PARTICIPANT COMPOSITION

A summary of the geographic, demographic, socio-economic, and other composition characteristics of individuals who participated in the 2014 Houston Area HIV/AIDS needs assessment provides both a "snapshot" of who is living with HIV/AIDS in the Houston Area today as well as context for other needs assessment results.

(**Table 1**) Overall, 95% of needs assessment participants were residing in Houston/Harris County at the time of data collection. The majority of participants were male (62%), African American/Black (65%), and heterosexual (56%). Over half was between the ages of 25 and 49 with an average age of 46.

The average household income of participants was $8,088 per year, with the majority living at 100% of federal poverty (FPL). Other socio-economic characteristics of participants include: 35% disabled, 39% unemployed, 57% using public transportation as their primary transportation means, and 60% using public health insurance in the form of Medicaid and/or Medicare. A majority reported living in their own house/apartment (67%) with a small proportion in group housing facilities (8%).

TABLE 1-Select Participant Characteristics, Houston Area HIV/AIDS Needs Assessment, 2014

	No.	%		No.	%		No.	%
County of residence			Age (range: 14 to 69; average: 46)			Sex assigned at birth		
Houston/Harris	646	95.3%	13 to 24	36	5.4%	Male	420	62.1%
Fort Bend	20	2.9%	25 to 49	350	52.1%	Female	254	37.6%
Liberty	2	0.3%	50 to 64	274	40.8%	Intersex	2	0.3%
Montgomery	4	0.6%	65+	12	1.8%	Transgender	24	3.5%
Other	5	0.7%	Adolescents (13 to 17)	8	1.2%	Currently pregnant	4	1.1%
Primary race/ethnicity			Sexual orientation			Education level		
White	102	15.0%	Heterosexual	374	55.7%	Less than high school	143	21.2%
African American/Black	440	64.9%	Gay/Lesbian	209	31.1%	High school diploma	235	34.8%
Hispanic/Latino	122	18.0%	Bisexual	67	10.0%	GED	108	16.0%
Asian American	2	0.3%	Other	22	3.3%	Technical degree	62	9.2%
Other/Mixed race	12	1.8%	MSM	250	37.4%	Post-secondary degree	113	16.7%
Employment status			Immigration status			Yearly income (average: $8,088)		
Employed (FT/PT)	128	18.9%	Born in the U.S.	504	75.8%	Federal Poverty Level (FPL)		
Temporary worker	52	7.7%	Citizen > 5 years	100	15.0%	100%	486	89.2%
Unemployed	265	39.1%	Citizen < 5 years	3	0.5%	150%	40	7.3%
Disabled	237	35.0%	Undocumented	6	0.9%	200%	10	1.8%
Retired	32	4.7%	Prefer not to answer	27	4.1%	250%	5	0.9%
Student	24	3.5%	Other	25	3.8%	300% or higher	4	0.7%
Health insurance			Housing status			Transportation		
Private insurance	32	4.7%	Own house/apartment	450	66.7%	Own vehicle	185	29.1%
Medicaid/Medicare	409	60.1%	Stay with others	125	18.5%	Public transportation	360	56.6%
Harris Health System	145	21.3%	Group facility	57	8.4%	Walk/bike	26	4.1%
Ryan White only	148	22.3%	Hotel/motel	4	0.6%	Borrow/carpool	42	6.6%
None	9	1.4%	Homeless	39	5.8%	None	9	1.4%

From the 2014 Houston Area HIV/AIDS Needs Assessment
condensed for FY2015 How to Best Meet the Need

Chapter 2:

Overall Service Needs and Barriers

OVERALL SERVICE NEEDS AND BARRIERS

The Ryan White HIV/AIDS Program provides a spectrum of HIV-related services to persons living with HIV/AIDS (PLWHA) who may not have sufficient resources for managing HIV disease. At the local level, determinations of which HIV services to provide are made by the Houston Area HIV Services Ryan White Planning Council. In addition, housing services for PLWHA are provided through the federal Housing Opportunities for People with AIDS (HOPWA) program. The primary purpose of an HIV/AIDS needs assessment is to gather information about the need for and barriers to services funded by the Ryan White HIV/AIDS Program locally as well as other federal programs like HOPWA.

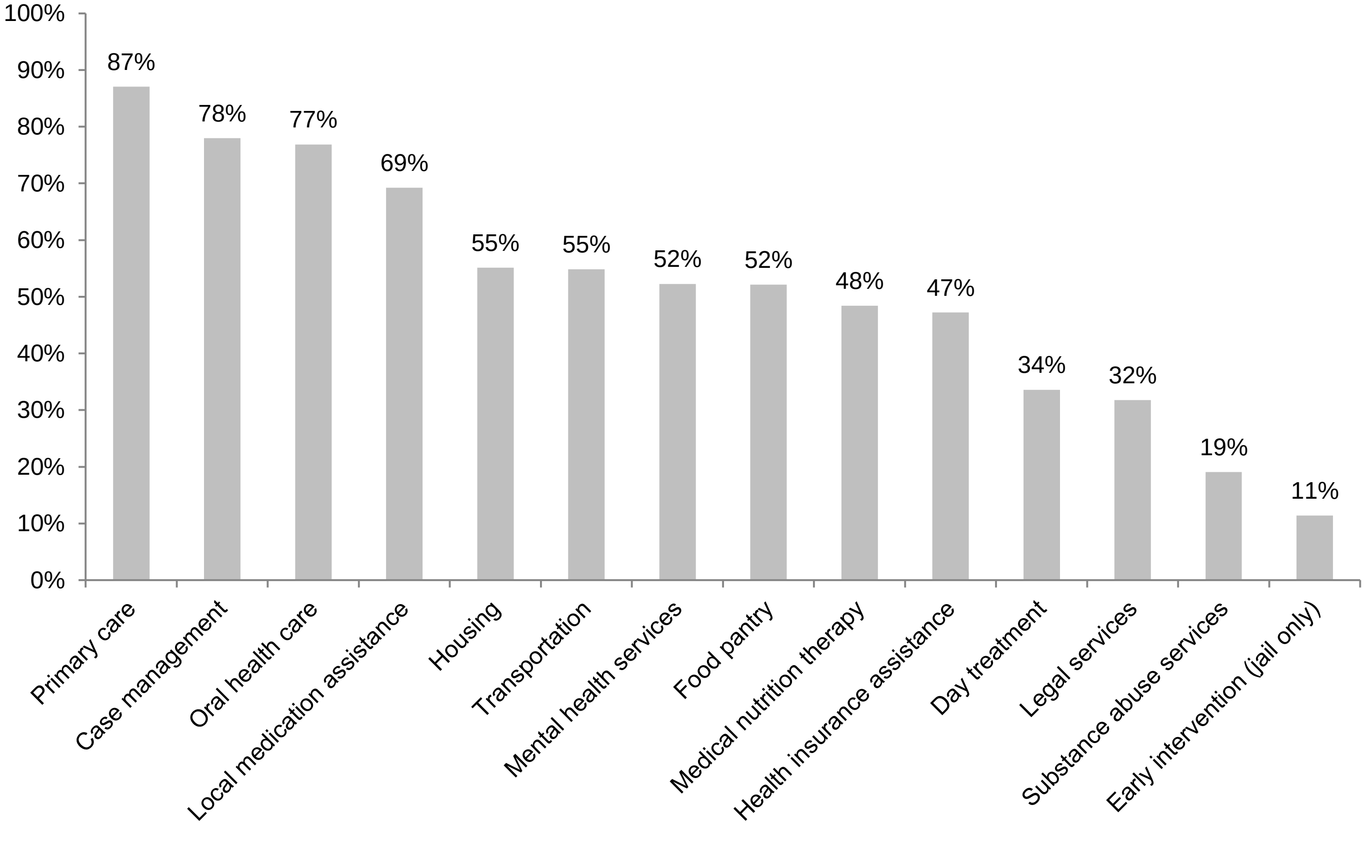
Overall Ranking of Funded Services, by Need

In 2013, 16 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. Participants of the 2014 Houston Area HIV/AIDS needs assessment were asked to indicate which of these funded services they needed in the past 12 months.

(**Graph 1**) All funded services received a ranking of need by needs assessment participants. At 87%, primary care was the most needed funded service in the Houston Area, followed by case management at 78% and oral health care at 77%. When compared to the last Houston Area HIV/AIDS needs assessment conducted in 2011, local medication assistance and medical nutrition therapy both fell in the ranking among core medical services, while transportation eclipsed food pantry as the most needed non-medical support service.

GRAPH 1-Ranking of HIV Services in the Houston Area, By Need, 2014

Definition: Percent of needs assessment participants stating they needed the service in the past 12 months, regardless of ease or difficulty accessing the service.



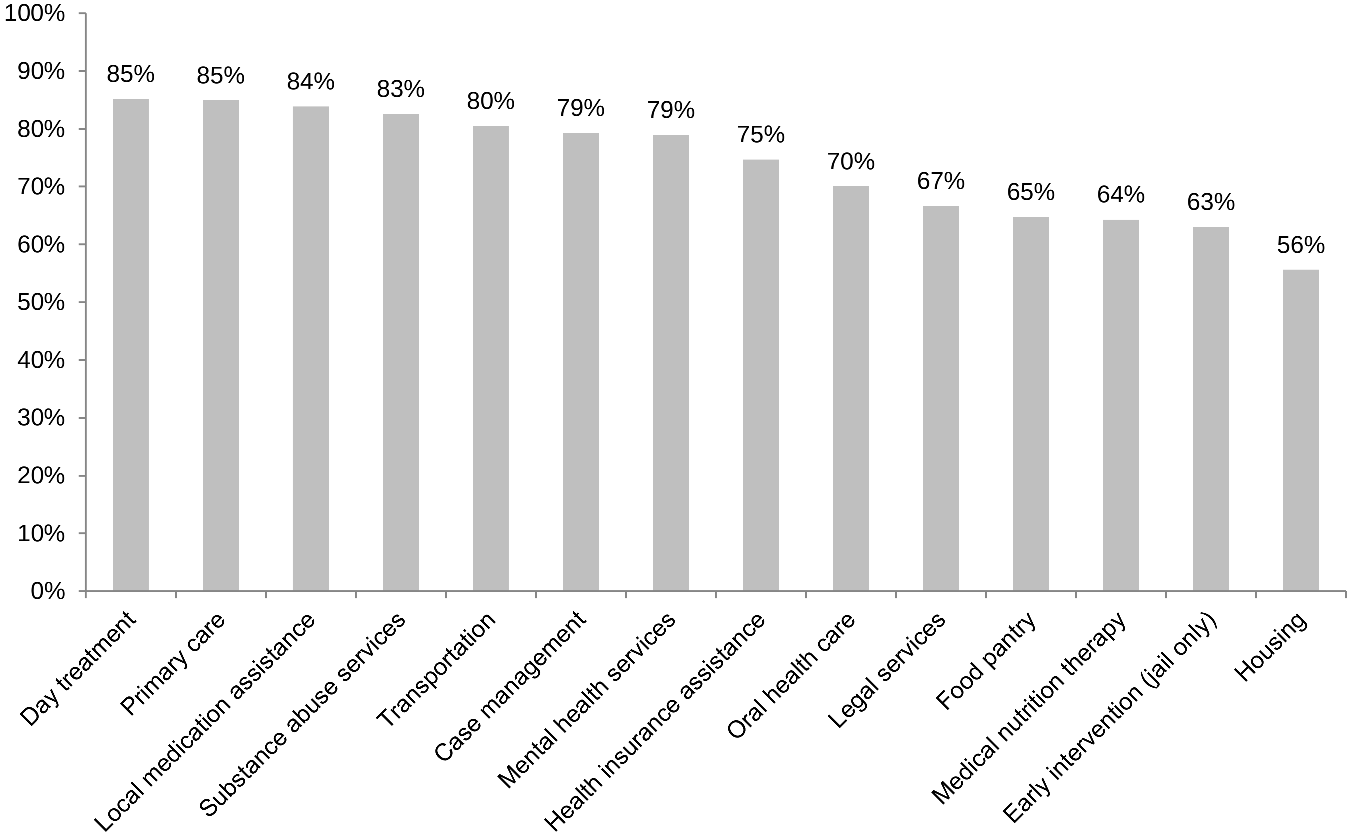
Overall Ranking of Funded Services, by Accessibility

Participants of the 2014 Houston Area HIV/AIDS 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. Furthermore, if difficulty was experienced, participants were asked to identify the specific issue or barrier that caused the difficulty. Results for both topics are presented below.

(**Graph 2**) For each funded service, at least half of the needs assessment participants who stated they needed the service in the past 12 months also stated the service was accessible to them. At 85% easy to access, both day treatment and primary care were the most accessible funded services in the Houston Area. At 56% easy to access, housing was the least accessible funded service in the Houston Area for those who reported a need for it. On average, all Houston Area services were accessible to 75% of the participants who stated they had a need for them.

GRAPH 2-Ranking of HIV Services in the Houston Area, By Accessibility, 2014

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.



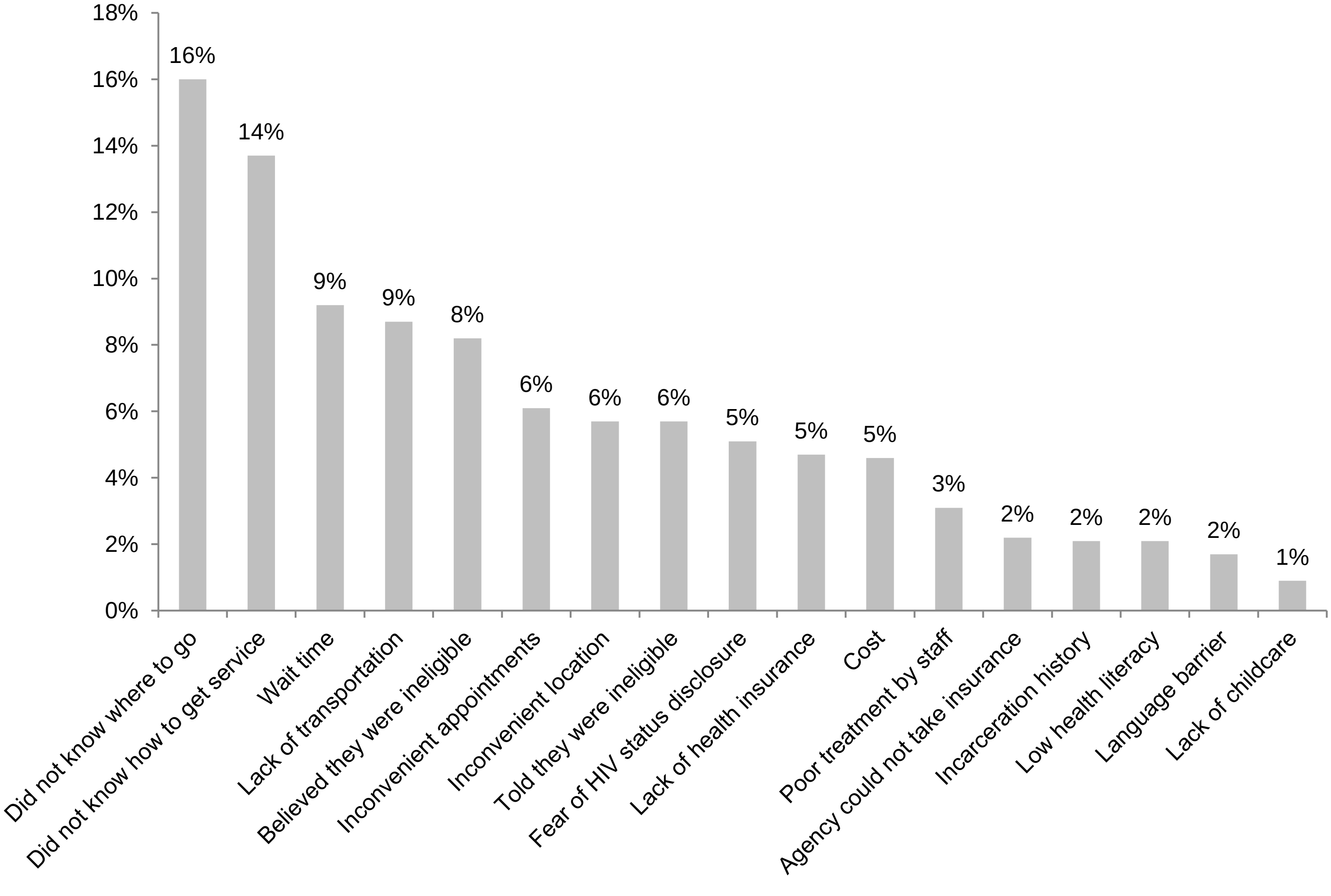
Overall Ranking of Barriers Experienced by Consumers

A list of 17 commonly experienced barriers to services was presented to needs assessment participants from which to select the specific condition or issue that made the service they needed *difficult* to access. Results show that all funded services were reported to have barriers. The average was 166 reports of barriers per service, with a low of 34 and a high of 366. In total, 2,483 reports of barriers were indicated in the sample across all services. This represents a 30% *decrease* in the number of reported barriers when compared to the last Houston Area HIV/AIDS needs assessment conducted in 2011.

(**Graph 3**) Overall, the barrier experienced most often by PLWHA (when barriers were reported) was lack of knowledge of where to go for the service (16% of all reported barriers), followed by lack of knowledge of *how* to access the service (14%), and wait time for the service (9%). Lack of childcare was reported least often (1%).

GRAPH 3-Ranking of Barriers to HIV Services in the Houston Area, 2014

Definition: Percent of times each barrier was reported by needs assessment participants, regardless of service, when barriers were present.



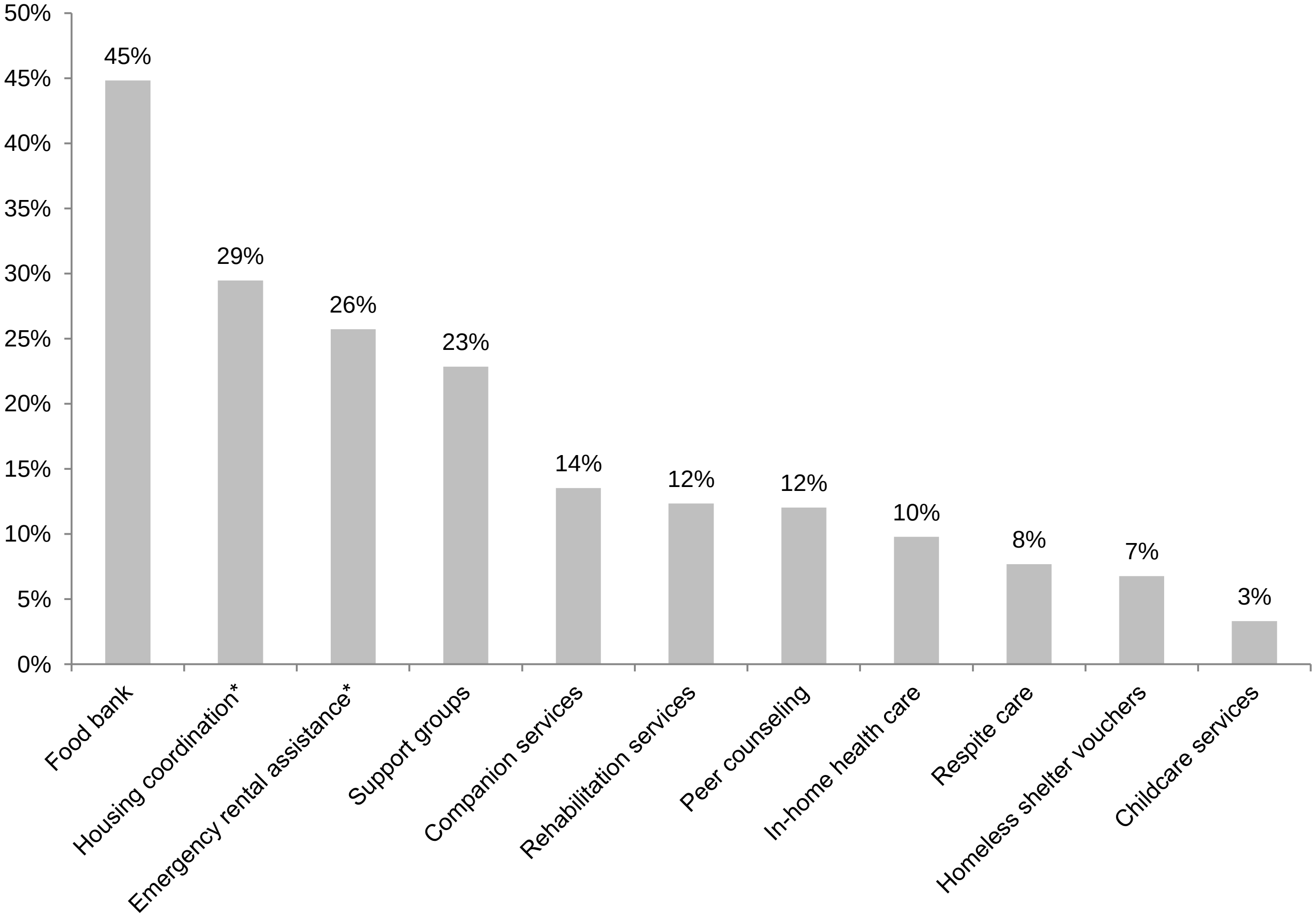
Other Identified Needs

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 2014 Houston Area HIV/AIDS needs assessment queried the need for these other services that are not currently funded by Ryan White in 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 4**) Eleven other/non-Ryan White funded HIV-related services were assessed in the consumer survey. Participants could also write-in other types of services that they needed. Of the 11 preset options provided, food bank was selected most often as a need at 45% of respondents. Housing-related services were cited second and third. It should be noted that

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, food stamps, and social groups.

GRAPH 4-Other Needs for HIV Services in the Houston Area, 2014

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.

From the 2014 Houston Area HIV/AIDS Needs Assessment
condensed for FY2015 How to Best Meet the Need

Service-Specific Fact Sheets

PRIMARY HIV MEDICAL CARE

Primary HIV medical care, technically referred to as *outpatient/ambulatory medical care*, refers to the diagnostic and therapeutic services provided to persons living with HIV/AIDS (PLWHA) by a physician or physician extender in an outpatient setting. This includes physical examinations, diagnosis and treatment of common physical and mental health conditions, preventative care, education, laboratory services, and specialty services as indicated.

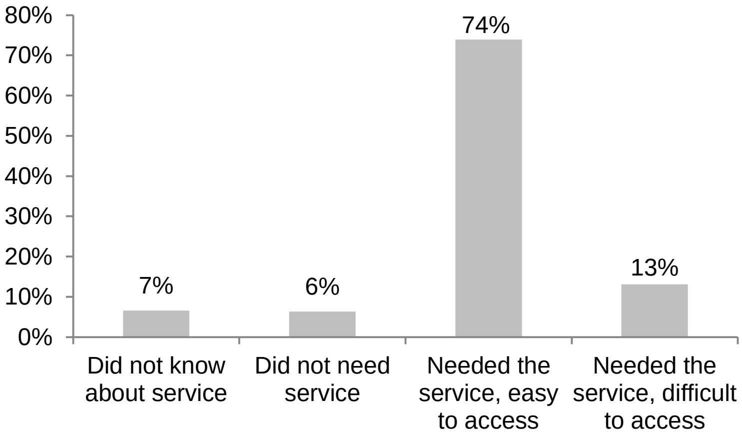
(**Graph 1**) In the 2014 Houston Area HIV/AIDS needs assessment, 87% of participants indicated a need for *primary HIV medical care* in the past 12 months. 74% reported the service was easy to access, and 13% reported difficulty. 7% stated that they did not know the service was available.

(**Table 1**) When barriers to *primary HIV medical care* were reported, the most common was wait time (14% of all reported barriers to this service).

TABLE 1-Top 10 Reported Barriers to Primary HIV Medical Care, 2014

	No.	%
1. Wait time	28	14%
2. Did not know where to go	25	12%
3. Lack of transportation	21	10%
4. Inconvenient appointments	19	9%
5. Fear of HIV status disclosure	19	9%
6. Did not know how to get service	12	6%
7. Inconvenient location	12	6%
8. Lack of health insurance	10	5%
9. Cost	10	5%
10. Agency could not take insurance	9	4%

GRAPH 1-Primary HIV Medical Care, 2014



(**Table 2 and Table 3**) Need and access to services can be analyzed for needs assessment participants according to demographic and other characteristics. This allows planners to review results for the presence of any potential disparities in access to services. For *primary HIV medical care*, this analysis shows the following:

- More males than females found the service accessible.
- More PLWHA of other/mixed race and whites found the service accessible than other race/ethnicities.
- More PLWHA age 45+ found the service accessible than other age groups.
- In addition, more homeless, out of care, recently released, and transgender PLWHA found the service difficult to access when compared to all participants.

