FY 2019 How to Best Meet the Need

Special Workgroup #1 - Outreach
11:00 a.m., Monday April 16, 2018

Houston Area Comprehensive HIV Prevention and Care Services Plan
2017 - 2021

Capturing the community's vision for an ideal system of HIV prevention and care for the Houston Area

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HOUSTON EMA HIV CARE CONTINUUM

What is the Care Continuum?

The HIV Care Continuum, previously known as a Treatment Cascade, was first released in 2012 by the Centers for Disease Control and Prevention (CDC). It represents the sequential stages of HIV care, from being diagnosed with HIV to suppressing the HIV virus through treatment. Ideally, the Care Continuum describes a seamless system of HIV prevention and care services, in which people living with HIV (PLWH) receive the full benefit of HIV treatment by being diagnosed, linked to care, retained in care, and taking HIV medications as prescribed to achieve viral suppression.

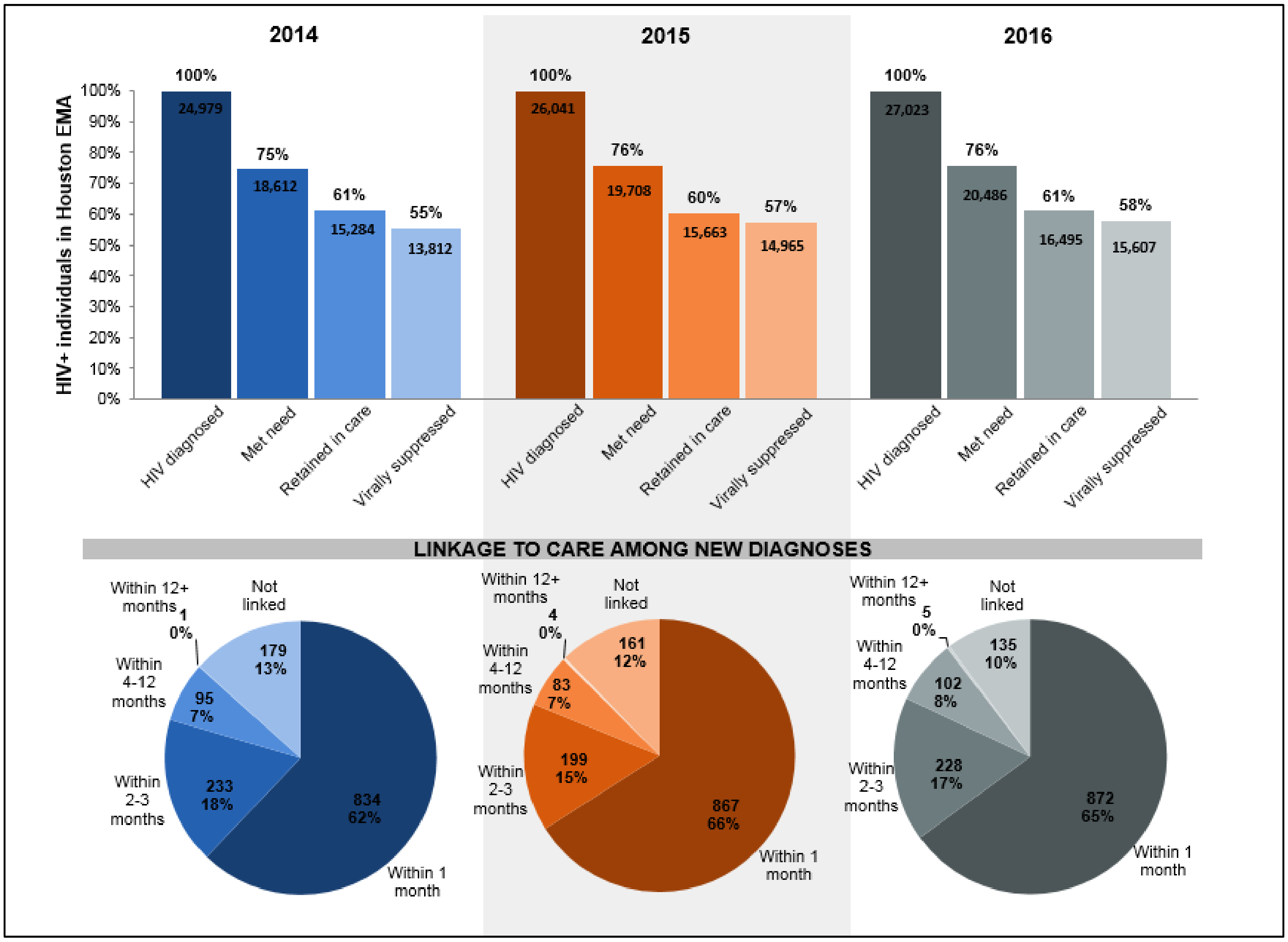
The Houston EMA Care Continuum (HCC)

The HCC is a diagnosis-based continuum. The HCC reflects the number of PLWH who have been diagnosed ("HIV diagnosed"); and among the diagnosed, the numbers and proportions of PLWH with records of engagement in HIV care ("Met need"), retention in care ("Retained in care"), and viral suppression ("Virally suppressed") within a calendar year. Although retention in care is a significant factor for PLWH to achieve viral suppression, 'Virally suppressed' also includes those PLWH in the Houston EMA whose most recent viral load test of the calendar year was <200 copies/mL but who did not have evidence of retention in care.

Linking newly diagnosed individuals into HIV medical care as quickly as possible following initial diagnosis is an essential step to improved health outcomes. In the HCC, initial linkage to HIV medical care ("Linkage to care") is presented separately as the proportion of *newly* diagnosed PLWH in the Houston EMA who were successfully linked to medical care within three months or within one year after diagnosis

Please see the last page for the Methodology used to develop the Houston EMA HIV Care Continuum.

Figure 1: **Houston EMA HIV Care Continuum, 2014-2016**



Source: Bureau of Epidemiology and Bureau of HIV/STD and Viral Hepatitis Prevention, Houston Health Department, 2017

From 2014-2016, the total number of HIV diagnosed increased each year, but the percentage of those with met need, retained in care, and virally suppressed also increased. The percentage of those retained in care remained constant

- There was a 3% increase in the percentage of those virally suppressed from 2014 to 2016.
- The percentage of newly diagnosed PLWH linked to care within one month of diagnosis increased by 3%, while the percentage of newly diagnosed PLWH not linked to care decreased by 3% from 2014 to 2016.

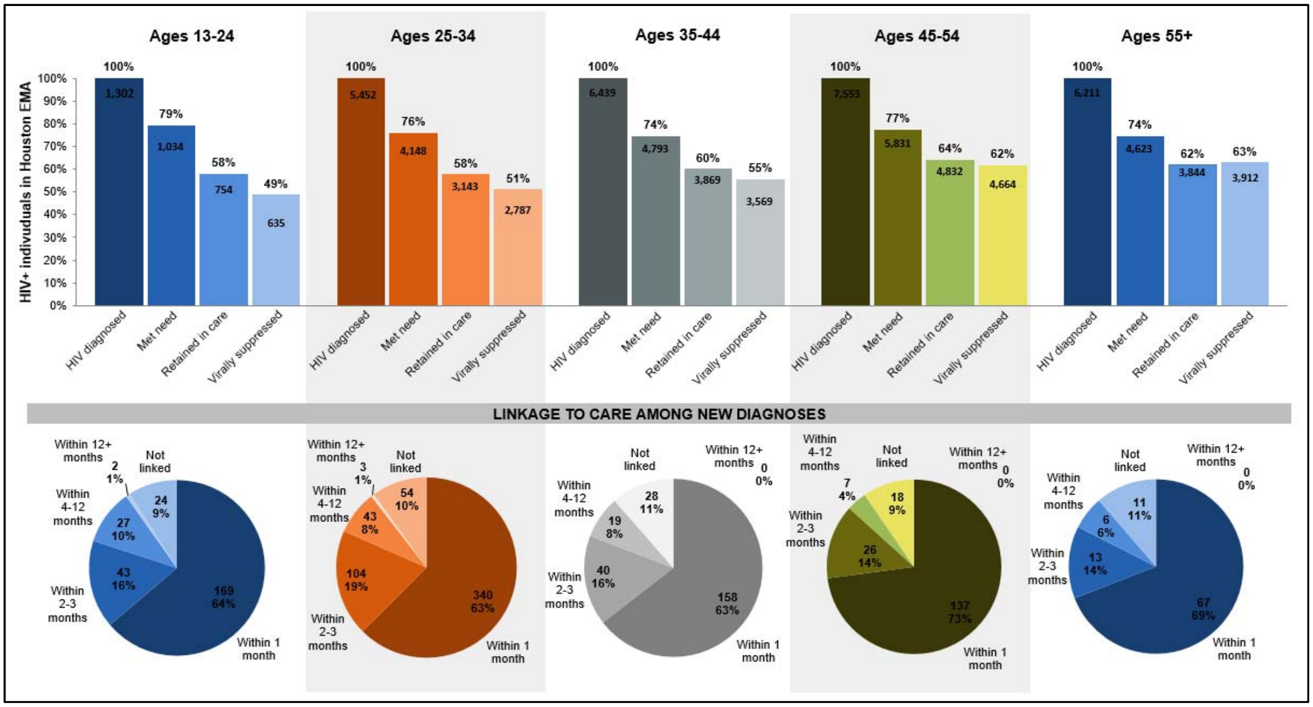
Disparities in Engagement among Key Populations

Multiple versions of the HCC have been created to illustrate engagement disparities and service gaps that key populations encounter in the Houston EMA.

It is important to note that available data used to construct each version of the Houston EMA HCC do not portray the need for activities to increase testing, linkage, retention, ART access, and viral suppression among many other at-risk key populations, such as those who are transgender or gender non-conforming, intersex, experiencing homelessness, or those recently released from incarceration

The Houston EMA Care Continuum, by Age

Figure 2: Houston EMA HIV Care Continuum by Age Groups, 2016

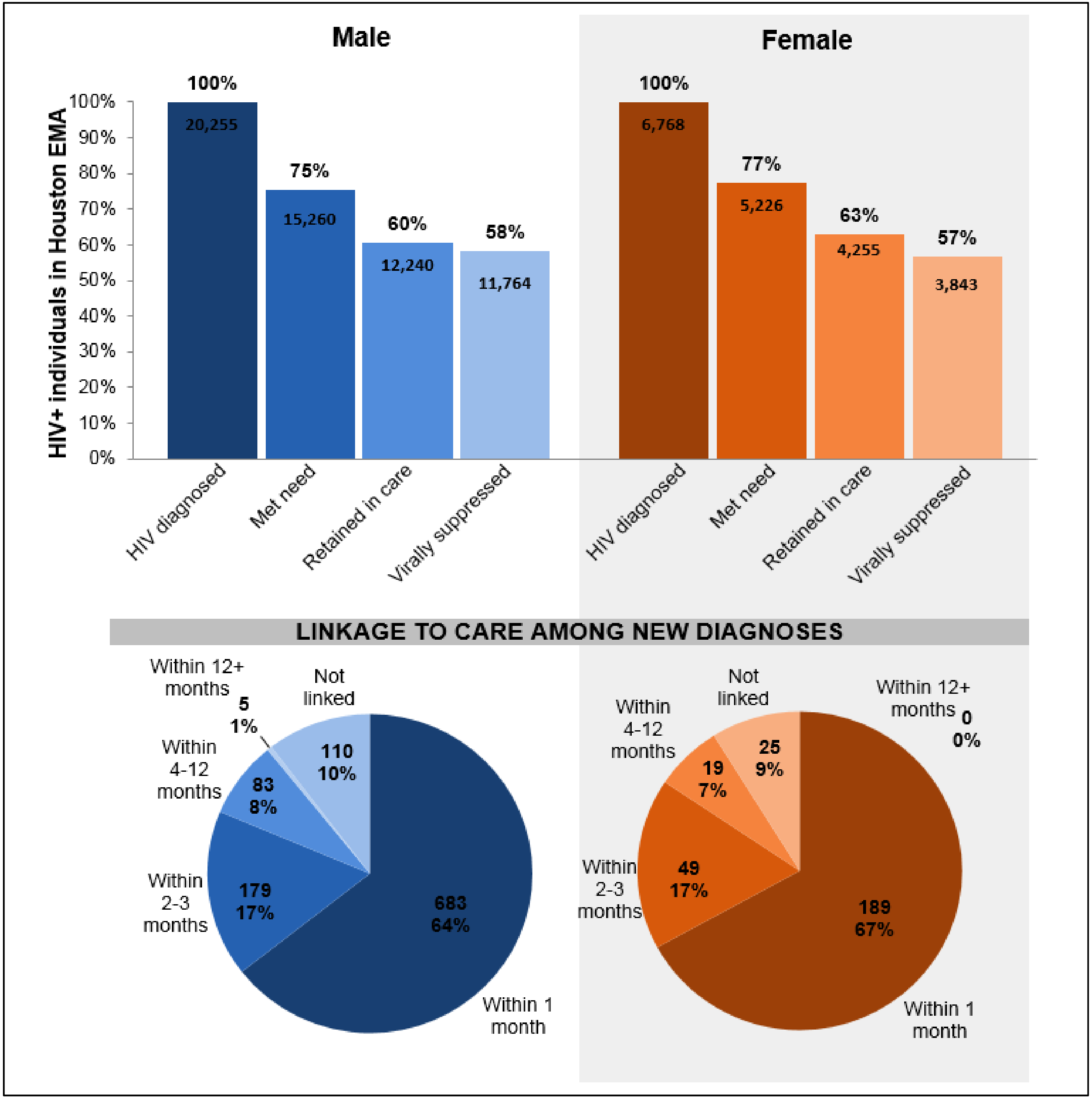


Source: Bureau of Epidemiology and Bureau of HIV/STD and Viral Hepatitis Prevention, Houston Health Department, 2017

- Younger adults had lower percentages of retention and viral suppression compared to older adults.
- Youth and young adults (13-24 years old) had the highest percentage of met need.
- Youth to middle age adults (13-44 years old) had the lowest proportion of newly diagnosed PLWH who were linked within three months of diagnosis when compared to the older adult age groups.

The Houston EMA Care Continuum, by Sex at Birth

Figure 3: Houston EMA HIV Care Continuum by Sex at Birth, 2016

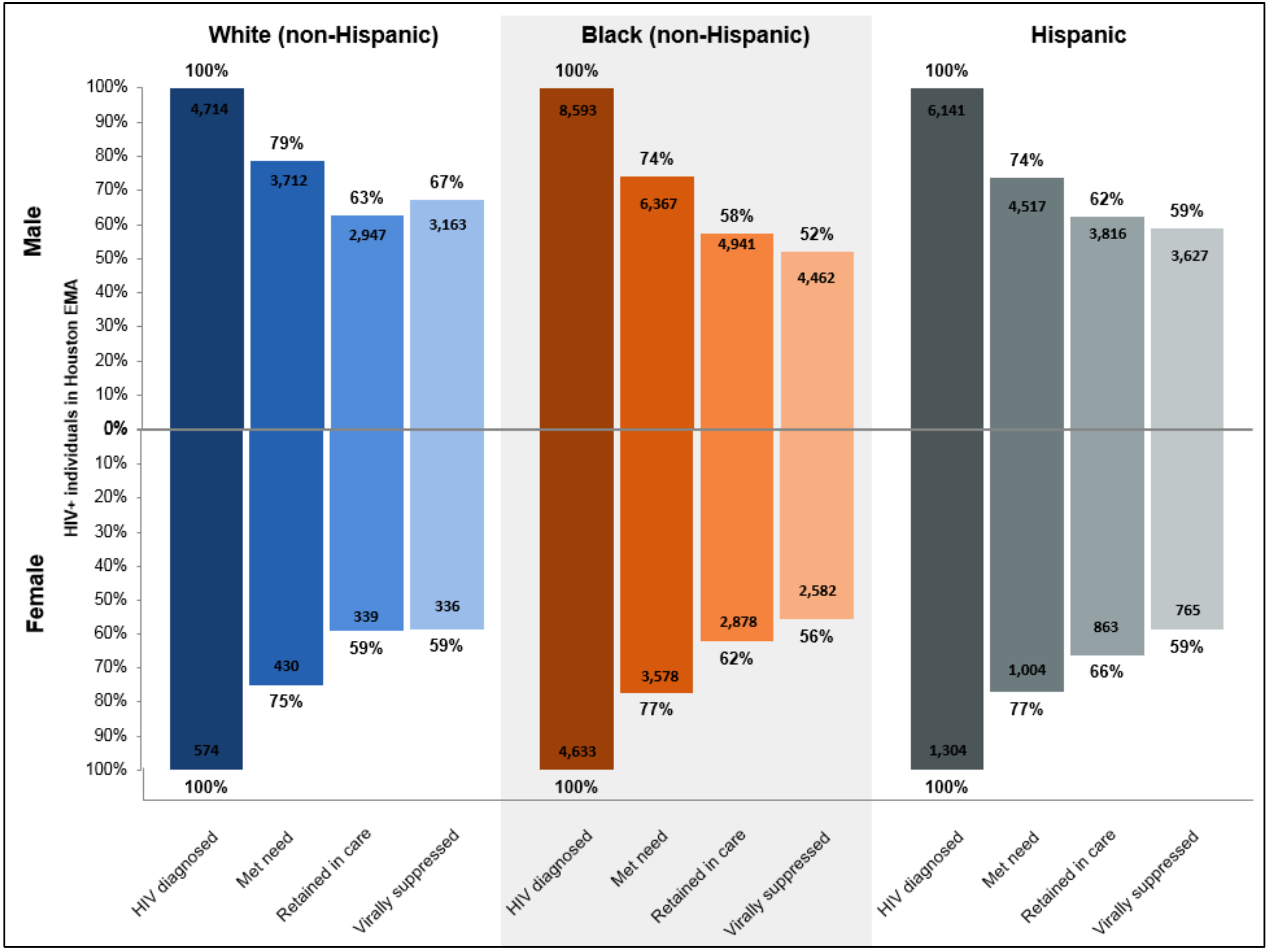


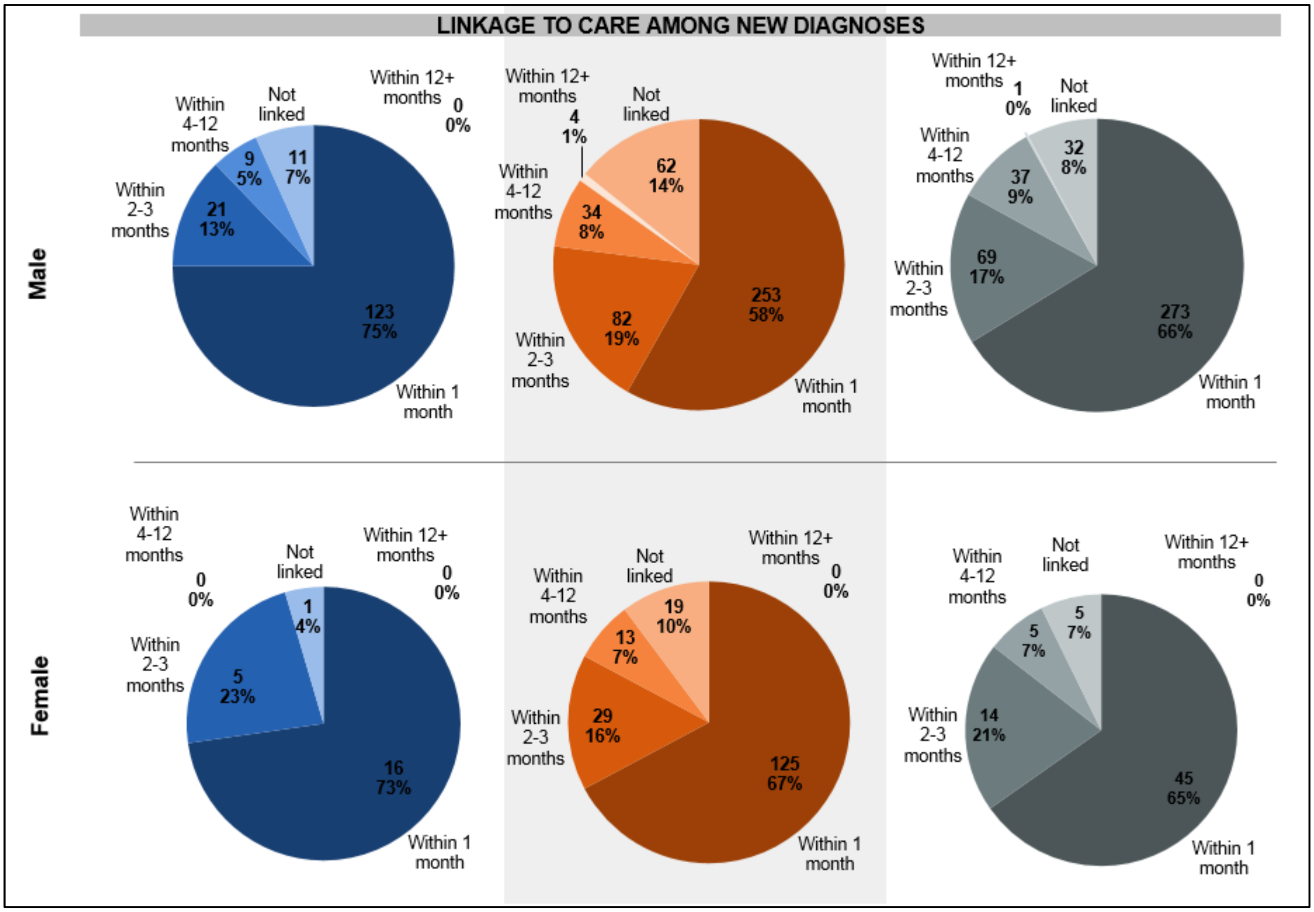
Source: Bureau of Epidemiology and Bureau of HIV/STD and Viral Hepatitis Prevention, Houston Health Department, 2017

- Females living with HIV in the Houston EMA in 2016 had a higher proportion of individuals with met need and retention in care than males living with HIV, although females had a slightly smaller proportion of viral suppression.
- The proportion of newly diagnosed female PLWH linked to care within the first month after diagnosis was 3% higher than males.

The Houston EMA Care Continuum, by Sex at Birth and Race/Ethnicity

Figure 4: Houston EMA HIV Care Continuum by Sex at Birth and Race/Ethnicity, 2016



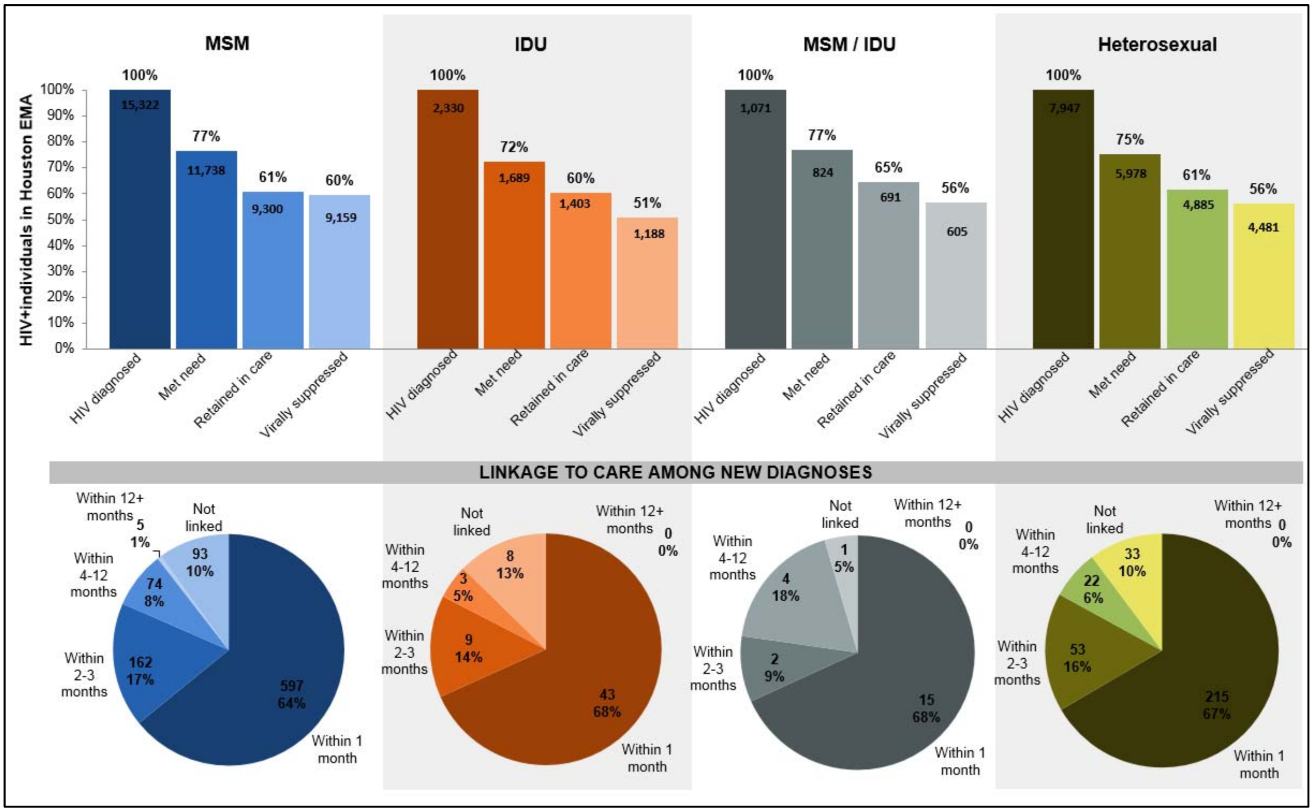


Source: Bureau of Epidemiology and Bureau of HIV/STD and Viral Hepatitis Prevention, Houston Health Department, 2017

- Hispanic and Black (non-Hispanic) males living with HIV had lower proportions of met need, retention in care, and viral suppression compared to White males in 2016.
- Among females, White (non-Hispanic) PLWH had the lowest proportion of individuals with evidence of met need and retention in care while Black (non-Hispanic) PLWH had the lowest proportion of individuals with evidence of viral suppression in 2016.
- Among those newly diagnosed with HIV, White (non-Hispanic) males and females had the highest proportion linked to care within 1 month of diagnosis
- **Overall, Black (non-Hispanic) males living with HIV had the lowest proportion of individuals in each care continuum stage across all birth sex and race/ethnicity groups.**

The Houston EMA Care Continuum, by Transmission Risk Factor*

Figure 5: **Houston EMA HIV Care Continuum by Transmission Risk Factor, 2016**



Source: Bureau of Epidemiology and Bureau of HIV/STD and Viral Hepatitis Prevention, Houston Health Department, 2017

***Transmission risk factors that are associated with increased risk of HIV exposure and transmission include men who have sex with men (MSM), injection drug use (IDU), MSM who also practice IDU (MSM/IDU), and heterosexual exposure.**

- Although MSM have higher numbers of PLWH than the other risk groups, the proportion of diagnosed MSM living with HIV with evidence of met need and retention in care is similar to those observed for other risk groups.
- MSM also have a higher proportion of diagnosed PLWH who are virally suppressed but a lower proportion of newly diagnosed PLWH who were successfully linked to care within one month of initial diagnosis.
- Those with IDU as a primary transmission risk factor exhibited the lowest proportions of individuals in each care continuum stage.

Questions about the Houston EMA HIV Care Continuum can be directed to: Amber Harbolt, Health Planner in the Office of Support: amber.harbolt@cjo.hctx.net

The methodology used to develop the Houston EMA HIV Care Continuum (HCC):

Measure	Description	Data source
HIV diagnosed	No. of persons diagnosed and living with HIV (PLWH) residing in Houston EMA through end of year (alive).	Texas eHARS data
Met need	No. (%) of PLWH in Houston EMA with met need (at least one: medical visit, ART prescription, or CD4/VL test) in year.	Texas Department of State Health Services HIV Unmet Need Project (incl. eHARS, ELR, ARIES, ADAP, Medicaid, private payer data)*
Linked to care (pie chart)	No. (%) of **newly diagnosed** PLWH in Houston EMA who were linked to medical care ("Met need") within N months of their HIV diagnosis.	
Retained in care	No. (%) of PLWH in Houston EMA with at least 2 medical visits, ART prescriptions, or CD4/VL tests in year, at least 3 months apart.	
Virally suppressed	No. (%) of PLWH in Houston EMA whose last viral load test of the year was ≤200 copies/mL.	Texas ELRs, ARIES labs, ADAP labs

★ ROADMAP ★

TO ENDING THE HIV EPIDEMIC IN HOUSTON

~December 2016~

Excerpt for How to Best Meet the Needs
Full document available at www.endhivhouston.org

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Access to Care

ACCESS TO CARE

The vision of the access to care work group is to ensure all residents of the Houston Area receive proactive and timely access to comprehensive and non-discriminatory care to prevent new diagnoses, and for those living with HIV/AIDS to achieve and maintain viral suppression.

Recommendation 1: Enhance the health care system to better respond to the HIV/AIDS epidemic

The ability of the local health care system to appropriately respond to the HIV/AIDS epidemic is a crucial component to ending the epidemic in Houston. FQHCs, in particular, represent a front line for providing comprehensive and appropriate access to care for people living with HIV/AIDS. While we acknowledge the commitment of many medical providers to provide competent care, ending the epidemic will require a more coordinated and focused response.

Ending the epidemic will require a more coordinated and focused response.

Some specific actions include:

- Develop a more coordinated and standard level of HIV prevention services and referrals for treatment, so that patients receive the same type and quality of services no matter where care is accessed.
- Integrate a women-centered care model approach to increase access to sexual and reproductive health services. Women-centered care meets the unique needs of women living with HIV and provides care that is non-stigmatizing, holistic, integrated, and gender-sensitive.
- Train more medical providers on the Ryan White care system.
- Explore feasibility of implementing a pilot rapid test and treat model, in which treatment would start immediately upon receipt of a positive HIV test.
- Better equip medical providers and case managers with training on best practices, latest developments in care and treatment, and opportunities for continuing education credits.
- Increase use of METRO Q® Fare Cards, telemedicine, mobile units, and other solutions to transportation barriers.
- Develop performance measures to improve community viral load as a means to improve health outcomes and decrease HIV transmission.
- Integrate access to support services such as Women, Infants and Children (WIC), food stamps, Children's Health Insurance Program (CHIP), and health literacy resources in medical settings.

Recommendation 2: Improve cultural competency for better access to care

Lack of understanding of the social and cultural norms of the community is one of the most cited barriers to care. These issues include race, culture, ethnicity, religion, language, poverty, sexual orientation and gender identity. Issues related to the lack of cultural competency are more often experienced by members of the very communities most impacted by HIV. Medical providers must improve their cultural understanding of the communities they serve in order to put the “care” back in health care. Individuals will not seek services in facilities they do not feel are designed for them or where they receive insensitive treatment from staff.

Develop cultural trainings in partnership with members of the community that address the specific cultural and social norms of the community.

Some specific actions include:

- Develop cultural trainings in partnership with members of the community that address the specific cultural and social norms of the community.
- Include training on interventions for trauma-informed care and gender-based violence. This type of care is a treatment framework that involves understanding, recognizing, and responding to the effects of all types of trauma that contribute to mental health issues including substance abuse, domestic violence, and child abuse.
- Establish measures to evaluate effectiveness of training.
- Revise employment applications to include questions regarding an applicant’s familiarity with the community being served. New hires with lack of experience working with certain communities should receive training prior to interacting with the community.

Recommendation 3: Increase access to mental health services and substance abuse treatment

Access to behavioral health and substance abuse treatment are two of the most critical unmet needs in the community. Individuals have difficulty staying in care and adhering to medication without access to mental health and substance abuse treatment. Comprehensive HIV/AIDS care must address the prevalence of these conditions.

Some specific actions include:

- Perform mental health assessments on newly diagnosed persons to determine readiness for treatment, the existence of an untreated mental health disorders, and need for substance abuse treatment.
- Increase the availability of mental health services and substance abuse treatment, including support groups and peer advocacy programs.
- Implement trauma-informed care in health care settings to respond to depression and post-traumatic stress disorders.

Increase the availability of mental health services and substance abuse treatment.

Recommendation 4: Improve health outcomes for people living with HIV/AIDS with co-morbidities

Because of recent scientific advances, people living with HIV/AIDS, who have access to antiretroviral therapy, are living long and healthy lives. HIV/AIDS is now treated as a manageable chronic illness and is no longer considered a death sentence. However, these individuals are developing other serious health conditions that may cause more complications than the virus. Some of these other conditions include Hepatitis C, hypertension, diabetes, and certain types of cancer. When coupled with an HIV diagnosis, these additional conditions are known as co-morbidities. HIV treatment must address the impact of co-morbidities on treatment of HIV/AIDS.

Some specific actions include:

- Utilize a multi-disciplinary approach to ensure that treatment for HIV/AIDS is integrated with treatment for other health conditions.
- Develop treatment literacy programs and medication adherence support programs for people living with HIV/AIDS to address co-morbidities.

Recommendation 5: Develop and publicize complete and accurate data for transgender people and those recently released from incarceration

There is insufficient data to accurately measure the prevalence and incidence of HIV among transgender individuals. In addition, there appears to be a lack of data on those recently released from incarceration. We need to develop data collection protocols to improve our ability to define the impact of the epidemic on these communities.

Recommendation 6: Streamline the Ryan White eligibility process for special circumstances

The Ryan White program is an important mechanism for delivering services to individuals living with HIV/AIDS. In order to increase access to this program, we must remove barriers to enrollment for qualified individuals experiencing special situations. We recommend creating a fast track process for Ryan White eligibility determinations for special circumstances, such as when an individual has recently relocated to Houston and/or has fallen out of care.

Recommendation 7: Increase access to care for diverse populations

According to the 2016 Kinder Houston Area Survey, the Houston metropolitan area has become "the single most ethnically and culturally diverse urban region in the entire country." Between 1990 and 2010, the Hispanic population grew from 23% to 41%, and Asians and others from 4% to 8%. It is imperative that we meet the needs of an increasingly diverse populace.[10]

Some specific actions include:

- Train staff and providers on culturally competent care.
- Hire staff who represent the communities they serve.
- Increase access to interpreter services.
- Develop culturally and linguistically appropriate education materials.
- Market available services directly to immigrant communities.

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[10] https://kinder.rice.edu/uploadedFiles/Center_for_the_Study_of_Houston/53067_Rice_HoustonAreaSurvey2016_Lowres.pdf

ROADMAP
TO ENDING THE HIV EPIDEMIC IN HOUSTON

~December 2016~

endhivhouston.org

PARTICIPANT COMPOSITION

The following summary of the geographic, demographic, socio-economic, and other composition characteristics of individuals who participated in the 2016 Houston HIV Care Services Needs Assessment provides both a "snapshot" of who is living with HIV in the Houston Area today as well as context for other needs assessment results.

(**Table 1**) Overall, 93% of needs assessment participants resided in Harris County at the time of data collection. The majority of participants were male (67%), African American/Black (63%), and heterosexual (54%). Greater than half were age 50 or over, with a median age of 50-54.

The average unweighted household income of participants was $9,380 annually, with the majority living below 100% of federal poverty (**FPL**). Most participants paid for healthcare using Medicaid/Medicare and assistance through Harris Health System (Gold Card).

