration, sex work, injection drug use and homelessness of any of the project participants. In addition, the Project Engage participants reported the most service gaps of any of the project sample groups. The incentivized social network referral and direct recruitment approach used to identify Project Engage participants was the first successful effort in LAC to identify and link to care a severely marginalized out of care population with unmet need.

MCC data clearly demonstrated that persons with unmet need were worse off for measures of overall health, clinical outcomes and psycho-social factors, compared to those who consistently see a clinician. As mentioned previously, some differences seen in participants across all of the projects are likely due to variations in recruitment methods and overall project goals, but suggest that even among a sample of persons with unmet need, varying levels of needs severity still exist and that this group is not monolithic.

In addition to the factors mentioned above, participants in both the Navigation and Project Engage projects were also asked to identify barriers to accessing necessary medical and ancillary services. In general, Project Engage participants primarily reported individual barriers (drug abuse, mental health, perceived stigma, lack of awareness, etc.) as the reasons they were unable to obtain needed services. This finding is consistent with the latest Ryan White Services Needs Assessment which indicated that many PLWHA in LAC are unaware of the full range of services available to them.²⁸ For both Project Engage and Navigation Program participants, besides primary HIV medical care, participants reported that oral health care and medication assistance were among the top five services they were currently lacking. Other top needed services among these groups included case management, nutritional support and housing/financial support. Taken together, these data show that persons with unmet need often report needs for multiple ancillary services. Such findings are in keeping with research showing that HIV-infected persons with multiple services needs also have inconsistent patterns of HIV care utilization.²⁷ These findings are important and highlight the structural factors affecting medical care retention, and support a growing body of research highlighting the need for more holistic interventions that target barriers to improve linkage to needed services.^{23,29,30}

With respect to HIV testing and care histories, on average, persons enrolled in the various projects with unmet need have been infected for at least five years, and data from the population with the most unmet need, the Project Engage participants, indicates that these PLWHA received treatment from multiple clinics in the past. This suggests that persons with unmet need have challenges making a lasting connection with an individual provider or clinic which would help them to sustain their HIV care. In addition, many are not unaware of where to obtain care and are experiencing other life circumstance challenges such as incarceration, substance use, homelessness and the disruptions of life as a sex worker, all of which serve as barriers to obtaining care.

A strong positive link between HIV medical care adherence and viral load suppression (less than 200 copies/ml) is well established.^{11,31-33} Increased viral load suppression is an important objective of the HIV care continuum, as it is so closely linked to reduced morbidity and mortality among HIV-infected patients.^{11,31-33} Based on LAC HIV surveillance data, 61% of HIV-infected persons in LAC in 2013 had met need or had at least one HIV laboratory test in the previous 12 months according to the HRSA definition. The percentage of all PLWHA in LAC with at least one HIV laboratory test in 12 months is higher than that for Project Engage and Navigation Program participants among whom 26% and 52% respectively were engaged in care at time of project enrollment. In addition, the overall percent virally suppressed in LAC for PLWHA in 2013 was 50% in contrast to 46% for Project Engage out of care participants, suggesting that the Project Engage method is able to identify additional persons with unsuppressed viral load. In contrast, 51% of the out of care Navigation Program participants were virally suppressed which makes sense since this population was more recently in care and may still be on self-managed ART use. These findings underscore the fact that the methods used in Project Engage in particular were effective at identifying an important hard-to-find subset of LAC's unmet need population.

In conclusion, targeted efforts to improve access to and retention in HIV care among PLWHA with unmet need will likely make a significant contribution towards reducing community viral loads and reducing the forward transmission of HIV in LAC.

V. Limitations

There are several limitations that should be taken into account when interpreting this data. First, the estimate of PLWHA who have moved out of LAC is likely underestimated in HIV surveillance data. A proportion of individuals (estimated at 7% from NAV) have emigrated from this jurisdiction; therefore, estimates of unmet need in HIV surveillance may be slightly inflated. In addition, the sample sizes for Project Engage and Navigation are small and are convenience samples and have limited generalizability. However when comparing the unmet need population in HIV surveillance to that of the Project Engage and Navigation Program populations, the groups were very similar demographically, suggesting that the demonstration project populations may be a good representation of LAC's unmet need population. As study objectives, designs and sampling methodology varied across data sources, results cannot be directly compared across projects. In addition, not all projects used a uniform definition of unmet need as described by HRSA, although when subpopulations were compared using the HRSA definition and the project specific definition of unmet need, no differences between groups were found.

VI. Policy Recommendations

Based on the above results, several recommendations to better identify, characterize and serve persons with unmet need are presented below. These include:

1. Modify unmet need definition to improve the identification of persons at risk of falling out of care:

As this report demonstrates, populations such as youth, African Americans, homeless persons, IDUs, sex workers and those with incarceration histories are at increased risk for experiencing unmet need. As HRSA definitions for linkage, engagement and retention in care may be appropriate measures in certain situations (e.g., monitoring progress for NHAS goals), its utility as a tool to determine who is in need of expanded services is too restrictive. Increasingly this definition is being used as a metric not only for HIV care retention, but also for determining when expanded services are necessary to maintain retention. As Project Engage and the Navigation Program demonstrate, persons meeting the HRSA unmet need definition were very similar to those using the expanded definition. Also, although 45% of persons assessed for MCC services do not meet the functional definition for unmet need, 23% of these individuals still score high/severe on the overall acuity scale. These data suggest that expanded guidelines based on acuity for socio-demographic variables related to unmet need (similar to MCC) might offer better metrics for providers.

2. Development of and/or modification to programs or protocols to better support persons with unmet need:

As many of these projects and programs demonstrate, persons with unmet needs experience multiple structural and interpersonal barriers to care. New efforts focused on retention and re-engagement should either work to expand existing county programs, or in tandem with existing programs, to ensure that individual with unmet need received the support necessary to maintain care. A recent review article recommended that to be effective, retention/re-engagement programs should adopt patient navigation techniques utilizing strengths-based case management approaches (e.g., ARTAS or Motivational Interviewing) to engage clients.²³ Additionally, other effective methods may include co-location of services, text-messaging appointment reminders, expanded bilingual/bicultural clinical services, ongoing transportation support and other practices to streamline administrative patient clinic enrollment procedures.²²⁻²³ Programs that incorporate these elements have effectively improved retention and re-engagement for patients. Future endeavors should incorporate these best practices to ensure effective service delivery for consumers.

3. Increase consumer awareness on the availability of HIV medical and ancillary services:

Strong evidence supports that use of RW-funded support services is positively associated with engagement in primarily HIV medical care.^{22,34-37} Data from LAC HIV Casewatch also supports this finding, as a much lower proportion of Ryan White clients report unmet need (5%) compared to PLWHA in surveillance (28.9%) or MCC (44.6%). As both the Navigation and Project Engage Programs demonstrated, a key structural barrier to accessing support services was a lack of awareness about service availability. An expanded marketing or public awareness campaign directed at both PLWHA and service providers has the potential to reduce barriers to services. With the introduction of ACA, the funding of medical services will not exclusively fall to Ryan White for low income HIV-infected persons. Despite this trend, many individuals may continue rely on Ryan White support services as these services may not be provided by their new medical care payer. Ensuring that low income persons receiving support services are also engaged in HIV medical care is important for ensuring that patients are engaged in care. Changes in funding of Ryan White services may provide opportunities for local policymakers to expand support services to reduce ongoing structural barriers to HIV care.

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