TABLE 2-Primary HIV Medical Care, by Demographic Categories, 2014

	Sex		Race/ethnicity				Age		
Experience with the Service	Male	Female	White	Black	Hispanic	Other	13-24	25-44	45+
Did not know about service	7%	7%	5%	6%	10%	0%	9%	8%	6%
Did not need service	6%	7%	7%	6%	6%	0%	12%	5%	7%
Needed, easy to access	75%	71%	78%	73%	70%	85%	76%	71%	77%
Needed, difficult to access	12%	16%	10%	14%	14%	15%	3%	17%	11%

TABLE 3-Primary HIV Medical Care, by Selected Special Populations, 2014

Experience with the Service	Adolescents[a]	Homeless[b]	MSM[c]	Out of care[d]	Recently Released[e]	Rural[f]	Transgender[g]
Did not know about service	33%	2%	6%	7%	9%	0%	11%
Did not need service	17%	2%	6%	22%	5%	0%	7%
Needed, easy to access	50%	70%	78%	11%	63%	96%	63%
Needed, difficult to access	0%	26%	11%	61%	23%	4%	19%

[a] Persons aged 13 to 17 [b] Persons living in a shelter, street, vehicle, or no defined location [c] Men who have sex with men [d] Persons with no evidence of HIV care for 12 mo.
[e] Persons released from incarceration in the past 12 mo. [f] Non-Houston/Harris County residents [g] Persons with discordant sex assigned at birth and current gender

CASE MANAGEMENT

Case management, technically referred to as *medical case management*, describes a range of services that help connect persons living with HIV/AIDS (PLWHA) to HIV care, treatment, and support services and to retain them in care. Case managers assess client needs, develop service plans, and facilitate access to services through referrals and care coordination. Case management also includes treatment readiness and adherence counseling.

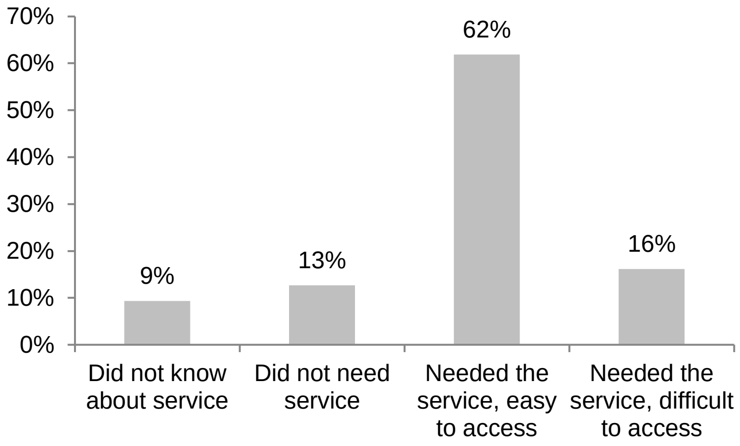
(**Graph 1**) In the 2014 Houston Area HIV/AIDS needs assessment, 78% of participants indicated a need for *case management* in the past 12 months. 62% reported the service was easy to access, and 16% reported difficulty. 9% stated they did not know the service was available.

(**Table 1**) When barriers to *case management* were reported, the most common was lack of knowledge, both of where to go for the service and of how to receive the service (both 16% of all reported barriers to this service).

TABLE 1-Top 10 Reported Barriers to Case Management, 2014

	No.	%
1. Did not know where to go	28	16%
2. Did not know how to get service	28	16%
3. Wait time	17	9%
4. Lack of transportation	15	8%
5. Believed they were ineligible	13	7%
6. Lack of health insurance	10	6%
7. Poor treatment by staff	10	6%
8. Inconvenient appointments	9	5%
9. Cost	8	4%
10. Fear of HIV status disclosure	8	4%

GRAPH 1-Case Management, 2014



(**Table 2 and Table 3**) Need and access to services can be analyzed for needs assessment participants according to demographic and other characteristics. This allows planners to review results for the presence of any potential disparities in access to care. For *case management*, this analysis shows the following:

- More males than females found the service accessible.
- More White PLWHA found the service accessible than other race/ethnicities.
- More PLWHA age 13 to 24 found the service accessible than other age groups.
- In addition, more homeless, out of care, recently released, and transgender PLWHA found the service difficult to access when compared to all participants.

TABLE 2-Case Management, by Demographic Categories, 2014

	Sex		Race/ethnicity				Age		
Experience with the Service	Male	Female	White	Black	Hispanic	Other	13-24	25-44	45+
Did not know about service	9%	11%	6%	8%	15%	10%	6%	9%	10%
Did not need service	14%	10%	11%	12%	16%	0%	18%	11%	13%
Needed, easy to access	63%	60%	68%	61%	57%	65%	70%	61%	61%
Needed, difficult to access	15%	18%	15%	18%	12%	25%	6%	18%	16%

TABLE 3-Case Management, by Selected Special Populations, 2014

Experience with the Service	Adolescents[a]	Homeless[b]	MSM[c]	Out of care[d]	Recently Released[e]	Rural[f]	Transgender[g]
Did not know about service	0%	14%	7%	7%	12%	0%	15%
Did not need service	33%	5%	12%	22%	10%	7%	7%
Needed, easy to access	67%	49%	67%	13%	57%	93%	56%
Needed, difficult to access	0%	33%	14%	58%	22%	0%	22%

[a] Persons aged 13 to 17 [b] Persons living in a shelter, street, vehicle, or no defined location [c] Men who have sex with men [d] Persons with no evidence of HIV care for 12 mo.
[e] Persons released from incarceration in the past 12 mo. [f] Non-Houston/Harris County residents [g] Persons with discordant sex assigned at birth and current gender

LOCAL HIV MEDICATION ASSISTANCE

Local HIV medication assistance, technically referred to as the *Local Pharmacy Assistance Program (LPAP)*, provides HIV-related pharmaceuticals to persons living with HIV/AIDS (PLWHA) who are not eligible for medications through other payer sources, including the state AIDS Drug Assistance Program (ADAP).

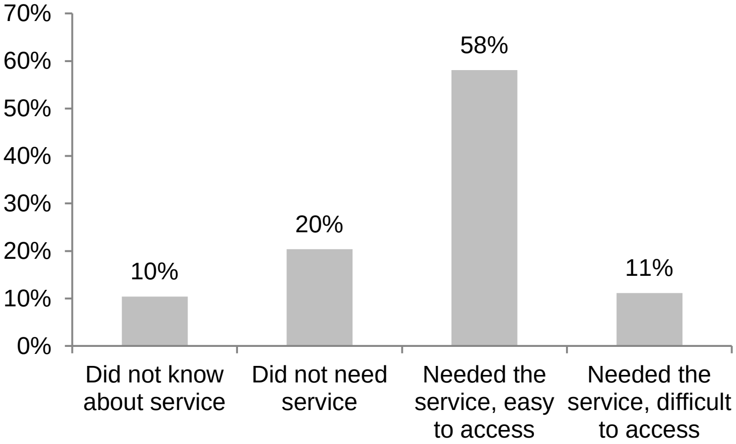
(**Graph 1**) In the 2014 Houston Area HIV/AIDS needs assessment, 69% of participants indicated a need for *local HIV medication assistance* in the past 12 months. 58% reported the service was easy to access, and 11% reported difficulty. 10% stated that they did not know the service was available.

(**Table 1**) When barriers to *local HIV medication assistance* were reported, the most common were lack of transportation and lack of knowledge of where to go for the service (both 13% of all reported barriers to this service).

TABLE 1-Top 10 Reported Barriers to Local HIV Medication Assistance, 2014

	No.	%
1. Lack of transportation	20	13%
2. Did not know where to go	19	13%
3. Lack of health insurance	15	10%
4. Inconvenient appointments	14	9%
5. Did not know how to get service	13	9%
6. Believed they were ineligible	12	8%
7. Fear of HIV status disclosure	10	7%
8. Cost	10	7%
9. Wait time	8	5%
10. Inconvenient location	20	13%

GRAPH 1-Local HIV Medication Assistance, 2014



(**Table 2 and Table 3**) Need and access to services can be analyzed for needs assessment participants according to demographic and other characteristics. This allows planners to review results for the presence of any potential disparities in access to services. For *local HIV medication assistance*, this analysis shows the following:

- More males than females found the service accessible.
- More Hispanic/Latino PLWHA than other race/ethnicities found the service accessible.
- More PLWHA age 45+ found the service accessible than other age groups.
- In addition, more adolescents, MSM, out of care, recently released, and transgender PLWHA found the service difficult to access when compared to all participants.

TABLE 2-Local HIV Medication Assistance, by Demographic Categories, 2014

	Sex		Race/ethnicity				Age		
Experience with the Service	Male	Female	White	Black	Hispanic	Other	13-24	25-44	45+
Did not know about service	9%	14%	11%	11%	10%	5%	18%	11%	9%
Did not need service	20%	22%	23%	23%	11%	29%	24%	19%	21%
Needed, easy to access	59%	55%	56%	56%	63%	62%	48%	58%	59%
Needed, difficult to access	12%	9%	11%	10%	16%	5%	9%	11%	11%

TABLE 3-Local HIV Medication Assistance, by Selected Special Populations, 2014

Experience with the Service	Adolescents[a]	Homeless[b]	MSM[c]	Out of care[d]	Recently Released[e]	Rural[f]	Transgender[g]
Did not know about service	60%	21%	7%	9%	13%	7%	7%
Did not need service	0%	16%	20%	57%	24%	14%	21%
Needed, easy to access	20%	58%	61%	6%	45%	72%	54%
Needed, difficult to access	20%	5%	13%	28%	18%	7%	18%

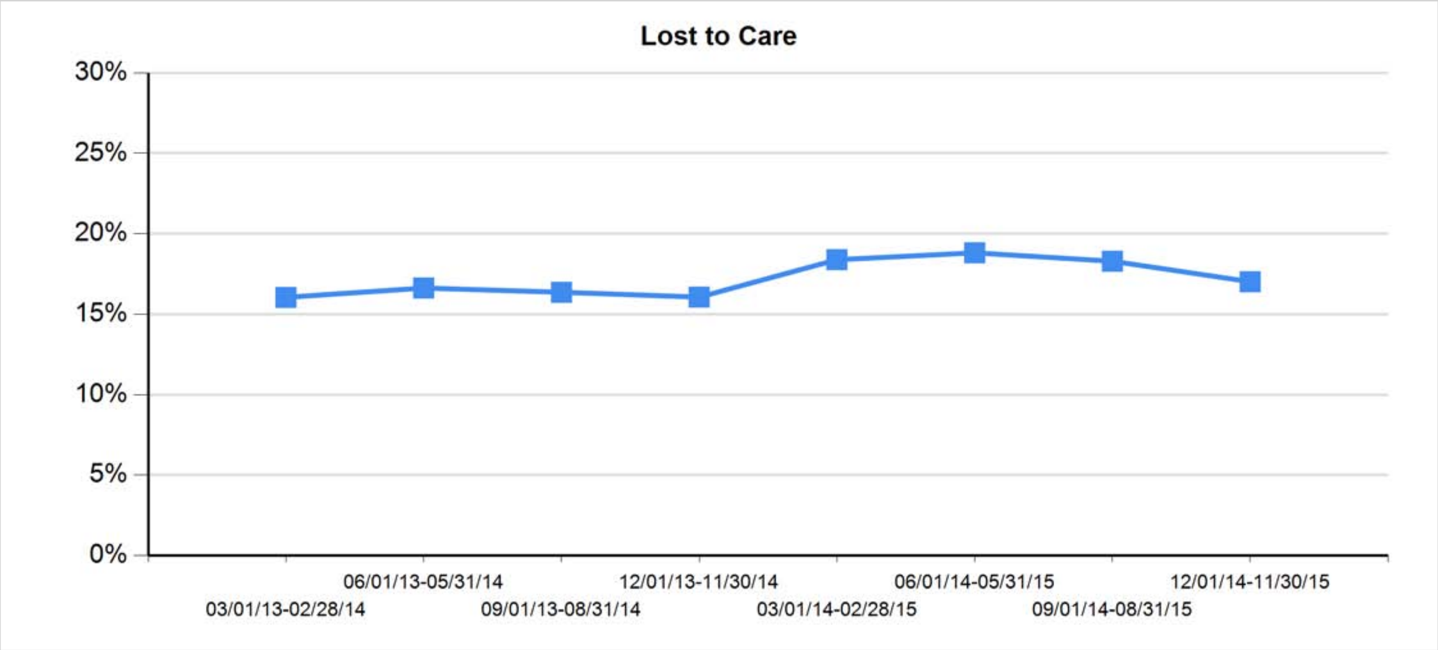
[a] Persons aged 13 to 17 [b] Persons living in a shelter, street, vehicle, or no defined location [c] Men who have sex with men [d] Persons with no evidence of HIV care for 12 mo.
[e] Persons released from incarceration in the past 12 mo. [f] Non-Houston/Harris County residents [g] Persons with discordant sex assigned at birth and current gender

HARRIS COUNTY PUBLIC HEALTH AND ENVIRONMENTAL SERVICES - RWGA

Clinical Quality Management Committee Quarterly Report

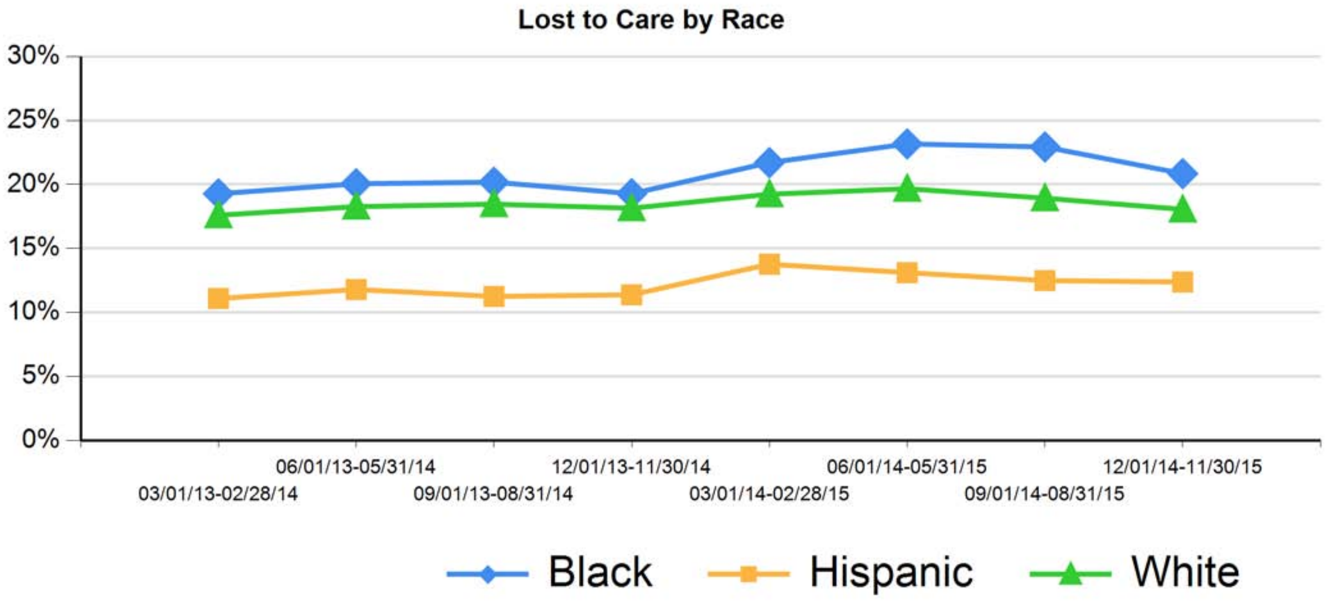
Last Quarter Start Date: **12/1/2014**

Lost to Care				
In+Care Campaign Gap Measure				
	03/01/14 - 02/28/15	06/01/14 - 05/31/15	09/01/14 - 08/31/15	12/01/14 - 11/30/15
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	859	892	854	807
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	4,672	4,741	4,669	4,742
Percentage	18.4%	18.8%	18.3%	17.0%
Change from Previous Quarter Results	2.3%	0.4%	-0.5%	-1.3%



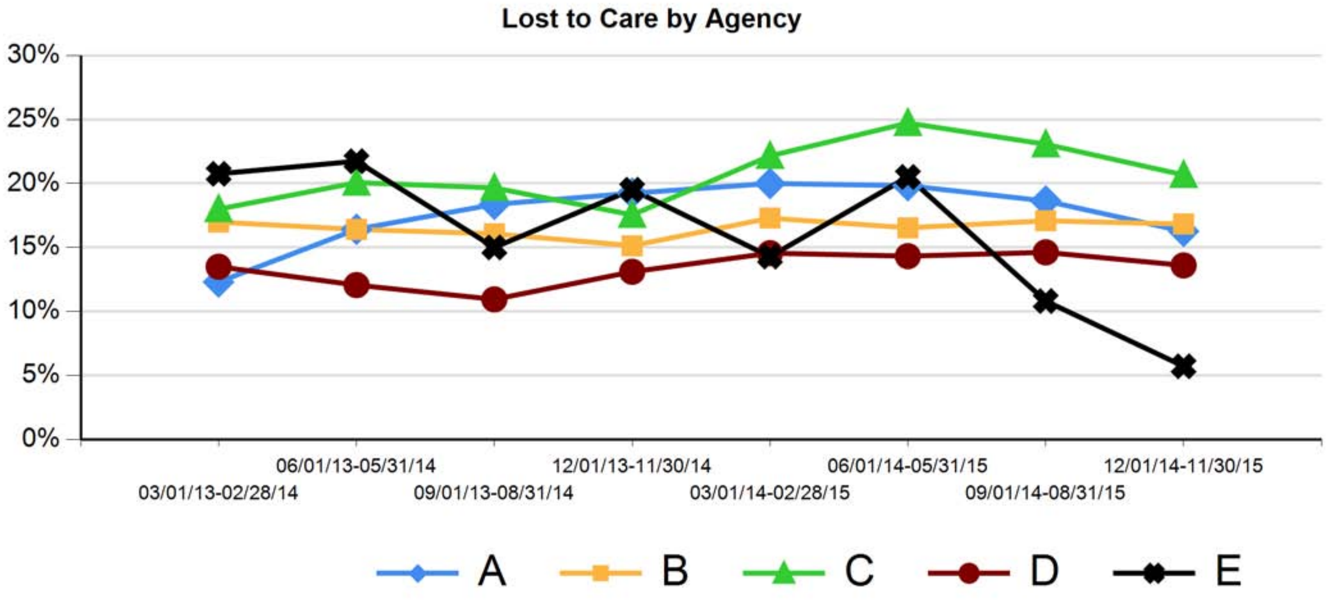
Lost to Care by Race/Ethnicity

	06/01/14 - 05/31/15			09/01/14 - 08/31/15			12/01/14 - 11/30/15		
	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	509	235	129	501	220	120	458	227	113
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	2,197	1,793	656	2,185	1,762	634	2,197	1,834	626
Percentage	23.2%	13.1%	19.7%	22.9%	12.5%	18.9%	20.8%	12.4%	18.1%
Change from Previous Quarter Results	1.5%	-0.7%	0.4%	-0.2%	-0.6%	-0.7%	-2.1%	-0.1%	-0.9%



Lost to Care by Agency

	09/01/14 - 08/31/15					12/01/14 - 11/30/15				
	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	125	351	247	126	4	107	357	217	124	2
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	671	2,055	1,071	862	37	658	2,121	1,050	912	35
Percentage	18.6%	17.1%	23.1%	14.6%	10.8%	16.3%	16.8%	20.7%	13.6%	5.7%
Change from Previous Quarter Results	-1.2%	0.5%	-1.7%	0.3%	-9.7%	-2.4%	-0.2%	-2.4%	-1.0%	-5.1%

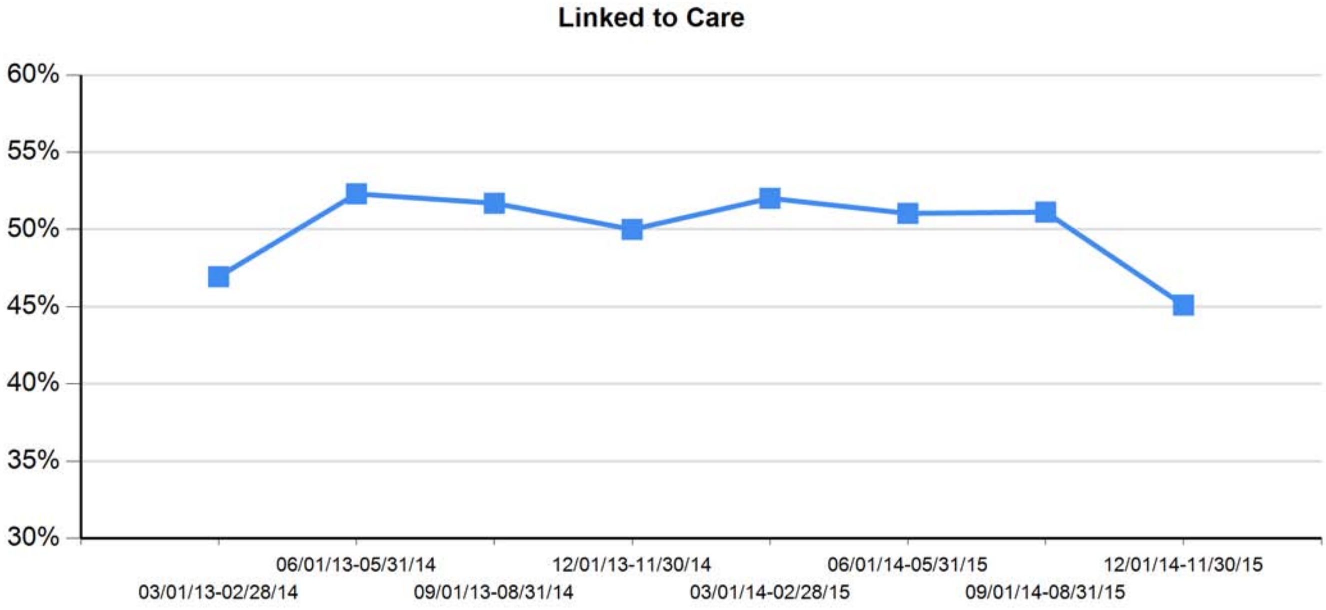


Linked to Care

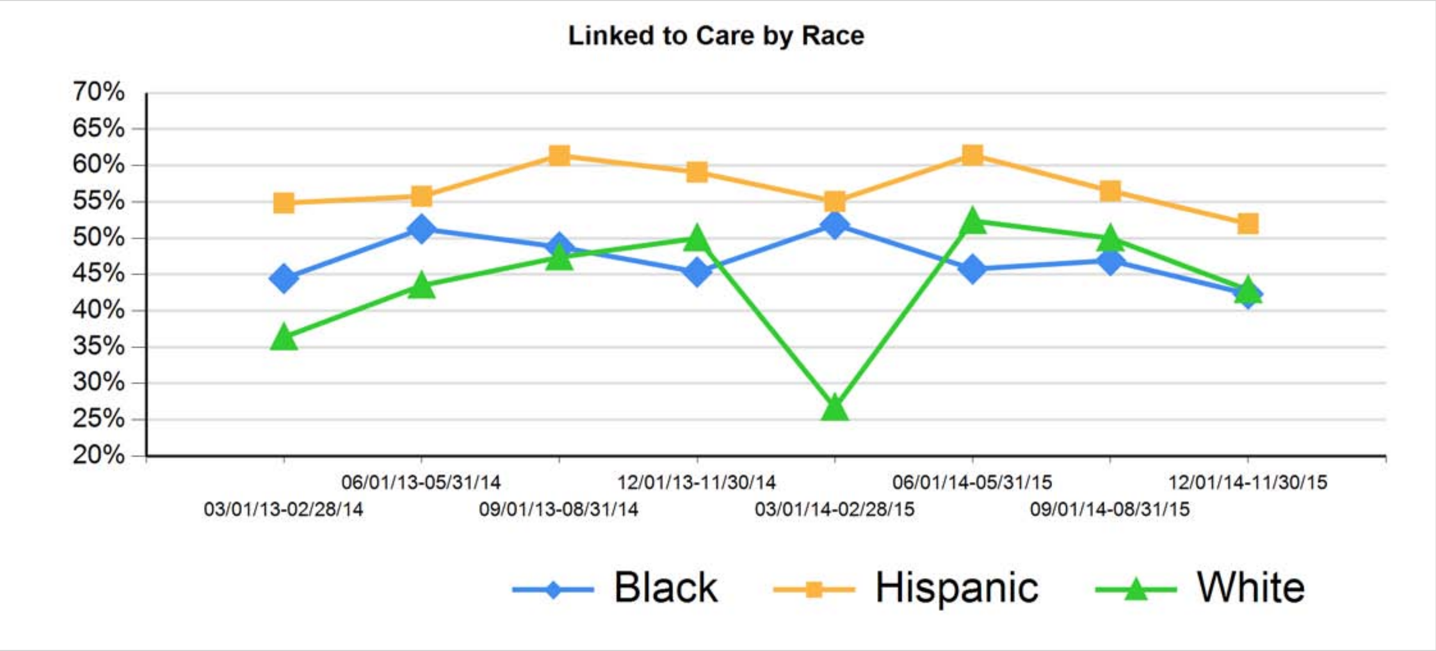
In+Care Campaign clients Newly Enrolled in Medical Care Measure