TABLE 1-Select Participant Characteristics, Houston Area HIV Needs Assessment, 2016

	No.	%		No.	%		No.	%
County of residence			Age range (median: 50-54)			Sex at birth		
Harris	464	93.4%	13 to 17	1	0.2%	Male	341	67.3%
Fort Bend	21	4.2%	18 to 24	17	3.4%	Female	166	37.7%
Liberty	1	0.2%	25 to 49	219	43.2%	Intersex	0	-
Montgomery	6	1.2%	50 to 54	123	24.3%	Transgender	20	3.9%
Other	5	1.0%	55 to 64	133	26.2%	Currently pregnant	1	0.2%
			≥65	14	2.8%			
			Seniors (≥50)	270	53.3%			
Primary race/ethnicity			Sexual orientation			Health insurance		
White	60	11.8%	Heterosexual	274	54.0%	Private insurance	53	8.6%
African American/Black	318	62.7%	Gay/Lesbian	171	33.7%	Medicaid/Medicare	307	49.8%
Hispanic/Latino	121	23.9%	Bisexual	39	7.7%	Harris Health System	146	23.7%
Asian American	5	1.0%	Other	23	4.5%	Ryan White	105	17.0%
Other/Multiracial	3	0.6%	MSM	216	42.6%	None	6	1.0%
Immigration status			Yearly income (average: $9,380)					
Born in the U.S.	427	84.6%	Federal Poverty Level (FPL)					
Citizen > 5 years	33	6.5%	Below 100%	278	78.8%			
Citizen < 5 years	4	0.8%	100%	45	12.7%			
Undocumented	10	2.0%	150%	13	3.7%			
Prefer not to answer	22	4.4%	200%	10	2.8%			
Other	9	1.8%	250%	2	0.6%			
			≥300%	5	1.4%			

(**Table 2**) Certain subgroups of PLWH have been historically underrepresented in HIV data collection, thereby limiting the ability of local communities to address their needs in the data-driven decision-making processes of HIV planning. To help mitigate underrepresentation in Houston Area data collection, efforts were made during the 2016 needs assessment process to *oversample* PLWH who were also members of groups designated as "special populations" due to socio-economic circumstances or other sources of disparity in the HIV service delivery system.

The results of these efforts are summarized in Table 2.

TABLE 2-Representation of Special Populations, Houston Area HIV Needs Assessment, 2016

	No.	%
Unstable Housing	142	28.0%
Injection drug users (IDU)*	8	1.6%
Men who have sex with men (MSM)	216	42.6%
Not retained in care (last 6 months)	4	0.8%
Recently released from incarceration	41	8.1%
Rural (non-Harris County resident)	33	6.4%
Transgender	20	3.9%

*See Limitations section for further explanation of identification of IDU

Chapter 2:
Service Needs and Barriers

OVERALL SERVICE NEEDS AND BARRIERS

As payer of last resort, the Ryan White HIV/AIDS Program provides a spectrum of HIV-related services to people living with HIV (**PLWH**) who may not have sufficient resources for managing HIV disease. The Houston Area HIV Services Ryan White Planning Council identifies, designs, and allocates funding to locally-provided HIV care services. Housing services for PLWH are provided through the federal Housing Opportunities for People with AIDS (**HOPWA**) program through the City of Houston Housing and Community Development Department. The primary function of HIV needs assessment activities is to gather information about the need for and barriers to services funded by the local Houston Ryan White HIV/AIDS Program, as well as other HIV-related programs like HOPWA and the Houston Health Department's (**HHD**) prevention program.

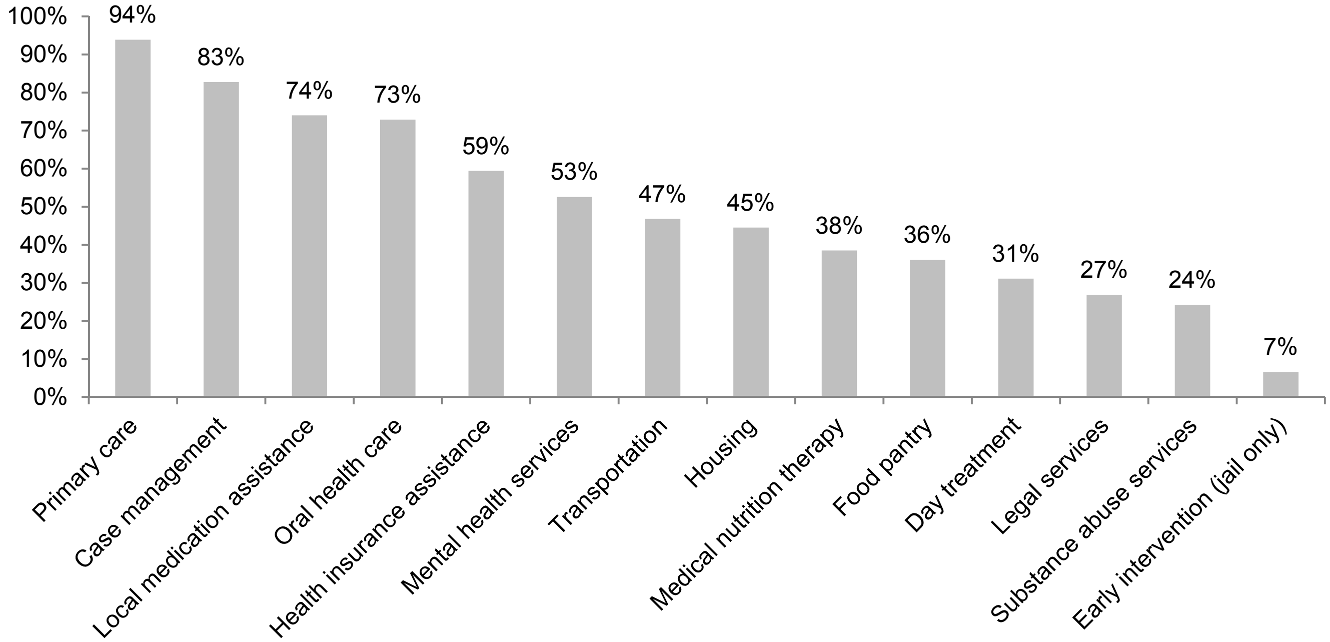
Overall Ranking of Funded Services, by Need

In 2016, 15 HIV core medical and support services were funded through the Houston Area Ryan White HIV/AIDS Program, and housing services were provided through the local HOPWA program. Though no longer funded through the Ryan White HIV/AIDS Program, Food Pantry was also assessed. Participants of the 2016 Houston HIV Care Services Needs Assessment were asked to indicate which of these funded services they needed in the past 12 months.

(**Graph 1**) All funded services except hospice and linguistics were analyzed and received a ranking of need. At 94%, primary care was the most needed funded service in the Houston Area, followed by case management at 83%, local medication assistance at 74%, and oral health care at 73%. Primary care had the highest need ranking of any core medical service, while transportation received the highest need ranking of any support service. Compared to the last Houston Area HIV needs assessment conducted in 2014, need ranking increased for many core medical services, and decreased for most support services. The percent of needs assessment participants reporting need for a particular service decreased the most for food pantry, housing, and medical nutrition therapy, while the percent of those indicating a need for health insurance assistance increased 12 percentage points from 2014, the most of any service measured.

GRAPH 1-Ranking of HIV Services in the Houston Area, By Need, 2016

Definition: Percent of needs assessment participants stating they needed the service in the past 12 months, regardless of service accessibility. Denominator:



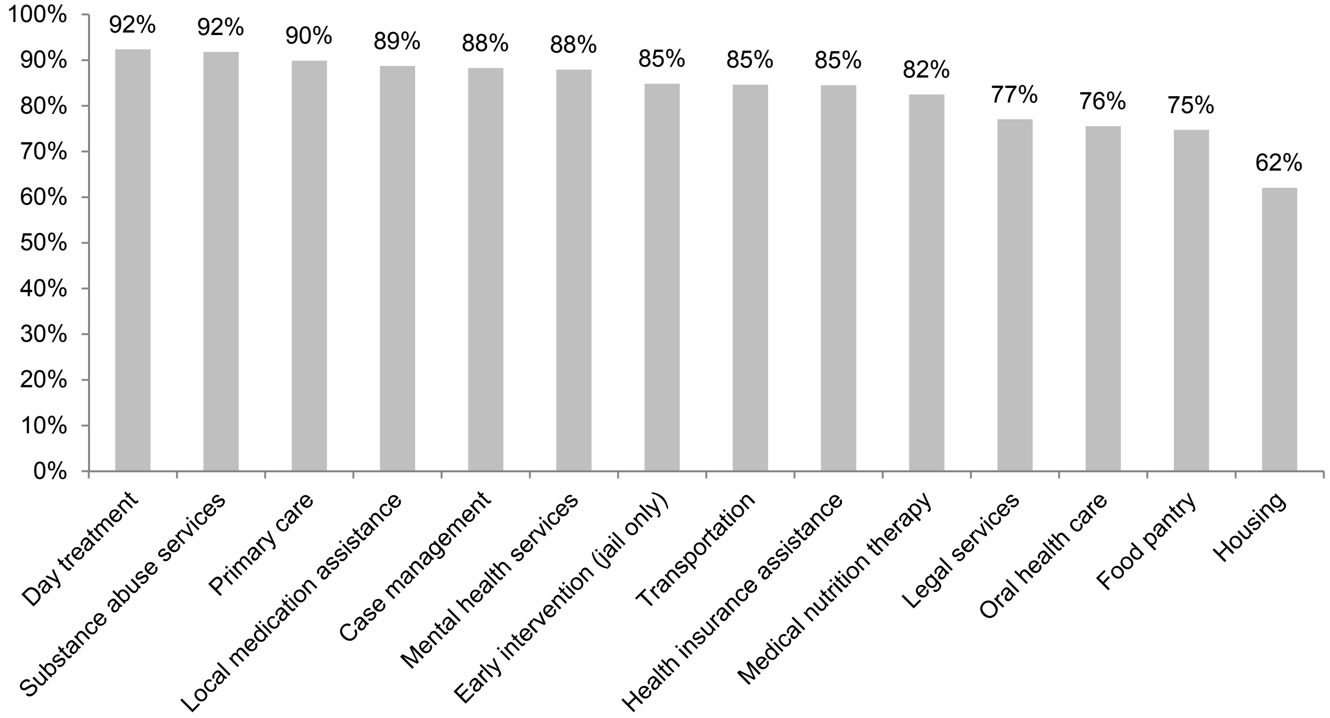
Overall Ranking of Funded Services, by Accessibility

Participants of the 2016 Houston HIV Care Services Needs Assessment were asked to indicate if each of the funded Ryan White HIV/AIDS Program services they needed in the past 12 months was easy or difficult for them to access. If difficulty was reported, participants were then asked to provide a brief description on the barrier experienced. Results for both topics are presented below.

(**Graph 2**) All funded services except hospice and linguistics were analyzed and received a ranking of accessibility. The two most accessible services were day treatment and substance abuse services at 92% ease of access, followed by primary care at 90% and local medication assistance at 89%. Day treatment had the highest accessibility ranking of any core medical service, while transportation received the highest accessibility ranking of any support service. Compared 2014 needs assessment, reported accessibility increased for each service category, with an average increase of 9 percentage points. The greatest increase in percent of participants reporting ease of access was observed in early intervention services, while transportation experienced the lowest increase in accessibility.

GRAPH 2-Ranking of HIV Services in the Houston Area, By Accessibility, 2016

Definition: Of needs assessment participants stating they needed the service in the past 12 months, the percent stating it was easy to access the service.



Overall Ranking of Barriers Types Experienced by Consumers

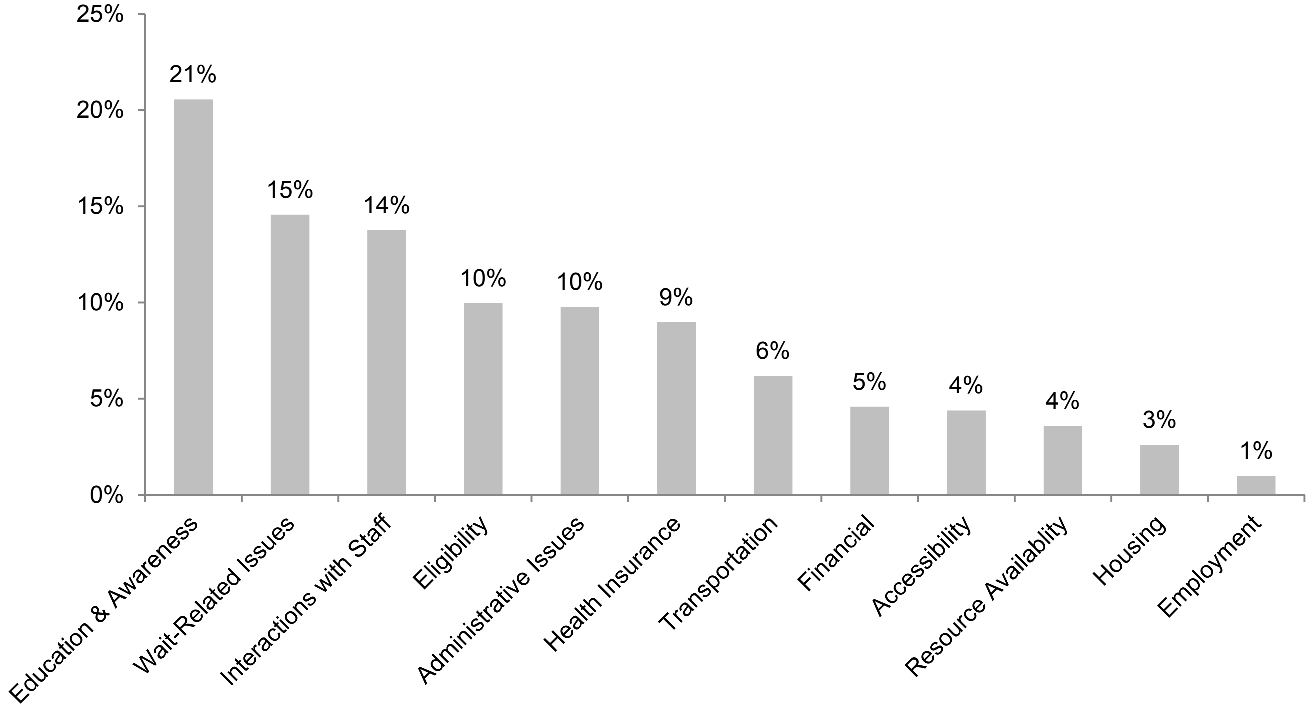
For the first time in the Houston Area HIV Needs Assessment process, participants who reported *difficulty* accessing needed services were asked to provide a brief description of the barrier or barriers encountered, rather than select from a list of pre-selected barriers. Recursive abstraction was used to categorize participant descriptions into 39 distinct barriers. These barriers were then grouped together into 12 nodes, or barrier types.

(**Graph 3**) Overall, the barrier types reported most often related to service education and awareness issues (21% of all reported barriers); wait-related issues (15%); interactions with staff (14%); eligibility issues (10%); and administrative issues (10%). Employment concerns were reported least often (1%). Due to the change in methodology for barrier assessment between the 2014 and 2016 HIV needs assessments, a comparison of the change in number of reports of barriers will not be available until the next HIV needs assessment.

For more information on barrier types reported most often by service category, please see the Service-Specific Fact Sheets.

GRAPH 3-Ranking of Types of Barriers to HIV Services in the Houston Area, 2016

Definition: Percent of times each barrier type was reported by needs assessment participants, regardless of service, when difficulty accessing needed services was reported.



Descriptions of Barriers Encountered

All funded services were reported to have barriers, with an average of 33 reports of barriers per service. Participants reported the least barriers for Hospice (two barriers) and the most barriers for Oral Health Care (86 barriers). In total, 525 reports of barriers across all services were indicated in the sample.

(**Table 1**) Within education and awareness, knowledge of the availability of the service and where to go to access the service accounted for 82% barriers reported. Being put on a waitlist accounted for a majority (66%) of wait-related issues barriers. Poor communication and/or follow up from staff members when contacting participants comprised a majority (51%) of barriers related to staff interactions. Almost all (86%) of eligibility barriers related to participants being told they did not meet eligibly requirements to receive the service or difficulty obtaining the required documentation to establish eligibility. Among administrative issues, long or complex processes required to obtain services sufficient to create a burden to access comprised most (59%) the barriers reported.

Most (84%) of health insurance-related barriers occurred because the participant was uninsured or underinsured and experiencing coverage gaps for needed services or medications. The largest proportion (81%) of transportation-related barriers occurred when participants had no access to transportation. It is notable that multiple participants reported losing bus cards and the difficulty of replacing the cards presented a barrier to accessing other services. Inability to afford the service accounted for all barriers relating to participant financial resources. The service being offered at a distance that was inaccessible to participants or being recently released from incarceration accounted for most (77%) of accessibility-related barriers, though it is worth note that low or no literacy accounted for 14% of accessibility-related barriers. Receiving resources that were insufficient to meet participant needs accounted for most resource availability barriers. Homelessness accounted for virtually all housing-related barriers. Instances in which the participant's employer did not provide sufficient sick/wellness leave for attend appointments comprised most (60%) employment-related barriers.

TABLE 1-Barrier Proportions within Each Barrier Type, 2016

Education & Awareness	%	Wait-Related Issues	%	Interactions with Staff	%
Availability (Didn't know the service was available)	50%	**Waitlist** (Put on a waitlist)	66%	**Communication** (Poor correspondence/ Follow up from staff)	51%
Definition (Didn't know what service entails)	7%	**Unavailable** (Waitlist full/not available resulting in client not being placed on waitlist)	15%	**Poor Treatment** (Staff insensitive to clients)	17%
Location (Didn't know where to go [location or location w/in agency])	32%	**Wait at Appointment** (Appointment visits take long)	7%	**Resistance** (Staff refusal/ resistance to assist clients)	13%
Contact (Didn't know who to contact for service)	11%	**Approval** (Long durations between application and approval)	12%	**Staff Knowledge** (Staff has no/ limited knowledge of service)	7%
				Referral (Received service referral to provider that did not meet client needs)	17%
Eligibility	%	Administrative Issues	%	Health Insurance	%
Ineligible (Did not meet eligibility requirements)	48%	**Staff Changes** (Change in staff w/o notice)	12%	**Uninsured** (Client has no insurance)	53%
Eligibility Process (Redundant process for renewing eligibility)	16%	**Understaffing** (Shortage of staff)	2%	**Coverage Gaps** (Certain services/medications not covered)	31%
Documentation (Problems obtaining documentation needed for eligibility)	38%	**Service Change** (Change in service w/o notice)	10%	**Locating Provider** (Difficulty locating provider that takes insurance)	13%
		Complex Process (Burden of long complex process for accessing services)	59%	**ACA** (Problems with ACA enrollment process)	17%
		Dismissal (Client dismissal from agency)	4%		
		Hours (Problem with agency hours of operation)	16%		
Transportation		Financial	%	Accessibility	%
No Transportation (No or limited transportation options)	81%	**Financial Resources** (Could not afford service)	100%	**Literacy** (Cannot read/difficulty reading)	14%
Providers (Problems with special transportation providers such as Metrolift or Medicaid transportation)	19%			**Spanish Services** (Services not made available in Spanish)	9%
				Released from Incarceration (Restricted from services due to probation, parole, or felon status)	32%
				Distance (Service not offered within accessible distance)	45%
Resource Availability	%	Housing	%	Employment	%
Insufficient (Resources offered insufficient for meeting need)	56%	**Homeless** (Client is without stable housing)	100%	**Unemployed** (Client is unemployed)	40%
Quality (Resource quality was poor)	44%	**IPV** (Interpersonal domestic issues make housing situation unsafe)	0%	**Leave** (Employer does not provide sick/wellness leave for appointments)	60%

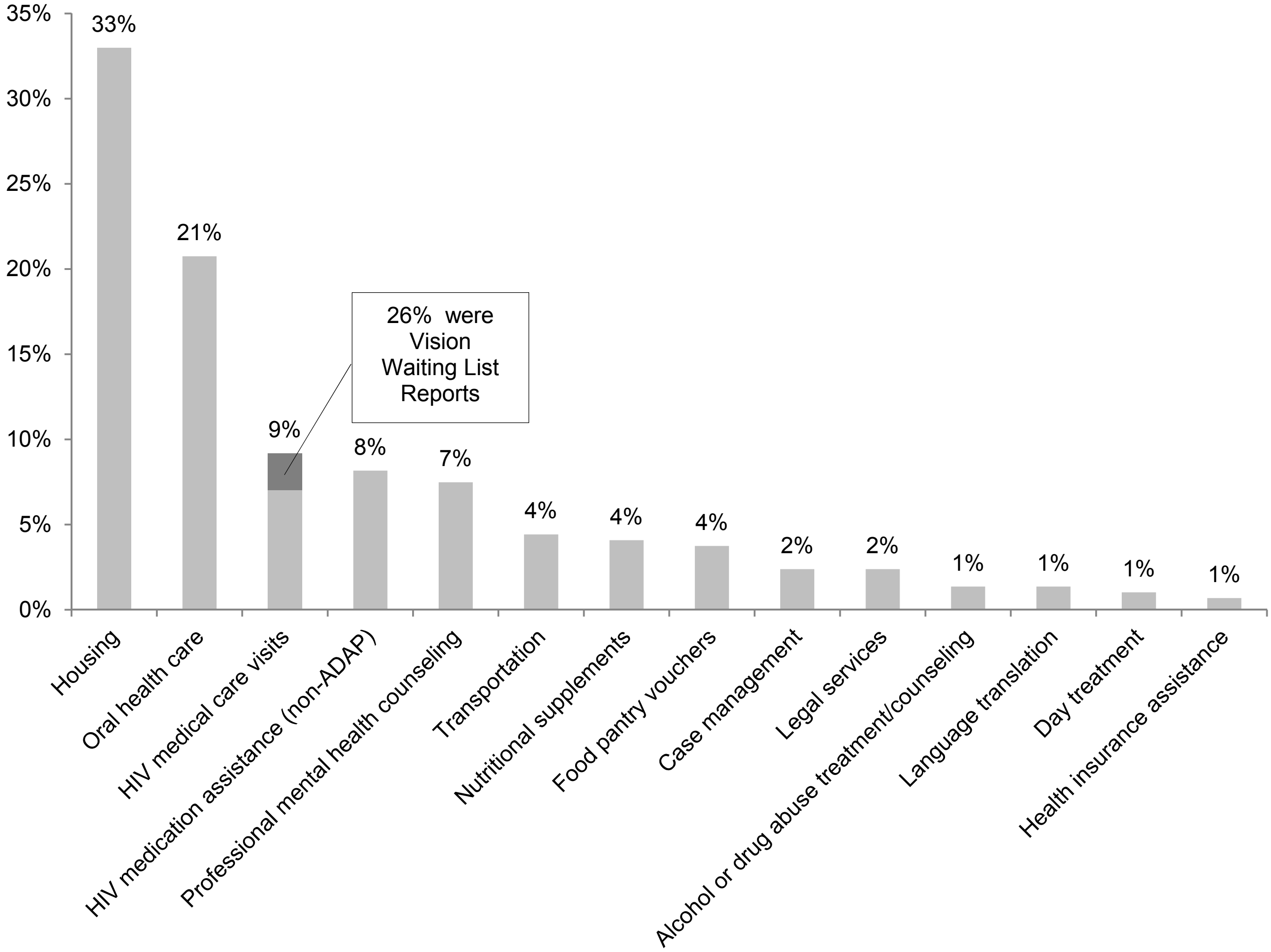
Waiting List Barriers and Experiences

In February 2014, the Ryan White Planning Council formed the ad-hoc Waiting List Workgroup to evaluate the extent to which waiting and waitlists impact the receipt of HIV care and treatment services in the Houston Area, and propose ways to address wait-related issues through changes to the HIV care and treatment system. With input from the Waiting List Workgroup, the 2016 Houston HIV Care Services Needs Assessment included questions specifically designed to elicit information from participants about which services they had been placed on a waiting list for in the past 12 months, the time period between first request for a service and eventual receipt of the service, awareness of other providers of waitlisted services, and services for which clients reported being placed on a waitlist more than once. Thirty-nine percent (39%) of participants indicated that they had been placed on a waiting list for at least one service in the past 12 months.

(**Graph 4**) A third of participant reports of being on a waiting list were for housing services. This was followed by oral health care (21%), HIV medical care (9%), local medication assistance (8%), and professional mental health counseling (7%). Of all participants reporting being on a wait list for HIV medical care visits, 26% indicated being placed on a waiting list specifically for vision services. There were no reports of participants being placed on a wait list for hospice or pre-discharge planning.

GRAPH 4-Percentage of Waiting List Reports by Service, 2016

Definition: Percent of times needs assessment participants reported being on a waiting list for each service.

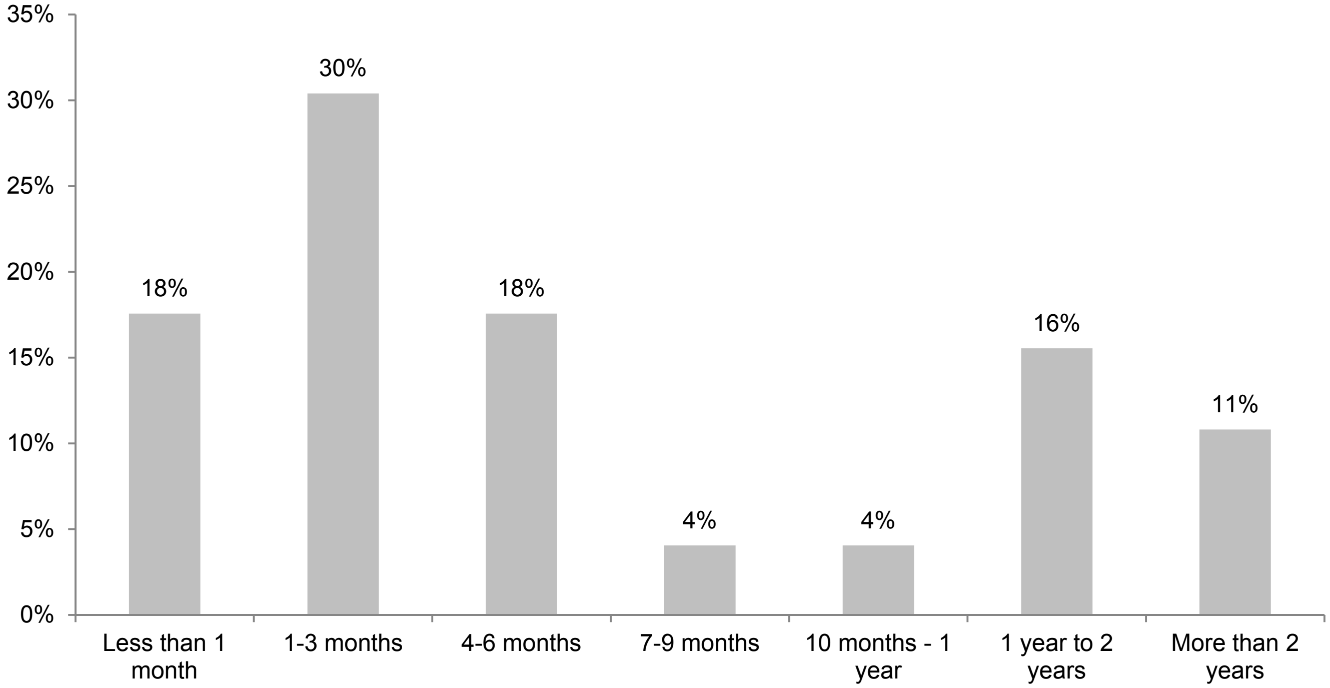


(**Graph 5**) Participant reports of time elapsed from the initial request for a service until receipt of the service vary from 1 day to over 2 years. The greatest number of reports of time elapsed occurred for wait times between one and three months (30%), followed by less than one month (18%) and four to six months 18%).

Most wait times reported for housing services occurred for one to three months (26%), one to two years (26%), or 10 months to one year (18%). It is worth noting that 8% of participants reporting a wait time for housing services had over two years elapse between first request and receipt of service, with several expressing that they were on a housing wait list at the time of survey. Most reports of wait times for oral health care were less than one month (26%) or four to six months (26%). However, 14% of participants indicating a wait time for oral health care services reported wait times of over one year. Finally, most participants (64%) indicating wait times for HIV medical care including vision services reported waiting one to three months.

GRAPH 5-Percentage of Wait Times Reports, 2016

Definition: Percent of times needs assessment participants reported time elapsed from the initial request for a service until receipt of the service each time period.



Awareness of other providers for services operating waiting lists can offer timely service to consumers with acute needs and reduce wait times for those remaining on wait lists. A majority (83%) of participants who reported being on a wait list for at least one in the past 12 months stated that they were not aware of another provider of the service for which they were waiting, or did not remember if they were aware of another provider. Of the remaining 35% of participants who were aware of another provider, over half (59%) reported not seeking service from the alternative provider.

Nearly one-third of participants who reported being placed on a wait list in the past 12 months also reported having been placed on a wait list for the service more than once. This was observed primarily for among participants reporting being placed on a wait list for housing services (34%) and oral health care (29%).

Other Identified Needs

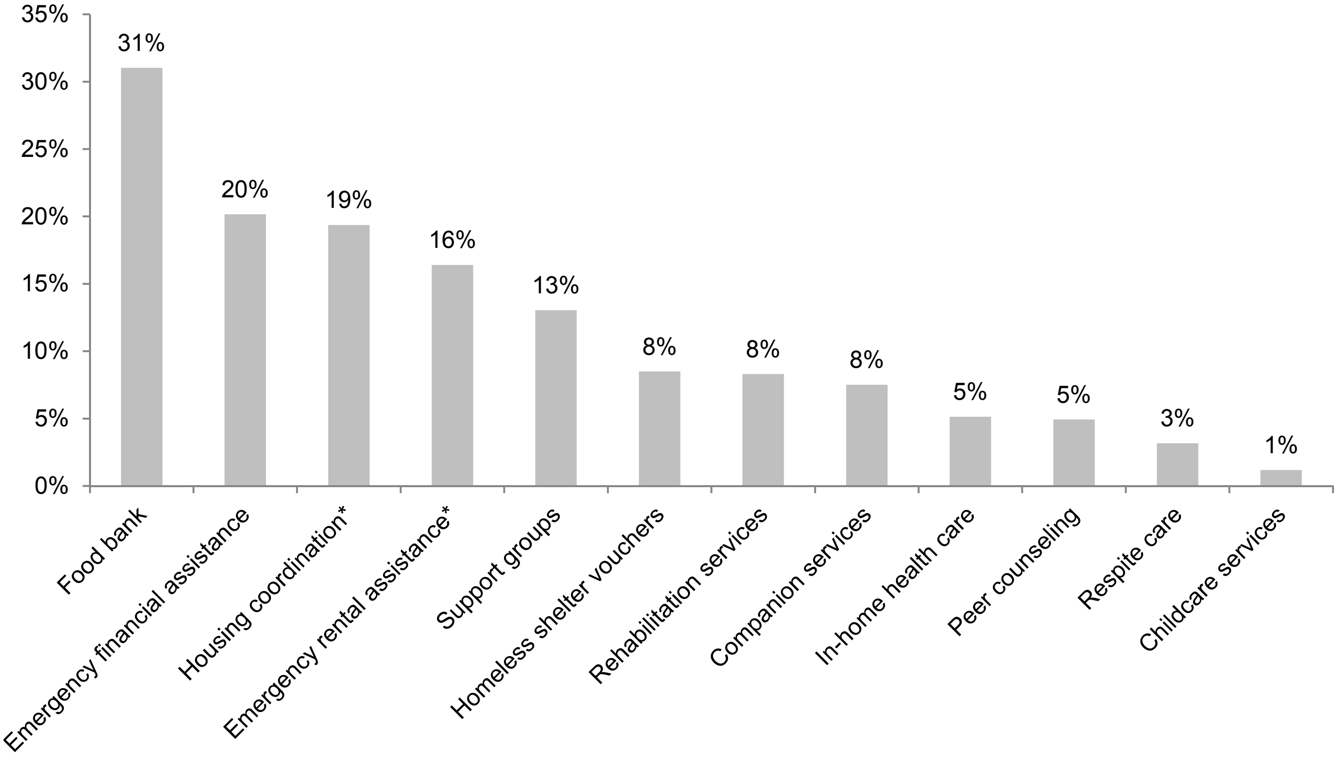
In addition to the HIV services listed above, there are other services allowable for funding by the Ryan White HIV/AIDS Program in local communities if there is a demonstrated need. Several of these other services have been funded by the Ryan White Program in the Houston Area in the past. The 2016 Houston HIV Care Services Needs Assessment measured the need for these services to order to gauge any new or emerging service needs in the community. In addition, some of these services are currently funded through other HIV-specific non-Ryan White sources, namely housing-related services provided by the Housing Opportunities with People with AIDS (HOPWA) program, as indicated.

(**Graph 6**) Twelve other/non-Ryan White funded HIV-related services were assessed to determine emerging needs for Houston Area PLWH. Participants were also encouraged to write-in other types of needed services. Of the 12 services options provided, 31% of participant selected food bank was needed services, a decrease of 14 percentage points from the 2014 needs assessment. Emergency financial assistance was selected second (20%), followed by housing-related services cited third (20%) and fourth (16%), and support groups cited fifth (13%).

Services that were written-in most often as a need (and that are not currently funded by Ryan White) were (*in order*): employment assistance and job training, vision hardware/glasses, and services for spouses/partners.

GRAPH 6-Other Needs for HIV Services in the Houston Area, 2016

Definition: Percent of needs assessment participants, who selected each service in response to the survey question, "What other kinds of services do you need to help you get your HIV medical care?"



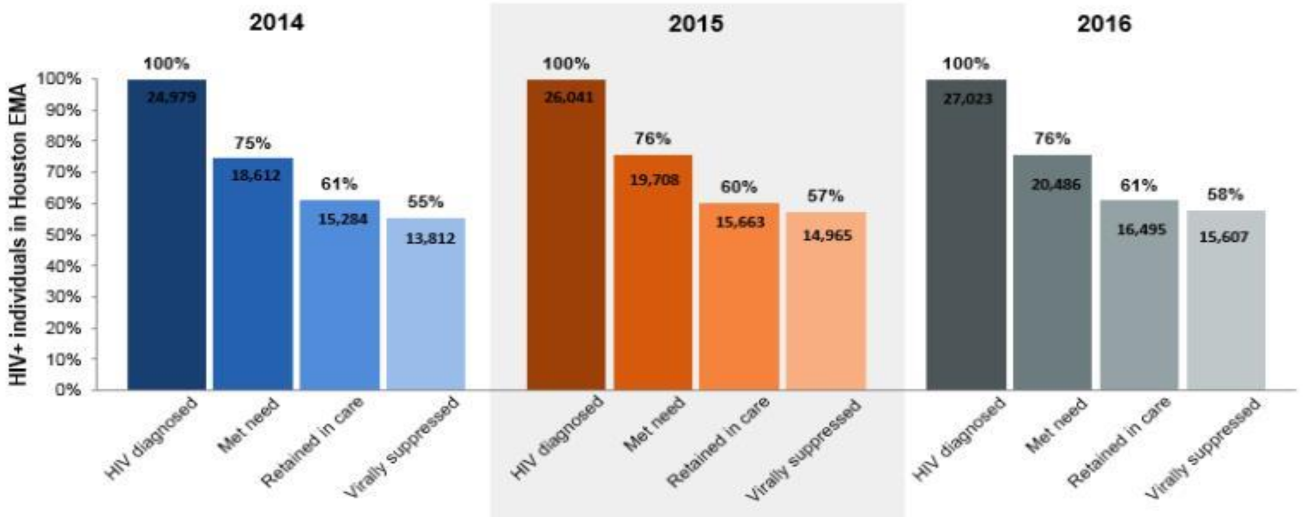
*These services are not currently funded by the Ryan White program; however, they are available through the Housing Opportunities for People with AIDS (HOPWA) program.