	03/01/14 - 02/28/15	06/01/14 - 05/31/15	09/01/14 - 08/31/15	12/01/14 - 11/30/15
Number of newly enrolled HIV-infected clients who had at least one medical visit in each of the 4-month periods of the measurement year	103	98	91	69
Number of newly enrolled 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	198	192	178	153
Percentage	52.0%	51.0%	51.1%	45.1%
Change from Previous Quarter Results	2.0%	-1.0%	0.1%	-6.0%

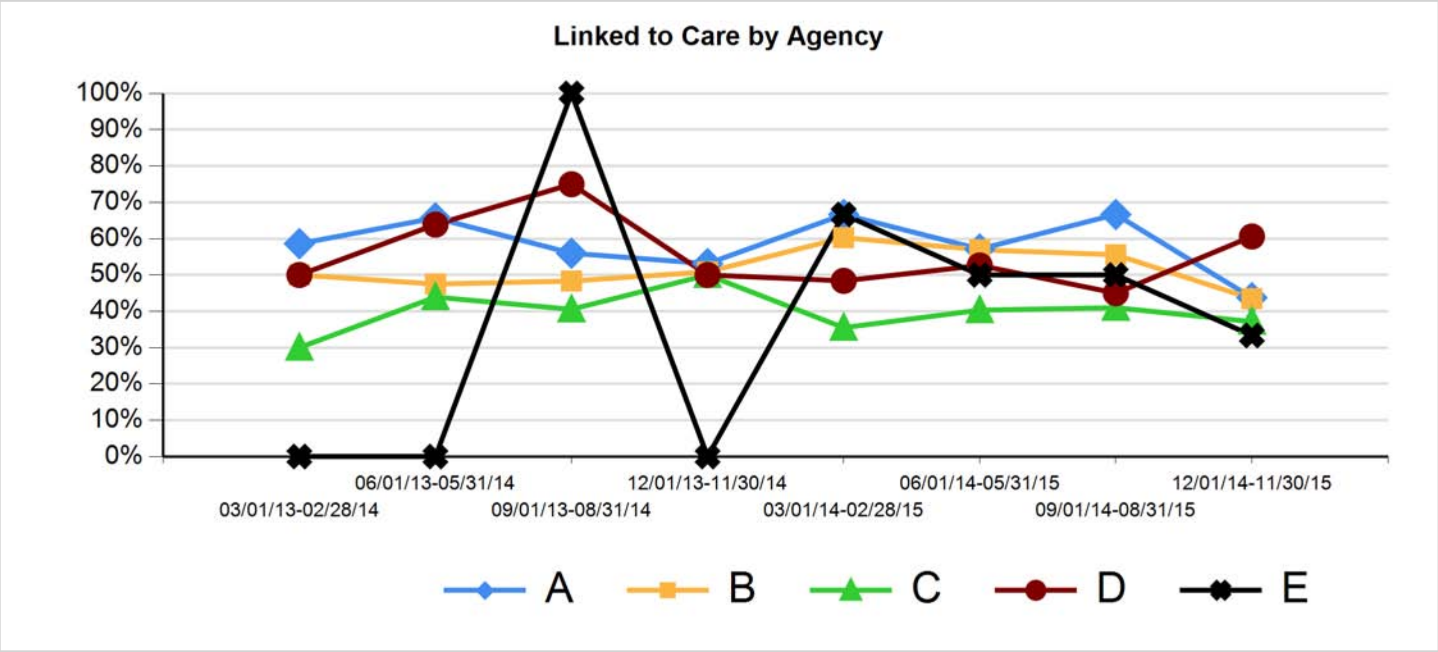
* exclude if vl<200 in 1st 4 months



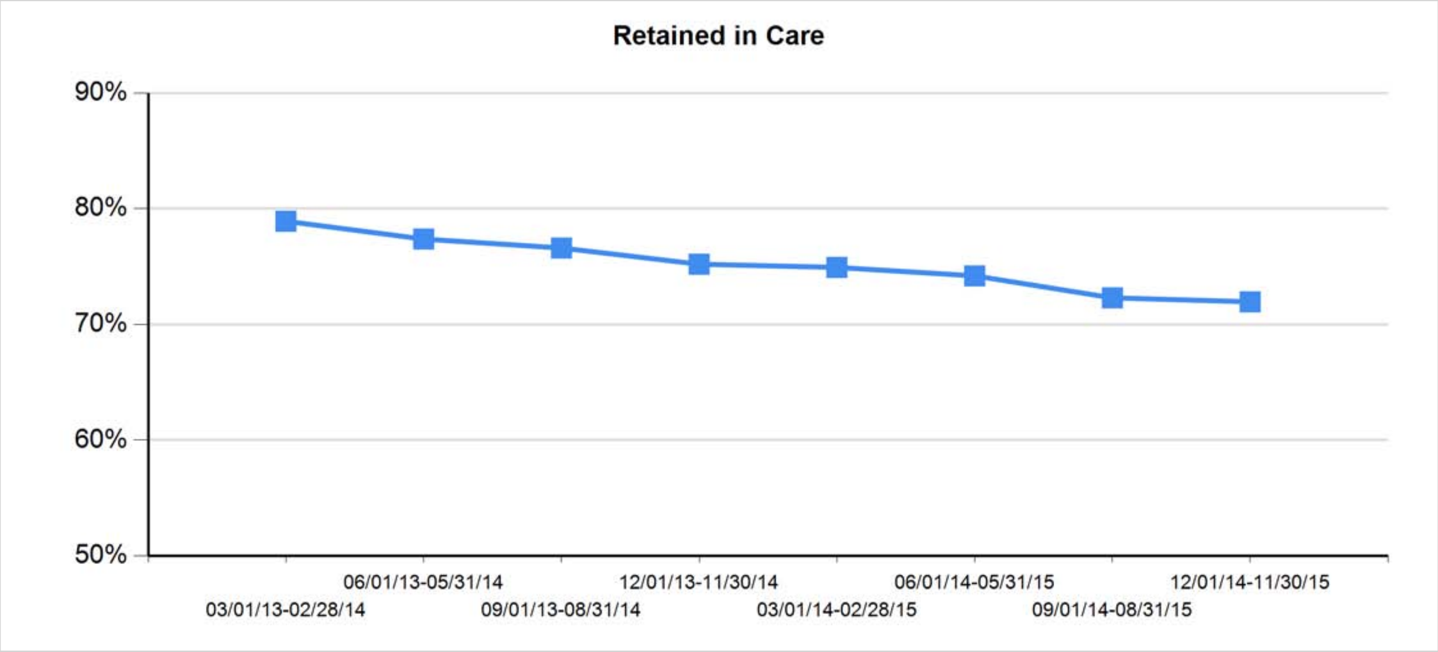
Linked to Care by Race/Ethnicity									
	06/01/14 - 05/31/15			09/01/14 - 08/31/15			12/01/14 - 11/30/15		
	Black	Hisp	White	Black	Hisp	White	Black	Hisp	White
Number of newly enrolled HIV-infected clients who had at least one medical visit in each of the 4-month periods of the measurement year	43	43	11	38	39	13	33	26	9
Number of newly enrolled 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	94	70	21	81	69	26	78	50	21
Percentage	45.7%	61.4%	52.4%	46.9%	56.5%	50.0%	42.3%	52.0%	42.9%
Change from Previous Quarter Results	-6.1%	6.4%	25.7%	1.2%	-4.9%	-2.4%	-4.6%	-4.5%	-7.1%
* exclude if vl<200 in 1st 4 months									



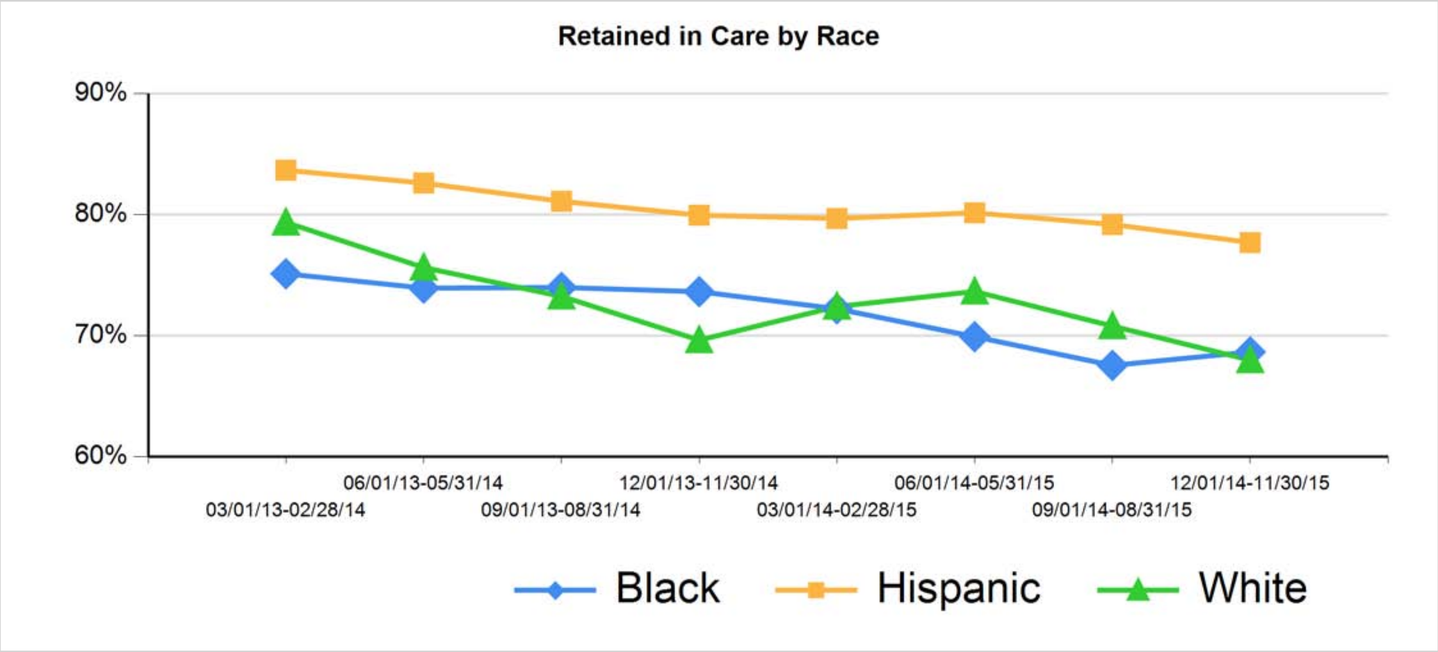
Linked to Care by Agency										
	09/01/14 - 08/31/15					12/01/14 - 11/30/15				
	A	B	C	D	E	A	B	C	D	E
Number of newly enrolled HIV-infected clients who had at least one medical visit in each of the 4-month periods of the measurement year	20	35	25	9	2	7	30	13	20	1
Number of newly enrolled HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the first 4 months of the measurement year	30	63	61	20	4	16	69	35	33	3
Percentage	66.7%	55.6%	41.0%	45.0%	50.0%	43.8%	43.5%	37.1%	60.6%	33.3%
Change from Previous Quarter Results	9.5%	-1.4%	0.7%	-7.6%	0.0%	-22.9%	-12.1%	-3.8%	15.6%	-16.7%
* exclude if vl<200 in 1st 4 months										



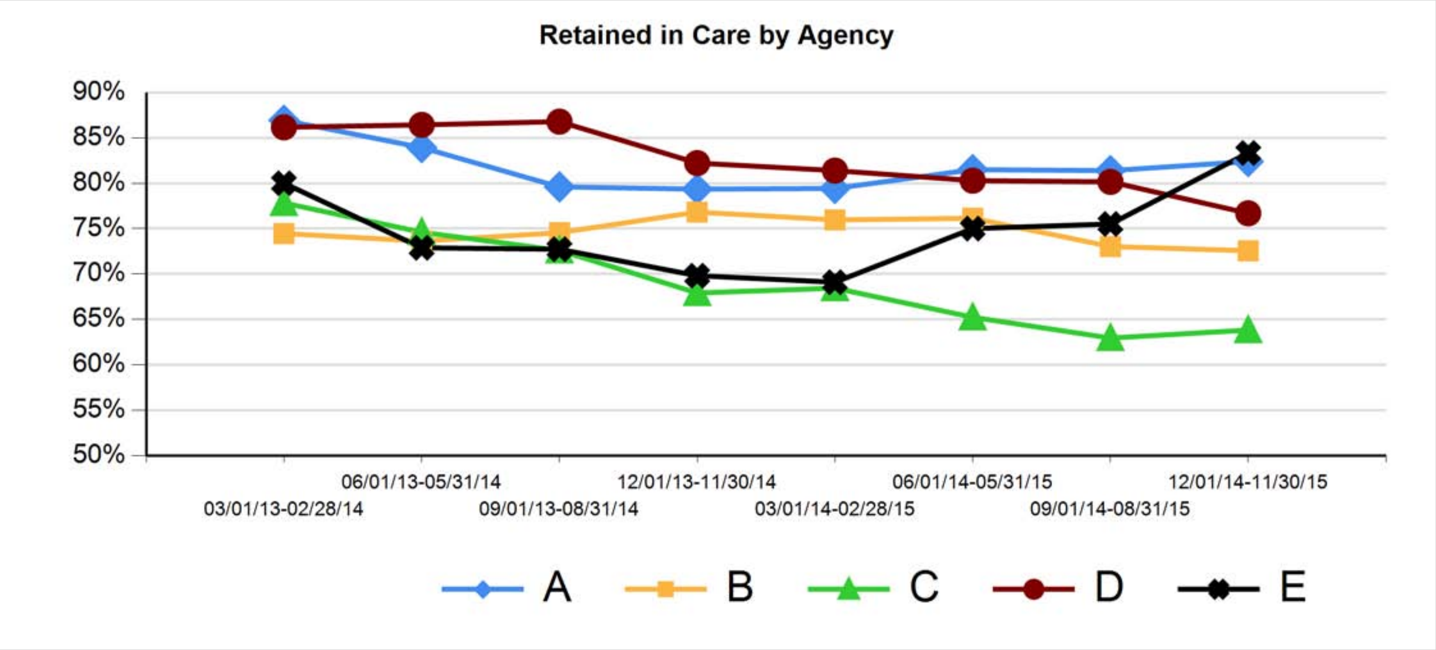
Retained in Care				
Houston EMA Medical Visits Measure				
	03/01/14 - 02/28/15	06/01/14 - 05/31/15	09/01/14 - 08/31/15	12/01/14 - 11/30/15
Number of HIV-infected clients who had 2 or more medical visits at least 3 months apart during the measurement year*	4,106	4,101	3,946	3,877
Number of HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the measurement year*	5,480	5,527	5,458	5,388
Percentage	74.9%	74.2%	72.3%	72.0%
Change from Previous Quarter Results	-0.3%	-0.7%	-1.9%	-0.3%
* Not newly enrolled in care				



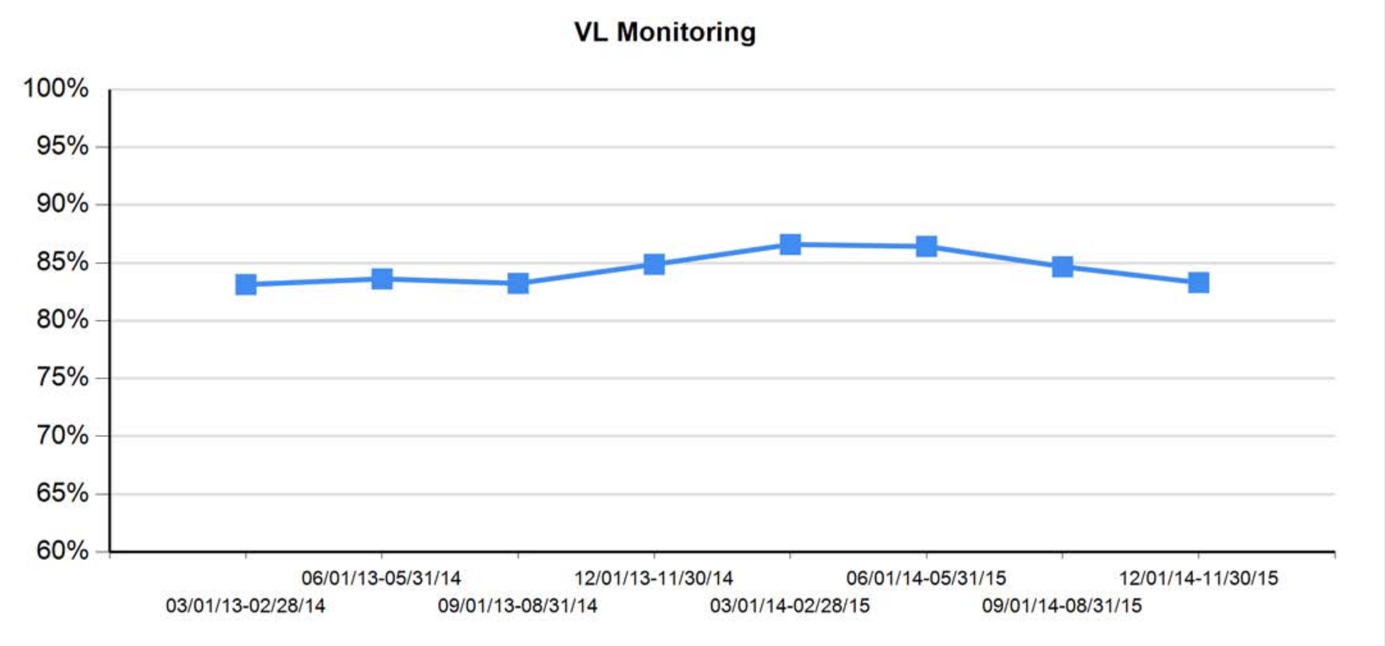
Retained in Care by Race/Ethnicity									
	06/01/14 - 05/31/15			09/01/14 - 08/31/15			12/01/14 - 11/30/15		
	Black	Hisp	White	Black	Hisp	White	Black	Hisp	White
Number of HIV-infected clients who had 2 or more medical visits at least 3 months apart during the measurement year	1,823	1,602	595	1,751	1,555	557	1,738	1,556	507
Number of HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the measurement year*	2,608	1,999	808	2,593	1,964	787	2,532	2,003	746
Percentage	69.9%	80.1%	73.6%	67.5%	79.2%	70.8%	68.6%	77.7%	68.0%
Change from Previous Quarter Results	-2.3%	0.5%	1.3%	-2.4%	-1.0%	-2.9%	1.1%	-1.5%	-2.8%



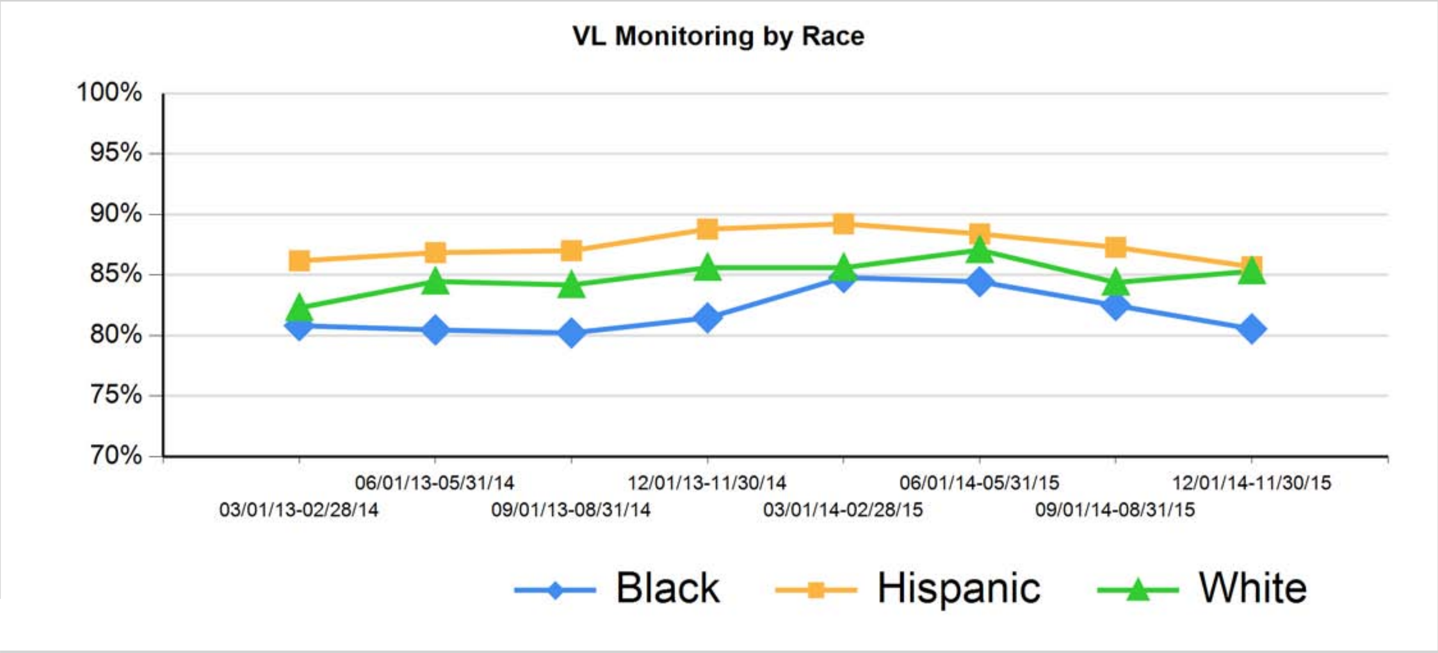
Retained in Care by Agency										
	09/01/14 - 08/31/15					12/01/14 - 11/30/15				
	A	B	C	D	E	A	B	C	D	E
Number of HIV-infected clients who had 2 or more medical visits at least 3 months apart during the measurement year	586	1,652	924	852	37	580	1,663	873	839	35
Number of HIV-infected clients who had a medical visit with a provider with prescribing privileges at least once in the measurement year*	720	2,262	1,468	1,063	49	704	2,292	1,368	1,094	42
Percentage	81.4%	73.0%	62.9%	80.2%	75.5%	82.4%	72.6%	63.8%	76.7%	83.3%
Change from Previous Quarter Results	-0.1%	-3.1%	-2.3%	-0.1%	0.5%	1.0%	-0.5%	0.9%	-3.5%	7.8%



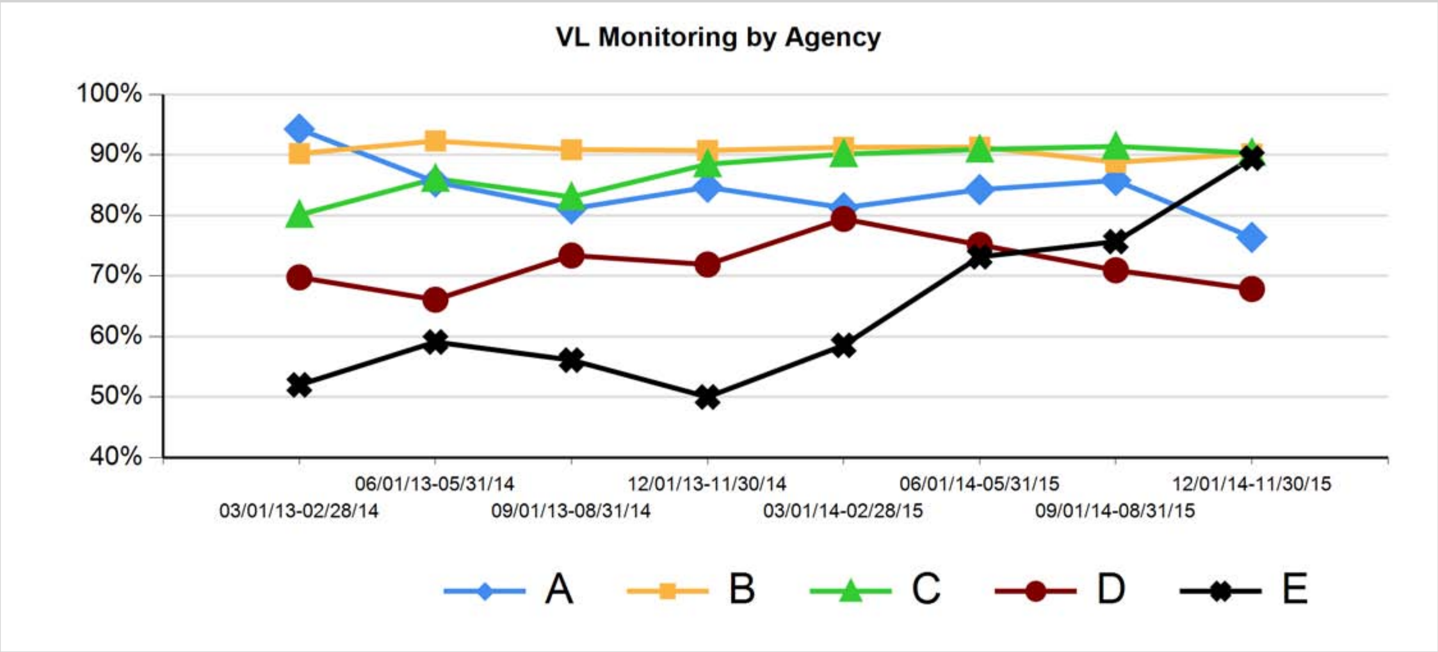
Viral Load Monitoring				
	03/01/14 - 02/28/15	06/01/14 - 05/31/15	09/01/14 - 08/31/15	12/01/14 - 11/30/15
Number of HIV-infected clients who had 2 or more Viral Load counts at least 3 months apart during the measurement year	3,797	3,742	3,546	3,475
Number of HIV-infected clients who had 2 or more medical visits at least 3 months apart with a provider with prescribing privileges, i.e. MD, PA, NP in the measurement year	4,385	4,330	4,188	4,172
Percentage	86.6%	86.4%	84.7%	83.3%
Change from Previous Quarter Results	1.7%	-0.2%	-1.7%	-1.4%



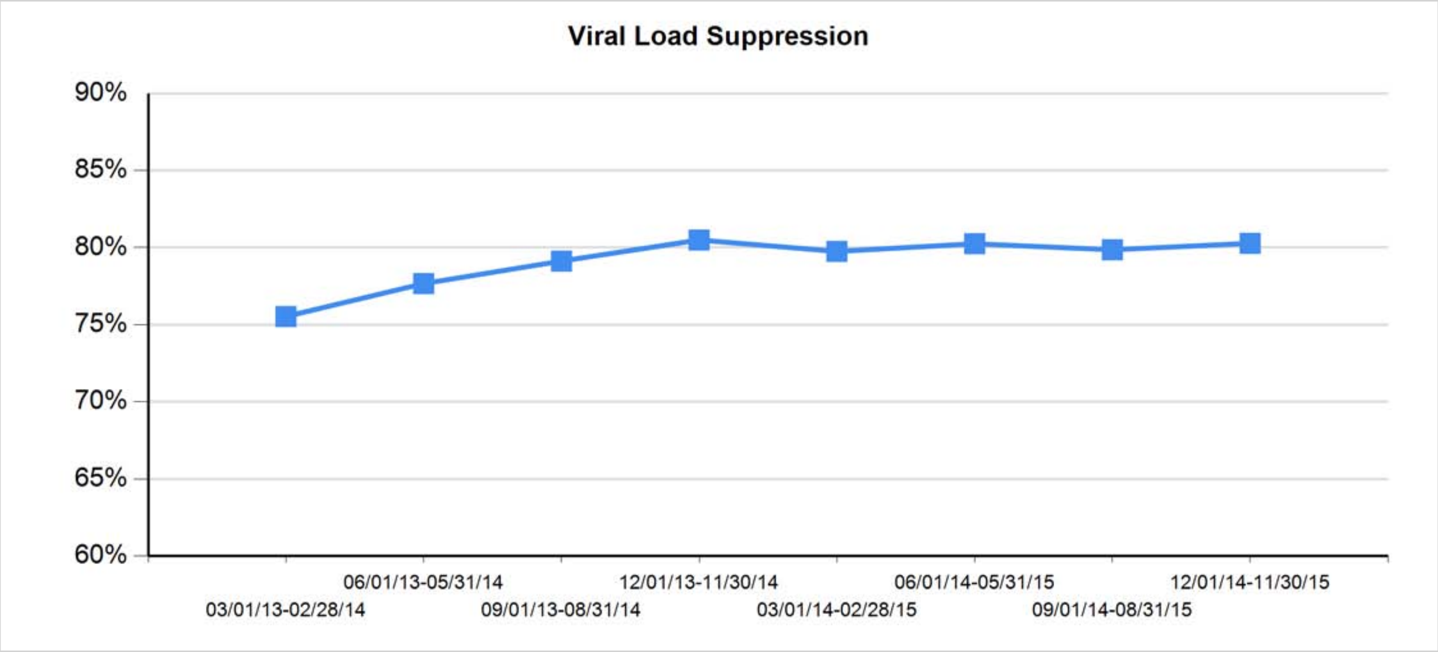
VL Monitoring Data by Race/Ethnicity									
	06/01/14 - 05/31/15			09/01/14 - 08/31/15			12/01/14 - 11/30/15		
	Black	Hisp	White	Black	Hisp	White	Black	Hisp	White
Number of HIV-infected clients who had 2 or more Viral Load counts at least 3 months apart during the measurement year	1,650	1,478	538	1,544	1,435	497	1,519	1,406	482
Number of HIV-infected clients who had 2 or more medical visits at least 3 months apart with a provider with prescribing privileges, i.e. MD, PA, NP in the measurement year	1,954	1,672	618	1,872	1,644	589	1,886	1,641	565
Percentage	84.4%	88.4%	87.1%	82.5%	87.3%	84.4%	80.5%	85.7%	85.3%
Change from Previous Quarter Results	-0.3%	-0.8%	1.5%	-2.0%	-1.1%	-2.7%	-1.9%	-1.6%	0.9%



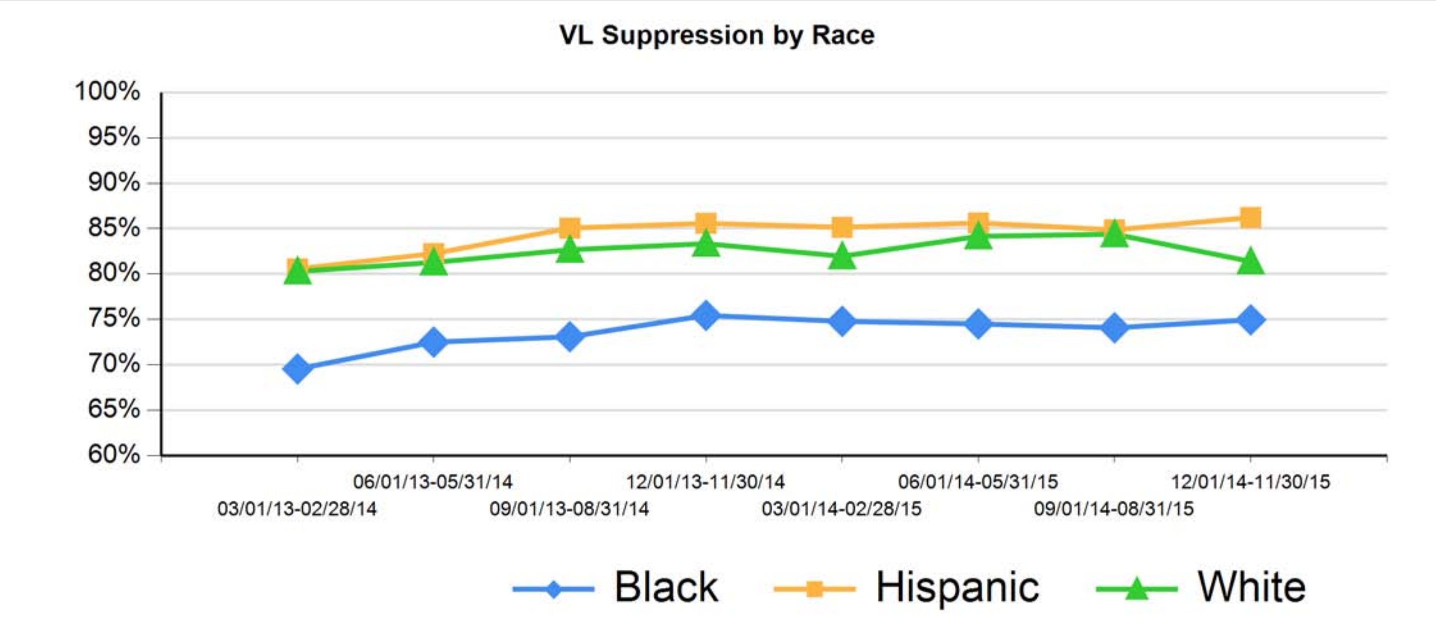
VL Monitoring by Agency										
	09/01/14 - 08/31/15					12/01/14 - 11/30/15				
	A	B	C	D	E	A	B	C	D	E
Number of HIV-infected clients who had 2 or more Viral Load counts at least 3 months apart during the measurement year	513	1,531	852	613	28	456	1,533	840	595	34
Number of HIV-infected clients who had 2 or more medical visits at least 3 months apart with a provider with prescribing privileges, i.e. MD, PA, NP in the measurement year	598	1,724	932	864	37	597	1,700	930	877	38
Percentage	85.8%	88.8%	91.4%	70.9%	75.7%	76.4%	90.2%	90.3%	67.8%	89.5%
Change from Previous Quarter Results	1.5%	-2.5%	0.5%	-4.2%	2.5%	-9.4%	1.4%	-1.1%	-3.1%	13.8%



Viral Load Suppression				
	03/01/14 - 02/28/15	06/01/14 - 05/31/15	09/01/14 - 08/31/15	12/01/14 - 11/30/15
Number of HIV-infected clients who have a viral load of <200 copies/ml during the measurement year	4,057	4,051	3,905	3,928
Number of HIV-infected clients who have had at least 2 medical visits with a provider with prescribing privileges and have been enrolled in care at least six month	5,087	5,048	4,890	4,893
Percentage	79.8%	80.2%	79.9%	80.3%
Change from Previous Quarter Results	-0.7%	0.5%	-0.4%	0.4%

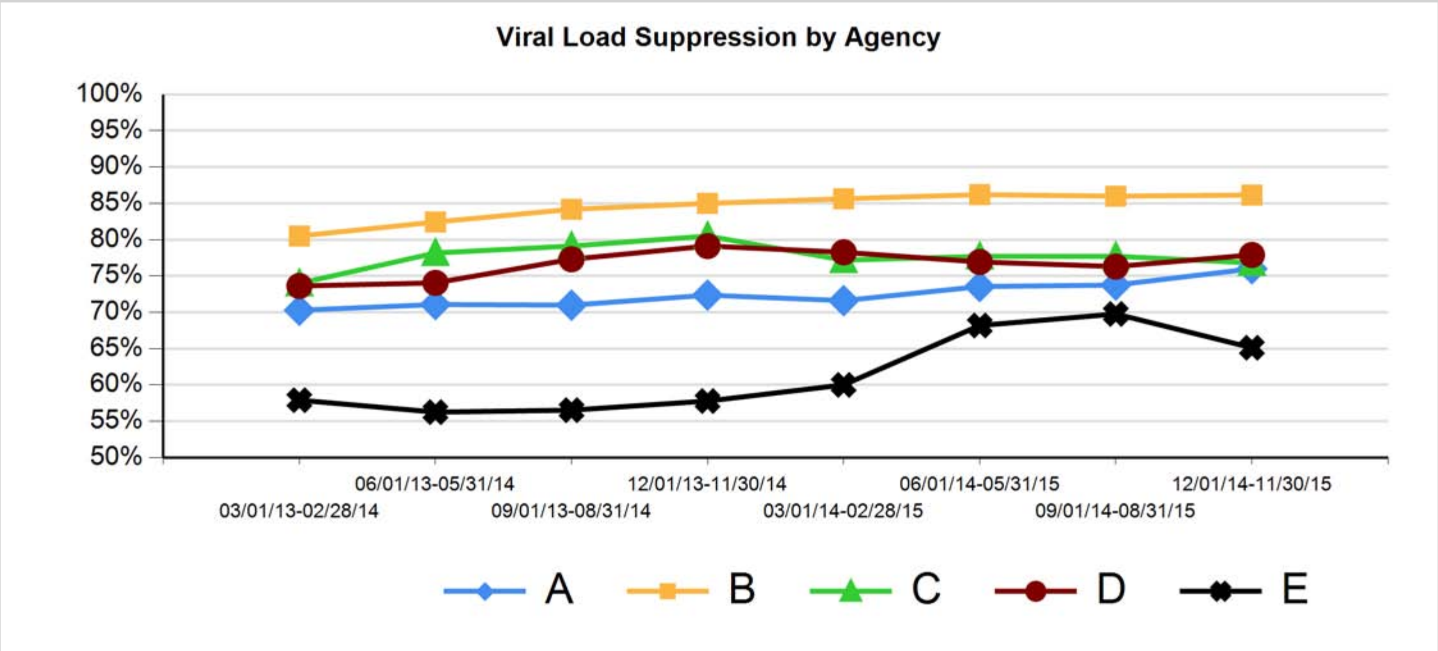


VL Suppression by Race/Ethnicity									
	06/01/14 - 05/31/15			09/01/14 - 08/31/15			12/01/14 - 11/30/15		
	Black	Hisp	White	Black	Hisp	White	Black	Hisp	White
Number of HIV-infected clients who have a viral load of <200 copies/ml during the measurement year	1,773	1,584	605	1,688	1,552	578	1,714	1,577	555
Number of HIV-infected clients who have had at least 2 medical visits with a provider with prescribing privileges and have been enrolled in care at least six month	2,380	1,850	719	2,279	1,829	685	2,287	1,829	682
Percentage	74.5%	85.6%	84.1%	74.1%	84.9%	84.4%	74.9%	86.2%	81.4%
Change from Previous Quarter Results	-0.3%	0.5%	2.2%	-0.4%	-0.8%	0.2%	0.9%	1.4%	-3.0%

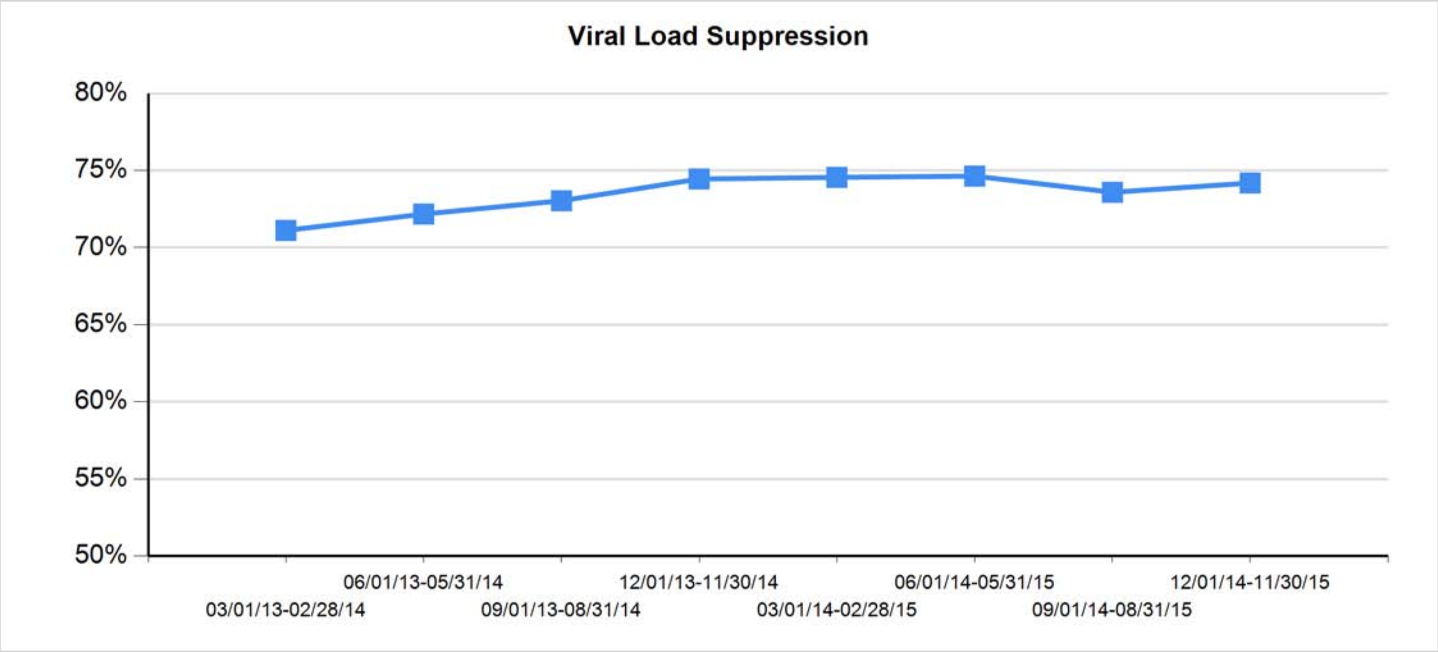


VL Suppression by Agency

	09/01/14 - 08/31/15					12/01/14 - 11/30/15				
	A	B	C	D	E	A	B	C	D	E
Number of HIV-infected clients who have a viral load of <200 copies/ml during the measurement year	531	1,669	924	792	30	535	1,680	904	825	28
Number of HIV-infected clients who have had at least 2 medical visits with a provider with prescribing privileges and have been enrolled in care at least six month	720	1,941	1,189	1,038	43	704	1,950	1,177	1,059	43
Percentage	73.8%	86.0%	77.7%	76.3%	69.8%	76.0%	86.2%	76.8%	77.9%	65.1%
Change from Previous Quarter Results	0.2%	-0.2%	0.0%	-0.6%	1.6%	2.2%	0.2%	-0.9%	1.6%	-4.7%

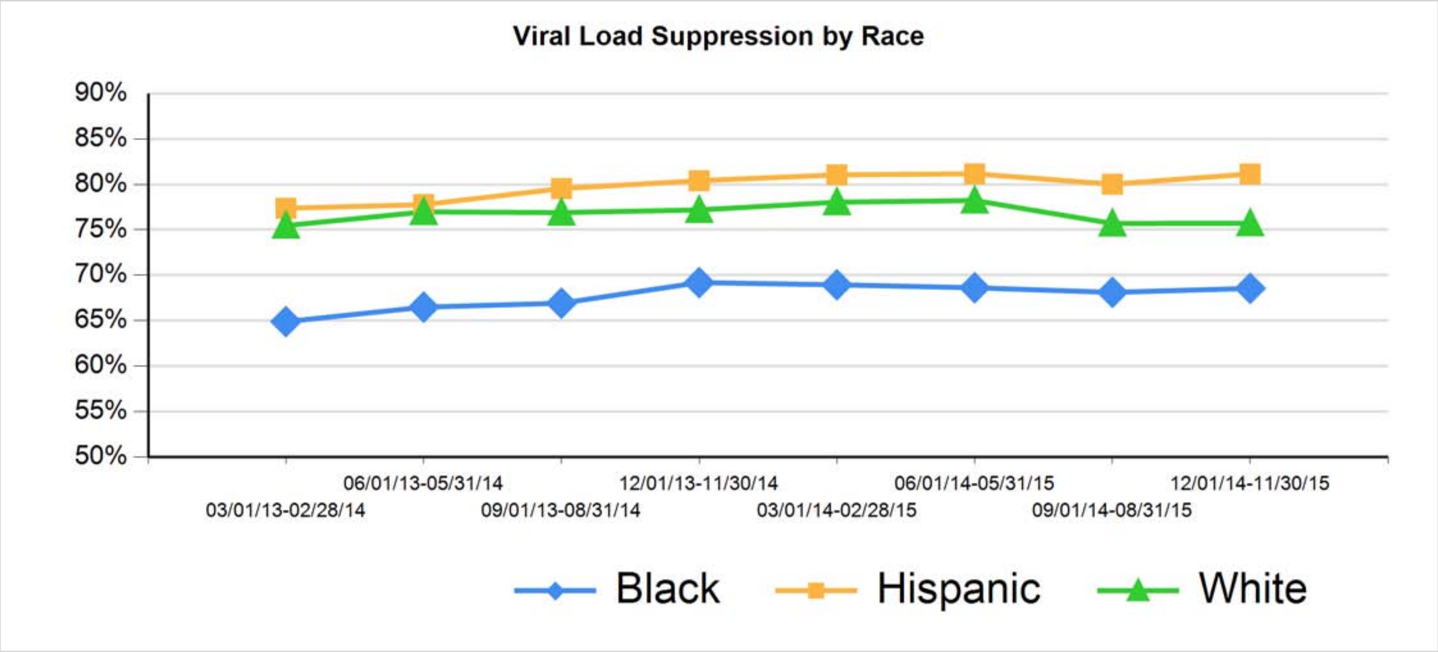


Viral Load Suppression 2- HAB Measure				
	03/01/14 - 02/28/15	06/01/14 - 05/31/15	09/01/14 - 08/31/15	12/01/14 - 11/30/15
Number of HIV-infected clients who have a viral load of <200 copies/ml during the measurement year	5,237	5,241	5,166	5,237
Number of HIV-infected clients who have had at least 1 medical visit with a provider with prescribing privileges	7,024	7,022	7,020	7,059
Percentage	74.6%	74.6%	73.6%	74.2%
Change from Previous Quarter Results	0.1%	0.1%	-1.0%	0.6%



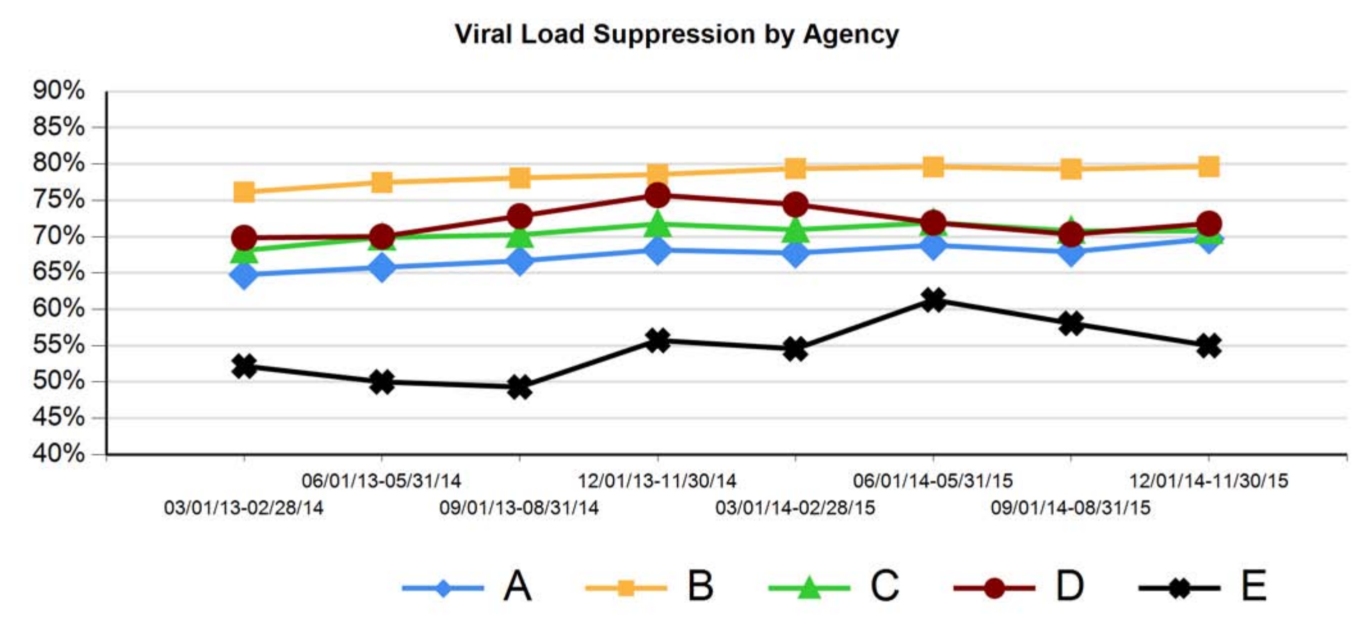
VL Suppression by Race/Ethnicity

	06/01/14 - 05/31/15			09/01/14 - 08/31/15			12/01/14 - 11/30/15		
	Black	Hisp	White	Black	Hisp	White	Black	Hisp	White
Number of HIV-infected clients who have a viral load of <200 copies/ml during the measurement year	2,348	1,995	783	2,332	1,958	769	2,360	2,001	764
Number of HIV-infected clients who have had at least 1 medical visits with a provider with prescribing privileges and have been enrolled in care at least six month	3,422	2,458	1,001	3,424	2,447	1,016	3,443	2,466	1,009
Percentage	68.6%	81.2%	78.2%	68.1%	80.0%	75.7%	68.5%	81.1%	75.7%
Change from Previous Quarter Results	-0.3%	0.1%	0.2%	-0.5%	-1.1%	-2.5%	0.4%	1.1%	0.0%