Retention in Care – Houston Area

Epidemiologic Data

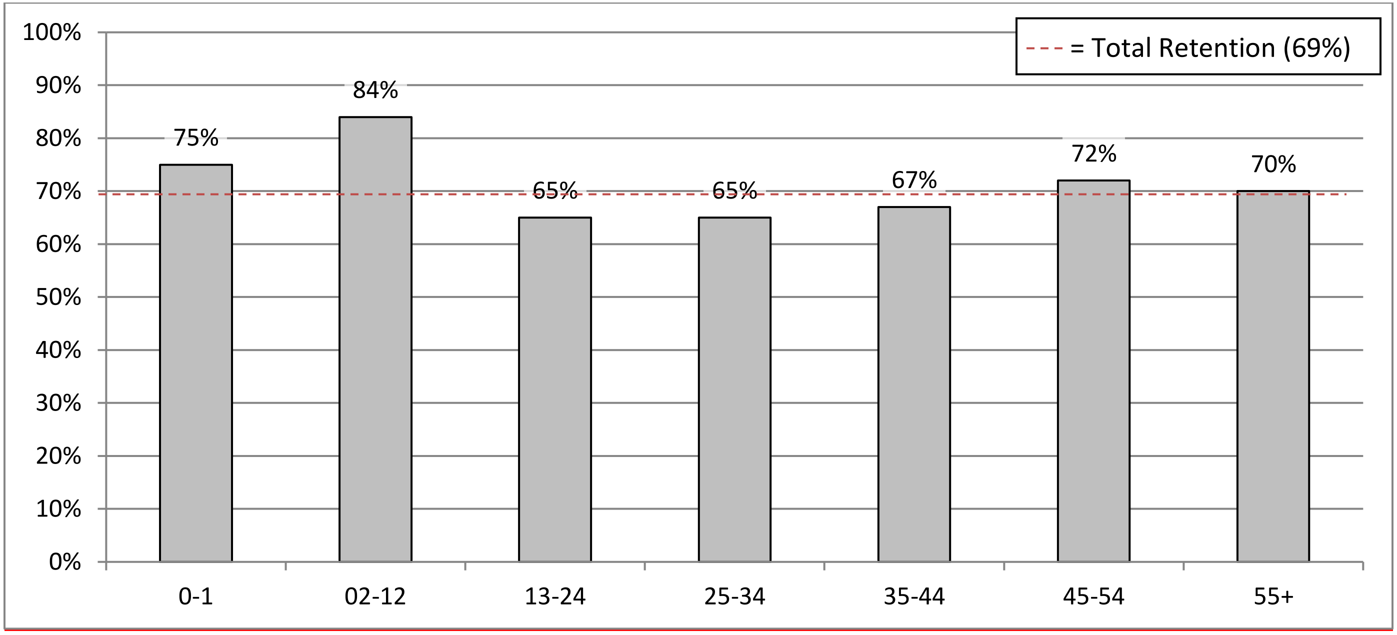
- 76% of diagnosed PLWH in the Houston EMA were ***in care*** (at least one: medical visit, ART prescription, VL test, or CD4 test) at the end of 2016
    - 61% of diagnosed PLWH in the Houston EMA were ***retained*** in care (at least 2 visits or labs, at least 3 months apart) at the end of 2016. This proportion increases to 69% when PLWH who were virally suppressed at the end of 2016 but did not meet formal retention measures are included.
- 58% of diagnosed PLWH in the Houston EMA reached ***viral suppression*** by the end of 2016

Houston EMA HIV Care Continuum, 2014-2016



Source: Bureau of Epidemiology and Bureau of HIV/STD and Viral Hepatitis Prevention, Houston Health Department, 2017

Houston EMA Retention[1] by Age Range, 2016



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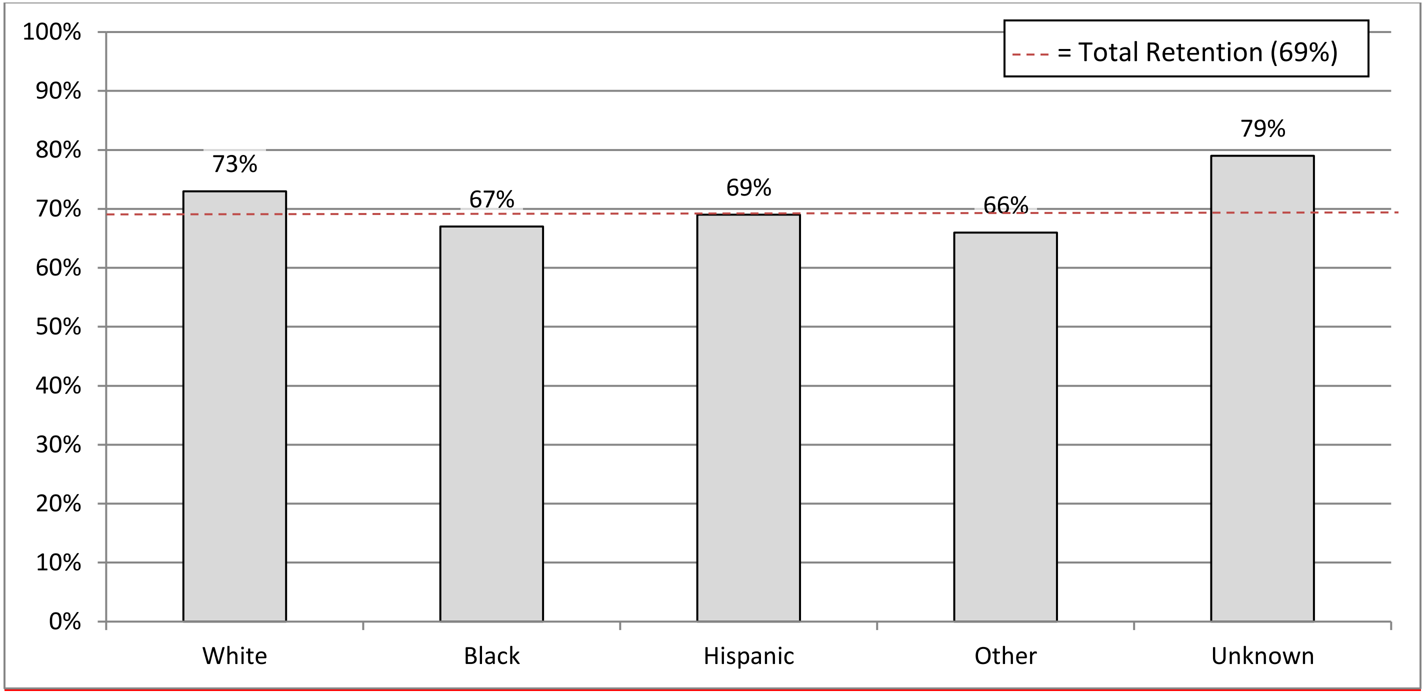
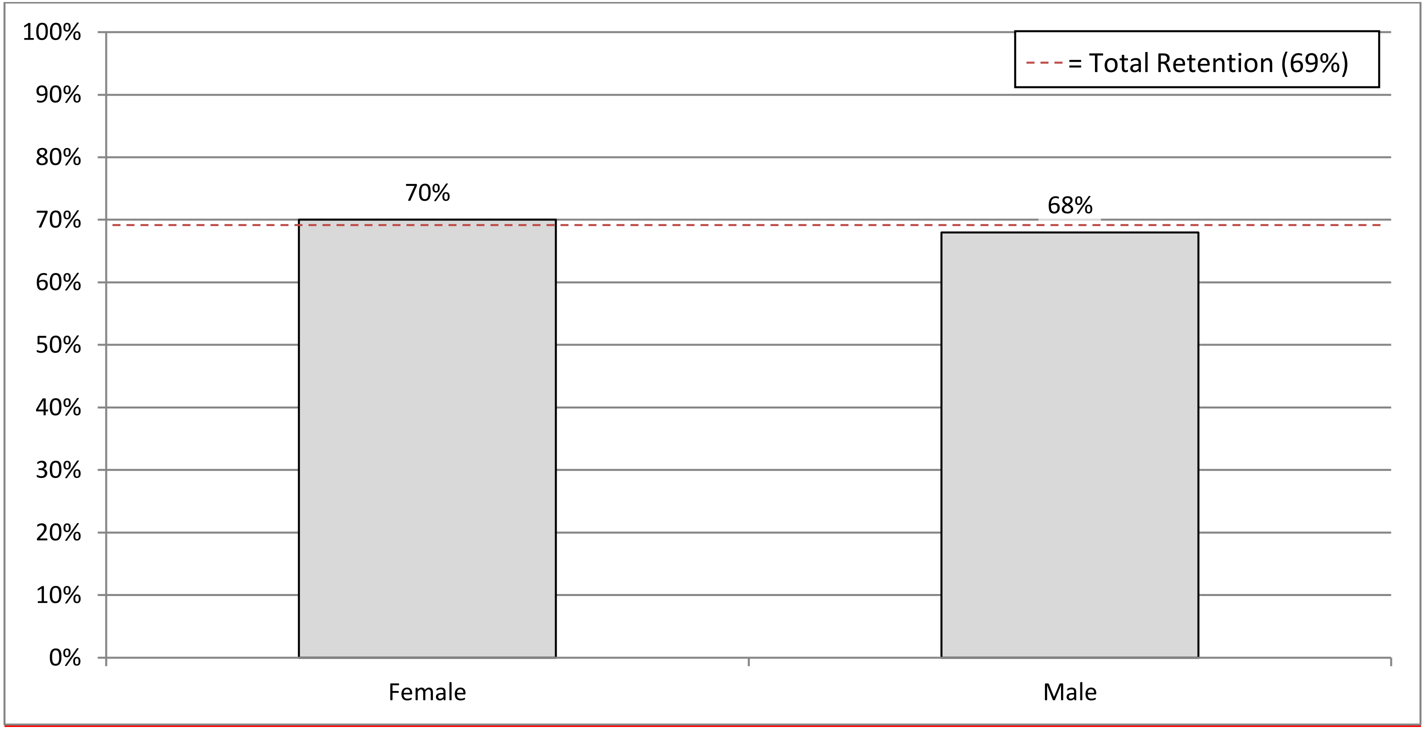
[1] Includes viral suppression

Houston EMA Retention[2] by Race/Ethnicity, 2016



Houston EMA Retention[3] by Sex at Birth, 2016



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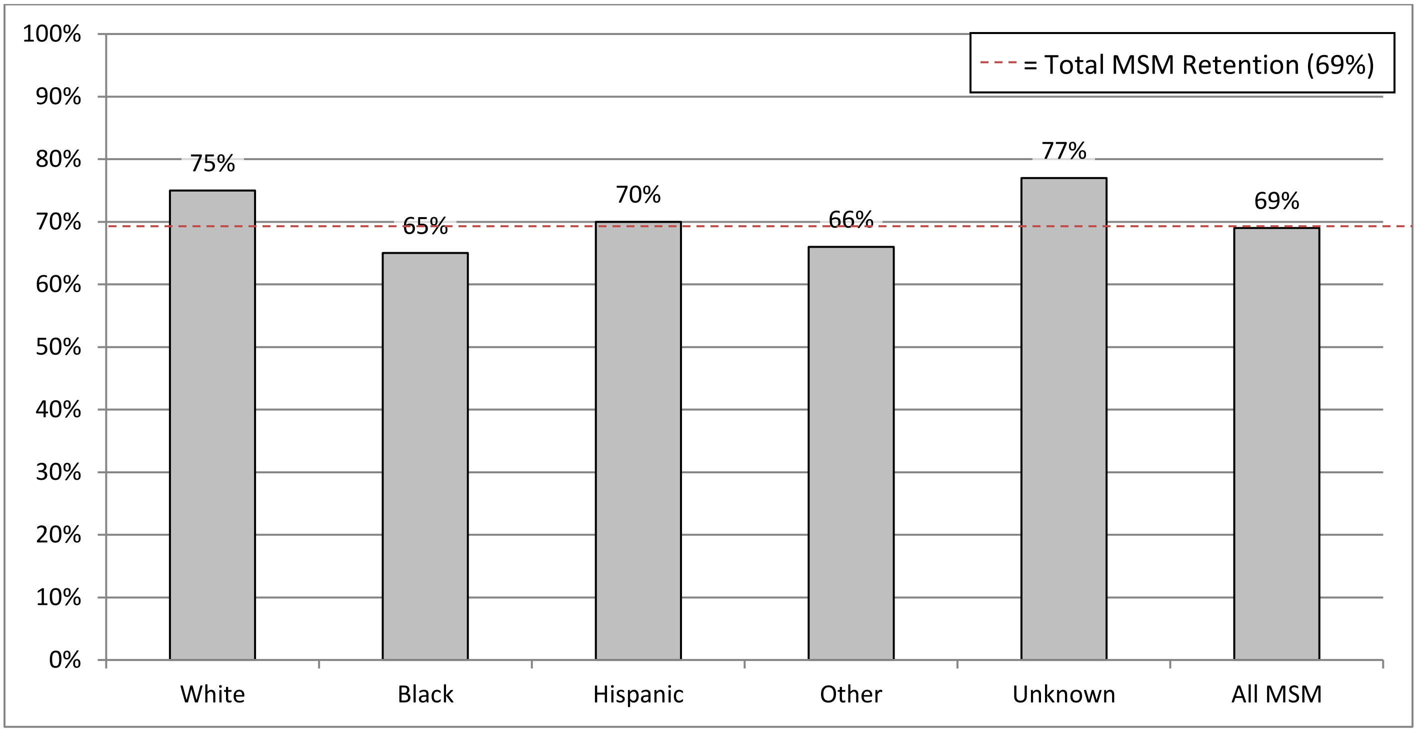
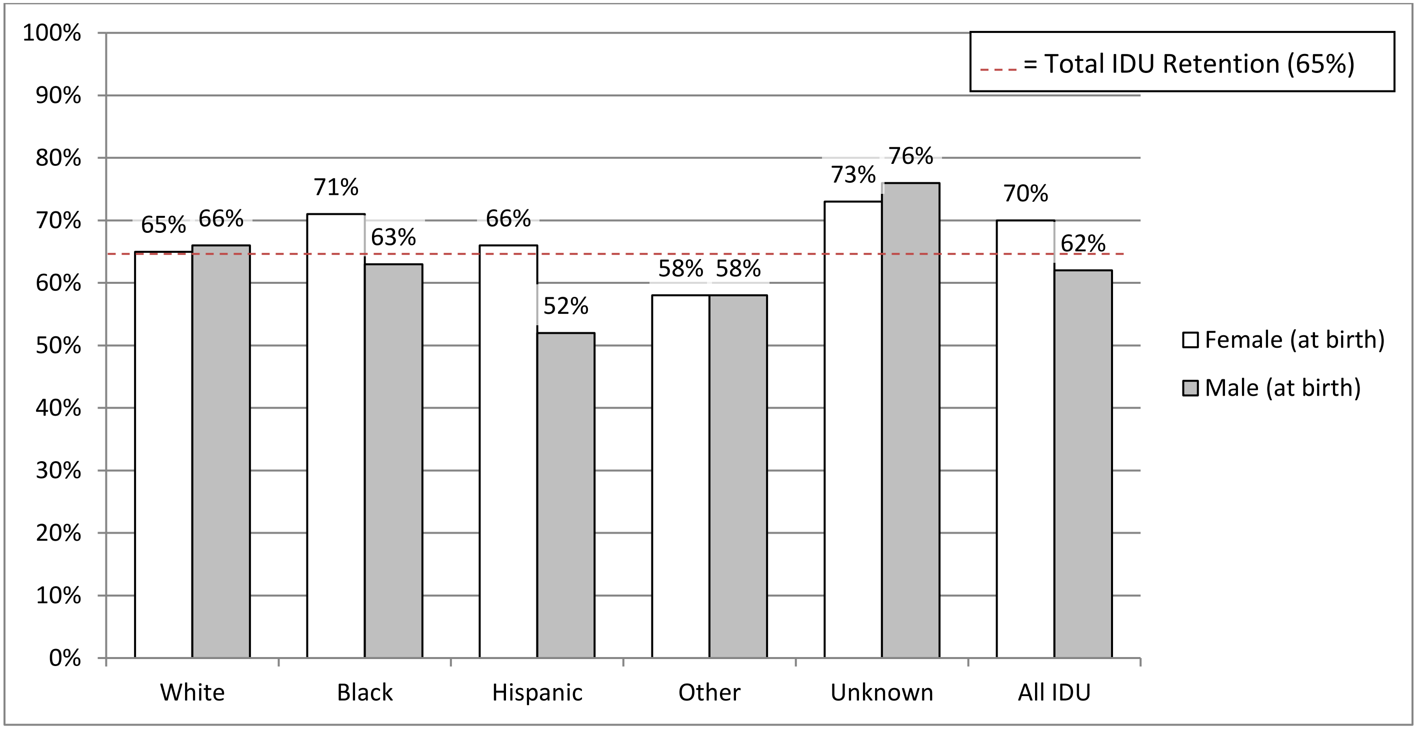
[2] Includes viral suppression
[3] Includes viral suppression

Houston EMA Retention[4] among Men Who Have Sex with Men (MSM) by Race/Ethnicity, 2016



Houston EMA Retention[5] among People Who Experience Injection Drug Use (IDU) by Race/Ethnicity and Sex at Birth, 2016



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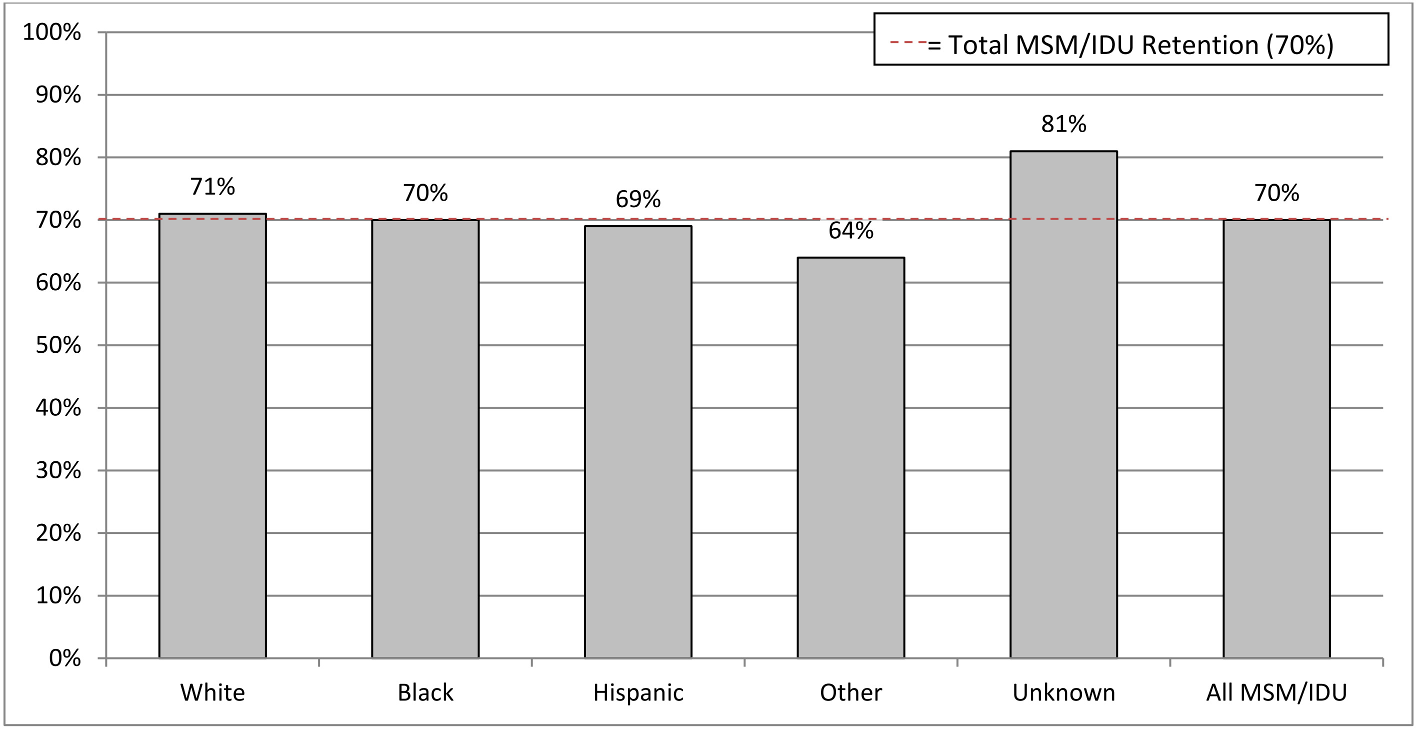
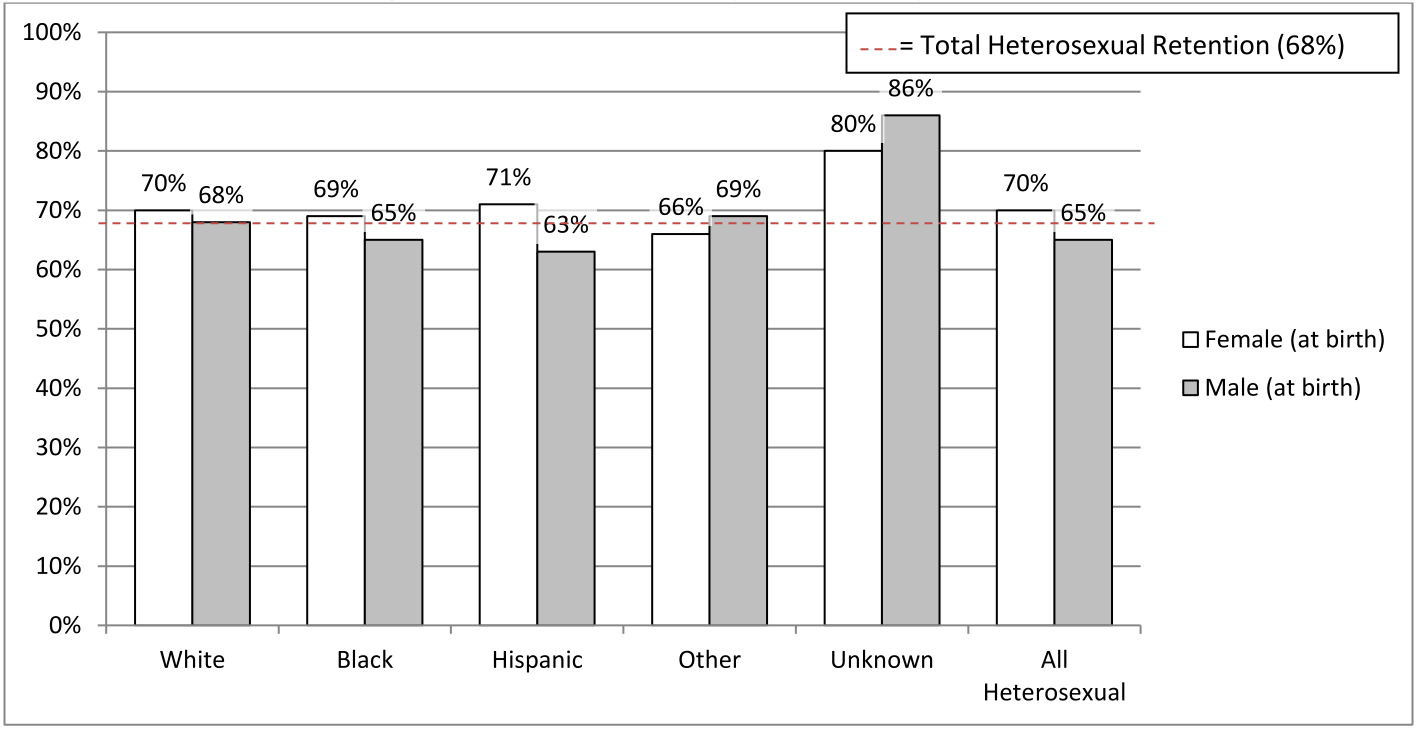
[4] Includes viral suppression

[5] Includes viral suppression

Houston EMA Retention[6] among MSM Who Experience Injection Drug Use (MSM/IDU) by Race/Ethnicity, 2016



Houston EMA Retention[7] among Heterosexual Individuals by Race/Ethnicity and Sex at Birth, 2016



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[6] Includes viral suppression

[7] Includes viral suppression

2016 Needs Assessment (NA)

- **Current unmet need:**
    - The National HIV/AIDS Strategy (**NHAS**): Updated to 2020 set the goal for met need to at least 90% of diagnosed PLWH by 2020.
    - 99% of NA respondents reported being in HIV care in the past 12 months (likely a result of the data collection process); According to the Texas Department of State Health Services, 61% of diagnosed PLWH in the Houston EMA were retained in care at the end of 2016. This proportion increases to 69% when PLWH who were virally suppressed at the end of 2016 but did not meet formal retention measures are included.
- **Continuity of care:**
    - 71% of NA respondents reported never experiencing an interruption in care (being out of care for at least 12 months) since their diagnosis.
- **Barriers to retention:**
    - 29% of respondents reporting an interruption in HIV care for 12 months or more since first entering care identified the following as the most common reasons for the interruption:
        - Substance abuse concerns
        - Wanting a break from treatment
        - Reluctance to take HIV medication
        - Not feeling sick
        - Mental health concerns
    - The most common write-in reason for interruption in care was:
        - Relocation
- **Social support for retention in care:**
    - 71% of NA respondents reported feeling that they have sufficient social support in their lives for managing HIV, including emotional support, assistance, advice, and/or companionship.
        - Perceptions of sufficient social support were higher among youth (18-24) at 92%, and lower among respondents age 50 and over (69%), unstably housed (51%), recently released from incarceration (57%), or who were transgender/gender non-conforming (59%).
    - The most frequently reported *existing* sources of social support were:
        - Family
        - Friends
        - A partner or significant other
        - A faith community
        - An HIV-related group or program
        - Common write-ins for existing social support were having a substance abuse counselor and doing volunteer work.
    - The most frequently reported *needed* sources of social support were:
        - A mentor
        - An HIV-related program or support group
        - A community group
        - Opportunities to mentor others

Program Outcomes

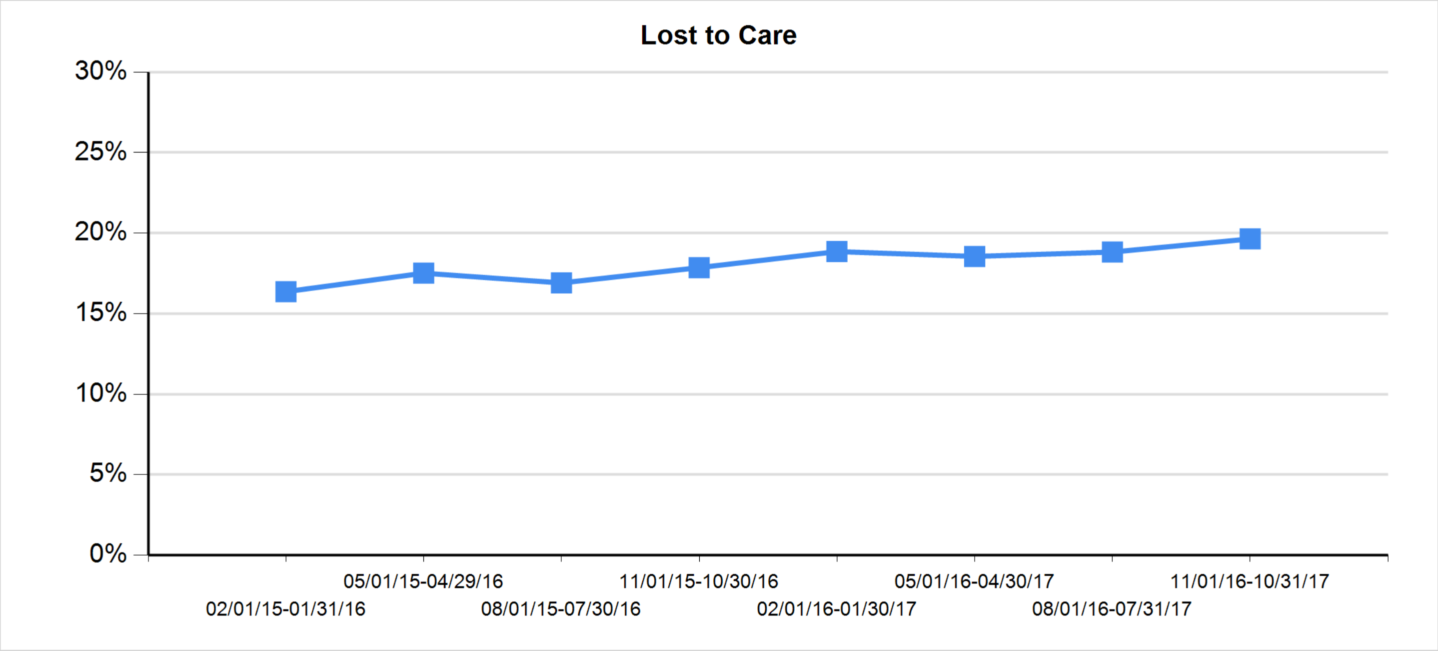
- **FY 2016 Ryan White Part A Performance Measures**
    - Percentages of RW/A Program clients retained in care in FY 2016 after accessing select services:
        - 75% - Primary medical care
        - 50% - Medical case management
        - 49% - Clinical case management
        - 45% - Service linkage

HARRIS COUNTY PUBLIC HEALTH AND ENVIRONMENTAL SERVICES - RWGA

Clinical Quality Management Committee Quarterly Report

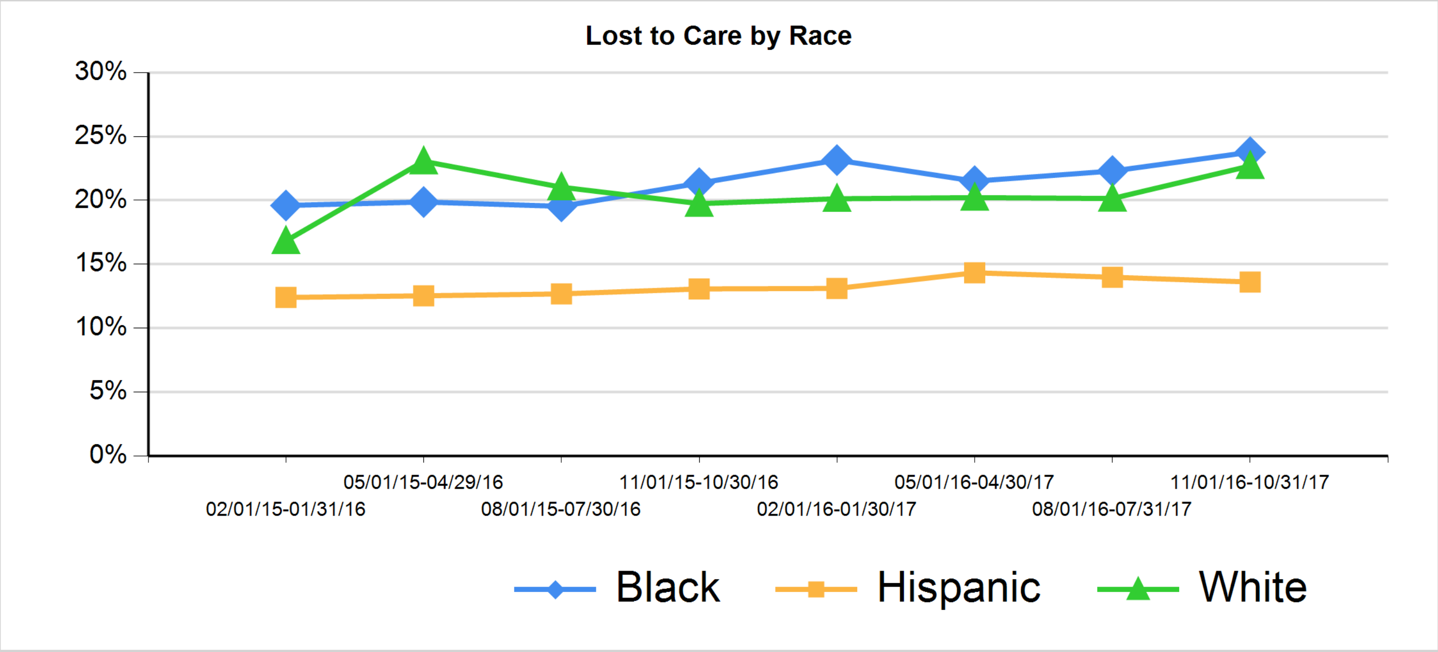
Last Quarter Start Date: **11/1/2016**

Lost to Care				
In+Care Campaign Gap Measure				
	02/01/16 - 01/30/17	05/01/16 - 04/30/17	08/01/16 - 07/31/17	11/01/16 - 10/31/17
Number of uninsured HIV-infected clients who had no medical visits and a detectable or missing viral load in the last 6 months of the measurement year	959	964	1,004	1,068
Number of uninsured HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the first 6 months of the measurement year	5,087	5,196	5,333	5,438
Percentage	18.9%	18.6%	18.8%	19.6%
Change from Previous Quarter Results	1.0%	-0.3%	0.3%	0.8%



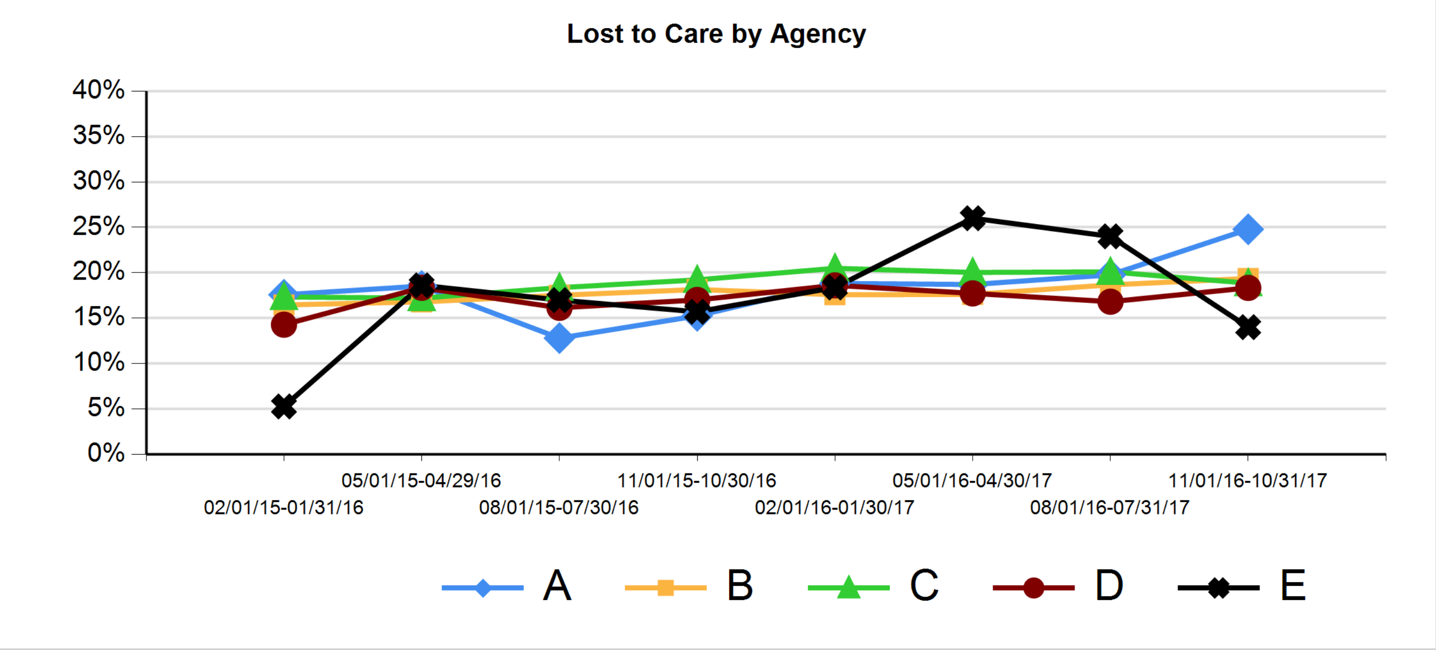
Lost to Care by Race/Ethnicity

	05/01/16 - 04/30/17			08/01/16 - 07/31/17			11/01/16 - 10/31/17		
	Black	Hisp	White	Black	Hisp	White	Black	Hisp	White
Number of uninsured HIV-infected clients who had no medical visits and a detectable or missing viral load in the last 6 months of the measurement year	533	278	134	560	279	141	617	278	155
Number of uninsured HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the first 6 months of the measurement year	2,479	1,940	663	2,512	1,996	700	2,596	2,043	683
Percentage	21.5%	14.3%	20.2%	22.3%	14.0%	20.1%	23.8%	13.6%	22.7%
Change from Previous Quarter Results	-1.6%	1.2%	0.1%	0.8%	-0.4%	-0.1%	1.5%	-0.4%	2.6%