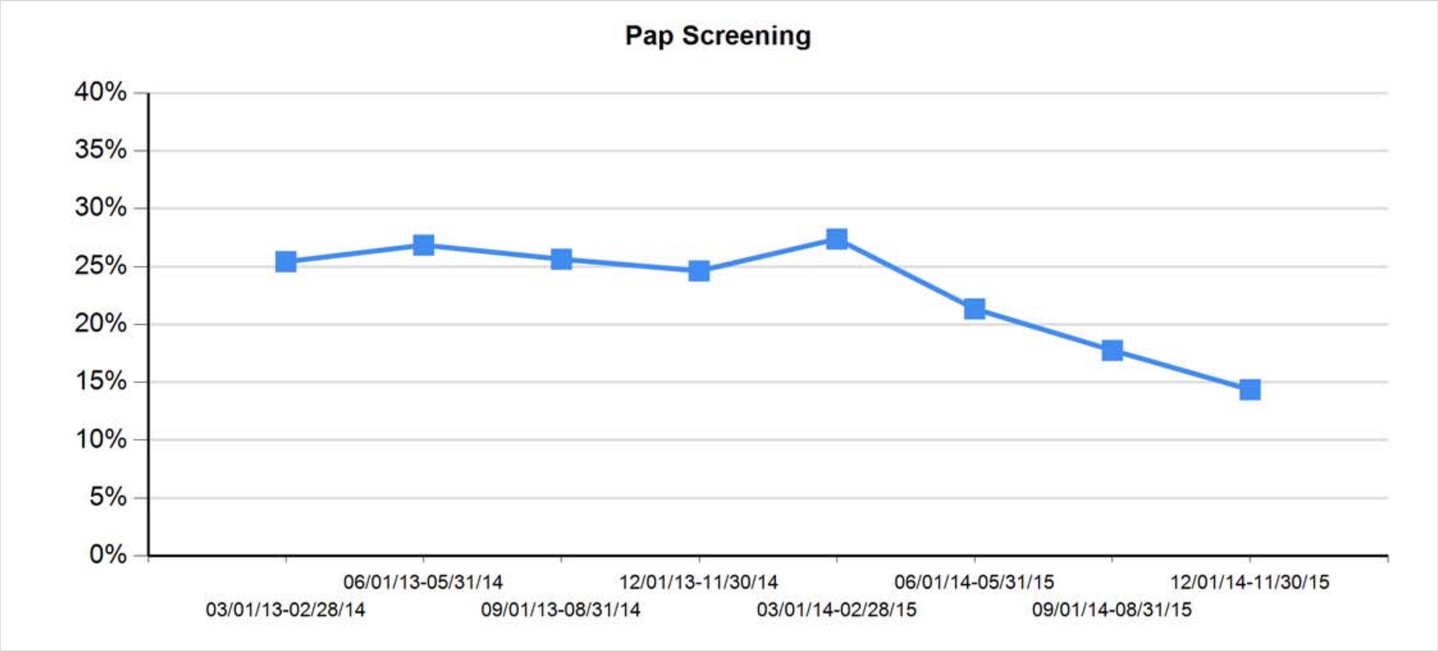


Viral Load Suppression by Agency

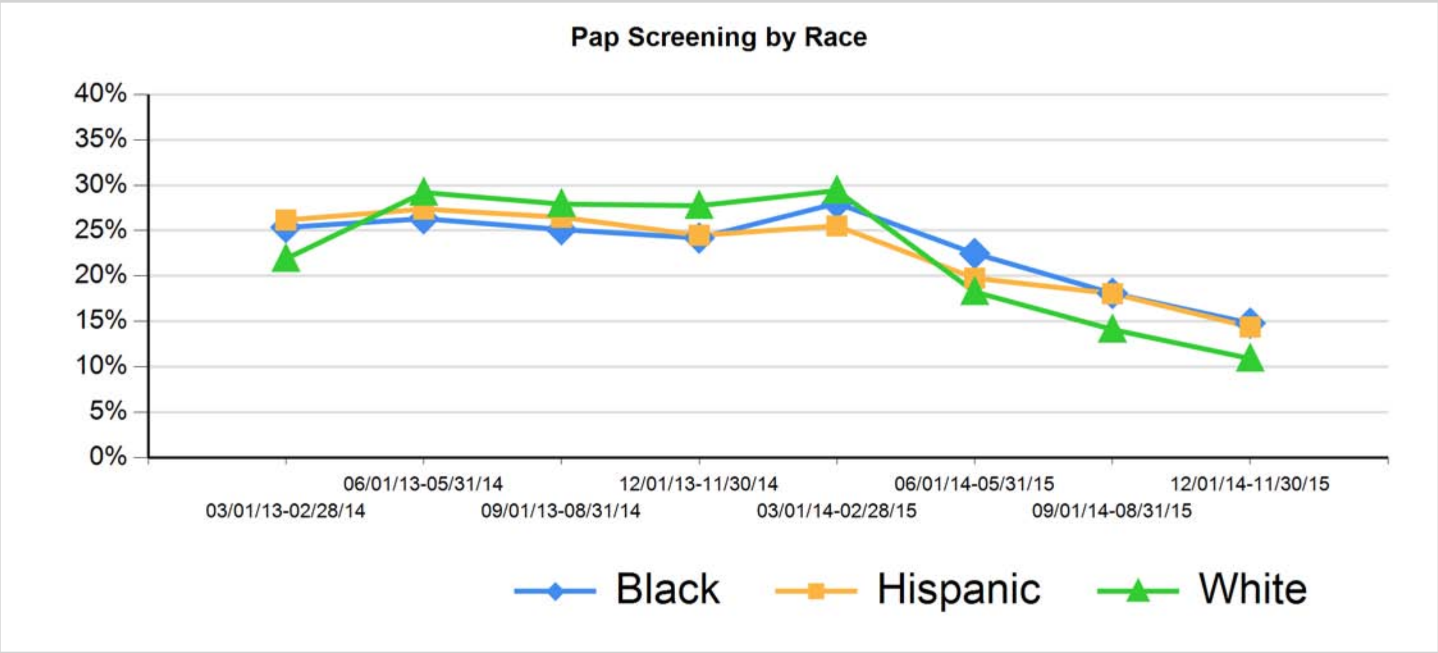
	09/01/14 - 08/31/15					12/01/14 - 11/30/15				
	A	B	C	D	E	A	B	C	D	E
Number of HIV-infected clients who have a viral load of <200 copies/ml during the measurement year	599	2,312	1,383	929	36	603	2,305	1,393	998	33
Number of HIV-infected clients who have had at least 1 medical visits with a provider with prescribing privileges and have been enrolled in care at least six month	882	2,915	1,953	1,321	62	865	2,894	1,968	1,390	60
Percentage	67.9%	79.3%	70.8%	70.3%	58.1%	69.7%	79.6%	70.8%	71.8%	55.0%
Change from Previous Quarter Results	-0.9%	-0.3%	-1.1%	-1.6%	-3.2%	1.8%	0.3%	0.0%	1.5%	-3.1%



Cervical Cancer Screening				
	03/01/14 - 02/28/15	06/01/14 - 05/31/15	09/01/14 - 08/31/15	12/01/14 - 11/30/15
Number of HIV-infected female clients who had Pap screen results documented in the measurement year	505	391	322	260
Number of HIV-infected female clients who had a medical visit with a provider with prescribing privileges at least once in the measurement year	1,844	1,832	1,813	1,811
Percentage	27.4%	21.3%	17.8%	14.4%
Change from Previous Quarter Results	2.8%	-6.0%	-3.6%	-3.4%

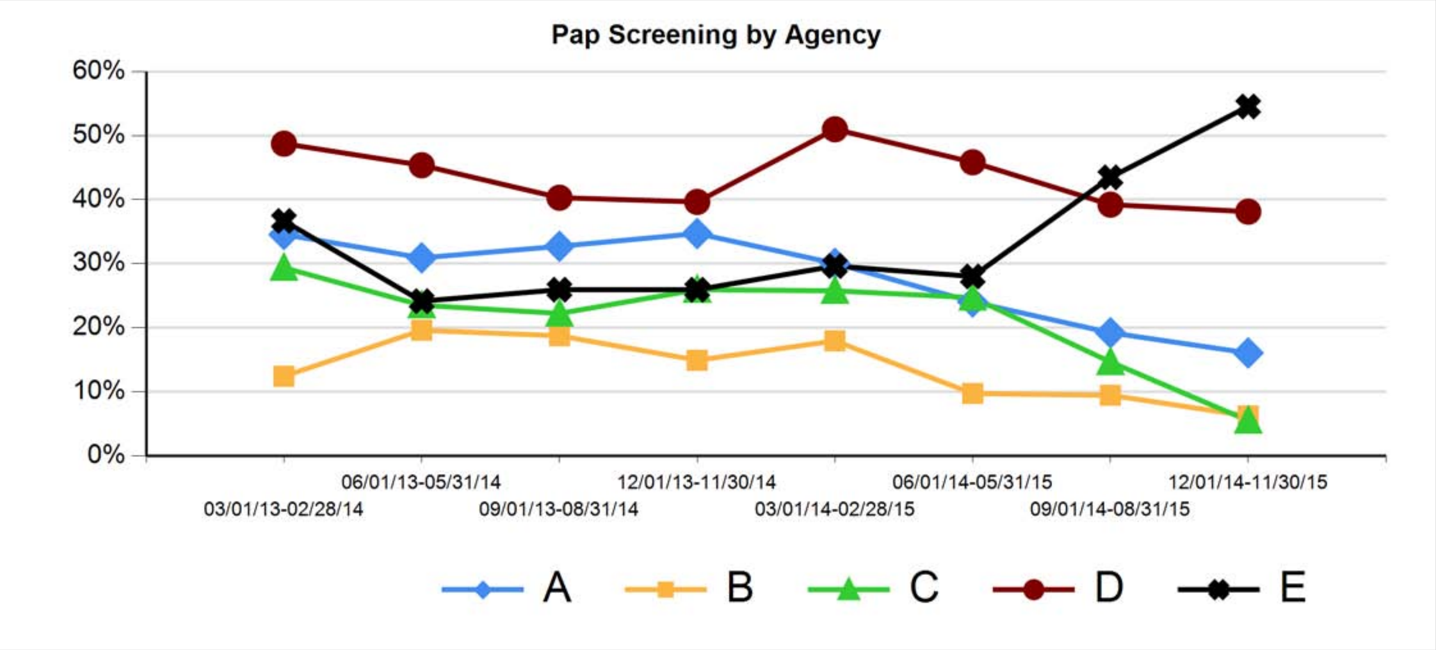


Cervical Cancer Screening Data by Race/Ethnicity									
	06/01/14 - 05/31/15			09/01/14 - 08/31/15			12/01/14 - 11/30/15		
	Black	Hisp	White	Black	Hisp	White	Black	Hisp	White
Number of HIV-infected female clients who had Pap screen results documented in the measurement year	260	99	27	206	89	22	169	70	17
Number of HIV-infected female clients who had a medical visit with a provider with prescribing privileges at least once in the measurement year	1,157	501	148	1,139	493	156	1,142	487	156
Percentage	22.5%	19.8%	18.2%	18.1%	18.1%	14.1%	14.8%	14.4%	10.9%
Change from Previous Quarter Results	-5.5%	-5.7%	-11.2%	-4.4%	-1.7%	-4.1%	-3.3%	-3.7%	-3.2%



Pap Smear Screening by Agency

	09/01/14 - 08/31/15					12/01/14 - 11/30/15				
	A	B	C	D	E	A	B	C	D	E
Number of HIV-infected female clients who had Pap screen results documented in the measurement year	48	84	47	140	10	39	55	17	146	12
Number of HIV-infected female clients who had a medical visit with a provider with prescribing privileges at least once in the measurement year	250	890	321	357	23	243	885	310	383	22
Percentage	19.2%	9.4%	14.6%	39.2%	43.5%	16.0%	6.2%	5.5%	38.1%	54.5%
Change from Previous Quarter Results	-4.8%	-0.3%	-10.0%	-6.6%	15.5%	-3.2%	-3.2%	-9.2%	-1.1%	11.1%



Footnotes:
1. Table/Chart data for this report run was taken from "ABR152 v3.3.1 9/2/15", "ABR076A v1.4.1 10/15/15 [ExcludeVL200=yes]", and "ABR163 v2.0.6 4/25/13"
   A. OPR Measures used for the ABR152 portions: "Viral Load Suppression", "Linked to Care", "CERV", "Medical Visits - 3 months", and "Viral Load Monitoring"

2016 Client Satisfaction Survey Update

A. CLIENT SATISFACTION SURVEY PROCESS OVERVIEW

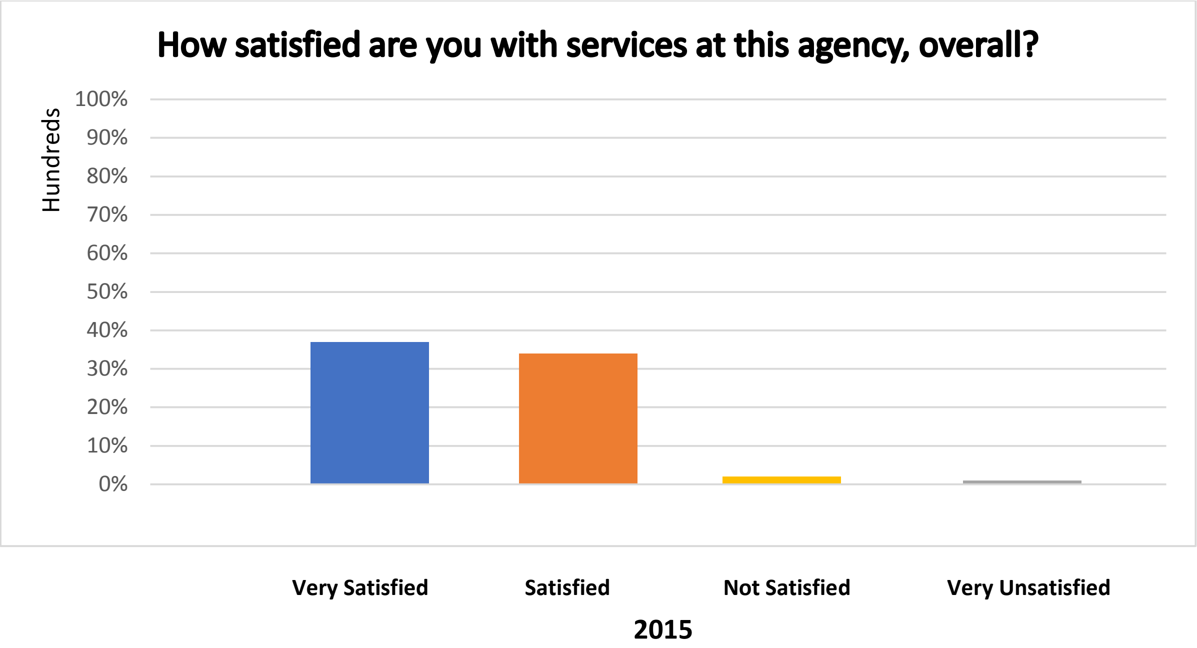
Ryan White Grant Administration has collected client satisfaction data since 2002. Client satisfaction is one method Ryan White Grant Administration uses to measure the quality of Part A funded HIV care delivery in the Houston EMA. Client satisfaction measurement activities in the Houston EMA are designed to assess satisfaction with Part A services, to highlight agency strengths, and to identify areas where clients may have problems with service delivery.

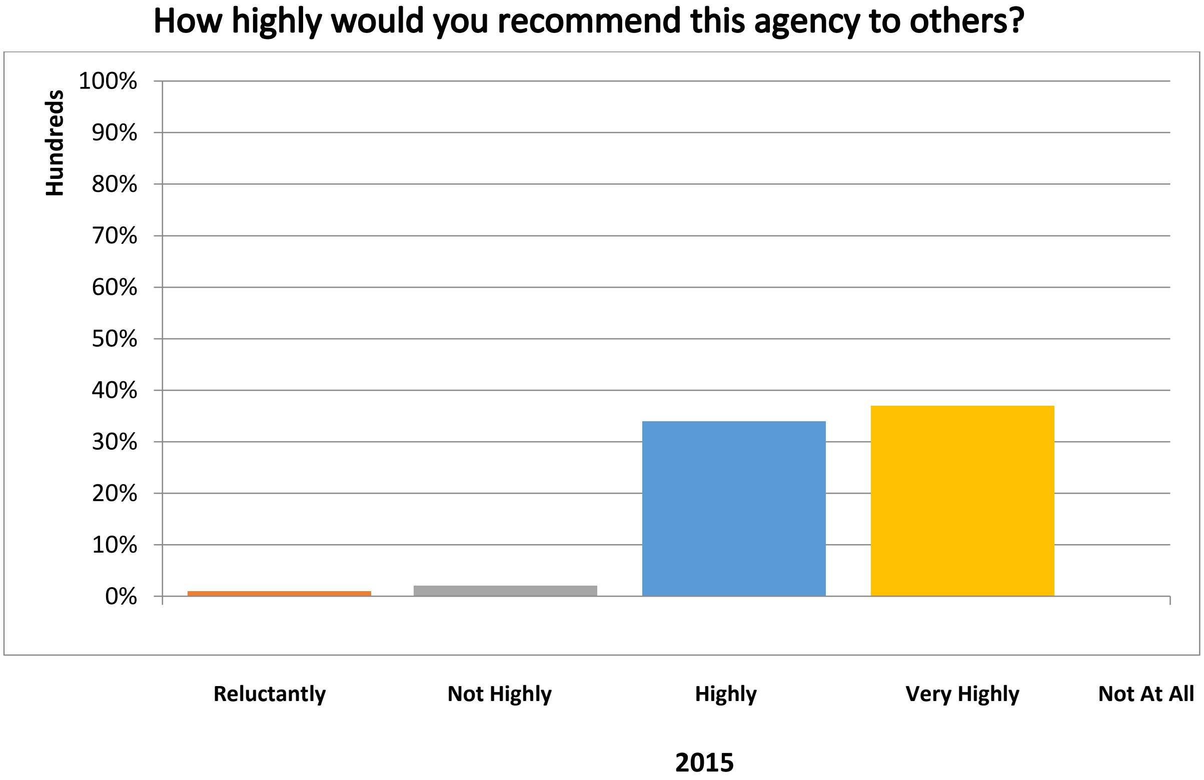
Data are collected using standardized client satisfaction surveys for each service provided through Part A of the Ryan White Program. The survey tools were developed to gather information on both service-specific and agency-focused topics. Each Part A service category utilizes a unique survey tool, with certain agency-focused questions being common to all surveys. This methodology allows for analysis of satisfaction with care using a standardized approach which ensures “apples to apples” comparisons across provider agencies and service areas. This also allows for examination of general trends in satisfaction each year.

In 2008 RWGA introduced the capability to complete online standardized client satisfaction surveys through the CPCDMS by using their unique CPCDMS client code. This addition to the client satisfaction survey process improved accessibility for consumers & was less burdensome for service providers. To encourage consumers to more routinely use this collection method, in 2012 RWGA introduced client incentives in the form of $5 gift cards as a component of our online client satisfaction process.

B. 2014 CLIENT SATISFACTION SURVEY RESULTS

Virtually all agencies are utilizing the online client satisfaction survey, with the exception of City of Houston. RWGA is excited about the renewed interest in the process from providers as well as from clients. RWGA Quality Management Development can provide an update to the Quality Improvement Committee on a bi-monthly basis or as necessary.


How satisfied are you with services at this agency, overall?
Hundreds
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Very Satisfied
Satisfied
Not Satisfied
Very Unsatisfied
2015


How highly would you recommend this agency to others?
Hundreds
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Reluctantly
Not Highly
Highly
Very Highly
Not At All
2015

2016-2017 HOUSTON ELIGIBLE METROPOLITAN AREA: RYAN WHITE CARE ACT PART A/B
STANDARDS OF CARE FOR HIV SERVICES
RYAN WHITE GRANT ADMINISTRATION SECTION
HARRIS COUNTY PUBLIC HEALTH AND ENVIRONMENTAL SERVICES (HCPHES)

TABLE OF CONTENTS

Service Specific Standards

Introduction

According to the Joint Commission on Accreditation of Healthcare Organization (JCAHO) 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, JCAHO 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/B 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, Part B and State Services, funded HRSA defined core and support services including the following services in FY 2015-2016:

- *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
- *Legal Services*
- *Medical Nutrition Supplement*
- *Non-Medical Case Management (Service Linkage)*
- *Transportation*
- Linguistic 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 applicable changes. Workgroup participants include physicians, nurses, case managers and executive staff from subcontractor agencies as well as consumers.

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

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 eight (8) hours HIV/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). Initial training must be completed within 60 days of hire.	• 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	Staff education on eligibility determination and fee schedule 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	Service Evaluation 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	Subcontractor Monitoring 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	Staff Guidelines Agency develops written guidelines for staff, which include, at a minimum, agency-specific policies and procedures (staff selection, resignation and termination process, job 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	<u>Staff Supervision</u> 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	<u>Professional Behavior</u> 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	<u>Communication</u> 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	<u>Accountability</u> There is a system in place to document staff work time.	• Staff time sheets or other documentation indicate compliance
2.9	<u>Staff Availability</u> 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 Agency has a Client Rights and Responsibilities Statement that is reviewed with each client in a language and format the client can understand. Agency will provide 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	• Documentation in client's record
3.2	Confidentiality Agency has Policy and Procedure regarding client confidentiality in accordance with RWGA /TRG 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	Consents 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	Up to date Release of Information 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	• Current Release of Information form with all the required elements signed by client or authorized person in client's record

	• Name of the client • The purpose of the disclosure • 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 • 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.).	• Documentation in client record and in the Centralized Patient Care Data Management System • A copy of written notice and a certified mail receipt for involuntary termination
3.7	Client Closure 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	Client Feedback 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	• Documentation of clients' evaluation of services is maintained • Documentation of CAB and public meeting minutes

	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 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 existence and appropriateness of a suggestion box or other client input mechanism • 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.	• Documentation in client record as per RWGA site visit guidelines or TRG Policy SG-03

	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.	• 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 HIV+ clients 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 TRG Policy SG-06 Documentation of Third Party Payer Eligibility or 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	• 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

	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. 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)	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 • 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 has a written substantiated annual plan to targeted populations • Zip code data show provider is reaching clients throughout service

	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.	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.	• Review of Agency's Policies and Procedures Manual indicates compliance • Documentation of compliance with TRG's Policy SG-19 Client Wait Lists • Documentation that agency notified their Administrative Agency when funds for services were either low or exhausted

	The Agency will notify The Resource Group (TRG) or 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 • Projected date that services will resume. The Agency will report to TRG or 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	<u>Intake</u> 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	<u>Continuous Quality Improvement (CQI)</u> 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	• Review of Agency's Policies and Procedures Manual indicates compliance • Up to date QM Manual • Source Citation: HAB Universal Standards; Section F: #2

	- Work products - QM program evaluation - Materials necessary for QM activities	
5.2	Data Collection and Analysis 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.	- Review of Agency's Policies and Procedures Manual indicates compliance - 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	- Emergency Preparedness Plan - Review of Agency's Policies and Procedures Manual indicates compliance

	response agencies and together shall identify the capability of its community in meeting their needs. The HVA shall be reviewed annually.	
7.2	Emergency Management Training In accordance with the Department of Human Services recommendations, all applicable agency staff must complete the following National Incident 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.	• Documentation of all training including certificate of completion in personnel file
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	<u>Required Permits</u> All agencies will maintain Occupancy and Fire Marshal's permits for the facilities.	- Current required permits on file

SERVICE SPECIFIC STANDARDS OF CARE

Case Management (All Case Management Categories)

Case management services in HIV care facilitate client access to health care services, assist clients to navigate through the wide array of health care programs and ensure coordination of services to meet the unique needs of PLWHA. It also involves client assessment to determine client's needs and the development of individualized service plans in collaboration with the client to mitigate clients' needs. Ryan White Grant Administration funds three case management models i.e. one psychosocial and two clinical/medical models depending on the type of ambulatory service within which the case management service is located. The scope of these three case management models namely, Non-Medical, Clinical and Medical case management services are based on Ryan White HIV/AIDS Treatment Modernization Act of 2006 (HRSA)[2] definition for non-medical and medical case management services. Other resources utilized include the current *National Association of Social Workers (NASW) Standards for Social Work Case Management*[3]. Specific requirements for each of the models are discussed under each case management service category.