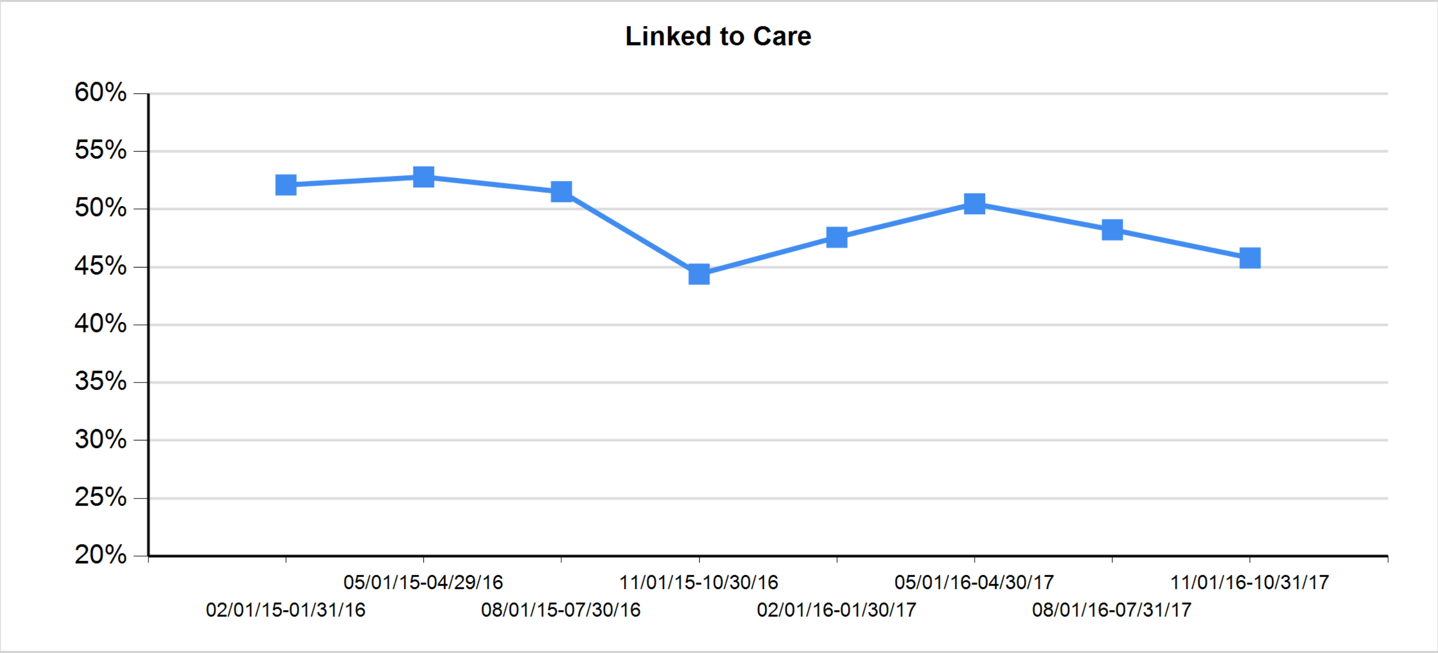


Lost to Care by Agency

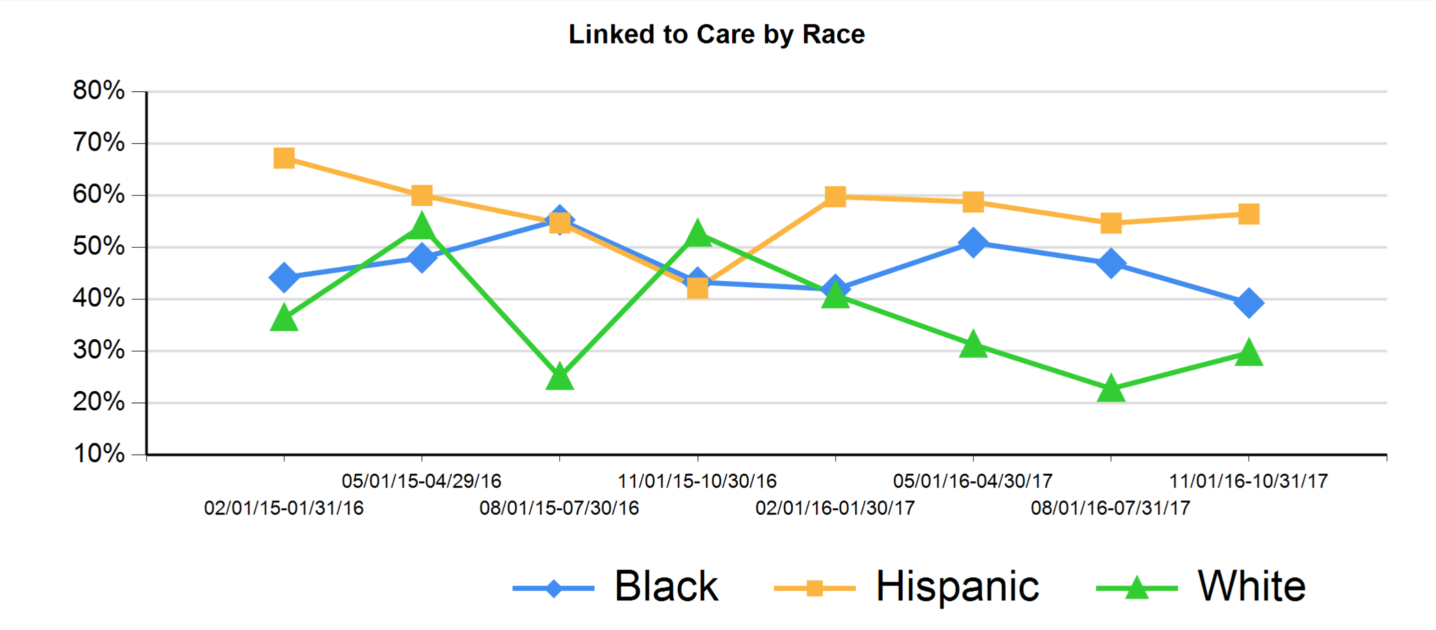
	08/01/16 - 07/31/17					11/01/16 - 10/31/17				
	A	B	C	D	E	A	B	C	D	E
Number of uninsured HIV-infected clients who had no medical visits and a detectable or missing viral load in the last 6 months of the measurement year	133	353	310	204	12	166	375	293	232	7
Number of uninsured HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the first 6 months of the measurement year	673	1,892	1,543	1,214	50	670	1,937	1,555	1,266	50
Percentage	19.8%	18.7%	20.1%	16.8%	24.0%	24.8%	19.4%	18.8%	18.3%	14.0%
Change from Previous Quarter Results	1.1%	1.1%	0.1%	-0.9%	-2.0%	5.0%	0.7%	-1.2%	1.5%	-10.0%



Linked to Care				
In+Care Campaign clients Newly Enrolled in Medical Care Measure				
	02/01/16 - 01/30/17	05/01/16 - 04/30/17	08/01/16 - 07/31/17	11/01/16 - 10/31/17
Number of newly enrolled uninsured HIV-infected clients who had at least one medical visit in each of the 4-month periods of the measurement year	108	108	109	87
Number of newly enrolled uninsured HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the first 4 months of the measurement year	227	214	226	190
Percentage	47.6%	50.5%	48.2%	45.8%
Change from Previous Quarter Results	3.2%	2.9%	-2.2%	-2.4%
* exclude if vl<200 in 1st 4 months				

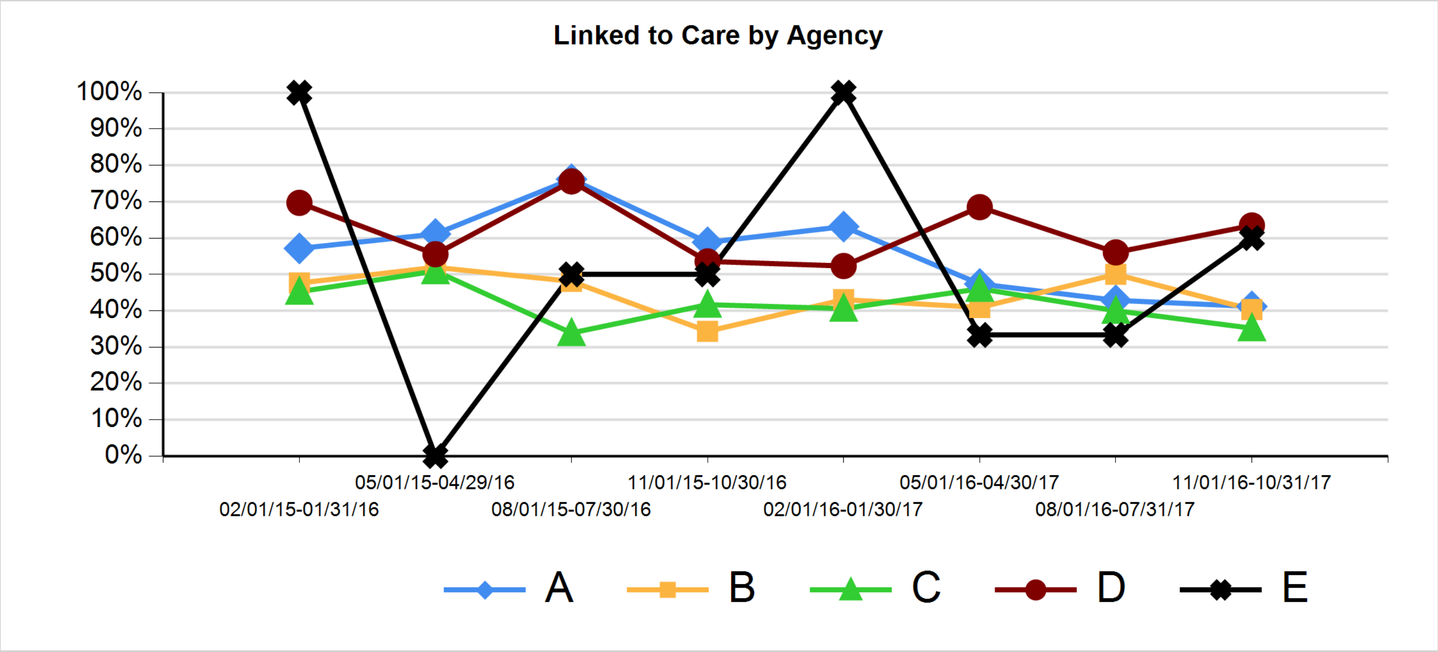


Linked to Care by Race/Ethnicity									
	05/01/16 - 04/30/17			08/01/16 - 07/31/17			11/01/16 - 10/31/17		
	Black	Hisp	White	Black	Hisp	White	Black	Hisp	White
Number of newly enrolled uninsured HIV-infected clients who had at least one medical visit in each of the 4-month periods of the measurement year	57	37	10	53	47	5	31	44	8
Number of newly enrolled uninsured HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the first 4 months of the measurement year	112	63	32	113	86	22	79	78	27
Percentage	50.9%	58.7%	31.3%	46.9%	54.7%	22.7%	39.2%	56.4%	29.6%
Change from Previous Quarter Results	9.0%	-1.0%	-9.5%	-4.0%	-4.1%	-8.5%	-7.7%	1.8%	6.9%
* exclude if vl<200 in 1st 4 months									

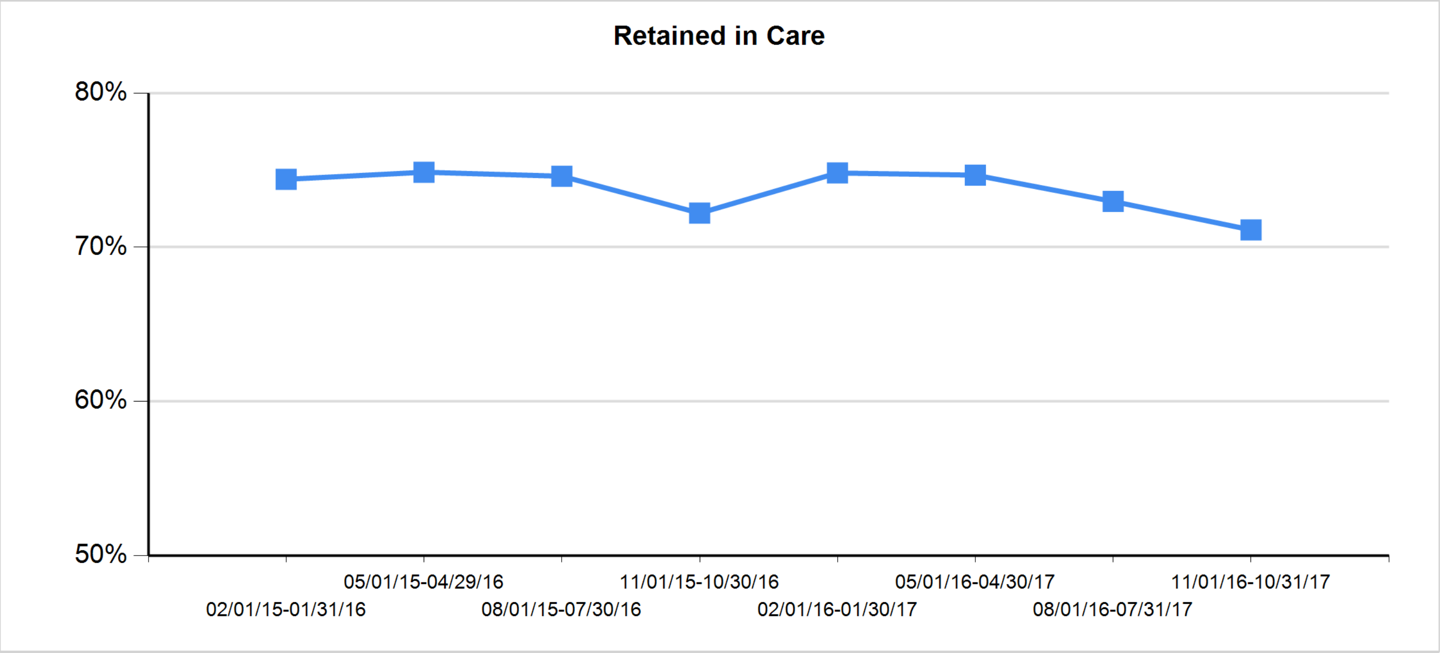


Linked to Care by Agency

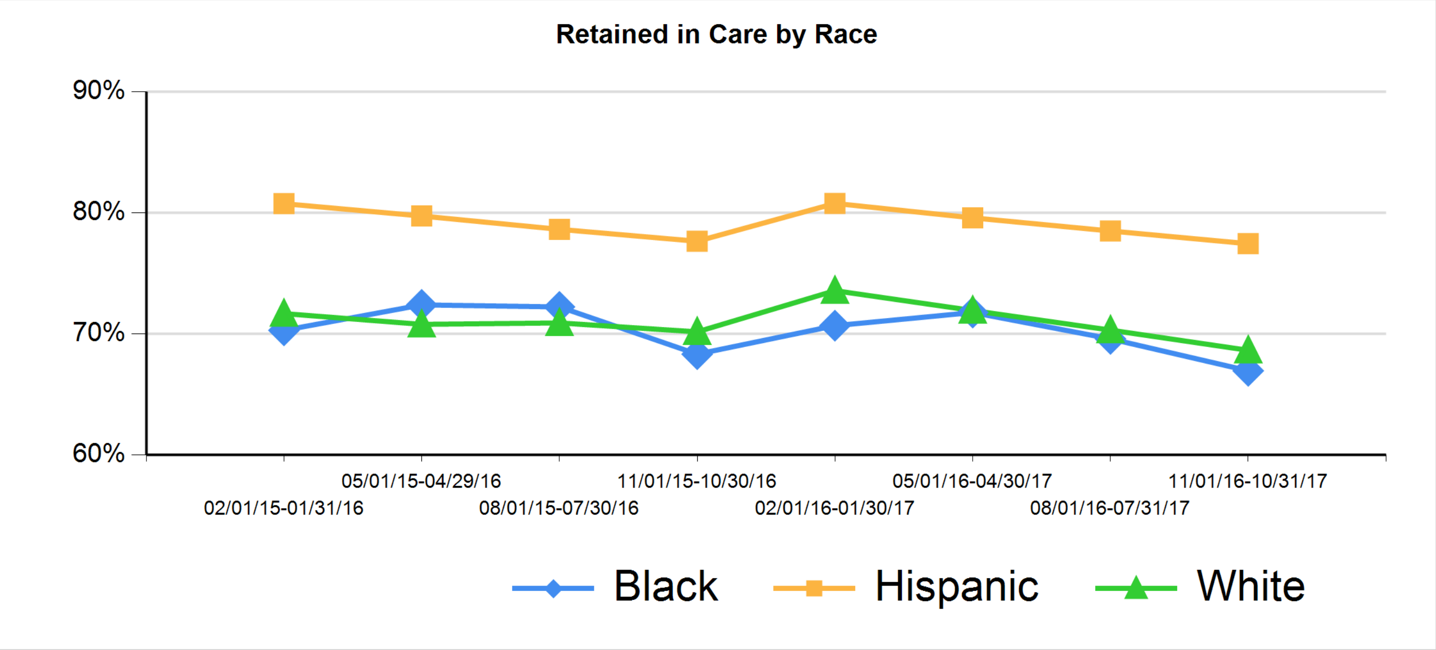
	08/01/16 - 07/31/17					11/01/16 - 10/31/17				
	A	B	C	D	E	A	B	C	D	E
Number of newly enrolled uninsured HIV-infected clients who had at least one medical visit in each of the 4-month periods of the measurement year	6	39	26	37	1	7	25	19	33	3
Number of newly enrolled uninsured HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the first 4 months of the measurement year	14	78	65	66	3	17	62	54	52	5
Percentage	42.9%	50.0%	40.0%	56.1%	33.3%	41.2%	40.3%	35.2%	63.5%	60.0%
Change from Previous Quarter Results	-4.5%	9.1%	-6.1%	-12.5%	0.0%	-1.7%	-9.7%	-4.8%	7.4%	26.7%
* exclude if vl<200 in 1st 4 months										



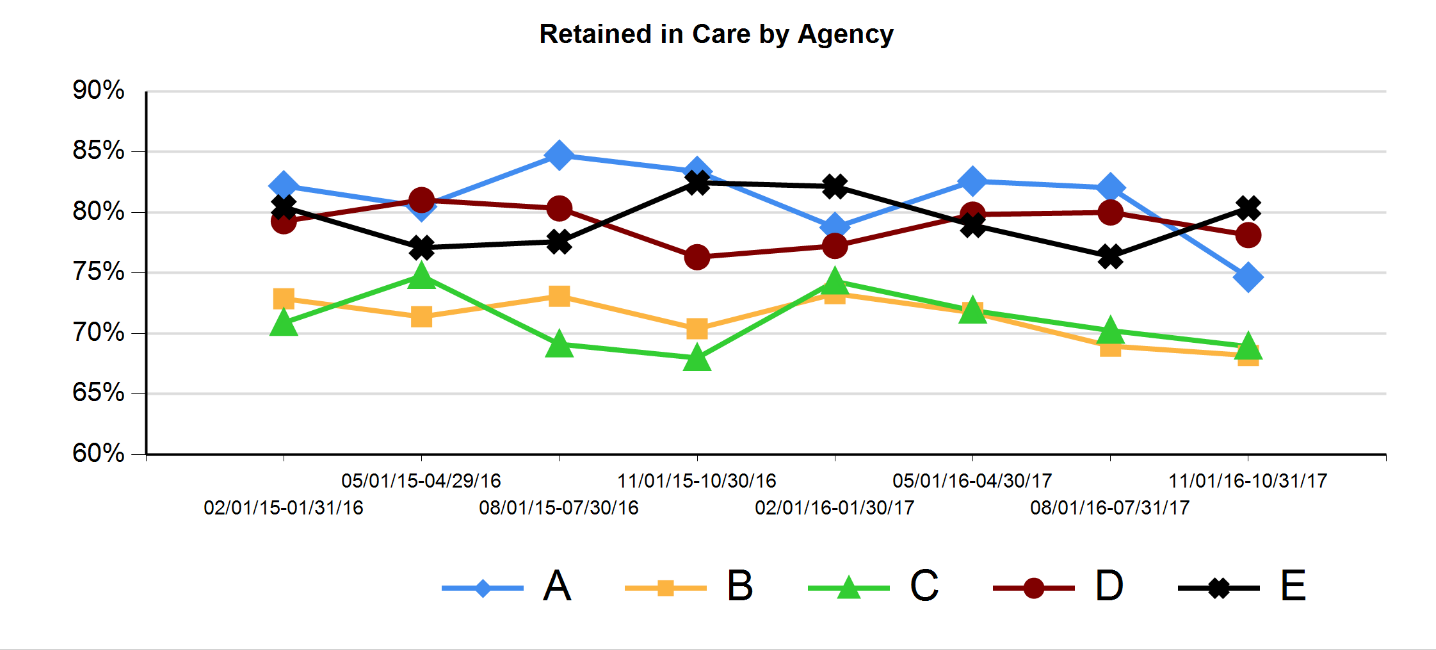
Retained in Care				
Houston EMA Medical Visits Measure				
	02/01/16 - 01/30/17	05/01/16 - 04/30/17	08/01/16 - 07/31/17	11/01/16 - 10/31/17
Number of HIV-infected clients who had 2 or more medical visits at least 3 months apart during the measurement year*	4,187	4,253	4,285	4,225
Number of HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the measurement year*	5,596	5,695	5,872	5,940
Percentage	74.8%	74.7%	73.0%	71.1%
Change from Previous Quarter Results	2.6%	-0.1%	-1.7%	-1.8%
* Not newly enrolled in care				



Retained in Care by Race/Ethnicity									
	05/01/16 - 04/30/17			08/01/16 - 07/31/17			11/01/16 - 10/31/17		
	Black	Hisp	White	Black	Hisp	White	Black	Hisp	White
Number of HIV-infected clients who had 2 or more medical visits at least 3 months apart during the measurement year	1,991	1,636	530	1,964	1,671	549	1,921	1,685	525
Number of HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the measurement year*	2,775	2,056	737	2,823	2,129	781	2,870	2,176	765
Percentage	71.7%	79.6%	71.9%	69.6%	78.5%	70.3%	66.9%	77.4%	68.6%
Change from Previous Quarter Results	1.1%	-1.2%	-1.6%	-2.2%	-1.1%	-1.6%	-2.6%	-1.1%	-1.7%



Retained in Care by Agency										
	08/01/16 - 07/31/17					11/01/16 - 10/31/17				
	A	B	C	D	E	A	B	C	D	E
Number of HIV-infected clients who had 2 or more medical visits at least 3 months apart during the measurement year	580	1,428	1,253	1,104	42	524	1,431	1,213	1,118	45
Number of HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the measurement year*	707	2,071	1,784	1,380	55	702	2,099	1,760	1,431	56
Percentage	82.0%	69.0%	70.2%	80.0%	76.4%	74.6%	68.2%	68.9%	78.1%	80.4%
Change from Previous Quarter Results	-0.5%	-2.8%	-1.7%	0.2%	-2.6%	-7.4%	-0.8%	-1.3%	-1.9%	4.0%



Harris County
Public Health
Building a Healthy Community

2018-2019 HOUSTON ELIGIBLE METROPOLITAN AREA: RYAN WHITE CARE ACT PART A
STANDARDS OF CARE FOR HIV SERVICES
RYAN WHITE GRANT ADMINISTRATION SECTION
HARRIS COUNTY PUBLIC HEALTH (HCPH)

TABLE OF CONTENTS

Service Specific Standards

Introduction

According to the Joint Commission (2008)[1], a standard is a "statement that defines performance expectations, structures, or processes that must be in place for an organization to provide safe, high-quality care, treatment, and services". Standards are developed by subject experts and are usually the minimal acceptable level of quality in service delivery. The Houston EMA Ryan White Grant Administration (RWGA) Standards of Care (SOCs) are based on multiple sources including RWGA on-site program monitoring results, consumer input, the US Public Health Services guidelines, Centers for Medicare and Medicaid Conditions of Participation (COP) for health care facilities, Joint Commission accreditation standards, the Texas Administrative Code, Center for Substance Abuse and Treatment (CSAT) guidelines and other federal, state and local regulations.

Purpose
The purpose of the Ryan White Part A SOCs is to determine the minimal acceptable levels of quality in service delivery and to provide a measurement of the effectiveness of services.

Scope
The Houston EMA SOCs apply to Part A funded HRSA defined core and support services including the following services in FY 2018-2019:

- *Primary Medical Care*
- *Vision Care*
- *Medical Case Management*
- *Clinical Case Management*
- *Local AIDS Pharmaceutical Assistance Program (LPAP)*
- *Oral Health*
- ***Health Insurance Assistance***
- Hospice Care
- Mental Health Services
- *Substance Abuse services*
- Home & Community Based Services (Facility-Based)
- *Early Intervention Services*
- *Medical Nutrition Supplement*
- *Outreach*
- *Non-Medical Case Management (Service Linkage)*
- *Transportation*
- Linguistic Services
- *Emergency Financial Assistance*
- Referral for Healthcare & Support Services

Part A funded services
Combination of Parts A, B, and/or Services funding

Standards Development
The first group of standards was developed in 1999 following HRSA requirements for sub grantees to implement monitoring systems to ensure subcontractors complied with contract requirements. Subsequently, the RWGA facilitates annual work group meetings to review the standards and to make

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[1] The Joint Commission (formerly known as Joint Commission on Accreditation of Healthcare Organization (2008)). Comprehensive accreditation manual for ambulatory care; Glossary

applicable changes. Workgroup participants include physicians, nurses, case managers and executive staff from subcontractor agencies as well as consumers.

Organization of the SOCs

The standards cover all aspect of service delivery for all funded service categories. Some standards are consistent across all service categories and therefore are classified under general standards.

These include:

- Staff requirements, training and supervision
- Client rights and confidentiality
- Agency and staff licensure
- Emergency Management

The RWGA funds three case management models. Unique requirements for all three case management service categories have been classified under Service Specific SOCs “Case Management (All Service Categories)”. Specific service requirements have been discussed under each service category.

All new and/or revised standards are effective at the beginning of the fiscal year.

GENERAL STANDARDS

	Standard	Measure
1.0	**Staff Requirements**	
1.1	Staff Screening (Pre-Employment) Staff providing services to clients shall be screened for appropriateness by provider agency as follows: • Personal/Professional references • Personal interview • Written application Criminal background checks, if required by Agency Policy, must be conducted prior to employment and thereafter for all staff and/or volunteers per Agency policy.	• Review of Agency's Policies and Procedures Manual indicates compliance • Review of personnel and/or volunteer files indicates compliance
1.2	Initial Training: Staff/Volunteers Initial training includes sixteen (16) hours HIV or AIDS basics, safety issues (fire & emergency preparedness, hazard communication, infection control, universal precautions), confidentiality issues, role of staff/volunteers, agency-specific information (e.g. Drug Free Workplace policy) and customer service training must be completed within 60 days of hire. https://tx.train.org/DesktopShell.aspx	• Documentation of all training in personnel file. • Specific training requirements are specified in Agency Policy and Procedure • Materials for staff training and continuing education are on file • Staff interviews indicate compliance
1.3	Staff Performance Evaluation Agency will perform annual staff performance evaluation.	• Completed annual performance evaluation kept in employee's file • Signed and dated by employee and supervisor (includes electronic signature)
1.4	Cultural and HIV Mental Health Co-morbidity Competence Training/Staff and Volunteers All staff tenured 0 – 5 year with their current employer must receive four (4) hours of cultural competency training and an additional one (1) hour of HIV/Mental Health co-morbidity sensitivity training annually. All new employees must complete these within ninety (90) days of hire.	• Documentation of training is maintained by the agency in the personnel file

	All staff with greater than 5 years with their current employer must receive two (2) hours of cultural competency training and an additional one (1) hour of HIV/Mental Health co-morbidity sensitivity training annually.	
1.5	<u>Staff education on eligibility determination and fee schedule</u> Agency must provide training on agency's policies and procedures for eligibility determination and sliding fee schedule for, but not limited to, case managers, and eligibility & intake staff annually. All new employees must complete within ninety (90) days of hire.	• Documentation of training in employee's record
2.0	**Services utilize effective management practices such as cost effectiveness, human resources and quality improvement.**	
2.1	<u>Service Evaluation</u> Agency has a process in place for the evaluation of client services.	• Review of Agency's Policies and Procedures Manual indicates compliance • Staff interviews indicate compliance.
2.2	<u>Subcontractor Monitoring</u> Agency that utilizes a subcontractor in delivery of service, must have established policies and procedures on subcontractor monitoring that include: • Fiscal monitoring • Program • Quality of care • Compliance with guidelines and standards Reviewed Annually	• Documentation of subcontractor monitoring • Review of Agency's Policies and Procedures Manual indicates compliance
2.3	<u>Staff Guidelines</u> Agency develops written guidelines for staff, which include, at a minimum, agency-specific policies and procedures (staff selection, resignation and termination process, and position descriptions); client confidentiality; health and safety requirements; complaint and grievance procedures; emergency procedures; and statement of client rights; reviewed annually	• Personnel file contains a signed statement acknowledging that staff guidelines were reviewed and that the employee understands agency policies and procedures
2.4	<u>Work Conditions</u> Staff/volunteers have the necessary tools, supplies, equipment and space to accomplish their work.	• Inspection of tools and/or equipment indicates that these are in good working order and in sufficient supply

		• Staff interviews indicate compliance
2.5	Staff Supervision Staff services are supervised by a paid coordinator or manager.	• Review of personnel files indicates compliance • Review of Agency's Policies and Procedures Manual indicates compliance
2.6	Professional Behavior Staff must comply with written standards of professional behavior.	• Staff guidelines include standards of professional behavior • Review of Agency's Policies and Procedures Manual indicates compliance • Review of personnel files indicates compliance • Review of agency's complaint and grievance files
2.7	Communication There are procedures in place regarding regular communication with staff about the program and general agency issues.	• Review of Agency's Policies and Procedures Manual indicates compliance • Documentation of regular staff meetings • Staff interviews indicate compliance
2.8	Accountability There is a system in place to document staff work time.	• Staff time sheets or other documentation indicate compliance
2.9	Staff Availability Staff are present to answer incoming calls during agency's normal operating hours.	• Published documentation of agency operating hours • Staff time sheets or other documentation indicate compliance
3.0	**Clients Rights and Responsibilities**	
3.1	Clients Rights and Responsibilities	• Documentation in client's record

	Agency reviews Client Rights and Responsibilities Statement with each client in a language and format the client understands. Agency provides client with written copy of client rights and responsibilities, including: • Informed consent • Confidentiality • Grievance procedures • Duty to warn or report certain behaviors • Scope of service • Criteria for end of services	
3.2	<u>Confidentiality</u> Agency maintains Policy and Procedure regarding client confidentiality in accordance with RWGA site visit guidelines, local, state and federal laws. Providers must implement mechanisms to ensure protection of clients' confidentiality in all processes throughout the agency. There is a written policy statement regarding client confidentiality form signed by each employee and included in the personnel file.	• Review of Agency's Policies and Procedures Manual indicates compliance • Clients interview indicates compliance • Agency's structural layout and information management indicates compliance • Signed confidentiality statement in each employee's personnel file
3.3	<u>Consents</u> All consent forms comply with state and federal laws, are signed by an individual legally able to give consent and must include the Consent for Services form and a consent for release/exchange of information for every individual/agency to whom client identifying information is disclosed, regardless of whether or not HIV status is revealed.	• Agency Policy and Procedure and signed and dated consent forms in client record
3.4	<u>Up to date Release of Information</u> Agency obtains an informed written consent of the client or legally responsible person prior to the disclosure or exchange of certain information about client's case to another party (including family members) in accordance with the RWGA Site Visit Guidelines, local, state and federal laws. The release/exchange consent form must contain: • Name of the person or entity permitted to make the disclosure • Name of the client • The purpose of the disclosure	• Current Release of Information form with all the required elements signed by client or authorized person in client's record

	- The types of information to be disclosed - Entities to disclose to - Date on which the consent is signed - The expiration date of client authorization (or expiration event) no longer than two years - Signature of the client/or parent, guardian or person authorized to sign in lieu of the client. - Description of the *Release of Information*, its components, and ways the client can nullify it Release/exchange of information forms must be completed entirely in the presence of the client. Any unused lines must have a line crossed through the space.	
3.5	Grievance Procedure Agency has Policy and Procedure regarding client grievances that is reviewed with each client in a language and format the client can understand and a written copy of which is provided to each client. Grievance procedure includes but is not limited to: - to whom complaints can be made - steps necessary to complain - form of grievance, if any - time lines and steps taken by the agency to resolve the grievance - documentation by the agency of the process, including a standardized grievance/complaint form available in a language and format understandable to the client - all complaints or grievances initiated by clients are documented on the Agency's standardized form - resolution of each grievance/complaint is documented on the Standardized form and shared with client - confidentiality of grievance - addresses and phone numbers of licensing authorities and funding sources	- Signed receipt of agency Grievance Procedure, filed in client chart - Review of Agency's Policies and Procedures Manual indicates compliance - Review of Agency's Grievance file indicates compliance, - Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section A: Access to Care #2
3.6	Conditions Under Which Discharge/Closure May Occur A client may be discharged from Ryan White funded services for the following reasons. - Death of the client	- Documentation in client record and in the Centralized Patient Care Data Management System

	• At the client's or legal guardian request • Changes in client's need which indicates services from another agency • Fraudulent claims or documentation about HIV diagnosis by the client • Client actions put the agency, case manager or other clients at risk. Documented supervisory review is required when a client is terminated or suspended from services due to behavioral issues. • Client moves out of service area, enters jail or cannot be contacted for sixty (60) days. Agency must document three (3) attempts to contact clients by more than one method (e.g. phone, mail, email, text message, in person via home visit). • Client service plan is completed and no additional needs are identified. Client must be provided a written notice prior to involuntary termination of services (e.g. due to dangerous behavior, fraudulent claims or documentation, etc.).	• A copy of written notice and a certified mail receipt for involuntary termination
3.7	<u>Client Closure</u> A summary progress note is completed in accordance with Site Visit Guidelines within three (3) working days of closure, including: • Date and reason for discharge/closure • Summary of all services received by the client and the client's response to services • Referrals made and/or • Instructions given to the individual at discharge (when applicable)	• Documentation in client record and in the Centralized Patient Care Data Management System
3.8	<u>Client Feedback</u> In addition to the RWGA standardized client satisfaction survey conducted on an ongoing basis (no less than annually), Agency must have structured and ongoing efforts to obtain input from clients (or client caregivers, in cases where clients are unable to give feedback) in the design and delivery of services. Such efforts may include client satisfaction surveys, focus groups and public meetings conducted at least annually. Agency may also maintain a visible suggestion box for clients' inputs. Analysis and use of results must be documented. Agency must maintain a	• Documentation of clients' evaluation of services is maintained • Documentation of CAB and public meeting minutes • Documentation of existence and appropriateness of a suggestion box or other client input mechanism

	file of materials documenting Consumer Advisory Board (CAB) membership and meeting materials (applicable only if agency has a CAB). • Agencies that serve an average of 100 or more unduplicated clients monthly under combined RW/A, MAI, RW/B and SS funding must implement a CAB. The CAB must meet regularly (at least 4 times per year) at a time and location conducive to consumer participation to gather, support and encourage client feedback, address issues which impact client satisfaction with services and provide Agency with recommendations to improve service delivery, including accessibility and retention in care.	• Documentation of content, use, and confidentiality of a client satisfaction survey or focus groups conducted annually • Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section A: Access to Care #1
3.9	<u>Patient Safety (Core Services Only)</u> Agency shall establish mechanisms to implement National Patient Safety Goals (NPSG) modeled after the current Joint Commission accreditation *for Ambulatory Care* (www.jointcommission.org) to ensure patients' safety. The NPSG to be addressed include the following as applicable: • "Improve the accuracy of patient identification • Improve the safety of using medications • Reduce the risk of healthcare-associated infections • Accurately and completely reconcile medications across the continuum of care • Universal Protocol for preventing Wrong Site, Wrong Procedure and Wrong Person Surgery" <u>(www.jointcommission.org)</u>	• Review of Agency's Policies and Procedures Manual indicates compliance
3.10	<u>Client Records</u> Provider shall maintain all client records.	• Review of agency's policy and procedure for records administration indicates compliance
4.0	**Accessibility**	
4.1	<u>Cultural Competence</u> Agency demonstrates a commitment to provision of services that are culturally sensitive and language competent for Limited English Proficient (LEP) individuals.	• Agency has procedures for obtaining translation services • Client satisfaction survey indicates compliance • Policies and procedures demonstrate commitment to the community and culture of the clients

		- Availability of interpretive services, bilingual staff, and staff trained in cultural competence - Agency has vital documents including, but not limited to applications, consents, complaint forms, and notices of rights translated in client record
4.2	Client Education Agency demonstrates capacity for client education and provision of information on community resources	- Availability of the blue book and other educational materials - Documentation of educational needs assessment and client education in clients' records
4.3	Special Service Needs Agency demonstrates a commitment to assisting individuals with special needs	- Agency compliance with the Americans with Disabilities Act (ADA). - Review of Policies and Procedures indicates compliance - Environmental Review shows a facility that is handicapped accessible
4.4	Provision of Services for low-Income Individuals Agency must ensure that facility is handicap accessible and is also accessible by public transportation (if in area served by METRO). Agency must have policies and procedures in place that ensures access to transportation services if facility is not accessible by public transportation. Agency should not have policies that dictate a dress code or conduct that may act as barrier to care for low income individuals.	- Facility is accessible by public transportation - Review of Agency's Policies and Procedures Manual indicates compliance - Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section A: Access to Care #4
4.5	Proof of HIV Diagnosis Documentation of the client's HIV status is obtained at or prior to the initiation of services or registration services. An anonymous test result may be used to document HIV status temporarily (up to sixty [60] days). It must contain enough information to ensure the identity of the subject with a reasonable amount of certainty.	- Documentation in client record as per RWGA site visit guidelines or TRG Policy SG-03 - Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section A: Access to Care #3

4.6	<u>Provision of Services Regardless of Current or Past Health Condition</u> Agency must have Policies and Procedures in place to ensure that clients living with HIV are not denied services due to current or pre-existing health condition or non-HIV related condition. A file must be maintained on all clients who are refused services and the reason for refusal.	• Review of Policies and Procedures indicates compliance • A file containing information on clients who have been refused services and the reasons for refusal • Source Citation: HAB Program Standards; Section D: #1
4.7	<u>Client Eligibility</u> In order to be eligible for services, individuals must meet the following: • HIV+ • Residence in the Houston EMA/ HSDA (With prior approval, clients can be served if they reside outside of the Houston EMA/HSDA.) • Income no greater than 300% of the Federal Poverty level (unless otherwise indicated) • Proof of identification • Ineligibility for third party reimbursement	• Documentation of HIV+ status, residence, identification and income in the client record • Documentation of ineligibility for third party reimbursement • Documentation of screening for Third Party Payers in accordance with RWGA site visit guidelines • Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section B:Eligibility Determination/Screening #1
4.8	<u>Re-certification of Client Eligibility</u> Agency conducts six (6) month re-certification of eligibility for all clients. At a minimum, agency confirms an individual's income, residency and re-screens, as appropriate, for third-party payers. Third party payers include State Children's Health Insurance Programs (SCHIP), Medicare (including Part D prescription drug benefit) and private insurance. At one of the two required re-certifications during a year, agency may accept client self-attestation for verifying that an individual's income, residency, and insurance status complies with the RWGA eligibility requirements. Appropriate documentation is required for changes in status and at least once a year (defined as a 12-month period) with renewed eligibility with the CPCDMS. Agency must ensure that Ryan White is the Payer of last resort and must have policies and procedures addressing strategies to enroll all eligible uninsured clients into Medicare, Medicaid, private health insurance and other programs.	• Client record contains documentation of re-certification of client residence, income and rescreening for third party payers at least every six (6) months • Review of Policies and Procedures indicates compliance • Information in client's files that includes proof of screening for insurance coverage (i.e. hard/scanned copy of results) • Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section B:Eligibility Determination/Screening #1 and #2

	Agency policy must also address coordination of benefits, billing and collection. Clients eligible for Department of Veterans Affairs (VA) benefits are duly eligible for Ryan White services and therefore exempted from the payer of last resort requirement - Agency must verify 3rd party payment coverage for eligible services at every visit or monthly (whichever is less frequent)	- Source Citation: HIV/AIDS Bureau (HAB) Policy Clarification Notice #13-02
4.9	Charges for Services Agency must institute Policies and Procedures for cost sharing including enrollment fees, premiums, deductibles, co-payments, co-insurance, sliding fee discount, etc. and an annual cap on these charges. Agency should not charge any of the above fees regardless of terminology to any Ryan White eligible patient whose gross income level (GIL)is ≤ 100% of the Federal Poverty Level (FPL) as documented in the CPCDMS for any services provided. Clients whose gross income is between 101-300% may be charged annual aggregate fees in accordance with the legislative mandate outlined below: - 101%-200% of FPL---5% or less of GIL - 201%-300% of FPL---7% or less of GIL - >300% of FPL ---------10% or less of GIL Additionally, agency must implement the following: - Six (6) month evaluation of clients to establish individual fees and cap (i.e. the six (6) month CPCDMS registration or registration update.) - Tracking of charges - A process for alerting the billing system when the cap is reached so client will not be charged for the rest of the calendar year. - Documentation of fees	- Review of Policies and Procedures indicates compliance - Review of system for tracking patient charges and payments indicate compliance - Review of charges and payments in client records indicate compliance with annual cap - Sliding fee application forms on client record is consistent with Federal guidelines
4.10	Information on Program and Eligibility/Sliding Fee Schedule Agency must provide broad-based dissemination of information regarding the availability of services. All clients accessing services must be provided with a clear description of their sliding fee charges in a simple understandable format at intake and annually at registration update. Agency should maintain a file documenting promotion activities including copies of HIV program materials and information on eligibility requirements. Agency must proactively inform/educate clients when changes occur in the program design or process, client eligibility rules, fee schedule, facility layout or access to program or agency.	- Agency has a written substantiated annual plan to targeted populations - Zip code data show provider is reaching clients throughout service area (as applicable to specific service category). - Agency file containing informational materials about agency services and eligibility requirements including the following:

		Brochures Newsletters Posters Community bulletins any other types of promotional materials • Signed receipt for client education/ information regarding eligibility and sliding fees on client record • Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section A: Access to Care #5
4.11	Linkage Into Core Services Agency staff will provide out-of-care clients with individualized information and referral to connect them into ambulatory outpatient medical care and other core medical services.	• Documentation of client referral is present in client record • Review of agency's policies & procedures' manual indicates compliance
4.12	Wait Lists It is the expectation that clients will not be put on a Wait List nor will services be postponed or denied due to funding. Agency must notify the Administrative agency when funds for service are either low or exhausted for appropriate measures to be taken to ensure adequate funding is available. Should a wait list become required, the agency must, at a minimum, develop a policy that addresses how they will handle situations where service(s) cannot be immediately provided and a process by which client information will be obtained and maintained to ensure that all clients that requested service(s) are contacted after service provision resumes. A wait list is defined as a roster developed and maintained by providers of patients awaiting a particular service when a demand for a service exceeds available appointments used on a first come next serviced method. The Agency will notify RWGA of the following information when a wait list must be created: An explanation for the cessation of service; and A plan for resumption of service. The Agency's plan must address: • Action steps to be taken Agency to resolve the service shortfall; and	• Review of Agency's Policies and Procedures Manual indicates compliance • Documentation that agency notified their Administrative Agency when funds for services were either low or exhausted

	- Projected date that services will resume. The Agency will report to RWGA in writing on a monthly basis while a client wait list is required with the following information: - Number of clients on the wait list. - Progress toward completing the plan for resumption of service. - A revised plan for resumption of service, if necessary.	
4.13	Intake The agency conducts an intake to collect required data including, but not limited to, eligibility, appropriate consents and client identifiers for entry into CPCDMS. Intake process is flexible and responsive, accommodating disabilities and health conditions. In addition to office visits, client is provided alternatives such as conducting business by mail, online registration via the internet, or providing home visits, when necessary. Agency has established procedures for communicating with people with hearing impairments.	- Documentation in client record - Review of Agency's Policies and Procedures Manual indicates compliance
5.0	**Quality Management**	
5.1	Continuous Quality Improvement (CQI) Agency demonstrates capacity for an organized CQI program and has a CQI Committee in place to review procedures and to initiate Performance Improvement activities. The Agency shall maintain an up-to-date Quality Management (QM) Manual. The QM Manual will contain at a minimum: - The Agency's QM Plan - Meeting agendas and/or notes (if applicable) - Project specific CQI Plans - Root Cause Analysis & Improvement Plans - Data collection methods and analysis - Work products - QM program evaluation - Materials necessary for QM activities	- Review of Agency's Policies and Procedures Manual indicates compliance - Up to date QM Manual - Source Citation: HAB Universal Standards; Section F: #2
5.2	Data Collection and Analysis	- Review of Agency's Policies and Procedures Manual indicates compliance

	Agency demonstrates capacity to collect and analyze client level data including client satisfaction surveys and findings are incorporated into service delivery. Supervisors shall conduct and document ongoing record reviews as part of quality improvement activity.	• Up to date QM Manual • Supervisors log on record reviews signed and dated • Source Citation: HAB Monitoring Standards; Part I: Universal Standards; Section A: Access to Care #2
6.0	**Point Of Entry Agreements**	
6.1	Points of Entry (Core Services Only) Agency accepts referrals from sources considered to be points of entry into the continuum of care, in accordance with HIV Services policy approved by HRSA for the Houston EMA.	• Review of Agency's Policies and Procedures Manual indicates compliance • Documentation of formal agreements with appropriate Points of Entry • Documentation of referrals and their follow-up
7.0	**Emergency Management**	
7.1	Emergency Preparedness Agency leadership including medical staff must develop an Emergency Preparedness Plan modeled after the Joint Commission's regulations and/or Centers for Medicare and Medicaid guidelines for Emergency Management. The plan should, at a minimum utilize "all hazard approach" (hurricanes, floods, earthquakes, tornadoes, wide-spread fires, infectious disease outbreak and other public health threats, terrorist attacks, civil disturbances and collapse of buildings and bridges) to ensure a level of preparedness sufficient to support a range of emergencies. Agencies shall conduct an annual Hazard Vulnerability Analysis (HVA) to identify potential hazards, threats, and adverse events and assess their impact on care, treatment, and services they must sustain during an emergency. The agency shall communicate hazards identified with its community emergency response agencies and together shall identify the capability of its community in meeting their needs. The HVA shall be reviewed annually.	• Emergency Preparedness Plan • Review of Agency's Policies and Procedures Manual indicates compliance
7.2	Emergency Management Training In accordance with the Department of Human Services recommendations, all applicable agency staff must complete the following National Incident	• Documentation of all training including certificate of completion in personnel file

	Management System (NIMS) courses developed by the Department of Homeland Security: • IS -100.HC – Introduction to the Incident command system for healthcare/hospitals • IS-200.HC- Applying ICS to Healthcare organization • IS-700.A-National Incident Management System (NIMS) Introduction • IS-800.B National Response Framework (management) The above courses may be accessed at: www.training.fema.gov . Agencies providing support services only may complete alternate courses listed for the above areas All applicable new employees are required to complete the courses within 90 days of hire.	
7.3	Emergency Preparedness Plan The emergency preparedness plan shall address the six critical areas for emergency management including • Communication pathways • Essential resources and assets • patients' safety and security • staff responsibilities • Supply of key utilities such as portable water and electricity • Patient clinical and support activities during emergency situations. (www.jointcommission.org)	• Emergency Preparedness Plan
7.4	Emergency Management Drills Agency shall implement emergency management drills twice a year either in response to actual emergency or in a planned exercise. Completed exercise should be evaluated by a multidisciplinary team including administration, clinical and support staff. The emergency plan should be modified based on the evaluation results and retested.	• Emergency Management Plan • Review of Agency's Policies and Procedures Manual indicates compliance
8.0	**Building Safety**	
8.1	Required Permits All agencies will maintain Occupancy and Fire Marshal's permits for the facilities.	• Current required permits on file

SERVICE SPECIFIC STANDARDS OF CARE

Outreach Services

Outreach workers focus on locating clients who are on the cusp of falling out of care, for reengagement back into care. The Ryan White Part A Outreach Worker (OW) provides field-based services to clients based on criteria identified by each agency. These services include the provision of information, referrals and assistance with linkage to medical, mental health, substance abuse and psychosocial services as needed and advocating on behalf of clients to decrease service gaps and remove barriers to services.

1.0	**Staff Training**	
1.1	**Minimum/Qualifications** Minimum Qualifications – High School Diploma or GED. Six months of working with or volunteering with PLWH.	• Documentation of credentials and job description in outreach worker's file • Documentation includes, but is not limited to high school diploma, GED and experience
1.2	Scope of Services The OW will generate EMR reports to determine eligibility for services. Monthly, during OW-RWGA meetings OW will provide client status updates on engagement activities. Outreach workers are expected to document client's immediate needs and barriers to service in order to relink and reengage them back in to care. Upon successfully re-engaging clients back in to care, outreach workers will provide a warm handoff to a service linkage worker or medical case manager for additional assistance of the client's needs as necessary.	• Review of reporting records indicates compliance • Monthly review of spreadsheet engagement activities • Documentation of assessment will be maintained in the client file
1.3	Ongoing Education/Training for Outreach Workers The Outreach Workers are required to attend a minimum of eleven (11) of the (12) Outreach Worker meetings within the grant year, and one of the Joint Prevention and Care Collaborative Workshops presented by RGWA & COH.	• Documentation of attendance will be maintain by the agency. RWGA will also maintain sign-in logs • Review of reporting records indicates compliance
1.4	Documentation and Reporting Outreach Workers are trained in the agency's policy and procedure for determining, documenting and reporting instances of abuse, sexual or nonsexual, in accordance with DSHS Child Abuse Screening, Documenting and Reporting Policy prior to interaction.	• Documentation of staff training in employee record
2.0	**Timeliness of Service/Documentation**	
2.1	**Progress Notes** All Outreach Worker activities, including but not limited to all contacts and attempted contacts with or on behalf of clients are documented in the client record within 72 hours of the occurrence.	• Documentation of client's needs and progress notes will be maintained in client's files

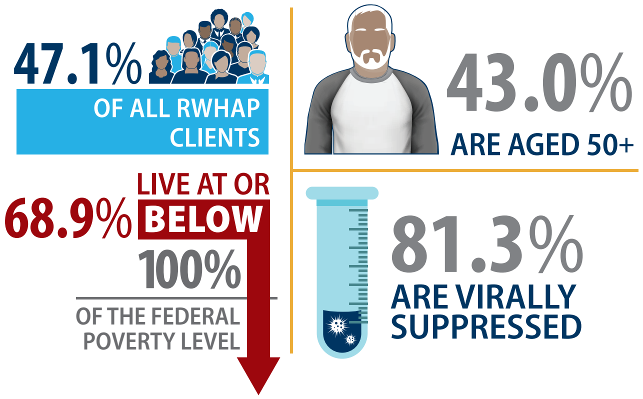
		- Legible signed and dated in documentation in the client record
2.2	Eligibility Criteria for Outreach Eligibility for outreach will vary and is specific to each agency. Criteria can include but is not limited to clients: - Who have missed 2 or more HIV-related medical appointments in the last 6 months, have one appointment scheduled in the next 3 weeks; - Missed 3 appointments in last 6 months and have one scheduled in next 3 weeks; - Clients who have not been seen in 4 months by their primary care provider; and/or - Three missed appointments in past 12 months (do not have to be consecutive).	- Documentation of eligibility criteria will be maintained in client's files - Legible signed and dated in documentation in the client record
3.0	**Supervision**	
3.1	Outreach Worker Supervision Four (4) hours of supervision per month must be provided to each outreach worker. At least one (1) hour of supervision must be individual supervision. The remaining three (3) hours may be individual or group. Supervision includes, but is not limited to, one-to-one consultation regarding issues that arise in the outreach worker relationship, case staffing meetings, group supervision, and discussion of gaps in services or barriers to services, intervention strategies, case assignments, case reviews and caseload assessments	- Documentation in supervision notes, which must include: ➢ Date & duration of time ➢ name(s) of outreach worker(s) present ➢ topic(s) covered and/or client(s) reviewed ➢ plan(s) of action ➢ supervisor's signature Supervision notes are never maintained in the client record
3.2	Case Reviews – Outreach Worker Supervisor reviews a random sample equal to 10% of unduplicated clients served by each Outreach Worker at least once every ninety (90) days, and concurrently ensures that all required record components are present, timely, legible and that services provided appropriately.	Documentation of case reviews in client record, signed and dated supervisor and/or quality assurance personnel and Outreach Worker.

HRSA's Ryan White HIV/AIDS Program

January 2018

BLACK/AFRICAN AMERICAN: RYAN WHITE HIV/AIDS PROGRAM CLIENTS, 2016

Ryan White HIV/AIDS Program Client Fast Facts: Black/African American



47.1% OF ALL RWHAP CLIENTS

43.0% ARE AGED 50+

68.9% LIVE AT OR BELOW 100% OF THE FEDERAL POVERTY LEVEL

81.3% ARE VIRALLY SUPPRESSED

The Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program (RWHAP) provides a comprehensive system of HIV primary medical care, medications, and essential support services for low-income people living with HIV (PLWH). More than half the people living with diagnosed HIV in the United States—an estimated 551,000 people in 2016—receive services through RWHAP each year. RWHAP funds grants to states, cities/counties, and local community-based organizations to provide care and treatment services to PLWH to improve health outcomes and reduce HIV transmission among hard-to-reach populations.

A critical population served by RWHAP is black/African American. Of the more than half a million clients served by the RWHAP, 73.3 percent are from racial or ethnic minority populations, with 47.1 percent of all RWHAP clients identifying as black/African American. Below are more details about this RWHAP client population:

- **The majority of black/African American clients served by RWHAP are low income.** Data show 68.9 percent of black/African American clients are living at or below 100 percent of the federal poverty level, which is higher than the national RWHAP average (62.8 percent).
- **The majority of black/African American clients served by RWHAP are male.** Data show that 62.9 percent of clients are male, 35.6 percent of clients are female, and 1.5 percent of clients are transgender. The proportion of black/African American males is lower than the national RWHAP average (71.4 percent), while the proportion of black/African American females is higher than the national RWHAP average (27.3 percent).
- **One in seven black/African American clients served by RWHAP has temporary or unstable housing.** Among black/African American clients served by RWHAP, 9.0 percent have temporary housing and 5.8 percent have unstable housing.
- **The black/African American RWHAP client population is aging.** Black/African American clients aged 50 years and older account for 43.0 percent of all black/African American RWHAP clients.
- **Among black/African American male clients, 53.8 percent are men who have sex with men (MSM).** Among all males served by RWHAP, MSM account for 64.1 percent.

Medical care and treatment improve health outcomes and decrease the risk of HIV transmission. Among black/African American RWHAP clients receiving HIV medical care, 81.3 percent are virally suppressed,* which is lower than the national RWHAP average (84.9 percent).

- 80.7 percent of black/African American men receiving RWHAP HIV medical care are virally suppressed.
- 82.6 percent of black/African American women receiving RWHAP HIV medical care are virally suppressed.

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* Viral suppression is defined as a viral load result of less than 200 copies/mL at most recent test, among PLWH who had at least one outpatient ambulatory health services visit and one viral load test during the measurement year.

HIV Among Gay and Bisexual Men

September 2017

Fast Facts

- Gay, bisexual, and other men who have sex with men[a] account for 70% of new HIV infections in the United States.
- New HIV infections among gay and bisexual men overall remained stable in recent years.
- More than 600,000 gay and bisexual men are living with HIV in the United States.

In 2014 gay and bisexual men made up an estimated 2% of the U.S. population, but accounted for 70% of new HIV infections. Approximately 492,000 sexually active gay and bisexual men are at high risk for HIV; however, we have more tools to prevent HIV (https://www.cdc.gov/hiv/basics/prevention.html) than ever before.

The Numbers

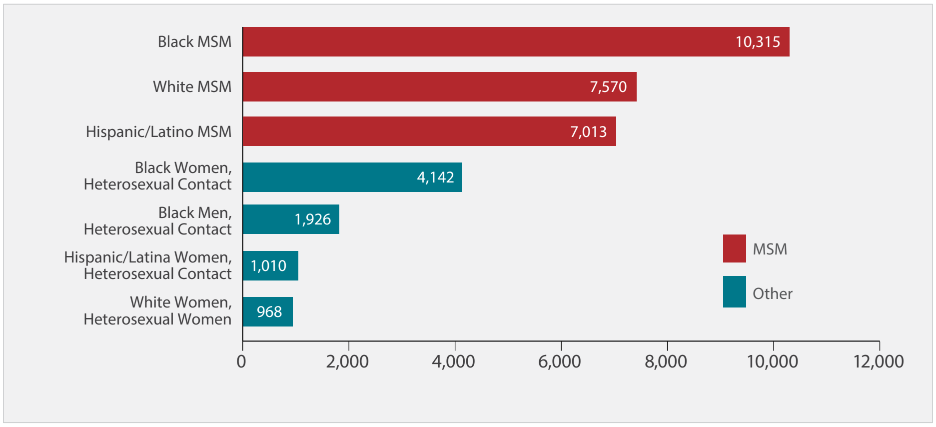
HIV Infections[b]

In 2014, gay and bisexual men accounted for an estimated 70% (26,200) of new HIV infections in the United States.

From 2010 to 2014, estimated annual HIV infections remained stable at about 26,000 per year among all gay and bisexual men. However, trends varied by age and race/ethnicity. Estimated HIV infections

- Declined 16% among gay and bisexual men aged 13 to 24.
- Increased 23% among gay and bisexual men aged 25 to 34.
- Declined 16% among gay and bisexual men aged 35 to 44.
- Declined 11% among white gay and bisexual men.
- Increased 14% among Hispanic/Latino[c] gay and bisexual men.
- Remained stable among black or African American[d] gay and bisexual men, at about 10,000 per year.

HIV Diagnoses Among the Most-Affected Subpopulations, 2015—United States



Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2015 (https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2015-vol-27.pdf). HIV Surveillance Report 2016;27. Subpopulations representing 2% or less of HIV diagnoses are not reflected in this chart. Abbreviation: MSM=men who have sex with men.

HIV and AIDS Diagnoses[e]

In 2015:

- Gay and bisexual men accounted for 82% (26,376) of new HIV diagnoses among all males aged 13 and older and 67% of the total new diagnoses in the United States.[f]
- Gay and bisexual men aged 13 to 24 accounted for 92% of new HIV diagnoses among all men in their age group and 27% of new diagnoses among all gay and bisexual men.
- Gay and bisexual men accounted for 55% (10,047) of people who received an AIDS diagnosis. Of those men, 39% were African American, 31% were white, and 24% were Hispanic/Latino.

From 2010 to 2014:

- HIV diagnoses remained stable at about 26,000 per year among all gay and bisexual men.
- After years of increases, diagnoses stabilized among young (aged 13-24) African American and white gay and bisexual men. Diagnoses increased 14% among young Hispanic/Latino gay and bisexual men.

Living With HIV and Deaths

- At the end of 2014, an estimated 615,400 gay and bisexual men were living with HIV. Of those, 17.3% were unaware of their infection.
- Among all gay and bisexual men living with HIV in 2014, 83% had received a diagnosis, 61% received HIV medical care in 2014, 48% were receiving continuous HIV care, and 51% had a suppressed viral load.[g] A person living with HIV who gets and stays virally suppressed can stay healthy and has effectively no risk of sexually transmitting HIV to HIV-negative partners.
- In 2014, there were 6,110 deaths among gay and bisexual men living with diagnosed HIV infection.[h]

Prevention Challenges

- **A much higher proportion of gay and bisexual men are living with HIV** compared to any other group in the United States. Therefore gay and bisexual men have an increased chance of having an HIV-positive partner.

- **1 in 6 gay and bisexual men living with HIV are unaware they have it.** People who don't know they have HIV cannot get the medicines they need to stay healthy and prevent transmitting HIV to their partners. Therefore, they may transmit the infection to others without knowing it.
- Most gay and bisexual men get HIV through having anal sex without condoms or medicines to prevent or treat HIV. **Anal sex is the riskiest type of sex for getting or transmitting HIV**. Receptive anal sex is 13 times as risky for getting HIV as insertive anal sex.
- Gay and bisexual men are also at increased risk for **other sexually transmitted diseases** (STDs), like syphilis, gonorrhea, and chlamydia. Condoms can protect from some STDs, including HIV.
- **Homophobia, stigma, and discrimination** may place gay and bisexual men at risk for multiple physical and mental health problems and affect whether they take protective actions with their partners or seek and are able to obtain high-quality health services.

What CDC Is Doing

CDC funds health departments and other community-based organizations (CBOs) to support HIV prevention services for gay and bisexual men. For example,

- Under the current funding opportunity, CDC has awarded (https://www.cdc.gov/hiv/funding/announcements/ps12-1201/index.html) at least $330 million per year to health departments to direct resources to the populations and geographic areas of greatest need and prioritize the HIV prevention strategies that will have the greatest impact. A new notice of funding opportunity (NOFO) (https://www.cdc.gov/hiv/funding/announcements/ps18-1802/index.html) will begin in 2018.
- In 2017, CDC awarded (https://www.cdc.gov/hiv/funding/announcements/ps17-1704/index.html) nearly $11 million per year for 5 years to 30 CBOs to provide HIV testing to young gay and bisexual men of color and young transgender persons of color, with the goals of identifying undiagnosed HIV infections and linking those who have HIV to care and prevention services.
- In 2015, CDC added three new NOFOs (https://www.cdc.gov/hiv/funding/index.html) to help health departments reduce HIV infections and improve HIV medical care among gay and bisexual men.
    - Targeted Highly Effective Interventions to Reverse the HIV Epidemic (THRIVE) (https://www.cdc.gov/hiv/research/thrive/about.html) supports state and local health department demonstration projects to develop community collaborations that provide comprehensive HIV prevention and care services for MSM of color.
    - Training and Technical Assistance for THRIVE (https://www.cdc.gov/hiv/funding/announcements/ps15-1510/) strengthens the capacity of funded health departments and their collaborative partners to plan, implement, and sustain (through ongoing engagement, assessment, linkage, and retention) comprehensive prevention, care, behavioral health, and social services models for MSM of color at risk for and living with HIV infection.
    - Project PrIDE (https://www.cdc.gov/hiv/research/demonstration/projectpride.html) (PrEP, Implementation, Data2Care, and Evaluation) supports 12 health departments in implementing PrEP (https://www.cdc.gov/hiv/basics/prep.html) and Data to Care (https://effectiveinterventions.cdc.gov/en/HighImpactPrevention/PublicHealthStrategies/DatatoCare.aspx) demonstration projects for gay and bisexual men of color.

CDC supports biomedical approaches to HIV prevention. People at very high risk for HIV can take HIV medicines daily (PrEP) to greatly reduce the chances that they will get HIV. Post-exposure prophylaxis (PEP) (https://www.cdc.gov/hiv/basics/pep.html), which means taking HIV medicines soon after possible exposure to HIV, also plays a role in HIV prevention, but should be not be considered a primary means of prevention.

Through its *Act Against AIDS* (https://www.cdc.gov/actagainstaids/index.html) campaigns and partnerships, **CDC provides gay and bisexual men with effective and culturally appropriate messages** about HIV prevention and treatment. For example,

- *Doing It* (https://www.cdc.gov/actagainstaids/campaigns/doingit/index.html), a national HIV testing and prevention campaign, encourages all adults to know their HIV status and make HIV testing a part of their regular health routine.
- *Start Talking. Stop HIV.* (https://www.cdc.gov/actagainstaids/campaigns/starttalking/index.html) helps gay and bisexual men communicate about safer sex, testing, and other HIV prevention issues.
- *HIV Treatment Works* (https://www.cdc.gov/actagainstaids/campaigns/hivtreatmentworks/index.html) shows how people living with HIV have overcome barriers to stay in care and provides resources on how to live well with HIV.
- *Partnering and Communicating Together (PACT) to Act Against AIDS* (https://www.cdc.gov/actagainstaids/partnerships/pact.html), a 5-year partnership with organizations such as AIDS United and the National Lesbian & Gay Journalists Association, is raising awareness about testing, prevention, and retention in care among populations disproportionately affected by HIV, including gay and bisexual men.

To learn more about a range of health issues affecting gay and bisexual men, visit the CDC Gay and Bisexual Men's Health site (https://www.cdc.gov/msmhealth/).

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[a] The term *male-to-male sexual contact* is used in CDC surveillance systems. It indicates a behavior that transmits HIV infection, not how individuals self-identify in terms of their sexuality. This fact sheet uses the term *gay and bisexual men.*

[b] *Estimated annual HIV infections* are the estimated number of new infections (HIV incidence) that occurred in a particular year, regardless of when those infections were diagnosed.

[c] Hispanics/Latinos can be of any race.

[d] Referred to as *African American* in this fact sheet.

[e] *HIV and AIDS diagnoses* refers to the number of people with HIV infection and AIDS diagnosed during a given time period, not when the people were infected.

[f] The numbers reported in this fact sheet include infections attributed to male-to-male sexual contact only, not those attributed to male-to-male sexual contact and injection drug use.

[g] Viral suppression is defined as having fewer than 200 copies of the virus per milliliter of blood on the most recent viral load test in 2014. Receiving continuous HIV care is defined as having two viral load or CD4 tests 3 or more months apart in 2014. (CD4 cells are the cells in the body's immune system that are destroyed by HIV.)

[h] Deaths may be due to any cause.

Additional Resources

CDC-INFO
1-800-CDC-INFO (232-4636)
www.cdc.gov/info

CDC HIV Website
www.cdc.gov/hiv

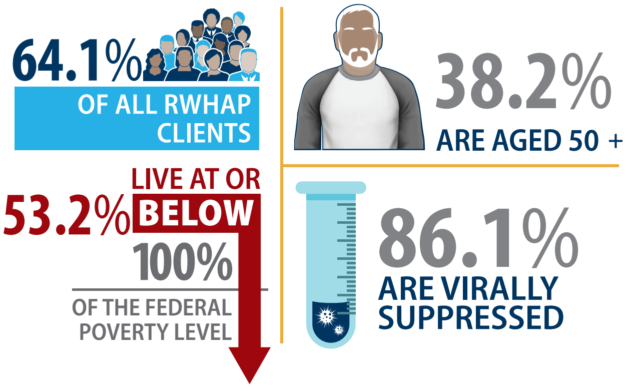
CDC Act Against AIDS Campaign
www.cdc.gov/actagainstaids

HRSA's Ryan White HIV/AIDS Program

January 2018

GAY, BISEXUAL, AND OTHER MEN WHO HAVE SEX WITH MEN (MSM): RYAN WHITE HIV/AIDS PROGRAM CLIENTS, 2016

Ryan White HIV/AIDS Program Client Fast Facts: Gay, Bisexual, and Other Men Who Have Sex with Men



64.1% OF ALL RWHAP CLIENTS

38.2% ARE AGED 50 +

53.2% LIVE AT OR BELOW 100% OF THE FEDERAL POVERTY LEVEL

86.1% ARE VIRALLY SUPPRESSED

The Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program (RWHAP) provides a comprehensive system of HIV primary medical care, medications, and essential support services for low-income people living with HIV (PLWH). More than half the people living with diagnosed HIV in the United States—an estimated 551,000 people in 2016—receive services through RWHAP each year. RWHAP funds grants to states, cities/counties, and local community-based organizations to provide care and treatment services to PLWH to improve health outcomes and reduce HIV transmission among hard-to-reach populations.

A significant proportion of RWHAP clients are men who have sex with men (MSM). Of the more than half a million clients served by RWHAP, 64.1 percent are MSM.

Below are more details about this RWHAP client population:

- **The majority of MSM clients served by RWHAP are from racial and ethnic minority populations.** Data show 62.1 percent of MSM RWHAP clients served are from racial and ethnic minority populations. Among MSM, 37.9 percent identify as white, 34.3 percent identify as black/African American, and 24.3 percent identify as Hispanic/Latino.
- **More than half of MSM clients served by RWHAP are low income.** Of MSM RWHAP clients served, 53.2 percent are living at or below 100 percent of the federal poverty level, which is lower than the national RWHAP average (62.8 percent).
- **Among MSM RWHAP clients, 4.3 percent have unstable housing.** This is slightly less than the national RWHAP average (5.2 percent).
- **The RWHAP MSM client population is aging.** MSM clients aged 50 years and older account for 38.2 percent of all RWHAP MSM clients.

Medical care and treatment improve health outcomes and decrease the risk of HIV transmission. 86.1 percent of MSM receiving RWHAP HIV medical care are virally suppressed,* which is higher than the national RWHAP average (84.9 percent).