1.0	**Staff Training**	
1.1	Required Meetings Case Managers and Service Linkage Workers Case managers and Service Linkage Workers will attend on an annual basis a minimum of four (4) of the five (5) bi-monthly networking meetings facilitated by RWGA. Case Managers and Service Linkage Workers will attend the "Joint Prevention and Care Coordination Meeting" held annually and facilitated by the RWGA and the City of Houston STD/HIV Bureau. Medical Case Management (MCM), Clinical Case Management (CCM) and Service Linkage Worker Supervisors will attend on an annual basis a minimum of five (5) of the six (6) bi-monthly Supervisor meetings facilitated by RWGA (in the event a MCM or CCM supervises SLW staff the MCM or CCM must attend the Supervisor meetings and may, as an option, attend the networking meetings)	• Agency will maintain verification of attendance (RWGA will also maintain sign-in logs)

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[2] US Department of Health and Human Services, Health Resources and Services Administration HIV/AIDS Bureau (2009). Ryan White HIV/AIDS Treatment Modernization Act of 2006: Definitions for eligible services

[3] National Association of Social Workers (1992). NASW standards for social work case management. Retrieved 02/9/2009 from www.socialworkers.org/practice/standards/sw_case_mgmt.asp

1.2	Required Training for New Employees Within the first ninety (90) days of employment in the case management system, case managers will successfully complete HIV Case Management 1012013 Update, through the State of Texas TRAIN website (https://tx.train.org) with a minimum of 70% accuracy. RWGA expects HIV Case Management 1012013 Update, course completion to take no longer than 16 hours. Within the first six (6) months of employment, case managers will complete at least four (4) hours review of Community resources, and at least four (4) hours cultural competency training offered by RWGA. For cultural competency training only, Agency may request a waiver for agency based training alternative that meets or exceeds the RWGA requirements for the first year training for case management staff.	• Certificates of completion for applicable trainings in the case manager's file • Sign-in sheets for agency based trainings maintained by Agency • RWGA Waiver is approved prior to Agency utilizing agency-based training curriculum
1.3	Certified Application Counselor (CAC) Training & Certification Within the first ninety (90) days of employment in the case management system, case managers will successfully complete CAC training and maintain CAC certification by their Certificated Application Counselor Designated Organization employer. RWGA expects CAC training completion to take no longer than 6 hours.	• Certificates of completion in case manager's file
1.4	Case Management Supervisor Peer-led Training Supervisory Training: On an annual basis, Part A/B-funded clinical supervisors of Medical, Clinical and Community (SLW) Case Managers must fully participate in the four (4) Case Management Supervisor Peer-Led three-hour training curriculum conducted by RWGA.	• Review of attendance sign-in sheet indicates compliance
1.5	Child Abuse Screening, Documenting and Reporting Training Case Managers are trained in the agency's policy and procedure for determining, documenting and reporting instances of abuse, sexual or nonsexual, in accordance with the DSHS Child Abuse Screening, Documenting and Reporting Policy prior to patient interaction.	• Documentation of staff training
2.0	**Timeliness of Services**	

2.1	Initial Case Management Contact Contact with client and/or referring agent is attempted within one working day of receiving a case assignment. If the case manager is unable to make contact within one (1) working day, this is documented and explained in the client record. Case manager should also notify their supervisor. All subsequent attempts are documented.	• Documentation in client record
2.2	Acuity The case manager should use an acuity scale or other standardized system as a measurement tool to determine client needs (applies to TDSHS funded case managers only).	• Completed acuity scale in client's records
2.3	Progress Notes All case management 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 their occurrence.	• Legible, signed and dated documentation in client record. • Documentation of time expended with or on behalf of patient in progress notes
2.4	Client Referral and Tracking Agency will have policies and procedures in place for referral and follow-up for clients with medical conditions, nutritional, psychological/social and financial problems. The agency will maintain a current list of agencies that provide primary medical care, prescription medications, assistance with insurance payments, dental care, transportation, nutritional counseling and supplements, support for basic needs (rent, food, financial assistance, etc.) and other supportive services (e.g. legal assistance, partner elicitation services and Client Risk Counseling Services (CRCS). The Case Manager will: • Initiate referrals within two (2) weeks of the plan being completed and agreed upon by the Client and the Case Manager • Work with the Client to determine barriers to referrals and facilitate access to referrals • Utilize a tracking mechanism to monitor completion of all case management referrals	• Review of Agency's Policies and Procedures Manual indicates compliance • Documentation of follow-up tracking activities in clients records • A current list of agencies that provide services including availability of the Blue Book
2.5	Client Notification of Service Provider Turnover	• Documentation in client record

	Client must be provided notice of assigned service provider's cessation of employment within 30 days of the employee's departure.	
2.6	<u>Client Transfers between Agencies: Open or Closed less than One Year</u> The case manager should facilitate the transfer of clients between providers. All clients are transferred in accordance with Case Management Policy and Procedure, which requires that a "consent for transfer and release/exchange of information" form be completed and signed by the client, the client's record be forwarded to the receiving care manager within five (5) working days and a Request for Transfer form be completed for the client and submitted to RWGA by the receiving agency.	• Documentation in client record
2.7	<u>Caseload</u> Case load determination should be based on client characteristics, acuity level and the intensity of case management activities.	• Review of the agency's policies and procedures for Staffing ratios

Clinical Case Management Services

The Ryan White HIV/AIDS Treatment Modernization Act of 2006 defines medical case management as "a range of client-centered services that link clients with health care, psychosocial, and other services" including coordination and follow-up of medical treatment and "adherence counseling to ensure readiness for and adherence to HIV complex treatments". The definition outlines the functions of the medical case manager as including assessments and reassessments, individualized comprehensive service planning, service plan implementation and periodic evaluation, client advocacy and services utilization review. The Ryan White Grant Administration categorizes medical case management services co-located in a Mental Health treatment/counseling and/or Substance Abuse treatment services as Clinical Case Management (CCM) services.

Each Ryan White Part A FTE CCM is expected to serve approximately 150 People with HIV/AIDS (PLWHA) within the contract term. CCM services may be targeted to underserved populations such as Hispanics, African Americans, MSM, etc.

1.0	**Staff Requirements**	
1.1	Minimum Qualifications All clinical case managers must have a current and in good standing State of Texas license (LBSW, LMSW, LCSW, LPC, LPC-I, LMFT, LMFT-A).	• A file will be maintained on each clinical case manager • Supportive documentation of credentials and job description is maintained by the agency in each clinical case manager file. Documentation should include transcripts and/or diplomas and proof of licensure
1.2	Scope of Services The clinical case management services will include at a minimum, comprehensive assessment including mental health and substance abuse/use; development, implementation and evaluation of care plans; follow-up; advocacy; direction of clients through the entire spectrum of health and support services and peer support. Other functions include facilitation and coordination of services from one service provider to another including mental health, substance abuse and primary medical care providers.	• Review of client records indicates compliance • Agency Policy and Procedures indicates compliance
1.3	Ongoing Education/Training for Clinical Case Managers After the first year of employment in the case management system each clinical case manager will obtain the minimum number of hours of	• Certificates of completion are maintained by the agency • Current License on case manager's file

	continuing education to maintain his or her licensure and four (4) hours of training in current Community Resources conducted by RWGA	
2.0	**Timeliness of Services/Documentation**	
2.1	Client Eligibility In addition to the general eligibility criteria, individuals must meet one or more of the following criteria in order to be eligible for clinical case management services: • HIV+ individual in mental health treatment/counseling and/or substance abuse treatment services or HIV+ individual whose history or behavior may indicate the individual may need mental health and/or substance abuse treatment/counseling now or in the future. • Clinical criteria for admission into clinical case management must include one of the following: ➢ Client is actively symptomatic with a DSM (most current, American Psychiatric Association approved) diagnosis, especially including substance-related disorders (abuse/dependence), mood disorders (Bipolar depression), depressive disorders, anxiety disorders, and other psychotic disorders; or DSM (most current, American Psychiatric Association approved) diagnosis personality disorders. ➢ Client has a mental health condition or substance abuse pattern that interferes with his/her ability to adhere to medical/medication regimen and needs motivated to access mental health or substance abuse treatment services. ➢ Client is in mental health counseling or chemical dependency treatment.	• Documentation of HIV+ status, mental health and substance abuse status, residence, identification, and income in the client record
2.2	Discharge/Closure from Clinical Case Management Services In addition to the general requirements, a client may be discharged from clinical case management services for the following reasons. • Client has achieved a sustainable level of stability and independence.	• Documentation in client record.

	- Substance Abuse – Client has successfully completed an outpatient substance abuse treatment program. - Mental Health – Client has successfully accessed and is engaged in mental health treatment and/or has completed mental health treatment plan objectives.	
2. 3	<u>Coordination with Primary Medical Care and Medical Case Management Provider</u> Agency will have policies and procedures in place to ensure effective clinical coordination with Ryan White **Part A/B**-funded Medical Case Management programs. Clinical Case Management services provided to clients accessing primary medical care from a Ryan White **Part A/B**-funded primary medical care provider other than Agency will require Agency and Primary Medical Care/Medical Case Management provider to conduct regular multi-disciplinary case conferences to ensure effective coordination of clinical and psychosocial interventions. Case conferences must at a minimum include the clinical case manager; mental health/counselor and/or medical case manager and occur at least every three (3) months for the duration of Clinical Case Management services. Client refusal to provide consent for the clinical case manager to participate in multi-disciplinary case conferences with their Primary Medical Care provider must be documented in the client record.	- Review of Agency's Policies and Procedures Manual indicates compliance - Case conferences are documented in the client record
2.4	<u>Assessment</u> Assessment begins at intake. The case manager will provide client, and if appropriate, his/her support system information regarding the range of services offered by the case management program during intake/assessment. The comprehensive client assessment will include an evaluation of the client's medical and psychosocial needs, strengths, resources (including financial and medical coverage status), limitations, beliefs, concerns and projected barriers to service. Other areas of assessment include demographic information, health history, sexual history, mental history/status, substance abuse history, medication adherence and risk	- Documentation in client record on the comprehensive client assessment form, signed and dated, or agency's equivalent form. Updates to the information included in the assessment will be recorded in the comprehensive client assessment. - A completed DSHS checklist for screening of suspected sexual child abuse and reporting is evident in case management records, when appropriate

	behavior practices, adult and child abuse (if applicable). A RWGA-approved comprehensive client assessment form must be completed within two weeks after initial contact. Clinical Case Management will use a RWGA-approved assessment tool. This tool may include Agency specific enhancements tailored to Agency's Mental Health and/or Substance Abuse treatment program(s).	
2.5	Reassessment Clients will be reassessed at six (6) month intervals following the initial assessment or more often if clinically indicated including when unanticipated events or major changes occur in the client's life (e.g. needing referral for services from other providers, increased risk behaviors, recent hospitalization, suspected child abuse, significant changes in income and/or loss of psychosocial support system). A RWGA or TRG -approved reassessment form as applicable must be utilized.	• Documentation in client record on the comprehensive client reassessment form or agency's equivalent form signed and dated • Documentation of initial and updated service plans in the URS (applies to TDSHS – funded case managers only)
2.6	Service Plan Service planning begins at admission to clinical case management services and is based upon assessment. The clinical case manager shall develop the service plan in collaboration with the client and if appropriate, other members of the support system. An RWGA-approved service plan form will be completed no later than ten (10) working days following the comprehensive client assessment. A temporary care plan may be executed upon intake based upon immediate needs or concerns). The service plan will seek timely resolution to crises, short-term and long-term needs, and may document crisis intervention and/or short term needs met before full service plan is completed. Service plans reflect the needs and choices of the client based on their health and related needs (including support services) and are consistent with the progress notes. A new service plan is completed at each six (6) month reassessment or each reassessment. The case manager and client will update the care plan upon achievement of goals and when other issues or goals are identified and reassessed. Service plan must reflect an ongoing discussion of primary care,	• Documentation in client record on the clinical case management service plan or agency's equivalent form • Service plan signed by client and the case manager

	mental health treatment and/or substance abuse treatment, treatment and medication adherence and other client education per client need.	
3.0	**Supervision and Caseload**	
3.1	Clinical Supervision and Caseload Coverage The clinical case manager must receive supervision in accordance with their licensure requirements. Agency policies and procedures should account for clinical supervision and coverage of caseload in the absence of the clinical case manager or when the position is vacant.	• Review of the agency's Policies and Procedures for clinical supervision, and documentation of supervisor qualifications in personnel files. • Documentation on file of date of supervision, type of supervision (e.g., group, one on one), and the content of the supervision

Non-Medical Case Management Services (Service Linkage Worker)

Non-medical case management services (Service Linkage Worker (SLW) is co-located in ambulatory/outpatient medical care centers. HRSA defines Non-Medical case management services as the "provision of advice and assistance in obtaining medical, social, community, legal, financial, and other needed services" and does not include coordination and follow-up of medical treatment. The Ryan White Part A/B SLW provides services to clients who do not require intensive case management services and these include the provision of information, referrals and assistance with linkage to medical, 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 to develop and utilize independent living skills and strategies.

1.0	**Staff Requirements**	
1.1	<u>Minimum Qualifications</u> Service Linkage Worker – unlicensed community case manager Service linkage workers must have a bachelor's degree from an accredited college or university with a major in social or behavioral sciences. Documented paid work experience in providing client services to PLWHA may be substituted for the bachelor's degree requirement on a 1:1 basis (1 year of documented paid experience may be substituted for 1 year of college). Service linkage workers must have a minimum of 1 year paid work experience with PLWHA. Bilingual (English/Spanish) targeted service linkage workers must have written and verbal fluency in English and Spanish. Agency will provide Service Linkage Worker a written job description upon hiring.	• A file will be maintained on service linkage worker. Supportive documentation of credentials and job description are maintained by the agency and in each service linkage worker's file. Documentation may include, but is not limited to, transcripts, diplomas, certifications and/or licensure.
2.0	**Timeliness of Services/Documentation**	
2.1	<u>Client Eligibility – Service Linkage targeted to Not-in-Care and Newly Diagnosed (COH Only)</u> In addition to general eligibility criteria individuals must meet the following in order to be eligible for non-medical case management services: • HIV+ and not receiving outpatient HIV primary medical care services within the previous 180 days as documented by the CPCDMS, or	• Documentation of HIV+ status, residence, identification and income in the client record • Documentation of "not in care" status through the CPCDMS

	- Newly diagnosed (within the last six (6) months) and not currently receiving outpatient HIV primary medical care services as documented by the CPCDMS, or - Newly diagnosed (within the last six (6) months) and not currently receiving case management services as documented by the CPCDMS	
2.2	Service Linkage Worker Assessment Assessment begins at intake. The service linkage worker will provide client and, if appropriate, his/her personal support system information regarding the range of services offered by the case management program during intake/assessment. The service linkage worker will complete RWGA -approved brief assessment tool within five (5) working days, on all clients to identify those who need comprehensive assessment. Clients with mental health, substance abuse and/or housings issues should receive comprehensive assessment. Clients needing comprehensive assessment should be referred to a licensed case manager. **Low-need, non-primary care clients who have only an intermittent need for information about services may receive brief SLW services without being placed on open status**.	- Documentation in client record on the brief assessment form, signed and dated - A completed DSHS checklist for screening of suspected sexual child abuse and reporting is evident in case management records, when appropriate
2.3	Service Linkage Worker Reassessment Clients on **open status** will be reassessed at six (6) month intervals following the initial assessment. A RWGA/ TRG-approved reassessment form as applicable must be utilized.	- Documentation in RWGA approved client reassessment form or agency's equivalent form, signed and dated
2.4	Transfer of Not-in-Care and Newly Diagnosed Clients (COH Only) Service linkage workers targeting their services to Not-in-Care and newly diagnosed clients will work with clients for a maximum of 90 days. Clients must be transferred to a Ryan White-funded primary medical care, clinical case management or medical case management program, or a private (non-Ryan White funded) physician within 90 days of the initiation of services.	- Documentation in client record and in the CPCDMS

	Those clients who chose to access primary medical care from a non-Ryan White funded source may receive ongoing service linkage services from provider or from a Ryan White-funded Clinic or Medical Case Management provider.	
2.5	<u>Primary Care Newly Diagnosed and Lost to Care Clients</u> Agency must have a written policy and procedures in place that address the role of Service Linkage Workers in the linking and re-engaging of clients into primary medical care. The policy and procedures must include at minimum: • Methods of routine communication with testing sites regarding newly diagnosis and referred individuals • Description of service linkage worker job duties conducted in the field • Process for re-engaging agency patients lost to care (no primary care visit in 6 months)	• Review of Agency's Policies and Procedures Manual indicates compliance.
3.0	**Supervision and Caseload**	
3.1	<u>Service Linkage Worker Supervision</u> A minimum of four (4) hours of supervision per month must be provided to each service linkage worker by a master's level health professional.) At least one (1) hour of supervision must be individual supervision. Supervision includes, but is not limited to, one-to-one consultation regarding issues that arise in the case management 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 ➢ name(s) of case manager(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	<u>Caseload Coverage – Service Linkage Workers</u> Supervisor ensures that there is coverage of the caseload in the absence of the service linkage worker or when the position is vacant. Service Linkage Workers may assist clients who are routinely seen by other CM team members in the absence of the client's "assigned" case manager.	• Documentation of all client encounters in client record and in the Centralized Patient Care Data Management System

3.3	<u>Case Reviews – Service Linkage Workers.</u> Supervisor reviews a random sample equal to 10% of unduplicated clients served by each service linkage worker at least once every ninety (90) days, and concurrently ensures that all required record components are present, timely, legible, and that services provided are appropriate.	• Documentation of case reviews in client record, signed and dated by supervisor and/or quality assurance personnel and SLW

Medical Case Management

Similarly to nonmedical case management services, medical case management (MCM) services are co-located in ambulatory/outpatient medical care centers (see clinical case management for HRSA definition of medical case management services). The Houston RWPA/B medical case management visit includes assessment, education and consultation by a licensed social worker within a system of information, referral, case management, and/or social services and includes social services/case coordination,”. In addition to general eligibility criteria for case management services, providers are required to screen clients for complex medical and psychosocial issues that will require medical case management services (see MCM SOC 2.1).

1.0	**Staff/Training**	
1.1	Qualifications/Training Minimum Qualifications - The program must utilize a Social Worker licensed by the State of Texas to provide Medical Case Management Services. A file will be maintained on each medical case manager. Supportive documentation of medical case manager credentials is maintained by the agency and in each medical case manager’s file. Documentation may include, but is not limited to, transcripts, diplomas, certifications, and/or licensure.	• Documentation of credentials and job description in medical case manager’s file
1.2	Scope of Services The medical case management services will include at a minimum, screening of primary medical care patients to determine each patient’s level of need for medical case management; comprehensive assessment, development, implementation and evaluation of medical case management service plan; follow-up; direction of clients through the entire spectrum of health and support services; facilitation and coordination of services from one service provider to another. Others include referral to clinical case management if indicated, client education regarding wellness, medication and health care compliance and peer support.	• Review of clients’ records indicates compliance
1.3	Ongoing Education/Training for Medical Case Managers After the first year of employment in the case management system each medical case manager will obtain the minimum number of hours of continuing education to maintain his or her licensure.	• Attendance sign-in sheets and/or certificates of completion are maintained by the agency

2.0	**Timeliness of Service/Documentation** Medical case management for persons with RWGA disease should reflect competence and experience in the assessment of client medical need and the development and monitoring of medical service delivery plans.	
2.1	<u>Screening Criteria for Medical Case Management</u> In addition to the general eligibility criteria, agencies are advised to use screening criteria before enrolling a client in medical case management. Examples of such criteria include the following: i. Newly diagnosed ii. New to ART iii. CD4<200 iv. VL>100,000 or fluctuating viral loads v. Excessive missed appointments vi. Excessive missed dosages of medications vii. Mental illness that presents a barrier to the patient's ability to access, comply or adhere to medical treatment viii. Substance abuse that presents a barrier to the patient's ability to access, comply or adhere to medical treatment ix. Housing issues x. Opportunistic infections xi. Unmanaged chronic health problems/injury/Pain xii. Lack of viral suppression xiii. Positive screening for intimate partner violence xiv. Clinician's referral Clients with one or more of these criteria would indicate need for medical case management services. Clients enrolling in medical case management services should be placed on "open" status in the CPCDMS. The following criteria are an indication a client may be an appropriate referral for Clinical Case Management services. • Client is actively symptomatic with an axis I DSM (most current, American Psychiatric Association approved) diagnosis especially including substance-related disorders (abuse/dependence), mood disorders (major depression, Bipolar depression), anxiety disorders, and other	• Review of agency's screening criteria for medical case management

	psychotic disorders; or axis II DSM (most current, American Psychiatric Association approved) diagnosis personality disorders; - Client has a mental health condition or substance abuse pattern that interferes with his/her ability to adhere to medical/medication regimen and needs motivated to access mental health or substance abuse treatment services; - Client is in mental health counseling or chemical dependency treatment.	
2.2	<u>Assessment</u> Assessment begins at intake. The case manager will provide client, and if appropriate, his/her support system information regarding the range of services offered by the case management program during intake/assessment. <u>Medical case managers will provide a comprehensive assessment at intake and at least annually thereafter</u>. The comprehensive client assessment will include an evaluation of the client's medical and psychosocial needs, strengths, resources (including financial and medical coverage status), limitations, beliefs, concerns and projected barriers to service. Other areas of assessment include demographic information, health history, sexual history, mental history/status, substance abuse history, medication adherence and risk behavior practices, adult and child abuse (if applicable). A RWGA-approved comprehensive client assessment form must be completed within two weeks after initial contact. Medical Case Management will use an RWGA-approved assessment tool. This tool may include Agency specific enhancements tailored to Agency's program needs.	- Documentation in client record on the comprehensive client assessment forms, signed and dated, or agency's equivalent forms. Updates to the information included in the assessment will be recorded in the comprehensive client assessment. - A completed DSHS checklist for screening of suspected sexual child abuse and reporting is evident in case management records, when appropriate.
2.3	<u>Reassessment</u> Clients will be reassessed at six (6) month intervals following the initial assessment or more often if clinically indicated including when unanticipated events or major changes occur in the client's life (e.g. needing referral for services from other providers, increased	- Documentation in client record on the comprehensive client reassessment form or agency's equivalent form signed and dated

	risk behaviors, recent hospitalization, suspected child abuse, significant changes in income and/or loss of psychosocial support system). A RWGA or TRG -approved reassessment form as applicable must be utilized.	• Documentation of initial and updated service plans in the URS (applies to TDSHS –funded case managers only)
2.4	Service Plan Service planning begins at admission to medical case management services and is based upon assessment. The medical case manager shall develop the service plan in collaboration with the client and if appropriate, other members of the support system. An RWGA-approved service plan form will be completed no later than ten (10) working days following the comprehensive client assessment. A temporary care plan may be executed upon intake based upon immediate needs or concerns). The service plan will seek timely resolution to crises, short-term and long-term needs, and may document crisis intervention and/or short term needs met before full service plan is completed. Service plans reflect the needs and choices of the client based on their health and related needs (including support services) and are consistent with the progress notes. A new service plan is completed at each six (6) month reassessment or each reassessment. The case manager and client will update the care plan upon achievement of goals and when other issues or goals are identified and reassessed. Service plan must reflect an ongoing discussion of primary care, mental health treatment and/or substance abuse treatment, treatment and medication adherence and other client education per client need.	• Documentation in client's record on the medical case management service plan or agency's equivalent form • Service Plan signed by the client and the case manager
2.5	Brief Interventions Clients who are not appropriate for medical case management services may still receive brief interventions. In lieu of completing the comprehensive client re-assessment, the medical case manager should complete the brief re-assessment and service plan and document in the progress notes. Any referrals made should be documented, including their outcomes in the progress notes.	• Documentation in the progress notes reflects a brief re-assessment and plan (referral) • Documentation in client record on the brief re-assessment form • Documentation of referrals and their outcomes in the progress notes • Documentation of brief interventions in the progress notes.
3.0	**Supervision and Caseload**	

3.1	Clinical Supervision and Caseload Coverage The medical case manager must receive supervision in accordance with their licensure requirements. Agency policies and procedures should account for clinical supervision and coverage of caseload in the absence of the medical case manager or when the position is vacant.	• Review of the agency's Policies and Procedures for clinical supervision, and documentation of supervisor qualifications in personnel files. • Documentation on file of date of supervision, type of supervision (e.g., group, one on one), and the content of the supervision

Local Pharmacy Assistance Program

The Local Pharmacy Assistance Programs (LPAP) are co-located in ambulatory medical care centers and provide HIV/AIDS and HIV-related pharmaceutical services to clients who are not eligible for medications through private insurance, Medicaid/Medicare, State ADAP, State SPAP or other sources. HRSA requirements for LPAP include a client enrollment process, uniform benefits for all enrolled clients, a record system for dispensed medications and a drug distribution system.