- 71.1 percent of young MSM (aged 13–24) receiving RWHAP HIV medical care are virally suppressed.
- 69.6 percent of young black/African American MSM (aged 13–24) receiving RWHAP HIV medical care are virally suppressed.

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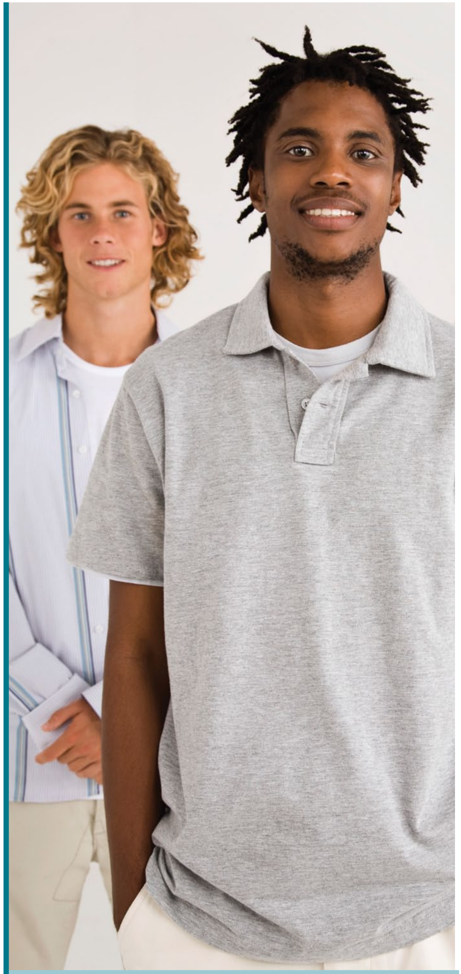
* Viral suppression is defined as a viral load result of less than 200 copies/mL at most recent test, among PLWH who had at least one outpatient ambulatory health services visit and one viral load test during the measurement year.

HIV and Young Men Who Have Sex with Men



Many young people in the United States remain at risk for HIV infection. An estimated 47,500 Americans were newly infected with HIV[1] in 2010. Of these, 26%—about 12,200—were adolescents or young adults aged 13–24 years.[1] Young men who have sex with men (YMSM),[a] especially black/African American[b] YMSM, are at highest risk. The ongoing risk for HIV infection among YMSM underscores the need to reach each new generation with effective HIV prevention messages and services. Schools and education agencies are important partners in this effort.

Fast Facts

HIV disproportionately affects young men who have sex with men (YMSM).

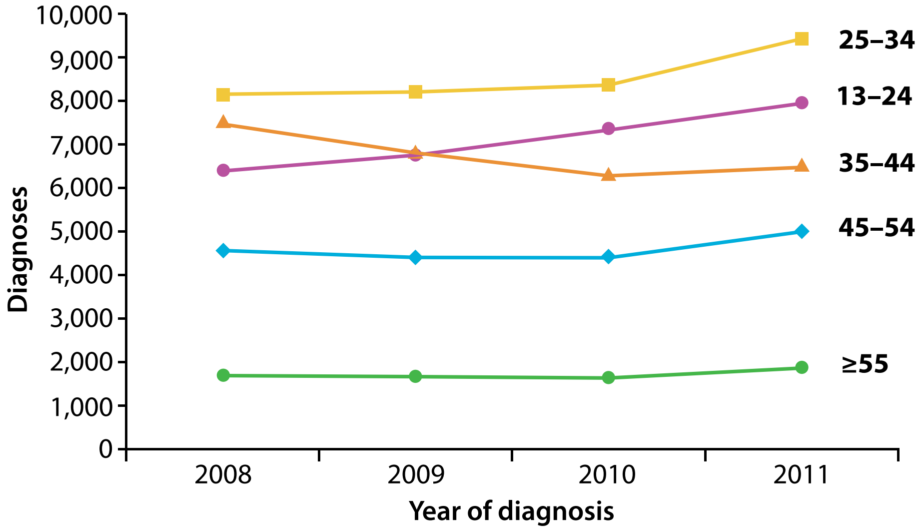
YMSM:

- In 2011, among adolescent males aged 13–19 years, approximately 93% of all diagnosed HIV infections were from male-to-male sexual contact.[2]
- From 2008–2011, YMSM aged 13–24 years had the greatest percentage increase (26%) in diagnosed HIV infections.[3] (Figure 1)

Black and Hispanic/Latino[c] YMSM:

- In 2011, among all YMSM aged 13–24 years with HIV infection, an estimated 58% were black; 20% were Hispanic/Latino.[3]
- Black YMSM also experienced the largest increase of all racial/ethnic groups in diagnosed HIV infections—from 3,762 diagnoses in 2008 to 4,619 diagnoses in 2011.[3] (Figure 2)

Figure 1. Diagnoses of HIV Infection among Men Who Have Sex with Men, by Age Group, 2008–2011—United States and 6 Dependent Areas



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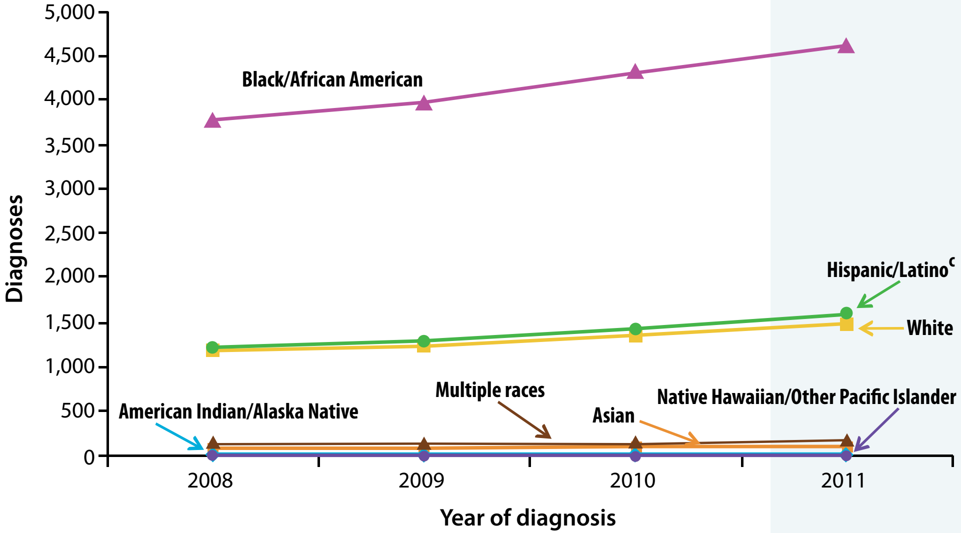
[a] CDC uses the term men who have sex with men (MSM) in its surveillance systems. MSM indicates the behaviors that transmit HIV infection, rather than how individuals self-identify in terms of their sexuality.

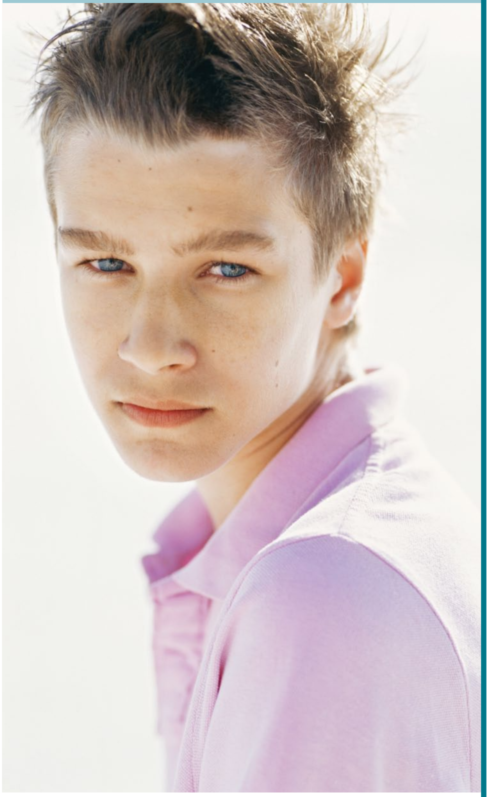
[b] Black/African American: Referred to as black in this fact sheet.

[c] Hispanics/Latinos can be of any race.

Figure 2. **Diagnoses of HIV Infection Among Men Who Have Sex with Men Aged 13–24 Years, by Race/Ethnicity, 2008–2011—United States and 6 Dependent Areas**



[c] Hispanics/Latinos can be of any race.



HIV Prevention Challenges

The reasons for disparities in HIV infection are varied and not well understood. These disparities do not appear to reflect individual racial or ethnic differences in risk behaviors.[4] Possible factors to explain these disparities may include the following:

- **Inadequate HIV prevention education and interventions.** Sex education programs that are not sensitive and appropriate to the needs of YMSM might not be effective in reducing sexual risk behaviors among those students.[5]
- **Limited awareness of infection.** Some HIV-infected men who have sex with men (MSM) may not know they are infected, especially MSM of color and YMSM.[6] Those who do not know they are infected might be less likely to take measures to keep from spreading the virus to others. Getting tested for HIV is an important part of prevention.
- **Low perception of risk.** Improved treatment for HIV has helped many people with HIV infection live longer and healthier lives. YMSM, who did not witness the toll of AIDS in the early years of the epidemic, might view HIV as less dangerous and disregard risks and important prevention practices.[7]
- **Alcohol and illegal drug use.** Alcohol, methamphetamine (commonly known as "meth" or "crystal meth"), and other "party drug" use is common among some YMSM. Alcohol and drug use can lead to risky sexual behavior.[7]
- **Feelings of rejection and isolation.** Bullying, harassment, family disapproval, social isolation, and sexual violence are experienced frequently by YMSM and other sexual minority youth.[d] These experiences can cause poor self-esteem and feelings of shame and can lead to more emotional distress, suicide attempts, substance use, and risky sexual behavior.[8-10]

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[d] Those who identify as gay, lesbian, or bisexual or who have sexual contact with persons of the same or both sexes.

School-Based Strategies for Addressing HIV Among YMSM

CDC funds state and local education and health agencies to help schools implement policies and practices to reduce health risks among sexual minority youth, including YMSM. Because black and Hispanic/Latino YMSM are at especially high risk of HIV infection, CDC collaborates with local education agencies and national nongovernmental organizations to reduce HIV and other sexually transmitted diseases (STDs) among this population. These partners are collaborating with local community-based organizations, health departments, and other health care organizations to collect data, promote safe and supportive environments, increase HIV/STD testing and treatment in schools and school-based health centers, refer students to youth-friendly health services, and implement evidence-based HIV/STD education and prevention activities.

Collect and use health risk behavior data.

Many states and large urban school districts use CDC's Youth Risk Behavior Survey (YRBS) data to monitor health risk behaviors and selected health outcomes among sexual minority students. In addition, starting in 2015, the national YRBS questionnaire and the state/local standard questionnaire will include questions about sexual identity and sex of sexual contacts. By documenting that some youth do engage in same-sex sexual activity and various health risk behaviors, YRBS data can help confirm the value of addressing the health needs of sexual minority youth in schools, adjust intervention priorities, and monitor health outcomes.

More information is available at www.cdc.gov/yrbs.

Establish safe and supportive school environments.

HIV prevention activities are more likely to have an impact if they address the challenges YMSM face at school, especially verbal harassment related to their sexual orientation.[11] For lesbian, gay, bisexual, or transgender students, having a safe and supportive school environment has been associated with decreases in depression, suicidal feelings, substance use, and unexcused school absences.[12,13] To help establish supportive school environments for YMSM, schools can address bullying and sexual harassment, help students feel cared for and valued, and foster parent engagement.

Provide key sexual health services.

Linking YMSM to HIV testing and treatment is key to preventing the spread of HIV and AIDS. Confidential clinical services can help prevent new cases of HIV by increasing testing and treating HIV and other STDs. Schools can help youth access key preventive sexual health services such as HIV and STD testing, counseling, and referral, either by providing these services at schools or connecting students with community providers.[14]

Implement exemplary sexual health education.[e]

Because sexual health education programs that ignore issues in the lives of YMSM might not work effectively, schools and education agencies should ensure that health education curricula include evidence-based prevention information relevant to this population. Professional development training can help school staff understand the health needs of YMSM and shape health messages accordingly.

[e] Sexual health education programs that are medically accurate, consistent with scientific evidence, and tailored to students' contexts; and that use effective classroom instructional methods.

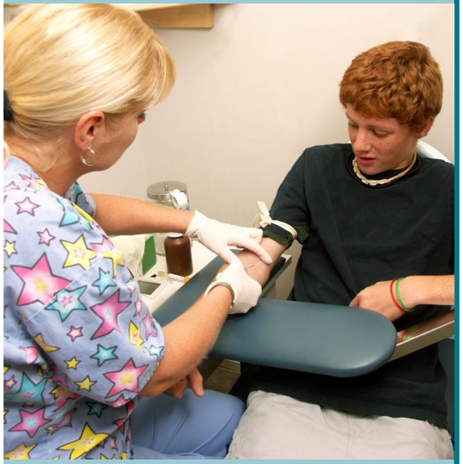
HIV and YMSM Resources

- Evidence-based HIV prevention interventions:
  www.cdc.gov/healthyyouth/adolescenthealth/registries.htm

- Specific CDC-funded YMSM program activities:
  www.cdc.gov/healthyyouth/disparities/ymsm/

- CDC resources on school connectedness and parent engagement in school health:
  www.cdc.gov/healthyyouth/adolescenthealth/protective.htm

- Parental influence on sexual minority youth:
  www.cdc.gov/healthyyouth/protective/positiveparenting/parents_influence.htm



Getting tested for HIV is a critical part of prevention.

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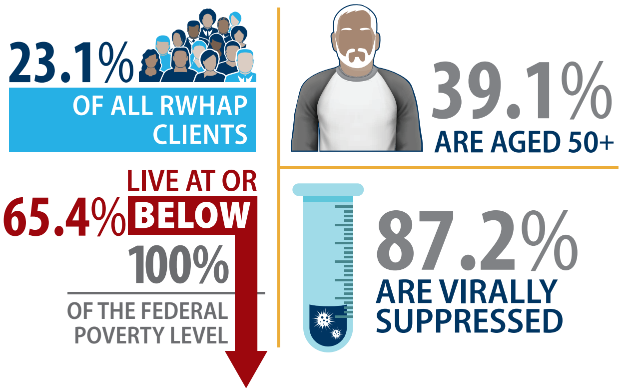
HRSA's Ryan White HIV/AIDS Program

January 2018

HISPANIC/LATINO: RYAN WHITE HIV/AIDS PROGRAM CLIENTS, 2016

Ryan White HIV/AIDS Program Client Fast Facts: Hispanic/Latino



23.1% OF ALL RWHAP CLIENTS

39.1% ARE AGED 50+

65.4% LIVE AT OR BELOW 100% OF THE FEDERAL POVERTY LEVEL

87.2% ARE VIRALLY SUPPRESSED

The Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program (RWHAP) provides a comprehensive system of HIV primary medical care, medications, and essential support services for low-income people living with HIV (PLWH). More than half the people living with diagnosed HIV in the United States—an estimated 551,000 people in 2016—receive services through RWHAP each year. RWHAP funds grants to states, cities/counties, and local community-based organizations to provide care and treatment services to PLWH to improve health outcomes and reduce HIV transmission among hard-to-reach populations.

A critical population served by RWHAP is Hispanic/Latino clients living with HIV. Of the more than half a million clients served by RWHAP, 73.3 percent are from racial or ethnic minority populations, with 23.1 percent of all RWHAP clients identifying as Hispanic/Latino.

Below are more details about this RWHAP client population:

- **The majority of Hispanic/Latino clients served by RWHAP are low income.** Data show that 65.4 percent of Hispanic/Latino clients are living at or below 100 percent of the federal poverty level, which is higher than the national RWHAP average (62.8 percent).
- **The majority of Hispanic/Latino clients served by RWHAP are male.** Data show that 75.1 percent of clients are male, 23.3 percent are female, and 1.6 percent are transgender.
- **Data show that 4.3 percent of Hispanic/Latino clients have unstable housing.** This is slightly less than the national RWHAP average (5.2 percent).
- **The Hispanic/Latino client population is aging.** Hispanic/Latino clients aged 50 years and older account for 39.1 percent of all Hispanic/Latino RWHAP clients.
- **Among Hispanic/Latino male clients, 63.3 percent are men who have sex with men (MSM).** This is slightly lower than the national RWHAP average of MSM clients (64.1 percent of all male clients).

Medical care and treatment improve health outcomes and decrease the risk of HIV transmission. Approximately 87.2 percent of Hispanic/Latino RWHAP clients receiving HIV medical care are virally suppressed,* which is higher than the national RWHAP average (84.9 percent).

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* Viral suppression is defined as a viral load result of less than 200 copies/mL at most recent test, among PLWH who had at least one outpatient ambulatory health services visit and one viral load test during the measurement year.

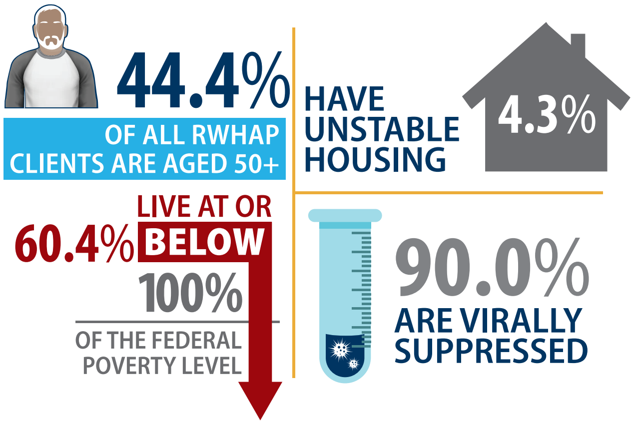
HRSA Ryan White & Global HIV/AIDS Programs

HRSA's Ryan White HIV/AIDS Program

January 2018

OLDER ADULTS: RYAN WHITE HIV/AIDS PROGRAM CLIENTS, 2016

Ryan White HIV/AIDS Program Client Fast Facts: Older Adults



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The RWHAP client population is aging. Of the more than half a million clients served by the RWHAP, 44.4 percent are aged 50 years and older.

Below are more details about this RWHAP client population:

- **The majority of RWHAP clients aged 50 and older are from racial and ethnic minority populations.** Among RWHAP clients aged 50 and older, 68.3 percent are from racial and ethnic minority populations. 45.6 percent of RWHAP clients in this age group identify as black/African American, which is slightly lower than the national RWHAP average (47.1 percent). Approximately 20.3 percent of RWHAP clients in this age group identify as Hispanic/Latino, which is lower than the national RWHAP average (23.1 percent).
- **The majority of RWHAP clients aged 50 and older are male.** Data show that 71.6 percent of clients aged 50 and older are male, 27.8 percent are female, and 0.6 percent are transgender.
- **The majority of clients aged 50 and older are low income.** Among RWHAP clients, 60.4 percent of people aged 50 and older are living at or below 100 percent of the federal poverty level, which is lower than the national RWHAP average (62.8 percent).
- **Data show 4.3 percent of clients aged 50 and older have unstable housing.** This is slightly lower than the national RWHAP average (5.2 percent).

Medical care and treatment improve health outcomes and decrease the risk of HIV transmission. 90.0 percent of clients aged 50 years and older receiving RWHAP HIV medical care are virally suppressed,* which is higher than the national RWHAP average (84.9 percent).

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* Viral suppression is defined as a viral load result of less than 200 copies/mL at most recent test, among PLWH who had at least one outpatient ambulatory health services visit and one viral load test during the measurement year.

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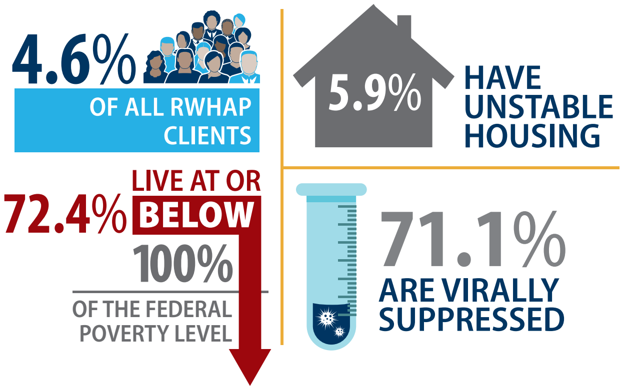
HRSA's Ryan White HIV/AIDS Program

January 2018

YOUTH AND YOUNG ADULTS: RYAN WHITE HIV/AIDS PROGRAM CLIENTS, 2016

Ryan White HIV/AIDS Program Client Fast Facts: Youth and Young Adults



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Youth and young adults aged 13 to 24 years represent 4.6 percent of the more than half a million RWHAP clients, slightly more than 25,000 clients. This age group accounts for the highest rate of new infections each year in the United States. Below are more details about this RWHAP client population:

- **The majority of RWHAP clients aged 13 to 24 years are from racial and ethnic minority populations.** Among clients in this age group, 86.3 percent are from racial and ethnic minority populations. Nearly two-thirds (61.4 percent) of youth and young adult clients identify as black/African American, which is higher than the national RWHAP average (47.1 percent). Hispanics/Latinos represent 21.0 percent of youth and young adults, which is slightly lower than the national RWHAP average (23.1 percent).
- **The majority of RWHAP clients aged 13 to 24 years are male.** Data show that 73.7 percent of clients aged 13 to 24 years are male, 24.3 percent are female, and 2.0 percent are transgender.
- **The majority of RWHAP clients aged 13 to 24 years are low income.** Of youth and young adult RWHAP clients, 72.4 percent are living at or below 100 percent of the federal poverty level, which is higher than the national RWHAP average (62.8 percent).
- **Data show that 5.9 percent of clients aged 13 to 24 years have unstable housing.** This is slightly higher than the national RWHAP average (5.2 percent).

Medical care and treatment improve health outcomes and decrease the risk of HIV transmission. Approximately 71.1 percent of clients aged 13 to 24 years receiving RWHAP HIV medical care are virally suppressed,* which is significantly lower than the national RWHAP average (84.9 percent).

- 72.8 percent of young men who have sex with men (MSM) receiving RWHAP HIV medical care are virally suppressed.
- 69.6 percent of young black/African American MSM receiving RWHAP HIV medical care are virally suppressed.
- 66.8 percent of young black/African American women receiving RWHAP HIV medical care are virally suppressed.
- 63.4 percent of transgender youth and young adults receiving RWHAP HIV medical care are virally suppressed.

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* Viral suppression is defined as a viral load result of less than 200 copies/mL at most recent test, among PLWH who had at least one outpatient ambulatory health services visit and one viral load test during the measurement year.

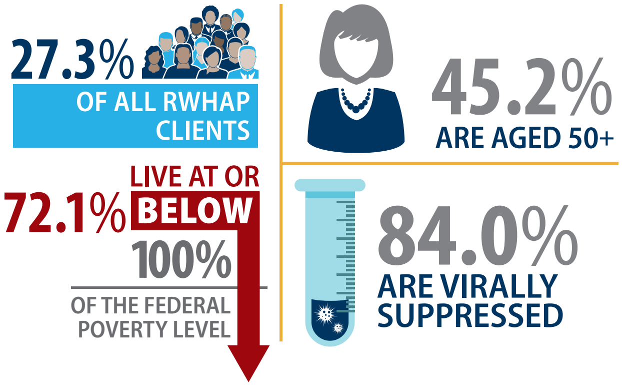
Ryan White & Global HIV/AIDS Programs

HRSA's Ryan White HIV/AIDS Program

January 2018

FEMALE: RYAN WHITE HIV/AIDS PROGRAM CLIENTS, 2016

Ryan White HIV/AIDS Program Client Fast Facts: Female



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Females are a substantial proportion of RWHAP clients. Of the more than half a million clients served by RWHAP, 27.3 percent are female.

Below are more details about this RWHAP client population:

- **The majority of female clients served by RWHAP are from racial and ethnic minority populations.** Data show 83.8 percent of female clients are from racial and ethnic minority populations. 61.5 percent of female clients identify as black/African American, which is higher than the national RWHAP average (47.1 percent). 19.7 percent of female clients identify as Hispanic/Latino, which is lower than the national RWHAP average (23.1 percent).
- **The majority of female clients served by RWHAP are low income.** Among female clients served, 72.1 percent are living at or below 100 percent of the federal poverty level, which is higher than the national RWHAP average (62.8 percent).
- **Data show that 4.1 percent of female clients have unstable housing situations.** This is lower than the national RWHAP average (5.2 percent).
- **The RWHAP female client population is aging.** Among female RWHAP clients served, 45.2 percent are aged 50 and older, while only 4.1 percent of female RWHAP clients are aged 13–24.

Medical care and treatment improve health outcomes and decrease the risk of HIV transmission. Approximately 84.0 percent of female clients receiving RWHAP HIV medical care are virally suppressed,* which is slightly lower than the national RWHAP average (84.9 percent).

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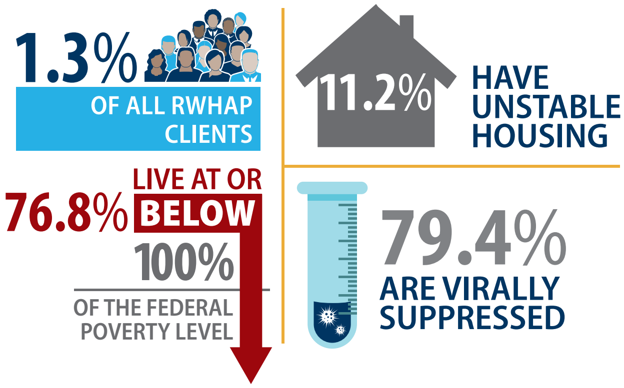
* Viral suppression is defined as a viral load result of less than 200 copies/mL at most recent test, among PLWH who had at least one outpatient ambulatory health services visit and one viral load test during the measurement year.

HRSA's Ryan White HIV/AIDS Program

January 2018

Transgender: Ryan White HIV/AIDS Program Clients, 2016

Ryan White HIV/AIDS Program Client Fast Facts: Transgender



1.3% OF ALL RWHAP CLIENTS

11.2% HAVE UNSTABLE HOUSING

76.8% LIVE AT OR BELOW 100% OF THE FEDERAL POVERTY LEVEL

79.4% ARE VIRALLY SUPPRESSED

The Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program (RWHAP) provides a comprehensive system of HIV primary medical care, medications, and essential support services for low-income people living with HIV (PLWH). More than half the people living with diagnosed HIV in the United States—an estimated 551,000 people in 2016—receive services through RWHAP each year. RWHAP funds grants to states, cities/counties, and local community-based organizations to provide care and treatment services to PLWH to improve health outcomes and reduce HIV transmission among hard-to-reach populations.

Transgender individuals are a critical population served by RWHAP. Of the more than half a million clients served, 1.3 percent are transgender, representing slightly more than 7,100 clients.

Below are more details about this RWHAP client population:

- **The majority of transgender clients served by RWHAP are from racial and ethnic minority populations.** Among transgender clients served, 88.4 percent are from racial and ethnic minority populations. Approximately 54.1 percent of transgender clients served by RWHAP identify as black/African American, which is higher than the national RWHAP average (47.1 percent). Approximately 29.2 percent identify as Hispanic/Latino, which also is higher than the national RWHAP average (23.1 percent).
- **The majority of transgender clients served by RWHAP are low income.** Among transgender RWHAP clients served, 76.8 percent live at or below 100 percent of the federal poverty level, which is higher than the national RWHAP average (62.8 percent).
- **Data show that 11.2 percent of transgender clients have unstable housing.** This is substantially higher than the national RWHAP average (5.2 percent).
- **The RWHAP transgender client population is aging.** Approximately 21.6 percent of RWHAP transgender clients are aged 50 years and older, and an additional 24.9 percent of transgender RWHAP clients are aged 40–49 years.

Medical care and treatment improve health outcomes and decrease the risk of HIV transmission.79.4 percent of transgender clients receiving RWHAP HIV medical care are virally suppressed,* which is lower than the national RWHAP average (84.9 percent).

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* Viral suppression is defined as a viral load result of less than 200 copies/mL at most recent test, among PLWH who had at least one outpatient ambulatory health services visit and one viral load test during the measurement year.

HIV Among Incarcerated Populations

July 2015

Fast Facts

- HIV is a serious health issue for correctional facilities and their incarcerated populations.
- Most incarcerated people with HIV got the virus before entering a correctional facility.
- HIV testing at a correctional facility may be the first time incarcerated people are tested and diagnosed with HIV.

More than 2 million people in the United States are incarcerated in federal, state, and local correctional facilities on any given day. In 2010, the rate of diagnosed HIV infection among inmates in state and federal prisons was more than five times greater than the rate among people who were not incarcerated. Most inmates with HIV acquire it in their communities, before they are incarcerated.

The Numbers

- In 2012, 1.57 million people were incarcerated in state and federal prisons and at midyear 2013 there were 731,208 people detained in local jails.[1]
- In 2010, there were 20,093 inmates with HIV/AIDS in state and federal prisons with 91% being men.
- Among state and federal jurisdictions reporting in 2010[2] there were 3,913 inmates living with an AIDS diagnosis.
- Rates of AIDS-related deaths among state and federal prisoners declined an average of 16% per year between 2001 and 2010, from 24 deaths/100,000 in 2001 to 5/100,000 in 2010.
- Among jail populations, African American men are 5 times as likely as white men, and twice as likely as Hispanic/Latino men, to be diagnosed with HIV.
- Among jail populations, African American women are more than twice as likely to be diagnosed with HIV as white or Hispanic/Latino women.

Prevention Challenges

- Lack of awareness about HIV and lack of resources for HIV testing and treatment in inmates' home communities. Most inmates with HIV become infected in their communities, where they may engage in high-risk behaviors or be unaware of available prevention and treatment resources.
- Lack of resources for HIV testing and treatment in correctional facilities. Prison and jail administrators must weigh the costs of HIV testing and treatment against other needs, and some correctional systems may not provide such services. HIV testing can identify inmates with HIV before they are released. Early diagnosis and treatment can potentially reduce the level of HIV in communities to which inmates return.
- Rapid turnover among jail populations. While most HIV programs in correctional facilities are in prisons, most incarcerated people are detained in jails. Nine out of ten jail inmates are released in under 72 hours, which makes it hard to test them for HIV and help them find treatment.
- Inmate concerns about privacy and fear of stigma. Many inmates do not disclose their high-risk behaviors, such as anal sex or injection drug use, because they fear being stigmatized. Health care providers should keep inmate's health care information confidential, know the public health confidentiality and reporting laws, and inform inmates about them.

What CDC Is Doing

Funding state, local, and territorial health departments. This is CDC's largest investment in HIV prevention. CDC funds health departments and community-based organizations (CBOs) to provide HIV prevention services in many settings, including prisons and jails.

- CDC funded selected state health departments to conduct voluntary rapid HIV testing in jails, identify previously undiagnosed cases, and refer inmates to medical care. Of the 33,211 inmates tested, 409 (1.2%) tested positive, and 269 (0.8%) undiagnosed cases of HIV were detected, many among people who had not disclosed their risk behaviors.

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[1] Jails are short-term facilities that are usually run by a local law enforcement agency. Jail sentences may range from a few hours up to one year. Compared with jail facilities, prisons are longer-term facilities owned by a state or by the federal government that typically hold people sentenced to more than one year.

[2] State and federal jurisdictions reporting in 2010 included 37 states and the Bureau of Federal Prisons.

Funding community-based pilot projects. CDC has joined with universities, CBOs, and other partners to find out which HIV prevention interventions are most effective among incarcerated populations and how they can be applied to other settings.

- CDC supported Project START (https://effectiveinterventions.cdc.gov/en/HighImpactPrevention/Interventions/ProjectSTART.aspx), a pre-release HIV intervention for young men. Project participants reduced their HIV risk behaviors after their release back into the community.
- CDC funded the University of North Carolina to evaluate Project POWER (http://www.ncbi.nlm.nih.gov/pubmed/23631715), an HIV intervention among women in state correctional facilities. Six months after release, participants reported significantly greater condom use than nonparticipants. Participants also reported greater HIV knowledge, and more social support.
- CDC partnered with Emory University to adapt and evaluate an HIV intervention program for African American girls aged 13-17 in a juvenile detention center. Three months after the intervention, participants reported greater condom use, HIV/STD prevention knowledge, and condom use skills.
- CDC joined with Morehouse Medical School to counsel African American male jail inmates about high-risk sexual behaviors and ways to reduce them. After six months, participants reported significantly more condom use during vaginal or anal sex than nonparticipants. Participants 14-18 years old reported significantly more condom use at last sex with a non-main female sex partner than nonparticipants.

Voluntary rapid HIV testing. CDC partnered with Emory University to support voluntary rapid HIV testing at a large county jail located in a community with a high prevalence of HIV. The jail's nursing staff provided more than 12,000 tests, and 52 cases of HIV infection were newly diagnosed.

CDC has published HIV testing guidance for correctional facilities (https://www.cdc.gov/hiv/pdf/group/cdc-hiv-correctional-settings-guidelines.pdf) which recommends testing inmates when they enter correctional facilities, during incarceration, and just prior to release. CDC also recommends medical treatment and counseling to educate inmates about HIV risk behaviors. HIV prevention education should address male to male sex, tattooing, injection drug use, and other high risk behaviors that occur during and after incarceration.

CDC recommends that condom distribution programs be evaluated for use in prisons and jails in the United States. The World Health Organization recommends such programs (http://whqlibdoc.who.int/publications/2007/9789241596190_eng.pdf?ua=1) as an effective way to reduce HIV among incarcerated populations.

The National Center for HIV/AIDS, Hepatitis, STD and TB Prevention, (NCHHSTP) Corrections Workgroup addresses the prevention and control of HIV, STDs, Viral hepatitis, and TB among incarcerated people. The workgroup includes experts in epidemiology, criminology, and corrections issues, and works to reduce health disparities among incarcerated populations.

CDC scientists edited a special issue of the journal Women & Health, "Infectious and Other Disease Morbidity and Health Equity among Incarcerated Adolescent and Adult Women," in November 2014, which focused on the health challenges, including HIV, faced by incarcerated women.

For more information on this topic visit www.cdc.gov/hiv/group/correctional.html.

Additional Resources

CDC-INFO
1-800-CDC-INFO (232-4636)
www.cdc.gov/info

CDC HIV Website
www.cdc.gov/hiv

CDC Act Against AIDS Campaign
www.cdc.gov/actagainstaids

Sociocultural dimensions of HIV/AIDS among Middle Eastern immigrants in the US: bridging culture with HIV/AIDS programmes

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Key words

HIV risk factors; sociocultural factors; immigrants; Middle Easterners; health disparity

Abstract

The population of Middle Eastern immigrants in the US has been increasing dramatically over the past 30 years, growing from 200,000 in 1970 to 1.5 million in 2000. These immigrants and their descendants constitute an important new population of interest for public health and other social programmes. With this addition to the cultural diversity of American society, it is important for healthcare programmes to be responsive to the unique cultural needs of those of Middle Eastern origin and to include them in healthcare curricula. This need is particularly imperative for human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) intervention programmes, where the reduction of risky behaviours is essential to controlling the epidemic. When Middle Easterners emigrate to the US they must adjust to the American culture, which leads to preservation of some aspects of their culture and adjustment of behaviors to match American customs. This article aims to present sociocultural factors of HIV risk behaviours that are specific to Middle Eastern culture. The article also provides recommendations for HIV/AIDS-culturally appropriate intervention programmes.

INTRODUCTION

Middle Eastern and HIV/AIDS epidemics

One of the fastest growing populations in the US is the Middle Eastern immigrant population, having increased from 200,000 in 1970 to 1.5 million in the 2000 census.[1] Recent statistics show that 40% of the Middle Eastern immigrant population in the US comes from Arab countries.[1] In addition, a sizable portion of Middle Easterners come from non-Arab countries, including Iran, Israel, Turkey and Pakistan.[1] For the purposes of this paper, the Middle East is defined as a region including Afghanistan, Bahrain, Iran, Iraq, Jordan, Kuwait, Lebanon, Oman, Pakistan, Palestine, Qatar, Saudi Arabia, Syria, Turkey, United Arab Emirates and Yemen (Figure 1), with a population of about 460 million.[2,3] While immigrants from this region are quite diverse in their heritage, history and languages, most Middle Easterners share a set of beliefs that are rooted in Islam. This is an important group to investigate with regard to HIV/AIDS because, according to one study of foreign and US-born populations in Los Angeles, HIV prevalence was highest among North African/Middle Easterners compared to other immigrant populations (3.3%), with North Africa/Middle Eastern males having a prevalence of 4.1%. The same study concluded that there is a need to develop HIV-prevention materials and treatment programmes that are sensitive to the needs of Middle Eastern immigrants, since the disease affects their communities so strongly.[4]

BACKGROUND

Middle Eastern immigrants: preservation or disintegration of cultural identities?

An individual's cultural beliefs and sexual behaviours are important risk factors for HIV-acquisition.[5,6,7] Like other immigrants, Middle Easterners find it necessary to adjust to Western

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Figure 1

Middle East

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culture over time, leading to their traditional values being challenged by new cultural norms.[7,8,9,10] The degree of adaptation and change varies within various cultural groups.[11,12] For example, among Middle Eastern immigrants in the US, social attitudes of Arab immigrants have been found to be less Americanized than their Iranian counterparts who come from a non-Arab culture.[11] In addition, the degree to which previous generations of Middle Eastern immigrants acculturated in the past may be very different from newer generations.[8,13] New generations may not preserve the customs and traditions of their forefathers while they are living in the US or travelling back to their home countries.

Furthermore, the mobility and growth of a population impacts on the overall spread of HIV among both immigrants and non-immigrants. It has also been shown that immigrants are more likely to engage in risky sexual behaviour than non-immigrants.[14,15] Studies of some immigrant groups have suggested that the majority of the foreign-born HIV-infected patients were infected after immigration to the US.[15,16] This aspect of behaviour among immigrants has not been studied in the Middle Eastern immigrant population. Therefore it is important to examine the behaviours and beliefs that might facilitate or retard risky behaviours in Middle Eastern immigrants.

Middle Eastern immigrants, particularly Arabs, usually tend to maintain their traditional customs as they explore new opportunities and take pride in their cultural heritage and identity.[8,13,17] National origin, *per se*, does not automatically make someone more or less at risk of HIV infection. Behaviours associated with certain cultural beliefs or values may make a person more or less likely to be at risk of infection. Several features of the immigration process can affect HIV risk behaviours in this population. Immigration tends to be dominated by males and often leaves the migrant with poor prospects for marriage within his cultural group. Also the control of behaviour that is often exercised in tight-knit communities where individuals are monitored by family and neighbours is lost when one is submerged in a large foreign culture.

There is no published study on risky behaviours with regard to HIV/AIDS among Middle Eastern immigrants in the US. In addition, no culturally appropriate HIV/AIDS educational programmes for this population were found to have been developed. This may be due to the fact that most HIV educators are not familiar with the sociocultural norms, beliefs and stigmas that may increase the risk of HIV transmission in this population. Therefore this paper has been prepared to review sociocultural factors and their potential impact on risky behaviours. These include norms with regard to sexual intercourse, drug use and perinatal behaviours that might result in HIV transmission, and attitudes towards health. Understanding these cultural beliefs is crucial in order for healthcare providers to design culturally appropriate programmes for these clients.

SEXUAL TRANSMISSION

Religious culture

Islam is the fastest growing faith worldwide and in the US. It is also the second largest religion worldwide and the dominant religion in the Middle East.[18,19] According to the US Census Bureau, in the year 2000, 73% of Middle Eastern immigrants to the US were Muslims, with a faster population growth rate than non-Muslim Middle Easterners.[1] Decades of Islamic domination and culture have influenced the Middle Eastern way of life.[20] HIV/AIDS challenges the religious beliefs of Middle Easterners due to the nature of the leading mode of transmission, which is sexual intercourse. Islam commands that followers practice a sexually healthy lifestyle, male circumcision and purification rituals.[18] Furthermore, Islam orders that believers avoid alcohol consumption, extra- and premarital sex, anal sex, homosexuality and vaginal sex during menses.[18] Adherence to these religious constraints constitutes behaviours consistent with reducing the incidence of HIV. As a result, it has been hypothesized that Islamic religious adherence is negatively related to HIV infection.[21] Conversely, polygamy and an attitude opposed to condom use appear to increase the risks of HIV.[20] In addition, some sects of the Muslim faith allow the practice of 'Nikah mut'ah', which allows temporary marriage and sexual intercourse with the temporary spouse.[20] This marriage has a preset duration, which may be as little as one hour. After the preset time period has ended, the marriage is automatically dissolved. Multiple, sequential, temporary marriages are allowed.[22]

Condom use

Condom use is seen as a sign of embarrassment, immorality and corruption in Middle Eastern culture. Embarrassment with regard to condoms in particular is a barrier to condom use.[23,24] Condoms are allowed only within legal marriages[18,25] and are intended for family planning.[20] The importance of fertility, particularly the importance of having male children,[20,26] is deeply ingrained in Middle Eastern culture, which hinders condom use even among married people. Hence, AIDS education programmes must be sensitive to these beliefs. Therefore when educating this population, safe sex with condom use as an HIV prevention message – particularly for singles – must be done within this cultural context.

Homosexuality

The practice of homosexuality is culturally and religiously prohibited, and if discovered may lead to community chastisement, rejection or a death sentence.[18,27] Despite the strong prohibition and social stigma, there is an increasingly visible presence of homosexuality among Middle Easterners around the world.[28,29] Unfortunately the fear of the disease along with societal rejection, denial and lack of education makes Middle Easterners who engage in male-to-male sex a particularly vulnerable population.

Sex industry

Approximately 50,000 people a year, most of them women and children, are trafficked to the US for illegitimate purposes including commercial sex work.[30] Although commercial sex is not culturally condoned, the sex industry has established itself as a mainstream business among Middle Easterners.[31,32] The practice of Islamic religious customs of polygamy and temporary marriages can result in promiscuity, especially among immigrants who are living far from their families. Some immigrants develop 'parallel lives' when they move out of their home country. Being away from their families, friends and communities allows them a certain degree of freedom which, if taken advantage of, can lead to promiscuity.[20] These are populations that need to be targeted with prevention programmes. However, it must be recognized that to be seen listening to these messages is stigmatizing; it may be seen as a violation of religious and cultural norms. Even where AIDS prevention programmes and care services exist, individuals whose culture condemns those practices (in the US or their home countries) may be reluctant to participate in programmes.

Cultural beliefs and taboos on sexuality

Sexual issues and sex education are considered shameful and therefore are not discussed in families or between sexual partners.[7,33,34] Cultural taboos and shame of talking openly about sex inhibit conservative families from seeking information concerning safe sex.[7,35] Despite the important role of family communication, Middle Easterners seem less likely to supply their children with critical sexual information and HIV/AIDS education, and parents may themselves be uninformed or misinformed. School-based, in-depth, culturally sensitive programmes on sexual education and HIV/AIDS (preferably in the presence of parents or guardians) could be used to accurately and appropriately address sexuality and HIV-related risks.

Female virginity is a social value. However, the tradition surrounding it is a taboo discussion topic among Middle Easterners.[20] Because the bride-price for virgins is higher than for non-virgins, the social authorities or family members may impose a virginity examination.[20,36] The prominent sign of virginity is the release of blood due to the breaking of the hymen; this evidence on a white sheet may be used later for further investigation. The absence of bleeding is considered a sign of disgrace for the bride's family and may result in shame, and in some sub-cultures, the bride's suicide or murder.[36,37,38] To avoid the stigma attached to losing her virginity, a woman can try alternative sex like oral or anal sex. She may also attempt to 'restore' her virginity through hymenoplasty, which if performed using non-sterile techniques can lead to increased HIV risk and significant risk of other infections like hepatitis B.[20]

Sexual subordination

The culture of patriarchy is not limited to Middle Easterners, but is highly visible and valued among them.[39,40] Strong male authority forces women to be dependent upon the men.[34,41] Women should be obedient to husbands and if a woman suspects that her husband has been unfaithful, she may be in danger of divorce if she voices her suspicions, initiates safe-sex practices or discusses HIV/AIDS.[34,41,42,43] In Middle Eastern culture, sexual satisfaction is considered a priority for men, although this is largely unrecognized and even considered inappropriate for women.[35,44] Divorce is taboo, especially for women. If a divorced woman wishes to remarry, many sub-cultures will limit remarriage to an older man or a married man as his second wife.[45,46]

Although increasingly common, sexual activity outside of marriage is decisively negative and stigmatizes a female's reputation.[20,34,47] The fear of being judged or discriminated against due to immoral behaviour adds another level of distress. Additionally, a mother and her child without a legally recognized father would face shame, social neglect and ridicule. Sexual liaisons resulting in unwanted pregnancies therefore contribute to illegal abortions.[20] Women's risk of HIV infection is affected by sociocultural values, economic need and poor access to HIV/AIDS education.[35,44,48] Even where sex education exists, Arab Americans tend to preserve cultural taboos on female sexuality and HIV/AIDS, which makes it more difficult for HIV/AIDS educational programmes to reach these women.[49] Most Middle Eastern Muslim women prefer or expect to have minimal casual contact with the opposite sex.[13,50,51] The conservative culture of the Middle East can either increase women's vulnerabilities to HIV/AIDS by deterring them from seeking safe sex, or it may protect them from unsafe sex due to its conservative nature.

BLOOD-BORNE TRANSMISSION

Information on Middle Eastern immigrants' drug use and HIV transmission through injection drug users (IDUs) in the US is unavailable.[20] The Joint United Nations Programme on HIV/AIDS (UNAIDS) has reported that sexual intercourse is the main transmission route of HIV infection in the Middle East, followed by IDUs.[52] There is also a high rate of drug trafficking from heroin-producing countries to Middle Eastern countries. There are approximately 400,000 IDUs in Arab countries and about 200,000 of these in Iran.[52] According to Islam, mind-altering substances including alcohol and injection drugs are prohibited.[18] Therefore information regarding needle-replacement or needle-cleaning practices needs to be transmitted in a fashion that avoids stigmatization.

Cutting one's skin is another traditional rite that is believed to improve one's health,[53] cure diseases and/or furnish heavenly rewards.[20] This is akin to bleeding practices that were practiced in Western countries in the early 20th century. These traditional practices are possible routes of HIV transmission when conducted with non-sterile or shared devices.

ABORTION AND PERINATAL TRANSMISSION

Islam like all of the major world religions forbids abortion. Therapeutic abortion is allowed under certain conditions such as AIDS but only if carried out before four months of gestation and only after that to save the life of the mother.[54] This in turn means that Islam does not permit abortion under normal health conditions, and considers it an elaborate act of killing an innocent human being, which is a crime under any law. Those who seek illegal abortions for unwanted pregnancies are highly stigmatized.[20] As a result, unsafe abortions performed by untrained persons and/or in improperly equipped institutions occur. These carry a high risk of death or disability for the woman and may increase the risk of HIV infection due to the unsterile circumstances of the procedure.

Anti-retroviral therapy for an HIV-positive mother and baby before, during and after delivery can drastically reduce the risk of HIV transmission to the neonate. Fortunately, Islam does not forbid taking medication to treat life-threatening diseases. So health professionals can explain the advantages and disadvantages of anti-retroviral treatments to their Middle Eastern patients in a manner that is similar to non-Muslims. However, while avoidance of breastfeeding can reduce mother-to-child transmission, there are strong Middle Eastern cultural and Islamic commands for breastfeeding that may make this preventive practice difficult.[18] Healthcare providers need to provide their patients with alternative explanations for not breastfeeding.

HEALTH AND DISEASE BELIEFS

Expression of health, diseases and death are influenced by cultural norms.[11,55,56] Commonly, Arabs tend to underutilize health services.[57,58] Muslims may believe that disease is a punishment from God due to sin and this is particularly true of AIDS.[18] This punitive belief may prevent Muslims from seeking HIV-related services including testing, treatment and counselling. This failure to seek care and health information may even carry over to more acculturated Arabs.

Middle Easterners generally value family ties and hold family institutions in high regard; the protection of and support for families is a matter of civil, moral and spiritual value.[59,60,61] In the Middle East, people who are ill habitually turn to their family members first for comfort, prayer and advice. Families are expected to help each other[41] and be engaged in the patient's treatment and support.[62] At least one family member usually accompanies the patient to a medical centre. It is common for a family member to stay with the patient when they are being seen by a physician to help answer questions. In Middle Eastern healthcare situations patients are only told the good news about their ailment. Physicians would normally report the significance of illnesses and consequences to a chosen family member. In the event of death or the immediate prospect of death, a guardian is designated to take care of the will and religious customs associated with burial. In the US, however, medical professionals are trained to talk frankly and directly with patients. This may have to be done more discreetly with Muslim patients and particular care must be exercised in stigmatized conditions such as HIV/AIDS. Clinicians should also be aware that if using an interpreter, their direct discussions of illnesses and their prognoses might not be accurately translated. For one thing, Middle Eastern cultural norms – particularly Islam – do not allow the discussion of certain fastidious sexual matters.[63] In addition, specific cultural concepts are not easily translated from one language to another.[64]

In Middle Eastern culture, prayer and spirituality are believed to enhance recovery and give comfort to patients and their families.[59] When patients are admitted to hospital, there is a social obligation for friends and family to visit them. This custom may be in conflict with hospital rules about number of visitors, hours of visiting, etc. Immigrants who have lived in the US for an extended time may understand these rules, reflecting the role of acculturation. However, new immigrants or the poorly acculturated may find this difficult. As a result, Middle Eastern people may postpone seeking professional treatment because they perceive that traditional methods bring psychological relief for patients and that their families may be denied to them. Therefore training and linking community leaders and traditional healers to modern health facilities is essential.[55,60,65]

CONCLUSION

Middle Easterners are one of the fastest growing immigrant populations in the US. Lack of valid, reliable information is a major barrier to providing effective HIV/AIDS prevention and treatment for this growing population, both in their homeland and in the US. Sex and IDU are the main HIV transmission routes, yet these are culturally and religiously stigmatized. Due to language and cultural barriers, immigrant populations may be less able to seek HIV educational information and access proper care.

It is important to highlight to Western hosts that the main HIV/AIDS risk factors (non-marital sex and IDU) are sins or against the law in most of the Middle Eastern countries. Consequently, Middle Easterners may be unwilling to disclose HIV risk behaviours. Finally, existing American HIV/AIDS intervention programmes and sexual orientation messages may not be culturally and religiously appropriate for Middle Easterners. It is strongly recommended that Middle Easterners be involved in the preparation of culturally sensitive curricula for these populations. It is particularly important to encourage religious and community leaders to take part in the development of such programmes. These individuals will differ from community to community among immigrants of various different countries of origin (e.g. Iranians versus Saudi Arabians).

The population of Middle Easterners in the US is rapidly growing. Lack of knowledge and an unwillingness to confront detested truths are harming people by perpetuating the stigma attached to HIV/AIDS. In order to combat the HIV/AIDS epidemic effectively, it is important to understand the sociocultural risk predictors of HIV/AIDS and address them through culturally competent programmes.

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FY 2018 Houston EMA/HSDA Ryan White Part A Service Definition **Outreach Services – Primary Care Re-Engagement** Revised June 2017	
HRSA Service Category Title: **RWGA Only**	Outreach Services
Local Service Category Title:	Outreach Services – Primary Care Re-Engagement
Budget Type: **RWGA Only**	Fee-for-Service
Budget Requirements or Restrictions: **RWGA Only**	Outreach services are restricted to those patients who have not returned for scheduled appointments with Provider as outlined in the RWGA approved Outreach Inclusion Criteria, and are included on the Outreach list.
HRSA Service Category Definition: **RWGA Only**	*Outreach Services* include the provision of the following three activities: Identification of people who do not know their HIV status and linkage into Outpatient/Ambulatory Health Services, Provision of additional information and education on health care coverage options, Reengagement of people who know their status into Outpatient/Ambulatory Health Services
Local Service Category Definition:	Providing allowable Ryan White Program outreach and service linkage activities to PLWHA who know their status but are not actively engaged in outpatient primary medical care with information, referrals and assistance with medical appointment setting, mental health, substance abuse and psychosocial services as needed; advocating on behalf of clients to decrease service gaps and remove barriers to services helping clients develop and utilize independent living skills and strategies. Assist clients in obtaining needed resources, including bus pass vouchers and gas cards per published HCPHES/RWGA policies. Outreach services must be conducted at times and in places where there is a high probability that individuals with HIV infection will be contacted, designed to provide quantified program reporting of activities and outcomes to accommodate local evaluation of effectiveness, planned and delivered in coordination with local and state HIV prevention outreach programs to avoid duplication of effort, targeted to populations known, through review of clinic medical records, to be at disproportionate risk of disengagement with primary medical care services.
Target Population (age, gender, geographic, race, ethnicity, etc.):	Services will be available to eligible HIV-infected clients residing in the Houston EMA/HSDA with priority given to clients most in need. Services are restricted to those clients who meet the contractor's RWGA approved Outreach Inclusion Criteria. The Outreach Inclusion Criteria components must include, at minimum 2 consecutive missed primary care provider and/or HIV lab appointments. Outreach Inclusion Criteria may also include VL

	suppression, substance abuse, and ART treatment failure components.
Services to be Provided:	Outreach service is field based. Outreach workers are expected to coordinate activities with PLWHA, including locations outside of primary care clinic in order to develop rapport with individuals and ensuring intakes to Primary Care services have sufficient support to make the often difficult transition into ongoing primary medical care. Outreach patients are those patients who have not returned for scheduled appointments with Provider as outlined in the RWGA approved Outreach Inclusion Criteria. Contractor must document efforts to re-engage Primary Care Re-Engagement Outreach patients prior to closing patients in the CPCDMS.
Service Unit Definition(s): **RWGA Only**	TBD
Financial Eligibility:	Refer to the RWPC's approved *FY 2018 Financial Eligibility for Houston EMA/HSDA Services*.
Client Eligibility:	PLWHA residing in the Houston EMA (prior approval required for non-EMA clients).
Agency Requirements:	Outreach Services must function within the clinical infrastructure of Contractor and receive ongoing supervision that meets or exceeds published Standards of Care.
Staff Requirements:	Must meet all applicable Houston EMA/HSDA Part A/B Standards of Care.
Special Requirements: **RWGA Only**	Not Applicable.

FY 2019 RWPC "How to Best Meet the Need" Decision Process

Step in Process: **Council**		Date: **06/14/18**
Recommendations:	Approved: Y_____ No: ______ Approved With Changes:______	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: **Steering Committee**		Date: **06/07/18**
Recommendations:	Approved: Y_____ No: ______ Approved With Changes:______	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: **Quality Improvement Committee**		Date: **05/15/18**
Recommendations:	Approved: Y_____ No: ______ Approved With Changes:______	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: **HTBMTN Workgroup**		Date: **04/16/18**
Recommendations:	Financial Eligibility:	
1.		
2.		
3.		

The Truth About the 7,000

Why are there still so many AIDS-related deaths?

April 2, 2018 By Mark S. King

A friend of mine, Antron-Reshaud Olukayode, died of an AIDS-related illness a few months ago. He was an Atlanta-based writer and HIV advocate. The news was quite a shock for me because an empowered person living with HIV isn’t supposed to die at age 33. Or so I believed.

During Antron’s last hospital stay, his friend Nina Martinez brought him food and comfort. “Antron was having trouble getting on his feet. Something was hurting,” she tells me during a conversation in which she doubted her choice to be open about the details, to tell the truth of it. “And then Antron pulled down his sock and showed me a black lesion on the bottom of his foot.”

Nina immediately recognized the spot as Kaposi’s sarcoma, known as KS, an often deadly AIDS-defining cancer. You can regularly see it on the faces and bodies of people with AIDS in old photos and documentaries. People think it doesn’t happen anymore. They’re wrong.

Nina herself is HIV positive. She contracted the virus through a blood transfusion when she was a few weeks old. She knows all too well the cunning ways that HIV can damage a body. Because people on effective treatment don’t just end up with late-stage complications, she realized that Antron had not been taking his medications, probably for a long time. Looking at Antron’s foot, Nina asked him whether the spot was KS.

“Antron looked at me and said yes,” Nina recalls, with the exhaustion of fresh grief in her voice, “and then there was this release, like a pressure cooker, and he started to cry. Antron was afraid of being judged. I wasn’t going to judge him, but he knew his community would.”

Antron had been a visible HIV advocate and volunteer, even appearing in a national media campaign by the Centers for Disease Control and Prevention as someone living with HIV. But somewhere along his journey, things changed. He seemed depressed. Medications stopped. Very few of his friends understood what was happening, much less what to do about it. Antron was an AIDS death hiding in plain sight.

A few days after his conversation with Nina, Antron lost his ability to speak. His family took him home to die in the town he had once escaped. His obituary did not mention AIDS.

I wasn’t going to judge him.
But he knew his community would.

Antron became one of the nearly 7,000 HIV-positive people who die of causes directly attributable to the virus every year in the United States. It’s a stunning number to reconcile in this day and age, and its effects multiply many times over when you include the grieving families and confused friends and frustrated clinicians. Each one of those 7,000 people represents a life that wasn’t supposed to end, at least not to incredulous onlookers who don’t understand how or why anyone with HIV could die anymore.

It’s a fair question, the why of it. Why would anyone never get an HIV test, ignore symptoms, stop their medications or hide their illness? Who exactly are these 7,000 people? What the hell happened?

In search of answers, I talked to workers on the front lines, in clinics and hospitals and community agencies. I talked to patients and activists and people in waiting rooms. Most of them were eager to share what they have seen. Very few wanted to be identified. The truth can be uncomfortable.

What I discovered is that when you ask why, there are so many, so terribly many, answers to the question.

In the first decades of AIDS, testing HIV positive meant joining a community in which you were embraced by an enormous support network. We had no choice but to be open about our HIV status because our very lives were at stake. Long-term survivors and community elders passed along shared history and survival skills.

Not anymore. People who test positive for the virus today often face the health care labyrinth alone. Some prefer it that way because they have a good doctor and pharmacy benefits and their status is none of your business. They are entitled, yes, indeed, to their privacy and to their limited interaction with what passes for an HIV community these days by showing up once a year for a walkathon that has stripped AIDS from its name and replaced the disfigured gay men in wheelchairs with baby strollers and French bulldogs and chicken on a stick.

Welcome to the public face of HIV in 2018. It is a parade, and it is warranted because there is so much to celebrate, after all. The parade has billboards at busy intersections and posts on Instagram. It has the pretty faces of empowered HIV-negative people taking pre-exposure prophylaxis, or PrEP, and people living with HIV taking pride in their undetectable viral load.

There are T-shirts and ball caps and posters. There are online memes and funny web videos and signs you hold up when you smile for the camera and blogs with names like—God, help me—My Fabulous Disease.

It is a parade we have all helped to create. It is a privileged affair, with few people talking about the homelessness and poverty and drug addiction that percolate upward from the forlorn and the forgotten. Meanwhile, HIV stigma keeps spreading over the spectacle like a rolling fog.

The 7,000 people who will die this year can’t hear the happy jamboree from the lonely confines of their apartment or hospital bed or shelter or prison cell. If they could, they might think we have all lost our fucking minds.

***

Campaigns that seek to normalize people living with HIV are missing an important truth, according to long-term survivor and activist Matt Ebert. “U=U feels like a lie,” he tells me, referring to the award-winning “Undetectable Equals Untransmittable” campaign heralding the fact that people with an undetectable viral load cannot transmit HIV. Matt believes the science of it, but the word standing in the middle of the catchphrase makes him cringe.

“I am not equal to someone who is negative,” Matt contends, “not in the way I am treated and not in the way I feel. These campaigns try to promote our sameness, but testing HIV positive is the same shot to the heart it has always been.”

“If I got HIV today, I would be devastated,” Matt explains. “It’s a very big deal. HIV affects every decision I make. People say I should be grateful to be alive. Well, it doesn’t work that way. No wonder people stop taking their meds.”

“And,” Matt adds pointedly, he feels this way despite being “white and privileged.”

Activist Kairo Brown, who founded the organization Meet for a Cause to help impoverished LGBTQ youth in Baltimore, doesn’t have time for endless discussions of privilege or racism, as bad as it may be, because he is consumed by the daily struggle for survival among those he serves. “I hear us blame white people,” Kairo says, “but what about what we as Black people are doing to other Black people? We must unite as a community.”

There is meager social support within the Black community for people living with HIV, Kairo believes. Many young Black men are trying to deal with their own feelings of brokenness, with their search for a crowd that will welcome them, even if for some it means never returning for treatment after testing positive because the price of transparency in their circle of friends is much too high. As in every other community, women are often left to fend almost entirely for themselves.

Community workers across the spectrum told me about impoverished clients who fill out clinic surveys in exchange for financial incentives, checking any box at all, signing anything handed to them, because they need a free bus pass a lot more than they care about the data making sense. They know people who allow themselves to become sick, treating HIV symptoms with an Advil from the gas station, because they believe illness will get them more services.

Case managers told me about clients who tested positive and then scoured the internet, searching for another answer that might explain things away, falling victim to fake potions and frauds, because a bullshit answer is better than the one that says HIV.

HIV providers talk of clients who store their medications under bushes because the shelter doesn't have lockers. They watch the treatment regimens of their patients start and stop at roughly the same rate as their monthly hospitalizations, when drugs are dripped from IV bags in a mad scramble to repair the damage. They draw blood from people addicted to opioids using the arm that hasn't been amputated because of an infected abscess.

And all the people living with HIV in the margins of our society, advocates and sex workers and mothers and addicts and case managers alike, know they are one disconnected cell phone, one bout of depression, one missed bus, one part-time paycheck away from total devastation.

There are even revelers in the grand parade who are privately troubled, who grit their teeth when they smile, who haven't admitted that it has been months since they took their meds because the co-pay got too expensive or the fatigue of it all has become too much to bear, who have chosen to delay treatment until things get bad or until they find a cheaper apartment or until some unseen solution comes along. It might. It might not.

***

These AIDS-related complications are real, and they exist in a world far away from happy Facebook status updates. Traveling the distance between them might as well be crossing the galaxy.

And yet, mercifully, even in the midst of all these challenges, success stories and moments of grace exist.

Brent Bible took an HIV test when he was 17 years old as a requirement to enter a teen drug rehab program. "They called me and said to come back in and bring my mom," Brent tells me. "When they said I was positive, my mom broke down. But I was like, Everything is OK. I'm not going to cry about it."

Sometimes, youthful resilience is nothing of the kind. The next day, Brent tried to kill himself.

"It didn't work," Brent says. "So, I just said, Fuck it, I'll party." He escaped his troubles—the absent dad and the addicted mother and the challenges of being a gay Black man—by defiantly choosing hard drugs over HIV medications. He remembers that time with tears in his eyes. "It was hard, for so many years," Brent tells me. He's 29 years old now, but some things still haunt him.

Brent eventually pulled himself from the brink, but getting HIV care required a stability he hadn't yet achieved. "I didn't have a place to stay," he tells me, "and I needed proof of where I lived, proof of this and proof of that. And I wasn't working and didn't have transportation. Some places were no help at all." Today, Brent makes his doctor appointments and takes his meds, and his viral load is undetectable. He knows he is lucky. He knows people who were broken by the pressure of life with HIV.

“Being around them, they seemed happy,” Brent recalls, remembering several friends in their 20s who are now lost to AIDS, “but behind closed doors, they might just be done with it all. You just don’t know. You never really know.”

We have a collective responsibility to Brent, to help him rise above the stigma, to continue his treatment in the months and years ahead, to ask him uncomfortable questions when he says he is just fine, to teach him survival skills and to assure him that everyone living with HIV doesn’t always feel as happy as they look on the posters.

Because the statistic that 7,000 people will die simply waits, year after year, to be satisfied. Because depression and fatigue can undermine the will to live. Because people deserve the truth about life with HIV and the support to face it. Because we don’t want to be shocked all over again and left wondering why.

Because you never really know.

Mark S. King was diagnosed with HIV in 1985. His blog, My Fabulous Disease, has been nominated for a 2018 GLAAD Media Award.

https://www.poz.com/article/truth-about-the-7000

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News

Men, Black People and Injection Drug Users Have Higher Risk of Discontinuous HIV Care

By Mark Mascolini

March 29, 2017

In a 17,000-person U.S./Canadian analysis, men, blacks, and drug injectors had a higher risk of discontinuous HIV care even after statistical adjustment for access to care, the competing risk of death and other risk factors. NA-ACCORD investigators suggest these groups need "improved outreach to prevent disruption of HIV care."

Previous research links inconsistent retention in HIV care to poor outcomes, including shorter survival. Because prior work found worse HIV care retention among men, blacks and drug injectors, the National HIV/AIDS Strategy aims to diminish these disparities. But previous research in this field remains limited because the studies sometimes lacked information on antiretroviral use or were performed in the context of clinical trials, at single centers or in resource-limited settings.

To get a better understanding of factors affecting discontinuity in HIV care, NA-ACCORD investigators analyzed data from this multicohort U.S./Canadian collaboration. The analysis involved adults who had one or more primary care visits and began antiretroviral therapy (ART) between January 2000 and December 2010. To focus on people likely to have equivalent access to care, the investigators also limited the study to individuals who had one or more CD4 counts after ART began and before death or the first discontinuity in care. They defined discontinuity as failure to keep two or more HIV care visits separated by at least 90 days in a calendar year. To assess risk factors for discontinuity, the NA-ACCORD team used regression analysis that considered the competing risk of death and other variables.

Related: The Impact of HIV Health Literacy on Viral Suppression

The analysis involved 17,171 adults with a median age of 47.1 years, 16% of them women, 44% black and 19% with drug injection as their HIV acquisition risk. During a median follow-up of 3.97 years, 49% of cohort members experienced discontinuity in care, 9% died before experiencing discontinuity and 42% had no discontinuity in care. After 10 years of follow-up, the adjusted cumulative incidence of discontinuity was 67%, while incidence of death before discontinuity was 9%.

In an analysis adjusted for demographics, baseline CD4 count and CD4 nadir after ART initiation, two factors were independently associated with a lower hazard of discontinuity in care: older age (hazard ratio [HR] 0.61 per 10 years older, 95% confidence interval [CI] 0.59 to 0.62) and female sex (HR 0.84, 95% CI 0.79 to 0.89). Two variables were independently associated with a higher hazard of discontinuity: black versus nonblack race (HR 1.17, 95% CI 1.12 to 1.23) and drug injecting versus other HIV risks (HR 1.33, 95% CI 1.25 to 1.41).

After adjusting for drug injecting status, black race was not associated with discontinuity among women. Risk of death did not differ significantly between women and men, blacks and non-blacks or drug injectors and other HIV risk groups. Additional analysis determined that reentry to care after first discontinuity did not differ by sex, race or drug injecting status.

The researchers believe their results can be generalized to the U.S. and Canadian HIV populations because the NA-ACCORD group is demographically representative of the national U.S. and Canadian HIV populations. "Beyond clinic-level interventions aimed at improving overall clinical retention," the researchers advise, "individual-level interventions such as enhanced medical case management, peer navigation, transportation subsidies, and mental health evaluation and treatment should be offered with greater vigilance and consistency to the identified vulnerable groups[.]"

Mark Mascolini writes about HIV infection.

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http://www.thebodypro.com/content/79621/men-black-people-and-injection-drug-users-have-hig.html

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Press Release

For immediate release: Monday, February 23, 2015
Contact: National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (http://www.cdc.gov/nchhstp/)
(404) 639-8895
NCHHSTPMediaTeam@cdc.gov (mailto:NCHHSTPMediaTeam@cdc.gov)

9 in 10 new U.S. HIV infections come from people not receiving HIV care

New CDC analysis reinforces importance of HIV testing and treatment for health and prevention

More than 90 percent of new HIV infections in the United States could be averted by diagnosing people living with HIV and ensuring they receive prompt, ongoing care and treatment. This finding was published today in *JAMA Internal Medicine* by researchers at the Centers for Disease Control and Prevention.

Using statistical modeling, the authors developed the first U.S. estimates of the number of HIV transmissions from people engaged at five consecutive stages of care (including those who are unaware of their infection, those who are retained in care and those who have their virus under control through treatment). The research also shows that the further people progress in HIV care, the less likely they are to transmit their virus.

“By quantifying where HIV transmissions occur at each stage of care, we can identify when and for whom prevention and treatment efforts will have the most impact,” said Jonathan Mermin, MD, MPH, director of CDC’s National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. “We could prevent the vast majority of new infections tomorrow by improving the health of people living with HIV today.”

“We could prevent the vast majority of new infections tomorrow by improving the health of people living with HIV today.”

Jonathan Mermin, MD, MPH, director, CDC’s National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention

The analysis showed that 30 percent of new HIV infections were transmitted from people who did not know that they were infected with the virus, highlighting the importance of getting tested. People who had been diagnosed were less likely to transmit their infection, in part because people who know they have HIV are more likely to take steps to protect their partners from infection.

“Positive or negative, an HIV test opens the door to prevention. For someone who is positive, it can be the gateway to care and the signal to take steps to protect partners from infection.

For someone who tests negative, it can be a direct link to important prevention services to help them stay HIV-free," said Eugene McCray, MD, director of CDC's Division of HIV/AIDS Prevention. "At CDC, we're working hard to make testing as simple and accessible as possible."

Today's analysis suggests that simply being in care can help people living with HIV avoid transmission of their virus. According to the model, people who were engaged in ongoing HIV care, but not prescribed antiretroviral treatment, were half as likely (51.8 percent) as those who were diagnosed but not in care to transmit their virus. Being prescribed HIV treatment further lowered the risk that a person would pass the virus to others.

People who were successfully keeping the virus under control through treatment were 94 percent less likely than those who did not know they were infected to transmit their virus. However, previous national estimates have indicated that just 30 percent of people with HIV have reached this critical step in care.

The study authors stress that effective HIV care offers multiple mechanisms to prevent transmission. For example, in addition to antiretroviral therapy, HIV care should include risk reduction counseling on how to protect their partners, screening and treatment for other sexually transmitted infections, and treatment for mental health and substance use disorders.

To estimate HIV transmission at each stage of care in 2009, the new analysis used statistical modeling based on three national HIV data sources: CDC's Medical Monitoring Project, National HIV Surveillance System, and National HIV Behavioral Surveillance System.

This is the latest in a growing body of evidence that prevention of new infections depends on reaching people who are HIV-positive with testing, care, and treatment. CDC has responded by more extensively focusing its prevention strategy on people living with HIV, while continuing to ensure HIV-negative people have tools and information about all available prevention options, including daily pre-exposure prophylaxis (/nchhstp/newsroom/docs/PrEP-FactSheet-508.pdf).

CDC efforts also include innovative partnerships to make HIV testing simple, accessible, and routine; programs to help health departments and community partners identify and reach out to infected individuals who have fallen out of care; and public awareness campaigns to urge testing and encourage people with HIV to seek ongoing care.