1.0	**Services are offered in such a way as to overcome barriers to access and utilization. Service is easily accessible to persons with HIV/AIDS.**	
1.1	Client Eligibility In addition to the general eligibility criteria individuals must meet the following in order to be eligible for LPAP services: • Income no greater than 500% of the Federal poverty level for HIV medications and no greater than 300% of the Federal poverty level for HIV-related medications	• Documentation of income in the client record.
1.2	Timeliness of Service Provision • Agency will process prescription for approval within two (2) business days • Pharmacy will fill prescription within one (1) business day of approval	• Documentation in the client record and review of pharmacy summary sheets • Review of agency's Policies & Procedures Manual indicates compliance
1.3	LPAP Medication Formulary RW funded prescriptions for program eligible clients shall be based on the current RWGA LPAP medication formulary. Ryan White funds may not be used for non-prescription medications or drugs not on the approved formulary. Providers wishing to prescribe other medications not on the formulary must obtain a waiver from the RWGA prior to doing so. Agency policies and procedures must ensure that MDs and physician extenders comply with the current clinical/Public Health Services guidelines for ART and treatment of opportunistic infections.	• Review of agency's Policies & Procedures Manual indicates compliance • Review of billing history indicates compliance • Documentation in client's record
2.0	**Staff HIV/AIDS knowledge is based on documented training.**	

2.1	Orientation Initial orientation includes twelve (12) hours of HIV/AIDS basics, confidentiality issues, role of new staff and agency-specific information within sixty (60) days of contract start date or hires date.	• Review of training curriculum indicates compliance • Documentation of all training in personnel file • Specific training requirements are specified in the staff guidelines
2.2	Ongoing Training Eight (8) hours annually of continuing education in HIV/AIDS related or medication/pharmacy – related topics is required for pharmacist and pharmacy tech staff.	• Materials for staff training and continuing education are on file • Staff interviews indicate compliance
2.3	Pharmacy Staff Experience A minimum of one year documented HIV/AIDS work experience is preferred.	• Documentation of work experience in personnel file
2.4	Pharmacy Staff Supervision Staff will receive at least two (2) hours of supervision per month to include client care, job performance and skill development.	• Review of personnel files indicates compliance • Review of agency's Policies & Procedures Manual indicates compliance • Review of documentation which includes, date of supervision, contents of discussion, duration of supervision and signatures of supervisor and all staff present

Primary Medical Care

The 2006 CARE Act defines Primary Medical Services as the “provision of professional diagnostic and therapeutic services rendered by a physician, physician’s assistant, clinical nurse specialist, nurse specialist, nurse practitioner or other health care professional who is certified in their jurisdiction to prescribe Antiretroviral (ARV) therapy in an outpatient setting….. Services include diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history tasking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, education and counseling on health issues, well-baby care, continuing care and management of chronic conditions and referral to and provisions of specialty care”.

The RW Part A primary care visit consist of a client examination by a qualified Medical Doctor, Nurse Practitioner, Clinical Nurse Specialist and/or Physician Assistant and includes all ancillary services such as eligibility screening, patient medication/treatment education, adherence education, counseling and support; medication access/linkage; and as clinically indicated, OB/GYN specialty procedures, nutritional counseling, routine laboratory and radiology. All primary care services must be provided in accordance with the current U.S. Department of Health and Human Services guidelines (HHS)

1.0	**Medical Care for persons with HIV disease should reflect competence and experience in both primary care and therapeutics known to be effective in the treatment of HIV infection and is consistent with the most current published HHS treatment guidelines**	
1.1	Minimum Qualifications Medical care for HIV infected persons shall be provided by MD, NP, CNS or PA licensed in the State of Texas and has at least two years paid experience in HIV/AIDS care including fellowship.	• Credentials on file
1.2	Licensing, Knowledge, Skills and Experience • All staff maintain current organizational licensure (and/or applicable certification) and professional licensure • The agency must keep professional licensure of all staff providing clinical services including physicians, nurses, social workers, etc. • Supervising/attending physicians of the practice show continuous professional development through the following HRSA recommendations for HIV-qualified physicians (www.hivma.org): • Clinical management of at least 25 HIV-infected patients within the last year	• Documentation in personnel record

	- Maintain a minimum of 15 hours of HIV-specific CME (including a minimum of 5 hours related to antiretroviral therapy) per year. Agencies using contractors must ensure that this requirement is met and must provide evidence at the annual program monitoring site visits. - Physician extenders must obtain this experience within six months of hire - All staff receive professional supervision - Staff show training and/or experience with the medical care of adults with HIV	
1.3	Peer Review Agency/Provider will conduct peer review for all levels of licensed/credentialed providers (i.e. MD, NP, PA).	- Provider will document peer review has occurred annually
1.4	**Standing Delegation Orders (SDO)** Standing delegation orders provide direction to RNs, LVNs and, when applicable, Medical Assistants in supporting management of patients seen by a physician. Standing Delegation Orders must adhere to Texas Administrative Code, Title 22, Part 9; Chapter 193; Rule §193.1 and. must be congruent with the requirements specified by the Board of Nursing (BON) and Texas State Board of Medical Examiners (TSBME).	- Standing Delegation Orders for a specific population shall be approved by the Medical Director for the agency or provider. - Standing Delegation Orders will be reviewed , updated as needed and signed by the physician annually. - Use of standing delegation orders will be documented in patient's primary record system.
1.5	Primary Care Guidelines Primary medical care must be provided in accordance with the most current published U.S. HHS treatment guidelines (**http://www.aidsinfo.nih.gov/guidelines/**).	- Documentation in client’s record - Exceptions noted in client’s record
1.6	Medical Evaluation/Assessment All HIV infected clients receiving medical care shall have an initial comprehensive medical evaluation/assessment and physical examination. The comprehensive assessment/evaluation will be completed by the MD, NP, CNS or PA in accordance with professional and established HIV practice guidelines (www.hivma.org) within 3 weeks of initial contact with the client.	- Completed assessment in client’s record

	A comprehensive reassessment shall be completed on an annual basis or when clinically indicated. The initial assessment and reassessment shall include at a minimum, general medical history, a comprehensive HIV related history and a comprehensive physical examination. Comprehensive HIV related history shall include: • Psychosocial history • HIV treatment history and staging • Most recent CD4 counts and VL test results • Resistance testing and co receptor tropism assays as clinically indicated • Medication adherence history • History of HIV related illness and infections • History of Tuberculosis • History of Hepatitis and vaccines • Psychiatric history • Transfusion/blood products history • Past medical care • Sexual history • Substance abuse history • Review of Systems	
1.7	<u>Medical Records</u> Medical Records should clearly document the following components, separate from progress notes: • A central "Problems List" which clearly prioritizes problems for primary care management, including mental health and substance use/abuse disorders (if applicable) • A vaccination record, including dates administered • The status of routine screening procedures (i.e., pap smears, mammograms, colonoscopies)	• Documentation in client's record
1.8	<u>Plan of Care</u>	• Plan of Care documented in client's record

	A plan of care shall be developed for each identified problem and should address diagnostic, therapeutic and educational issues in accordance with the current U.S. HHS treatment guidelines.	
1.9	Follow- Up Visits All patients shall have follow –up visits every three to six months or as clinically indicated for treatment monitoring and also to detect any changes in the client's HIV status. At each clinic visit the provider will at a minimum: • Measure vital signs including height and weight • Perform physical examination and update client history • Measure CBC, CD4 and VL levels every 3-6 months or in accordance with current treatment guidelines, • Evaluate need for ART • Resistance Testing if clinical indicated • Evaluate need for prophylaxis of opportunistic infections • Document current therapies on all clients receiving treatment or assess and reinforce adherence with the treatment plan • Update problem list • Refer client for ophthalmic examination by an ophthalmologist every six months when CD4 count falls below 50CU/MM • Refer Client for dental evaluation or care every 12 months • Incorporate HIV prevention strategies into medical care for of persons living with HIV • Screen for risk behaviors and provide education on risk reduction • Assess client comprehension of treatment plan and provide education/referral as indicated • Refer for other clinical and social services where indicated	• Content of Follow-up documented in client's record • Documentation of specialist referral including dental in client's records
1.10	Yearly Surveillance Monitoring and Vaccinations • All HIV–infected women should have regular pap tests	• Documentation in client's record

	➢ An initial negative pap test should be followed with another pap test in 6-12 months and if negative, annually thereafter. ➢ If 3 consecutive pap tests are normal, follow-up pap tests should be done every 3 years ➢ Women 30 years old and older may have pap test and HPV co-testing, and if normal, repeated every 3 years ➢ A pap test showing abnormal results should be managed per guidelines • Screening for anal cancer, if indicated • Resistance Testing if clinical indicated • Chem. panel with LFT and renal function test • Influenza vaccination • Annual Mental Health Screening with standardized tool • TST or IGRA (this should be done in accordance with current U.S Public Health Service guidelines (US Public Health Service, Infectious Diseases Society of America. *Guidelines for preventing opportunistic infections among HIV-infected persons*) (Available at aidsinfo.nih.gov/Guidelines/) • Annual STD testing including syphilis, gonorrhea and Chlamydia for those at risk, or more frequently as clinically indicated	
1.11	Preconception Care for HIV Infected Women of Child Bearing Age In accordance with the US Department of Health and Human Services recommendations (http://aidsinfo.nih.gov/contentfiles/PerinatalGL.pdf), preconception care shall be a component of routine primary care for HIV infected women of child bearing age and should include preconception counseling. In addition to the general components of preconception counseling, health care providers should, at a minimum: • Assess women's pregnancy intentions on an ongoing basis and discuss reproductive options • Offer effective and appropriate contraceptive methods to women who wish to prevent unintended pregnancy	• Documentation of preconception counseling and care at initial visit and annual updates in Client's record as applicable

	• Counsel on safe sexual practices • Counsel on eliminating of alcohol, illicit drugs and smoking • Educate and counsel on risk factors for perinatal HIV transmission, strategies to reduce those risks, and prevention and potential effects of HIV and treatment on pregnancy course and outcomes • Inform women of interventions to prevent sexual transmission of HIV when attempting conception with an HIV-uninfected partner Other preconception care consideration should include: • The choice of appropriate antiretroviral therapy effective in treating maternal disease with no teratogenicity or toxicity should pregnancy occur • Maximum suppression of viral load prior to conception	
1.12	<u>Obstetrical Care for HIV Infected Pregnant Women</u> Obstetrical care for HIV infected pregnant women shall be provided by board certified obstetrician experienced in the management of high risk pregnancy and has at least two years experience in the care of HIV infected pregnant women. Antiretroviral therapy during ante partum, perinatal and postpartum should be based on the current HHS guidelines <u>http://www.aidsinfo.nih.gov/Guidelines</u>.	• Documentation in client's record
1.13	<u>Coordination of Services in Prenatal Care</u> To ensure adherence to treatment, agency must ensure coordination of services among prenatal care providers, primary care and HIV specialty care providers, mental health and substance abuse treatment services and public assistance programs as needed.	• Documentation in client's records.
1.14	<u>Care of HIV-Exposed and HIV- Infected Infants, Children and Pre-pubertal Adolescents</u> Care and monitoring of HIV-exposed children must be done in accordance to the HHS guidelines. Treatment of HIV infected infants and children should be managed by a specialist in pediatric and adolescent HIV infection. Where this is not possible, primary care providers must consult with such specialist. Providers must utilize current HHS Guidelines for the Use	• Documentation in client's record

	of Antiretroviral Agents in Pediatric HIV Infection (http://aidsinfo.nih.gov/contentfiles/PediatricGuidelines.pdf) in providing and monitoring antiretroviral therapy in infants, children and pre pubertal adolescents. Patients should also be monitored for growth and development, drug toxicities, neurodevelopment, nutrition and symptoms management. A multidisciplinary team approach must be utilized in meeting clients' need and team should consist of physicians, nurses, case managers, pharmacists, nutritionists, dentists, psychologists and outreach workers.	
1.15	Patient Medication Education All clients must receive comprehensive documented education regarding their most current prescribed medication regimen. Medication education must include the following topics, which should be discussed and then documented in the patient record: the names, actions and purposes of all medications in the patient's regimen; the dosage schedule; food requirements, if any; side effects; drug interactions; and adherence. Patients must be informed of the following: how to pick up medications; how to get refills; and what to do and who to call when having problems taking medications as prescribed. Medication education must also include patient's return demonstration of the most current prescribed medication regimen. The program must utilize an RN, LVN, PA, NP, CNS, pharmacist or MD licensed by the State of Texas, who has at least one year paid experience in HIV/AIDS care, to provide the educational services.	• Documentation in the patient record. Documentation in patient record must include the clinic name; the session date and length; the patient's name, patient's ID number, or patient representative's name; the Educator's signature with license and title; the reason for the education (i.e. initial regimen, change in regimen, etc.) and documentation of all discussed education topics.
1.16	Adherence Assessment Agency will incorporate adherence assessment into primary care services. Clients who are prescribed on-going ART regimen must receive adherence assessment and counseling on every HIV-related clinical encounter. Adherence assessment shall be provided by an RN, LVN, PA, NP, CNS, Medical/Clinical Case Manager, pharmacist or MD licensed by the State of Texas. Agency must utilize the RWGA standardized adherence assessment tool. Case managers must refer clients with adherence issues beyond their scope of practice to the appropriate health care professional for counseling.	• Completed adherence tool in client's record • Documentation of counseling in client records

1.17	<u>Documented Non-Compliance with Prescribed Medication Regimen</u> The agency must have in place a written policy and procedure regarding client non-compliance with a prescribed medication regimen. The policy and procedure should address the agency's process for intervening when there is documented non-compliance with a client's prescribed medication regimen.	• Review of Policies and Procedures Manual indicates compliance.
1.18	<u>Client Mental Health and Substance Use Policy</u> The agency must have in place a written policy and procedure regarding client mental health and substance use. The policy and procedure should address: the agency's process for assessing clients' mental health and substance use; the treatment and referral of clients for mental illness and substance abuse; and care coordination with mental health and/or substance abuse providers for clients who have mental health and substance abuse issues.	• Review of Policies and Procedures Manual indicates compliance.
1.19	<u>Intimate Partner Violence Screening Policy</u> The agency must have in place a written policy and procedure regarding client Intimate Partner Violence (IPV) Screening that is consistent with the Houston EMA IPV Protocol. The policy and procedure should address: • process for ensuring clients are screened for IPV no less than annually • intervention procedures for patients who screen positive for IPV, including referral to Medical/Clinical Case Management • State reporting requirements associated with IPV • Description of required medical record documentation • Procedures for patient referral including available resources, procedures for follow-up and responsible personnel • Plan for training all appropriate staff (including non-RW funded staff)	• Review of Policies and Procedures Manual indicates compliance. • Documentation in patient record
1.20	<u>Patient Retention in Care</u> The agency must have in place a written policy and procedure regarding client retention in care. The policy and procedure must include:	• Review of Agency's Policies and Procedures Manual indicates compliance

	• process for client appointment reminders (e.g. timing, frequency, position responsible) • process for contacting clients after missed appointments (e.g. timing, frequency, position responsible) • measures to promote retention in care • process for re-engaging those lost to care (no primary care visit in 6 months)	
2.0	**Psychiatric care for persons with HIV disease should reflect competence and experience in both mental health care and therapeutics known to be effective in the treatment of psychiatric conditions and is consistent with the most current published Texas Society of Psychiatric Physicians/American Psychiatric Association treatment guidelines**	
2.1	<u>Psychiatric Guidelines</u> Outpatient psychiatric care must be provided in accordance with the most current published treatment guidelines, including: Texas Society of Psychiatric Physicians guidelines (<u>www.txpsych.org</u>) and the American Psychiatric Association (<u>www.psych.org/aids</u>) guidelines.	• Documentation in patient record
3.0	**In addition to demonstrating competency in the provision of HIV disease specific care, HIV clinical service programs must show evidence that their performance follows norms for ambulatory care.**	
3.1	<u>Access to Care</u> Primary care providers shall ensure all new referrals from testing sites are scheduled for a new patient appointment within 15 working days of referral. (All exceptions to this timeframe will be documented) Agency must assure the time-appropriate delivery of services, with 24 hour on-call coverage including: • Mechanisms for urgent care evaluation and/or triage • Mechanisms for in-patient care • Mechanisms for information/referral to: ➢ Medical sub-specialties: Gastroenterology, Neurology, Psychiatry, Ophthalmology, Dermatology, Obstetrics and Gynecology and Dentistry ➢ Social work and case management services ➢ Mental health services	• Agency Policy and Procedure regarding continuity of care.

	➢ Substance abuse treatment services ➢ Anti-retroviral counseling/therapy for pregnant women ➢ Local federally funded hemophilia treatment center for persons with inherited coagulopathies ➢ Clinical investigations	
3.2	<u>Continuity with Referring Providers</u> Agency must have a formal policy for coordinating referrals for inpatient care and exchanging patient information with inpatient care providers.	• Review of Agency's Policies and Procedures Manual indicates compliance
3.3	<u>Clients Referral and Tracking</u> Agency receives referrals from a broad range of sources and makes appropriate referrals out when necessary. Agencies must implement tracking systems to identify clients who are out of care and/or need health screenings (e.g. Hepatitis b & c, cervical cancer screening, etc., for follow-up).	• Documentation of referrals out • Staff interviews indicate compliance • Established tracking systems
3.4	<u>Client Notification of Service Provider Turnover</u> Client must be provided notice of assigned service primary care provider's cessation of employment within 30 days of the employee's departure.	• Documentation in patient record
3.5	<u>Recommended Format for Operational Standards</u> Detailed standards and routines for program assessment are found in most recent Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) performance standards.	• Ambulatory HIV clinical service should adopt and follow performance standards for ambulatory care as established by the Joint Commission on the Accreditation of Healthcare Organizations.

Vision Services

The Vision Services is an integral part of the Outpatient Ambulatory Medical Care Services. Primary Care Office/Clinic Vision Care consist of comprehensive examination by a qualified Optometrist or Ophthalmologist, including Eligibility Screening as necessary. Allowable visits with a credentialed Ophthalmic Medical Assistant include routine and preliminary tests such as muscle balance test, Ishihara color test, Near Point of Conversion (NPC), visual acuity testing, visual field testing, Lensometry and glasses dispensing.

1.0	**Staff HIV/AIDS knowledge is based on documented training.**	
1.1	Ongoing Training Four (4) hours of continuing education in vision-related or other specific topics is required annually.	• Documentation of all training in personnel file • Staff interviews indicate compliance
1.2	Staff Experience/Qualifications Minimum of one (1) year HIV/AIDS work experience for paid staff (optometry interns exempt) is preferred. Provider must have a staff Doctorate of Optometry licensed by the Texas Optometry Board as a Therapeutic Optometrist, or a medical doctor who is board certified in ophthalmology.	• Documentation of work experience in personnel file
1.3	Staff Supervision Staff services are supervised by a paid coordinator or manager. Supervision of clinical staff shall be provided by a practitioner with at least two (2) years experience in vision care and treatment of persons with HIV. All licensed personnel shall receive supervision consistent with the State of Texas license requirements.	• Review of personnel files indicates compliance • Review of agency's Policy and Procedure Manual indicates compliance
2.0	**Patient Care**	
2.1	Physician Contact Information Agency obtains and documents primary care physician contact information for each client. At minimum, agency should collect the physician's name and telephone number.	• Documentation of physician contact information in the client record
2.2	Client Intake Agency collects the following information for all new clients: Health history;	• Documentation in the client record

	Ocular history; Current medications; Allergies and drug sensitivities; Reason for visit (chief complaint).	
2.3	CD4/Viral Loads When clinically indicated, current (within the last 6 months) CD4 and Viral Load laboratory test results for clients are obtained.	• Documentation in the client record
2.4	Comprehensive Eye Exam The comprehensive eye exam will include documentation of the following: Visual acuity, refraction test, binocular vision muscle assessment, observation of external structures, Fundus/retina Exam, Dilated Fundus Exam (DFE) when clinically indicated, Glaucoma test, findings of exam - either normal or abnormal, written diagnoses where applicable, Treatment Plan. Client may be evaluated more frequently based on clinical indications and current US Public Health Service guidelines.	• Documentation in the client record
2.5	Lens Prescriptions Clients who have clinical indications for corrective lens must receive prescriptions, and referrals for such services to ensure they are able to obtain their eyeglass.	• Documentation in the client record

HIV Among African Americans

February 2016

Fast Facts

- African Americans are the racial/ethnic group most affected by HIV in the United States.
- Gay and bisexual men account for more than half of estimated new HIV diagnoses among African Americans.
- The number of HIV diagnoses among African American women has declined, though it is still high compared to women of other races/ethnicities.

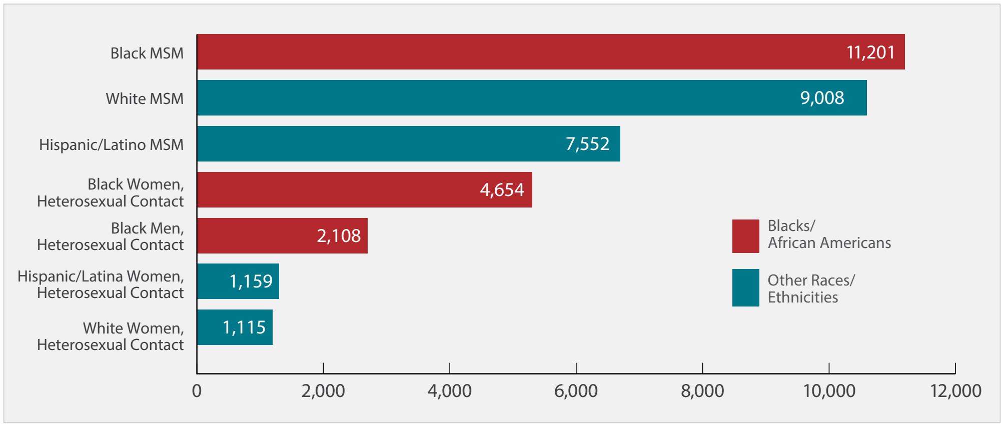
Blacks/African Americans[a] have the most severe burden of HIV of all racial/ethnic groups in the United States. Compared with other races and ethnicities, African Americans account for a higher proportion of new HIV diagnoses, those living with HIV, and those ever diagnosed with AIDS.

The Numbers

HIV and AIDS Diagnoses[b]

- In 2014, 44% (19,540) of estimated new HIV diagnoses in the United States were among African Americans, who comprise 12% of the US population.
- Among all African Americans diagnosed with HIV in 2014, an estimated 73% (14,305) were men and 26% (5,128) were women.
- Among all African Americans diagnosed with HIV in 2014, an estimated 57% (11,201) were gay or bisexual men.[c] Of those gay and bisexual men, 39% (4,321) were young men aged 13 to 24.
- From 2005 to 2014, the number of new HIV diagnoses among African American women fell 42%, though it is still high compared to women of other races/ethnicities. In 2014, an estimated 1,350 Hispanic/Latino women and 1,483 white women were diagnosed with HIV, compared to 5,128 African American women.
- From 2005 to 2014, the number of new HIV diagnoses among African American gay and bisexual men increased 22%. But that number stabilized in recent years, increasing less than 1% since 2010.
- From 2005 to 2014, the number of new HIV diagnoses among young African American gay and bisexual men (aged 13 to 24) increased 87%. But that trend has leveled off recently, with the number declining 2% since 2010.
- In 2014, an estimated 48% (10,045) of those diagnosed with AIDS in the United States were African Americans. By the end of 2014, 42% (504,354) of those ever diagnosed with AIDS were African Americans.