For more on the new analysis and CDC's HIV prevention efforts, visit www.cdc.gov/nchhstp/newsroom (/nchhstp/newsroom).

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Re-engagement in HIV Care: A Clinical and Public Health Priority

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Abstract

As many as 40-50% of persons living with HIV (PLWH) who once were in HIV care are no longer in care. It is estimated that these individuals account for over 60% of HIV transmissions. So, preventing the leaving of care and re-engaging PLWH with care are crucial if the HIV epidemic is to be brought under control. Clinicians can improve retention by keeping in close contact with patients. Governmental public health agencies have great expertise in finding and engaging in care persons with sexually transmitted infections. This expertise can be used to re-engage PLWH with HIV care, but it can only be utilized if the agencies know that someone is out of care. Data on who has left care are in the hands of HIV providers. This requires a close working relationship between HIV providers and public health agencies.

Introduction

Public health departments in the United States have been at the forefront of HIV education, testing and surveillance. Effectiveness of education programs is unclear as the reported incidence of HIV has remained relatively constant from 2008 to 2014 at approximately 45,000 (±3,000) cases per year [1,2]. The effects of testing and surveillance are much clearer. For example, during 2011 nearly 1.6 million individuals were tested for HIV by public health departments and over 22,000 were found to be HIV positive [3]. In the United States, all HIV infections are reported to local and state health departments where they provide a picture of local HIV trends. These data are then forwarded to the Centers for Disease Control and Prevention and form the basis of an accurate picture of the trends in the epidemic for the whole country [4].

Operating in parallel with public health, HIV clinicians in the United States have coped with a rapidly changing array of medications and guidelines for use in treating persons living with HIV (PLWH). Between 2005 and 2015, the guidelines for treatment of HIV infected adolescents have changed 14 times [5]. Clinicians' use of these medications has changed HIV infection from a death sentence to a chronic disease. In the United States, clinical care

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of HIV positive persons has been the purview of agencies and/or individuals who were not offen affiliated with public health departments; however, clinicians have contributed to surveillance efforts as many providers conduct HIV testing and report cases.

Changing Perspectives

This separation between clinical medicine and public health has been logical and effective. However, there are three new changes in thinking about the care process of PLWH. The first is based on research that showed that HIV infected persons with low levels of virus are less likely to transmit the virus [6]. This new understanding of transmission dynamics made clinicians essential partners in controlling the epidemic through their use of medications to suppress the virus.

The second shift in thinking was the realization that achieving low viral loads in the community is a process of testing those at risk, linking newly diagnosed HIV positive persons to care, retaining those who entered care, and returning to care those PLWH who have left care [7]. The majority of PLWH are not under the care of HIV providers. Including both those that have never been in care and those that have fallen out of care, it is estimated that about 60% of PLWH in the United States were not in care for their HIV infection in 2009 At any point in time, one third of those who were once in care are no longer being seen by a HIV provider [8,9]. A study of over 100,000 HIV infected individuals from 13 areas showed that 52% of people who were in HIV care did not have two visits for HIV care in the previous year although the standard of care was a quarterly visit [10]. A meta-analysis of 28 retention studies showed that 41% of 75,655 individuals did not have more than 1 HIV care visit over six months [11]. These cross sectional studies did not recognize that the out-of-care population is fluid; a PLWH may enter and leave care multiple times during their infection. Therefore, the numbers of persons who are irregular in their care is likely to be greater than reported in these studies.

The third change in perspective was the recognition that those who have left care are major drivers of the epidemic with one study estimating that PLWH who have left care are responsible for 61.3% of all HIV transmissions [12]. Individuals who do not take HIV medications and do not suppress their viral load are twenty times more likely to transmit HIV than those with suppressed virus [13]. The majority of PLWH were infected through unprotected sex which may continue for some after their HIV diagnosis. One study showed that 6.3% of HIV infected males received a syphilis diagnosis within ten years of their HIV diagnosis [14]. A multisite review article showed the average HIV prevalence rate among syphilis patients was 15.7% [15]. So, some patients are not only having unprotected sex, but they also have open lesions that facilitate onward transmission of the virus. If out-of-care persons are engaging in unprotected sex, they have the elevated viral loads that increase the probability of HIV transmission, and they may have open lesions from a co-occurring sexually transmitted infection (STI) that allows the shedding of HIV during sex.

This means that finding and returning to care PLWH who have left HIV care is a very high priority for controlling the HIV epidemic.

Implications for Clinicians and Public Health

Given the likelihood of PLWH leaving care and the high level of risk for transmission by these individuals, there is an obvious need to prevent PLWH from leaving care. There are a number of studies that suggest ways to prevent loss to care. Two review papers examined multiple studies on interventions to improve retention in care [16,17]. They described a wide variety of interventions that include personal contact before appointments and when patients miss visits, home visits, education on the importance of staying in care, directly observed therapy, case management, transportation assistance, patient navigators, counseling, mental health services, substance abuse treatment, housing assistance, motivational interviewing and peer mentoring. Most of the studies used more than one method, and it was impossible to determine which part of the intervention was responsible for the outcome. In any event, Okeke et al. reported on nine studies that used a pre-post design and reported improvement in retention in care by PLWH. In seven of the nine studies, the improvement was less than 15% [16]. These studies provide little guidance for what clinicians may do to retain their patients in care.

However, there are studies that may give guidance on retention. A study evaluated African American and Hispanic youth being cared for at three types of clinics: a usual clinic mixed with patients of all ages, a youth-specific clinic, or a youth-specific clinic enhanced with additional services. This study showed that retention in care as measured by visit consistency nearly doubled with the opening of the youth specific clinic (31% to 57%). There was a modest improvement when more services were added (65%), but patients with no gaps in care rose to 96% with the addition of these services [18]. So, targeting services to a particular group may help in retaining patients. In another study, patients from clinics in six different U.S. cities were randomly assigned to three groups: 1) standard of care, 2) having a staff member assigned to maintain regular contact with the patient (face to face introduction, regular phone calls, appointment reminders and calls after missed visits), or 3) having an assigned contact and receiving a one-hour training in motivational interviewing. Those with an assigned staff person were 10% more likely to attend at least three consecutive scheduled visits than the standard of care group. The addition of the motivational interviewing component did not improve this. The percent of scheduled visits that were attended was about 5% higher in the groups with the assigned staff person [19]. A potentially more feasible intervention used computer-generated reminders to clinicians at any time when anomalies occurred in their patients. This included abnormal lab results, detectable viral loads and missed visits. This allowed clinicians to immediately follow up with patients for retesting and rescheduling visits. These patients were compared to those who simply had anomalies placed in their electronic charts. Suboptimal follow up was reduced from 30% to 20% by using real time informing of the clinician so that patients could be immediately contacted [20]. What seems to be the most important intervention that prevents leaving care is regular contact with the patient, including prior to appointments and follow up after missed appointments. However, the research seems to show that these interventions only show modest improvements in retention.

So, it would seem that the best efforts of clinicians will not prevent PLWH from leaving care. This has negative health effects on PLWH. HIV infected patients who are not in care or who are in irregular care are far more likely to contract HIV-related opportunistic diseases [21], to develop drug resistant virus [22] and to die [23]. This is a matter of great concern for HIV clinicians; however, they are often overwhelmed with the day-to-day patient care demands and have little time or resources to find those who have left care. Re-engagement in care is also beyond the scope of practice and expertise of clinicians.

Public health departments are the community's experts in locating and linking persons with STIs to care. They have been performing contact tracing to locate sex partners of people with STIs for many years. This expertise could be of great value in controlling HIV transmission if these departments were aware of those PLWH who were no longer in care. Some health departments have used HIV-related laboratory surveillance data to identify individuals with significant gaps between HIV viral loads and/or CD4 counts [24,25]. PLWH who have, for example, greater than six month gaps between these necessary laboratory tests can be identified for follow up. This is feasible for the forty states that require laboratory reporting of CD4 and viral loads [26].

While gaps in lab tests can be a starting point for locating those who have left care, this method has drawbacks. Individuals may have died, become incarcerated or moved out of the area. Laboratories may not be timely in reporting results, leading to misclassifying PLWH who have returned to care before the lab values were reported. Finally, the proper gap to determine when one has left care is not clear. One expert guideline says that laboratory testing be done every “six months for adherent patients who have appropriate values for more than 2–3 years” [27]. Using an interval of six months between laboratory tests may identify adherent PLWH with suppressed virus as having left care. So, conducting follow ups based on laboratory-based surveillance may be futile or inefficient.

Furthermore, using time intervals may not be the best way to measure retention. Mugavero et al. identified six different ways to measure retention in care and applied them to a large cohort of patients from six cities. Three measures used time intervals between visits ranging from four months to a year. These measures correlated poorly with one another. (range $r=0.51$ to $r=0.76$). The other measures used missing of scheduled visits as the retention measure. These were highly correlated with one another with $r \approx 0.85$ [28]. Missing scheduled visits has been shown to predict the risk of mortality [29]. This was true even when using a criterion of time intervals between visits would have classified them as retained in care [30]. So, while public health personnel may be able to use laboratory surveillance data, they may not be using the most clinically relevant information of missed visits, which is only known to providers.

Locating and re-engaging PLWH in care is not easy. Traditional STI contact tracing is based on recent treatment and recent location information. Because there must be a gap of time before a PLWH is defined as not retained in care, individuals are more likely to have relocated. And, unless public health workers are in close contact with HIV providers, the patient location data (address and phone number) in clinic records will not be available. HIV infection also carries with it a significant risk of death, so searches may be a hunt for the deceased. One of the risk factors for HIV transmission is IV drug use which can be associated with criminal behavior, so out-of-care persons may be incarcerated. Also, some

PLWH may not wish to be found and will not respond to attempts at contact. Others may be difficult to locate because they are homeless, a condition that is more likely in PLWH [31,32]. Evidence of these difficulties is found in the study by Udeagu et al. which concluded that, of 797 PLWH who were identified as having left care because of gaps in their laboratory tests, 14% were never located. Of those who were located, a third were already back in care, 4% had moved or were incarcerated, and 2% had died [33].

Conclusion

While admonitions to practice abstinence and/or safe sex may be helpful, rhetoric is unlikely to significantly alter the spread of HIV. Prevention must focus on those who have left care. Prevention science shows that persons with unsuppressed virus are 20 times more likely to transmit HIV and that out-of-care PLWH are responsible for over 60% of transmissions [8,13]. So, if every PLWH achieved viral suppression, transmission would be close to nil while the PLWH's health would be greatly improved. Out-of-care persons must be found and re-engaged in care. Unfortunately, this will be unlikely as long as we maintain a system where the relevant data for determining who left care is in the hands of clinicians while the capability for locating and re-engaging individuals in care is with health departments. Clinicians and public health departments have to be partners in preventing HIV transmission.

There are good examples of what can be accomplished when clinicians and public health departments work together. In the state of Washington, there is a program whereby clinicians and the public health department jointly identify and seek PLWH who have left care and re-engage them with care. The program was able to identify those individuals who were in need of re-linkage services by eliminating those who were deceased, had moved out to the area, were incarcerated or had found another provider of HIV care. This allowed providers and health department personnel to concentrate their efforts on those who were actually eligible to be re-engaged in care. When compared to a historical control group, the cooperative program was 70% more likely to re-engage PLWH with care [34]. Another example of clinical/public health cooperation was conducted in Louisiana. PLWH who had not had a VL or CD4 count in over one year were identified and an alert was placed in the Louisiana State University Health Care Services Division's electronic medical record which notified affiliated clinicians seeing the patient for any disease or condition that the patient may be out of HIV care. Because there was recent location data for these PLWH, contact was efficient and 81.6% of the PLWH who were in care or who refused to return to care and were, therefore, eligible for re-linkage services were returned to care [35].

Because clinical care is administered by multiple providers in both the public and private sectors, health departments need to take the lead in developing systems that assure PLWH who are out of care re-engage with their clinical providers and achieve viral suppression. If public health authorities are not leading in this effort, providers need to contact them and establish ways to involve them in following up on their lost-to-care patients. By working together, clinicians and public health agencies can significantly alter the course of the HIV epidemic.

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Barriers and Facilitators to Retaining and Reengaging HIV Clients in Care: A Case Study of North Carolina

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Abstract

Retention in HIV care is critical to decrease disease-related mortality and morbidity and achieve national benchmarks. However, a myriad of barriers and facilitators impact retention in care; these can be understood within the social–ecological model. To elucidate the unique factors that impact consistent HIV care engagement, a qualitative case study was conducted in North Carolina to examine the barriers and facilitators to retain and reengage HIV clients in care. HIV professionals (n = 21) from a variety of health care settings across the state participated in interviews that were transcribed and analyzed for emergent themes. Respondents described barriers to care at all levels within the HIV prevention and care system including intrapersonal, interpersonal, institutional, community, and public policy. Participants also described recent statewide initiatives with the potential to improve care engagement. Results from this study may assist other states with similar challenges to identify needed programs and priorities to optimize client retention in HIV care.

Keywords

HIV/AIDS, retention, reengagement, health providers, social–ecological model

Introduction

In the United States, only half of the people diagnosed with HIV are estimated to be consistently retained in HIV care,[1] although large variations exist across states.[2] Retention in care is critical for access to antiretroviral treatment and, therefore, achieving and maintaining viral suppression.[3] The HPTN 052 study in 2011 demonstrated the importance of viral load suppression in reducing the transmission of HIV within serodiscordant couples and has become a benchmark for defining prevention efforts around the world.[4] Numerous studies have found that poor participation in HIV care is associated with adverse outcomes for persons living with HIV (PLWH). These include increased risks of HIV treatment failure and AIDS-defining illnesses, as well as increased chances for patient mortality,[5-7] particularly for those who miss medical appointments.[8-10] Thus, improving patient engagement in care has become a national priority, and targeted retention measures have been established by the National HIV/AIDS Strategy (NHAS) and the Health Resources and Services Administration (HRSA), Ryan White HIV/AIDS Program.[11-13] Appropriately addressing patient HIV care engagement requires a better understanding of the facilitators and barriers to retention and reengagement across US states and regions.

The social–ecological model is a useful conceptual tool for examining patient engagement within an HIV care system. This framework posits that 5 levels of factors reciprocally interact to influence health behavior, moving from the individual (intrapersonal and interpersonal) to institutional, community, and, finally, public policy.[14] Mugavero et al[15] applied the social–ecological framework to a review of the literature

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examining the interaction of factors that impede the diagnosis, linkage, and retention of HIV clients in care, including the role of supportive services (eg, case management, substance abuse treatment, and housing assistance), infrastructure of clinical care (eg, hours of clinic, availability of appointments, and culturally sensitive medical care), and impacts of national and local policies on testing, linkage, and treatment (eg, funding and medical provider shortages and the fragmentation of testing and care provider networks). The authors also highlighted successful models from the literature to promote care engagement, including case management and patient navigation programs, and the integration of health care systems.

Other studies have examined barriers and facilitators at multiple levels within the health care system which influence HIV care engagement. Some have looked at individual factors on intrapersonal and interpersonal levels and have concluded that maintaining strong personal relationships, managing psychosocial issues, remaining committed to self-care, perceiving providers in a positive way, and developing autonomy are often associated with more consistent engagement in HIV care.[16-22] Others have identified institutional-level barriers to care, such as long clinic appointment wait times and inflexible clinic hours.[16,23] Lastly, community- and policy-level barriers to HIV care have been identified, including limited access to transportation, inadequate medical insurance coverage, and the high costs of care.[16,20] Undoubtedly, salient barriers and facilitators to engagement in care vary across settings and individuals. Clarifying these context-specific factors within state and regional HIV care systems can inform efforts to reduce health disparities and improve public health.

One geographic area in which to examine these disparities and their impacts on HIV care systems is within the US Census Bureau-defined South,[24] a region that carries a disproportionate burden of the nation's HIV epidemic.[25] In 2011, 48% of US HIV diagnoses were from the South, although the area was only home to 37% of the national population.[26,27] The South also has the highest adjusted death rate for PLWH among the Census regions.[28] To explain these disparities in HIV incidence and HIV-related mortality, the unique social, political, and demographic factors of the region are often cited, including higher levels of poverty, HIV-related stigma, and sexually transmitted diseases; fewer HIV providers; and more restrictive government policies, such as a dearth of needle exchange and comprehensive sex education programs.[25,29] In addition, the vast majority of Southern states have opted not to expand Medicaid under the Affordable Care Act (ACA),[30] leaving many adults in the South without insurance coverage and thus access to affordable care. Living within these nonexpanding Southern states is especially problematic for PLWH, as they are more likely to be low income and childless and less likely to be privately insured; therefore, they would benefit from expanded Medicaid eligibility based on the ACA.[31] Numerous studies have demonstrated that inadequate health insurance coverage can worsen patient retention in HIV care,[32-35] and the expansion of safety net programs, such as Medicaid and the Ryan White HIV/AIDS Program, can improve patient clinical outcomes and participation in HIV care.[36-39]

As a Southern state that has not expanded Medicaid, contains many uninsured residents, and possesses a large HIV disease burden,[30,40,41] North Carolina represents a relevant case study among the South to explore the barriers and facilitators to retaining and reengaging HIV clients in care. In North Carolina, at the end of 2013, an estimated 28 101 people were living with HIV/AIDS, the vast majority of whom were male (71%). African Americans made up 65% of all diagnosed cases with HIV/AIDS, and African American females were the largest racial/ethnic group among women living with the disease (75%). Although rates of new HIV infections have been on the decline in recent years, in 2012, the state's HIV diagnosis rate ranked it eighth among all US states and dependent areas reporting HIV diagnoses to the Centers for Disease Control and Prevention (CDC).[42] In addition, in 2013, 16% of North Carolinians lacked health insurance, a rate that was higher than the US average (13%) and was also one of the highest uninsured rates in the country.[40]

North Carolina's sociodemographic landscape and disproportionate burden of HIV have created opportunities and challenges within the HIV prevention and care systems to meet the medical and support service needs of PLWH in the state. To deliver these services, North Carolina uses a regional network model, funded by the HRSA Ryan White Part B Program and overseen by the North Carolina Department of Health and Human Services (NCDHHS) AIDS Care Program. The state has 10 regional networks of care that cover 95 of the 100 North Carolina counties. The remaining 5 counties within the Charlotte metropolitan Transitional Grant Area receive direct funds from the Ryan White Part A Program. Within these regional networks, individual providers may receive additional funding for HIV medical and support services through other sources, such as Ryan White Parts C and D.[42]

Health professionals working within the state's HIV networks of care possess unique opportunities to directly observe the implementation of programs and policies and, ultimately, their impacts on PLWH. Soliciting their input is therefore important to shape HIV policy priorities.[43] This valuable and often understudied perspective provides necessary insight to inform efforts to improve patient engagement in care.

Methods

This study used a qualitative approach to explore the perspectives of professionals working in the HIV field in North Carolina about the barriers and facilitators within the state's HIV prevention and care systems to test, link, retain, and reengage PLWH. Two researchers conducted in-depth interviews with 21 stakeholders from a variety of organizations in 2012. Written informed consent was obtained from all participants prior to in-person or telephone interviews, which lasted between 30 and 60 minutes. At the conclusion, each participant was offered a US$25 gift card for his or her time. All study procedures were conducted with Institutional Review Board approvals from the

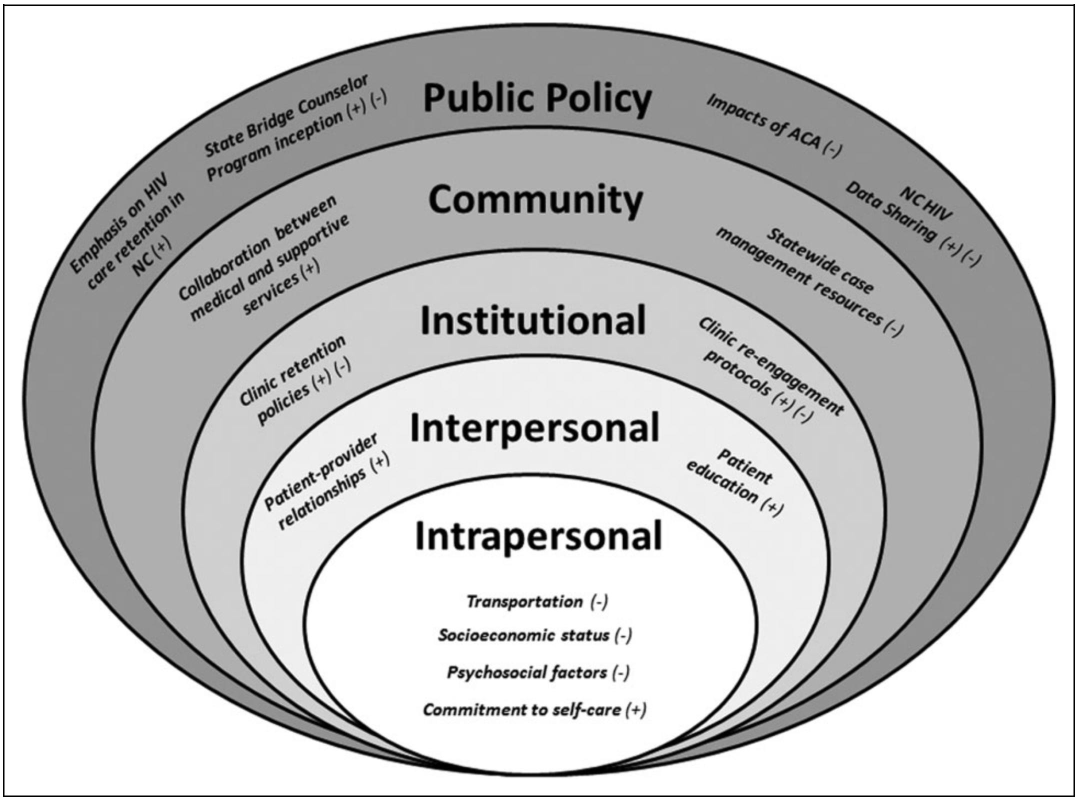

Figure 1. Summary of results, presented within the social–ecological framework, as described by participants. (+) indicates a facilitator to care engagement and (−) indicates a barrier to care engagement.

Duke University School of Medicine and the North Carolina Division of Public Health.

Recruitment

Initial participant recruitment was conducted through purposive sampling of known professionals working within the HIV prevention and care systems in North Carolina to achieve participant variability in geographic location, employee position, and organizational type. Description of the recruitment of additional participants is described in Sullivan et al.[44] Inclusion criteria was being an adult professional working within the North Carolina HIV prevention or care system, being willing to discuss North Carolina's HIV prevention and care systems, and speaking and reading English.

Data Analysis

Interview transcripts were double coded for emergent themes by 2 researchers using NVivo 10 software; discrepancies in coding were discussed until consensus was reached. Responses were compared within and across participants, with similarities and differences noted. Themes were then further examined and placed within the context of the social–ecological framework. Results from interview questions on the barriers to and facilitators of testing and linkage in North Carolina are described in Sullivan et al.[44] Analyses included here focus on North Carolina's barriers and facilitators to retention and reengagement in care on the individual, community, and policy levels.

Results

Participants

The 21-study participants represented a variety of organizations and positions throughout North Carolina. Most participants worked in clinical care settings, as HIV health care providers (n = 8, 38%), or in ancillary care and administrative support roles (n = 5, 24%). The remaining participants were employed by the NCDHHS (n = 5, 24%), and a few (n = 3, 14%) were employed at local AIDS service organizations or county health departments. Over half (57%) of the participants had worked in the North Carolina HIV prevention and care system for more than 10 years. A summary of the main themes as described by the respondents is included (Figure 1).

Retention in Care: Intrapersonal Factors

A majority of respondents described individual barriers that often impede full client engagement in HIV care. The most frequently mentioned obstacles included socioeconomic, transportation, and psychosocial issues.

Socioeconomic Barriers

Many respondents discussed client financial problems negatively affecting engagement in care. As one medical provider explained:

> Many of them [our patients] are from low socioeconomic status and have other life issues that take priority over their health care, so you have women who have young children at home who need food in the cabinet.

Transportation

A lack of a reliable form of transportation was also cited numerous times as an obstacle for consistent HIV care, particularly for PLWH who live in rural regions of the state and must travel several hours to reach an HIV provider, often with limited transportation options. As one respondent described:

> In metropolitan areas, [retention] percentages are better .... In rural areas, you don't have providers in those areas and transportation poses a big problem and funding has been cut.

Psychosocial Factors

The vast majority of respondents who discussed client barriers described the adverse impacts of psychosocial factors on care engagement, particularly mental health and substance use issues, as was summarized by a medical provider:

> People that are ... found dealing with very active mental health issues can be very challenging to engage them into medical care ... and I think our options for outpatient substance abuse treatment in the clinic setting are very limited.

Client Facilitators

Several respondents discussed the strength of clients who prioritized care engagement, which some attributed to client self-esteem and a commitment to self-care. As one respondent described:

> Generally, the people that we see who ... have confidence in us and they want to take care of themselves, and I think there may be ... positive self-esteem. I think they want to really take care of themselves and realize they need to keep coming in and they'll do that.

Retention in Care: Interpersonal Level

Patient–Provider Relationships

Several respondents described the importance of PLWH forging strong relationships with staff members in the clinic. As a medical provider commented:

> If they [patients] seem to have connected to staff in our clinic.... If we can get them on therapy and see that they're successfully taking meds, then we feel more positive about how we've engaged in them in care.

Patient Education

In addition, several respondents mentioned the need for providers to reinforce health education information to maximize client comprehension of HIV disease progression and the importance of consistent care engagement. As one respondent commented, providers should:

> Educate the client on the importance of being in care other than just saying, 'You need to go to the doctor.' Having those tools to really be able to counsel the client and help them make that behavior change that's going to keep them in care.

Retention in Care: Institutional Level

Clinic Policies and Procedures

Standardizing client policies and procedures at the clinic level was cited by a few participants as a successful and critical component to help patients remain engaged in care. However, not all clinics and agencies possessed standardized policies for retention efforts. Variability in attempts to locate patients who miss medical appointments was described, depending on the structure and available resources at the clinic. As one respondent stated:

> We don't have a really strong protocol for reengagement in any sense. Some regions, some providers, really go all out. Most can't do that, so they might make a call or 2, and then that's it—click—we're done. And we really haven't emphasized that that's just not good enough.

Retention in Care: Community Level

Coordinated and Collaborative Care

A majority of respondents who worked in medical or ancillary care settings discussed local collaboration with partnering agencies as a strength for retention efforts. A few respondents described the importance of co-located services (eg, medical providers working in the same location as case managers, financial counselors, psychiatrists, etc) to efficiently and comprehensively address complex client needs. In addition, the collaborative nature of relationships between medical personnel and case management teams was mentioned as important for client retention. However, the lack of resources to devote to case management was described as a limitation within the HIV care system. A few respondents mentioned that clinics were challenged to conduct case management activities with a paucity of staff. Thus, case managers were burdened to handle large client volumes and an array of complex client needs.

Retention in Care: Public Policy Level

Emphasis on HIV Care Retention in North Carolina

Several respondents stated that in recent years in North Carolina, there have been increased efforts dedicated to HIV care retention, as indicated by this respondent:

> I think a lot of places are starting to ... really focus on retention ... and I think that's a huge factor in keeping them engaged. So, the fact that that's becoming a focus in more than just a few places is a good thing.

Some of these respondents attributed this emphasis to research, demonstrating the efficacy of early and continuous HIV therapy in preventing HIV transmission. A few respondents mentioned the HPTN 052 study,[4] including 1 respondent who summarized the importance of the study for care retention:

> It's not just about the individual's health. It's about the health of their partners as well. If they're out of care and off medication, your risk of transmission is so much higher. We have the science to prove that now.

A few respondents also expressed concerns regarding the impacts of the ACA on the health care system, specifically the potential for increased client loads for clinics, fragmentation of current health care networks, and inadequate insurance coverage to meet client needs.

State Bridge Counselors

Several respondents discussed the work of the State Bridge Counselors (SBCs), a new program within the NCDHHS that began in 2011. At that time, a few Disease Intervention Specialists (DIS) began to transition into positions as SBCs. The role of DIS was to link new HIV-infected patients to care, educate them about HIV disease control measures, and notify partners of potential HIV exposure. In contrast, the role of the new SBCs was to receive referrals from DIS and regional providers to locate and reengage patients deemed out of care.

Overall, the SBC program was described by several respondents as an innovative component of the North Carolina system to reengage HIV-infected patients. The experience of SBCs as former DIS allowed them to be resourceful at finding clients in the field when clinics lacked current client contact information and local reengagement efforts were unsuccessful. Several respondents stated that this was a strength in addition to the authority of SBCs to work with or on behalf of clients without special permission. A clinic staff member commented on this:

> I ... think it's a good thing that the bridge counselors, at least ours, are DIS, because they're trained to go find people and interview people. They're also empowered to do so, and they're empowered to call providers.

However, the large geographic territory and caseload for fieldwork was noted as a weakness of the program. Moreover, the transitioning of DIS to new positions as SBCs, and thus temporarily fulfilling 2 roles, was viewed as a limitation. A few participants felt that this challenged state personnel to simultaneously balance public health needs (preventing the spread of HIV to others) with client care needs (keeping clients in care). Consequently, a few respondents stated that the newly transitioned SBCs needed clarification on what was required of them as SBCs in contrast to their previous work as DIS.

State HIV Data Sharing

In North Carolina, all Ryan White Part B-funded providers are required to use CAREWare—a free and scalable HIV software platform provided by HRSA—to enter their Part B client services and clinical data on the state's CAREWare server. Recently, the NCDHHS AIDS Care Program opened data sharing within the state's CAREWare server, allowing providers to determine whether clients receive services in other locations. A clinic staff member described the role of data sharing as helpful for client retention:

> [Data-sharing] is a huge help because I can see if patients are getting case management in other areas besides mine. I think just that very even small piece of data sharing has helped immensely.

In addition, the NCDHHS expanded the use of a communicable disease surveillance database, North Carolina Electronic Disease Surveillance System (NC EDSS), to include HIV and syphilis case reports. This system was designed with the potential to monitor cases over time and includes a package for the DIS to make referrals to SBCs. Consequently, NC EDSS was mentioned as another potentially effective way to track HIV client retention in care. However, several participants stated that access to NC EDSS was restricted to state health department personnel; thus, a few respondents suggested the need for state-managed reports to offer clinical data to providers throughout the state, allowing clinics and agencies to more easily monitor client HIV care data. A medical provider elaborated on this:

> I would love to see improved transfer of information amongst the different systems we have in the state .... It's sort of a one-directional flow at this time, other than receiving large aggregate quality data which is important, but doesn't address individual needs.

Discussion

This qualitative case study captures the landscape of the HIV prevention and care systems in North Carolina and the impact of state and local infrastructures on the retention and reengagement of HIV-infected persons in care. Study participants highlighted myriad factors that hinder or strengthen client engagement in consistent HIV care on individual, institutional, community, and public policy levels. Examining the strengths and barriers to retention and reengagement in HIV care as was discussed by participants through a social–ecological lens provides a needed framework to understand the complex issues that often influence care engagement.

This study contributes to the limited available literature on the application of the social–ecological model to HIV care engagement. One study by Olson et al[45] included a qualitative analysis of the underuse of Alabama's AIDS Drug Assistance

Program (ADAP) within a social–ecological model. Focus groups conducted with ADAP clients described barriers to full participation in the program and were then characterized into levels within the social–ecological model. This North Carolina study echoes the findings of Olson et al[45] that barriers and facilitators on the intrapersonal and interpersonal levels (eg, substance abuse, health literacy, and relationships with providers), clinic level (eg, presence of social workers and other providers in the clinic) as well as the policy level (eg, ADAP prescription dispensing and recertification processes), all have implications for care engagement. In addition, the findings from this study support Mugavero et al[15] in their identification of promising approaches to improve retention in HIV care, namely, strong case management services and coordinated health service, as well as a need for increased integration of surveillance data into routine HIV care.

This case study also demonstrated how barriers at the intrapersonal level may impede client engagement in care, as identified in prior research.[20,46-48] In this study, challenges discussed were namely socioeconomic, transportation, and psychosocial in nature, which are often difficult to address and which were also mentioned by the respondents as barriers to HIV testing and linkage, as described by Sullivan et al.[44] Nonetheless, they are important to consider, as they are impacted by policies such as health insurance premiums, mass transit planning, and funding of substance abuse and mental health treatment programs.

In addition, the presence of strong interpersonal relationships between patients and providers was mentioned by respondents as important for involvement in care, a point that has been documented in the literature.[17,19,49,50] Flickinger et al[51] found that PLWH were more likely to attend their appointments when they felt that their providers treated them with respect and explained information in an understandable way. Thus, assessing the quality of provider communication with their patients and providing skills-based training, as needed, may enhance client engagement.

Respondents also identified the new SBC program as promising to improve HIV care retention outcomes, particularly to employ dedicated personnel to actively search for out-of-care patients and assist clients to overcome barriers to care engagement. This echoes findings from the literature that the provisions of strengths-based counseling and patient navigation services, as well as the removal of individual and systems-level barriers, can yield improved client retention rates.[52] However, some participants also noted that future efforts should continue to identify how the work of the DIS and SBCs can best complement one another. A key component of the NC-LINK project—a collaboration between the NCDHHS, Duke University, and University of North Carolina at Chapel Hill—is to standardize the distinct personnel roles of the SBCs and DIS and evaluate the effects of the SBC program on locating and reengaging lost-to-care clients.

Statewide HIV data-sharing policies and systems were also identified as a strength and an area in need of additional focus. Several participants noted the impetus for data systems that allowed public health officials and care providers to obtain more complete pictures of patient retention in care. Recent initiatives in NC to share client data were mentioned as significant improvements; however, some participants suggested that allowing nonstate personnel to access surveillance data would further improve retention and reengagement efforts. The importance of using such surveillance data to monitor care has been documented in the literature.[53,54] An evaluation of the information exchange system in Louisiana that integrated HIV surveillance data within HIV care clinics for out-of-care clients demonstrated improved client retention and reengagement in care.[55] In addition, the CDC recently created a national initiative, "Data to Care," to standardize the use of state surveillance data to identify and engage PLWH who are otherwise not virally suppressed, which NC and other states are adopting to improve HIV care engagement.[56]

This study also possesses some limitations to consider. Some of the respondents were involved with the planning and implementation of the NC-LINK project, of which this case study was a component. This may have biased their responses; however, due to their key roles in the delivery of HIV care in North Carolina, their contribution and perspectives were deemed important to include. In addition, only a small number of participants ($n = 3$) were interviewed from county health departments or AIDS service organizations. The sample size of 21, however, was within an appropriate range for qualitative research,[57] and a saturation effect was observed among participant responses.

Overall, this study provides important contributions to the literature about patient engagement in HIV care. First, many studies have examined the importance of clients remaining retained in care, but further research is needed within a Southern context to examine care engagement within ever-evolving HIV care landscapes. In addition, understanding system responses to the unique situations of patients who are inconsistently retained in care or who are lost to care is critical to realize the updated NHAS target of 90% of PLWH remaining engaged in HIV medical care by 2020.[11] Finally, these findings may offer insight into all states, especially those within the Southern United States, regarding the successes and challenges seen in North Carolina to engage and reengage HIV clients in care. This may ultimately assist other states with similar challenges to identify needed programs and priorities to optimize client engagement in care.

Authors' Note

This information, content, and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, the US Government, or the NCDHHS.

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