Estimated New HIV Diagnoses in the United States for the Most-Affected Subpopulations, 2014



Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2014 (http://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-us.pdf). *HIV Surveillance Report* 2015;26. Subpopulations representing 2% or less of HIV diagnoses are not reflected in this chart. Abbreviation: MSM, men who have sex with men.

Living With HIV and Deaths

- At the end of 2012, an estimated 496,500 African Americans were living with HIV, representing 41% of all Americans living with the virus. Of African Americans living with HIV, around 14% do not know they are infected.
- Of African Americans diagnosed with HIV in 2013, 79% were linked to HIV medical care within 3 months, but only 51% were retained in HIV care (receiving continuous HIV medical care).[d]
- Only 37% of African Americans living with HIV at the end of 2012 were prescribed antiretroviral therapy (ART), the medicines used to treat HIV, and only 29% had achieved viral suppression.[e]
- In 2013, 3,742 African Americans died of HIV or AIDS, accounting for 54% of total deaths attributed to the disease that year.

Prevention Challenges

A number of challenges contribute to the higher rates of HIV infection among African Americans. The **greater number of people living with HIV (prevalence)** in African American communities and the fact that African Americans tend to **have sex with partners of the same race/ethnicity** mean that African Americans face a greater risk of HIV infection with each new sexual encounter.

African American communities continue to experience higher rates of **other sexually transmitted diseases (STDs)** than other racial/ethnic communities in the United States. Having another STD can significantly increase a person's chance of getting or transmitting HIV.

Lack of awareness of HIV status can affect HIV rates in communities. Diagnosis late in the course of HIV infection is common in African American communities, which results in missed opportunities to get early medical care and prevent transmission to others.

The poverty rate is higher among African Americans than other racial/ethnic groups. The **socioeconomic issues** associated with poverty—including limited access to high-quality health care, housing, and HIV prevention education—directly and indirectly increase the risk for HIV infection and affect the health of people living with and at risk for HIV. These factors may explain why African Americans have worse outcomes on the **HIV continuum of care**, including lower rates of linkage to care, retention in care, being prescribed HIV treatment (ART), and viral suppression. **Stigma, fear, discrimination, homophobia, and negative perceptions about HIV testing** may also place many African Americans at higher risk and discourage testing.

What CDC Is Doing

CDC and its partners are pursuing a high-impact prevention approach to advance the goals of the *National HIV/AIDS Strategy: Updated to 2020* (https://www.aids.gov/federal-resources/national-hiv-aids-strategy/overview/) and maximize the effectiveness of current HIV prevention methods. Some of CDC's activities include:

- Support for health departments and community-based organizations to deliver effective prevention interventions for African Americans and other populations.
    - Support (http://www.cdc.gov/hiv/funding/announcements/ps15-1509/index.html) for health departments to develop comprehensive models of prevention, care, and social services for gay and bisexual men of color living with or at risk for HIV, as well as training and technical assistance (http://www.cdc.gov/hiv/funding/announcements/ps15-1510/index.html) to implement and sustain those models.
    - The Comprehensive HIV Prevention Programs for Health Departments (http://www.cdc.gov/hiv/funding/announcements/ps12-1201/index.html), a 5-year, $339 million HIV prevention initiative for health departments in states, territories, and select cities, including those serving African American clients.
- The *Act Against AIDS* (http://www.cdc.gov/actagainstaids/index.html) campaigns, including
    - *Doing It* (http://www.cdc.gov/actagainstaids/campaigns/doingit/index.html), a new national HIV testing and prevention campaign that encourages all adults to know their HIV status and protect themselves and their community by making HIV testing a part of their regular health routine;
    - *Let's Stop HIV Together* (http://www.cdc.gov/actagainstaids/campaigns/lsht/index.html), which raises HIV awareness and fights stigma among all Americans and provides many stories about people living with HIV;
    - *HIV Treatment Works* (http://www.cdc.gov/actagainstaids/campaigns/hivtreatmentworks/index.html), which shows how people living with HIV have overcome barriers to stay in care and provides resources on how to live well with HIV; and
    - *Partnering and Communicating Together (PACT) to Act Against AIDS* (http://www.cdc.gov/actagainstaids/partnerships/pact.html), a new 5-year partnership with organizations such as the National Black Justice Coalition, the National Urban League, and the Black Men's Xchange to raise awareness about testing, prevention, and retention in care among populations disproportionately affected by HIV, including African Americans.

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

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[a] Referred to as *African Americans* in this fact sheet.

[b] HIV and AIDS diagnoses indicate when a person is diagnosed with HIV infection or AIDS, not when the person was infected.

[c] The term *men who have sex with men* 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*.

[d] In 27 states and the District of Columbia (the areas with complete lab reporting by December 2014).

[e] A person with a suppressed viral load has a very low level of the virus. That person can stay healthy and has a dramatically reduced risk of transmitting the virus to others.

HIV Among African American Gay and Bisexual Men

February 2016

Fast Facts

- Among all gay and bisexual men, African American gay and bisexual men are most affected by HIV.
- Diagnoses among all African American gay and bisexual men increased 22% in the last decade but have leveled off since 2010.
- Diagnoses among young African American gay and bisexual men increased 87% in the last decade but actually declined 2% in the last 5 years.

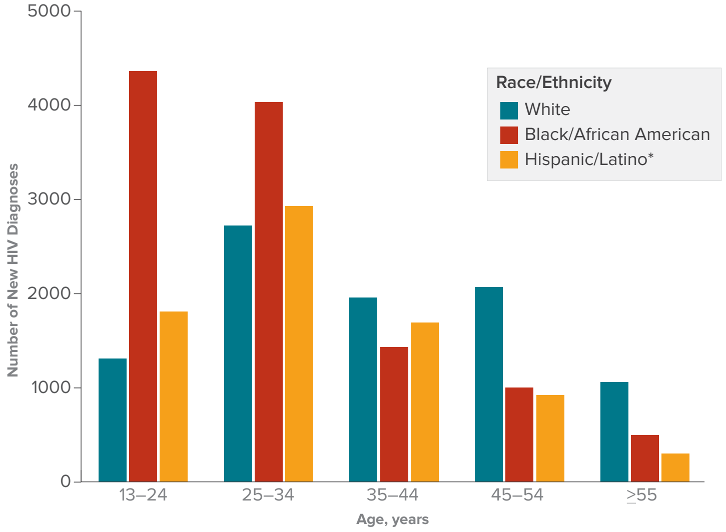
In the United States, gay, bisexual, and other men who have sex with men[a] are disproportionately affected by HIV. Among gay and bisexual men, black/African American[b] men—especially those who are younger—are the group most affected by HIV. While the number of new diagnoses declined for African Americans as a whole in recent years, diagnoses among African American gay and bisexual men increased between 2005 and 2014. However, that upward trend has stabilized since 2010.

The Numbers

HIV and AIDS Diagnoses[c]

- Among all gay and bisexual men diagnosed with HIV in the United States in 2014, African Americans accounted for the highest number (estimated 11,201; 38%), followed by whites (estimated 9,008; 31%) and Hispanics/Latinos[d] (estimated 7,552; 26%).
- In 2014, an estimated 39% (4,321) of African American gay and bisexual men diagnosed with HIV were aged 13-24. An estimated 36% (3,995) were aged 25-34; 13% (1,413) were aged 35-44; 9% (989) were aged 45-54; and 4% (486) were aged 55 or older.
- From 2005 to 2014, the number of new HIV diagnoses among African American gay and bisexual men increased 22%. But that number stabilized in recent years, increasing less than 1% between 2010 and 2014.
- From 2005 to 2014, the number of new HIV diagnoses among young African American gay and bisexual men (aged 13 to 24) increased 87%. But that trend has leveled off, with the number declining 2% between 2010 and 2014.
- Among all gay and bisexual men diagnosed with AIDS in the United States in 2014, African Americans accounted for the highest number (estimated 4,343; 39%), followed by whites (estimated 3,564; 32%) and Hispanics/Latinos (estimated 2,665; 24%).

Estimated New HIV Diagnoses Among Men Who Have Sex With Men, by Race/Ethnicity and Age at Diagnosis, 2014—United States



Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2014 (http://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-us.pdf). *HIV Surveillance Report* 2015;26. **Hispanics/Latinos can be of any race.*

Living With HIV

- By the end of 2013, an estimated 493,543 gay and bisexual men were living with diagnosed HIV infection. Of those, 152,303 (31%) were African American, 210,299 (43%) were white, and 104,529 (21%) were Hispanic/Latino.

Prevention Challenges

In addition to risk factors affecting all gay and bisexual men (a larger percentage of men with HIV in sexual networks, sexual risk factors such as anal sex, more sex partners compared to other men), several factors are specific to African American gay and bisexual men. These include:

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[a] The term *men who have sex with men* 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] Referred to as *African American* in this fact sheet.

[c] HIV and AIDS diagnoses indicate when a person is diagnosed with HIV infection or AIDS, not when the person was infected.

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

[e] A person with a suppressed viral load has a very low level of the virus. That person can stay healthy and has a dramatically reduced risk of transmitting the virus to others.

[f] Based on CDC's National HIV Behavioral Surveillance, which conducts behavioral surveys among populations at increased risk of HIV infection.

- **Socioeconomic factors.** African Americans are more likely than men of some other races/ethnicities to experience socioeconomic factors—such as limited access to and use of quality health care, lower income and educational levels, and higher rates of unemployment and incarceration—that place them at higher risk for HIV infection. These factors may help explain why African Americans have not made greater gains on the HIV continuum of care. Of African Americans living with HIV infection at the end of 2012, 86% had been diagnosed, but only 37% had been prescribed antiretroviral therapy (medicines to treat HIV) and only 29% had achieved viral suppression.[e]
- **Smaller and more exclusive sexual networks.** African American gay and bisexual men are a small subset of all gay and bisexual men, and their partners tend to be of the same race. Because of the small population size and the higher prevalence of HIV in that population relative to other races/ethnicities, African American gay and bisexual men are at greater risk of being exposed to HIV within their sexual networks.
- **Sexual relationships with older men.** Having sexual relationships with older men, who are more likely to have HIV, may increase risk for exposure among some young African American gay and bisexual men.
- **Lack of awareness of HIV status.** Though African American gay and bisexual men report higher HIV testing in the past year than Hispanic/Latino or white gay and bisexual men, they are also more likely to be HIV-positive and not know it because of the higher prevalence of HIV in the population.[f] People who do not know they have HIV cannot take advantage of HIV care and treatment and may unknowingly pass HIV to others.

Stigma, homophobia, and discrimination put gay and bisexual men of all races/ethnicities at risk for multiple physical and mental health problems and may affect whether they seek and are able to receive high-quality health services, including HIV testing, treatment, and other prevention services.

What CDC Is Doing

CDC is addressing HIV among African American gay and bisexual men with three areas of commitment:

- Engaging African American gay and bisexual communities and strategic partners.
- Expanding and focusing on the prevention strategies and programs with the greatest impact.
- Evaluating and disseminating information on prevention strategies and programs.

CDC **funds state and local health departments and community-based organizations** (CBOs) to support HIV prevention services for gay and bisexual men. In 2015, CDC added two new funding opportunities (FOAs) to help health departments reduce HIV infections and improve HIV medical care among gay and bisexual men of color. These FOAs will increase gay and bisexual men's access to pre-exposure prophylaxis (PrEP) (http://www.cdc.gov/hiv/risk/prep/index.html), increase health departments' surveillance capacity, and support effective models of prevention and care for gay and bisexual men of color.

CDC is also supporting Capacity Building Assistance for High-Impact HIV Prevention (http://www.cdc.gov/hiv/funding/announcements/ps14-1403/index.html), a national program that **addresses gaps in each step of the HIV care continuum** by providing training and technical assistance for staff of health departments, CBOs, and health care organizations. The estimated annual funding is $22 million.

CDC awarded (http://www.cdc.gov/nchhstp/newsroom/2011/ngmhaad2011pressrelease.html) $55 million over 5 years to 34 CBOs **to provide HIV testing to more than 90,000 young gay and bisexual men of color**, with the goals of identifying more than 3,500 previously unrecognized HIV infections and linking those who have HIV to care and prevention services.

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

- *Doing It* (http://www.cdc.gov/actagainstaids/campaigns/doingit/index.html), a new national HIV testing and prevention campaign, encourages all adults to know their HIV status and protect themselves and their community by making HIV testing a part of their regular health routine.
- *Start Talking. Stop HIV.* (http://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* (http://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* (http://www.cdc.gov/actagainstaids/partnerships/pact.html), a new 5-year partnership with organizations such as the National Black Justice Coalition and the Black Men's Xchange, is raising awareness about testing, prevention, and retention in care among populations disproportionately affected by HIV, including African Americans.

To learn more, visit the CDC Gay and Bisexual Men's Health (http://www.cdc.gov/msmhealth/) site.

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

CDC FACT SHEET

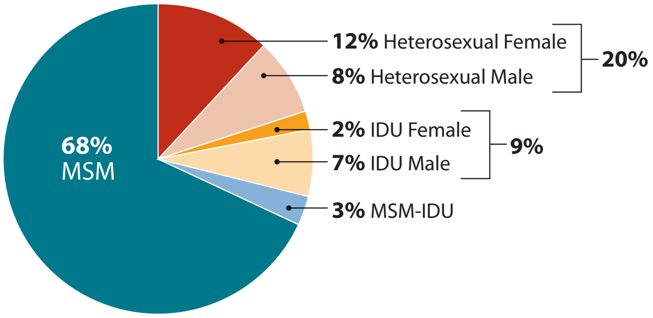
HIV and AIDS among Latinos

HIV is a serious health threat to Latino communities, who bear a disproportionate share of the HIV burden in the United States. Because there is no single Latino culture, the factors driving the epidemic in this population are as diverse as the communities themselves. While prevention efforts have helped to maintain stability in the overall level of new HIV infections among Latinos for more than a decade, this population continues to be affected by HIV at far too high a level.

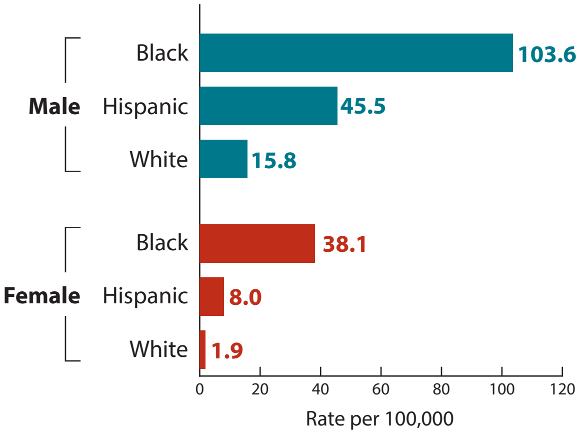
A Snapshot

- Hispanics represent approximately 17 percent of the U.S. population, but account for an estimated 21 percent of people living with HIV (251,700 persons) and an estimated 21 percent of new infections (9,800) in the United States each year.
- Approximately 1 in 48 Hispanic men will be diagnosed with HIV during their lifetime. For Hispanic women, the risk of lifetime diagnosis is 1 in 227.
- Men account for 87 percent of new infections among Hispanics.
- The rate of new HIV infections among Hispanic men is almost three times that among white men, with gay and bisexual men particularly affected.
  - Most new infections among Hispanic men (79 percent) occur among men who have sex with men (MSM).[1]
  - In a study of 20 major U.S. cities in 2011, approximately 15 percent of Hispanic MSM were infected. Among those who were HIV-infected, more than one-third (37 percent) were unaware that they were infected.
- The rate of new HIV infections among Hispanic women is more than four times that of white women.
- There are substantial regional differences in the burden of HIV among Latinos across the United States. For example:
  - The HIV diagnosis rate is highest among Latinos in the Northeast.
  - While male-to-male sexual contact is the predominant mode of transmission among all Latinos newly diagnosed with HIV, Latinos in the Northeast are more likely than those in other regions to have been infected by intravenous drug use.
  - Latinos diagnosed with HIV in the South are more likely than those in the Northeast to have been infected through male-to-male sexual contact.
- AIDS continues to claim the lives of too many Latino men and women. Since the beginning of the epidemic, more than 100,000 Hispanics with AIDS have died.

Estimated New HIV Infections among Hispanics, 2010, by Transmission Category



Estimated Rate of New HIV Infections, 2010, by Gender and Race/Ethnicity



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[1] The term men who have sex with men is used in CDC surveillance systems. It indicates the behaviors that transmit HIV infection, rather than how individuals self-identify in terms of their sexuality.

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

FEBRUARY 2016

- HIV treatment helps people with HIV live healthy lives and prevents transmission of the virus to partners. However, too few Latinos living with HIV receive the care and treatment they need. A recent CDC study found that, among the estimated 251,700 Latinos living with HIV, 85 percent were diagnosed with HIV, 35 percent were engaged in medical care, 33 percent were prescribed antiretroviral therapy, and 27 percent were virally suppressed (i.e., the virus is under control at a level that helps them stay healthy and reduces the risk of transmission).

Complex Factors Increase Risk

- **Social and economic factors:** The social and economic realities of some Latinos' lives, including poverty, discrimination, and lack of access to healthcare, can increase HIV risk. Language barriers may also affect the quality of care.
- **Stigma:** The stigma associated with HIV and homosexuality may help to spread HIV in Latino communities. In some communities, the cultural value of machismo may create reluctance to acknowledge sensitive, yet risky behaviors, such as male-to-male sexual contact or substance abuse. Fear of disclosing risk behavior or sexual orientation may prevent Latinos from seeking testing, treatment and prevention services, and support from friends and family. As a result, too many Latinos lack critical information about how to prevent infection.
- **Cultural factors:** There is no single Latino culture in the United States. Research shows that Latinos born in different countries have different behavioral risk factors for HIV. For example, data suggest that Hispanics born in Puerto Rico are more likely than other Hispanics to contract HIV as a result of injection drug use or high-risk heterosexual contact. By contrast, sexual contact with other men is the primary cause of HIV infection among men born in places such as Mexico and the 50 U.S. states.
- **High prevalence of sexually transmitted diseases (STDs) and higher rates of HIV:** Data show that the burden of STDs among Latinos is high. Because STDs can place individuals at higher risk for HIV infection, high STD prevalence may contribute to higher HIV incidence among Latino men and women. Additionally, disproportionate rates of HIV among Latinos and the current high prevalence of HIV in Latino communities increase the likelihood that Latinos will encounter an HIV-infected sex or drug-injecting partner, placing them at greater risk.

HIV: Protect Yourself

Be smart about HIV. Here's what you can do to reduce your risk of infection:

Get the facts — Arm yourself with basic information: Are you at risk? How is HIV spread? How can you protect yourself?

Take control — You have the facts; now protect yourself and your loved ones. There are three essential ways to reduce your risk:

1. Don't have sex (i.e., anal, vaginal or oral)
2. Only have sex (i.e., anal, vaginal or oral) if you're in a mutually monogamous relationship with a partner you know is not infected
3. Use a condom every time you have anal, vaginal or oral sex. (Correct and consistent use of the male latex condom is highly effective in reducing HIV transmission.)

Put yourself to the test — Knowing your HIV status is a critical step toward stopping HIV transmission, because if you know you are infected, you can take steps to protect your partners. Also, if you are infected, the sooner you find out, the sooner you can receive life-extending treatment. In fact, CDC recommends that all adults and adolescents be tested for HIV. Because other STDs can play a role in the acquisition of HIV, knowing whether you are infected with either is critical in reducing your risk for infection.

Call 1-800-CDC-INFO or visit www.hivtest.org to find HIV and STD testing locations near you.

Start talking — Talk to everyone you know about HIV — friends and family, coworkers and neighbors, at work and at places of worship. Have ongoing and open discussions with your partners about HIV testing and risk behaviors. Talking openly about HIV can reduce the stigma that keeps too many from seeking the testing, prevention and treatment services, and support they need.

HIV doesn't have to become part of your life. Each of us can and must be part of the solution.

Visit www.cdc.gov/actagainstaids for more information about HIV and what you can do to stop HIV.

If you are a member of the news media and need more information, please visit www.cdc.gov/nchhstp/Newsroom or contact the News Media Line at CDC's National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention: 404-639-8895 or NCHHSTPMediaTeam@cdc.gov.

HIV Among People Aged 50 and Older

October 2015

Fast Facts

- People aged 50 and older have many of the same HIV risk factors as younger people, but may be less aware of their risk.
- People aged 55 and older accounted for one-quarter of all Americans living with HIV in 2012.
- Older Americans are more likely to be diagnosed with HIV infection later in the course of their disease.

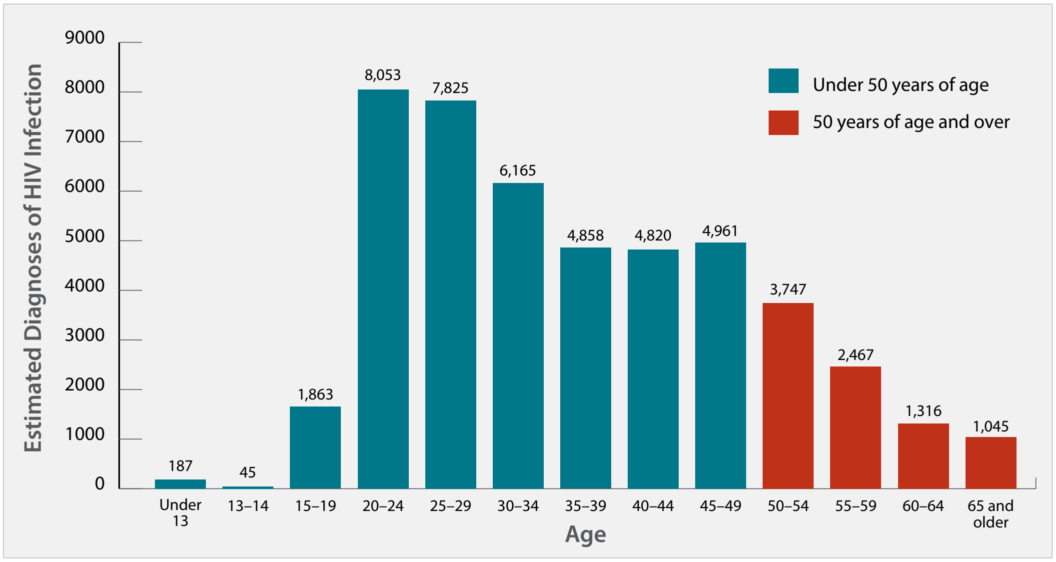
In 2012, people aged 55 and older accounted for about one-quarter (24%, 288,700) of the estimated 1.2 million people living with HIV infection in the United States.

The Numbers

HIV and AIDS Diagnoses[a] and Deaths

- In 2013, people aged 50 and over accounted for 21% (8,575) of an estimated 47,352 HIV diagnoses in the United States. Of these, the largest number (44%, 3,747) were among those aged 50 to 54.
- In 2013, among persons aged 50 to 54, the estimated rate (per 100,000) of HIV diagnoses by race/ethnicity was 59.3 among African Americans/blacks, 23.3 among Hispanics/Latinos,[b] and 8.7 among whites.
- In 2013, people aged 50 and older accounted for 27% (7,108) of the estimated 26,688 AIDS diagnoses in the United States.
- Of the 6,955 deaths related to AIDS in 2013, 2,588 (37%) were among people aged 55 and older.

Estimated Diagnoses of HIV Infection by Age, 2013, United States



Source: CDC. *Diagnoses of HIV infection in the United States and dependent areas, 2013* . HIV Surveillance Report 2015;25. (http://www.cdc.gov/hiv/pdf/g-l/hiv_surveillance_report_vol_25.pdf)

Prevention Challenges

Older people in the United States are more likely than younger people to be diagnosed with HIV infection late in the course of the disease, which means starting treatment late and possibly suffering more immune-system damage. This can lead to a poorer prognosis and shorter survival after an HIV diagnosis. Among people aged 20 to 24 who were diagnosed with HIV infection during 2004-2009, 99% survived more than 12 months after diagnosis, compared with an estimated 89% of people aged 50 to 54, 86% of people aged 55 to 59, 82% of people aged 60 to 64, and 73% of people aged 65 and older (for those who did not survive more than 12 months, death could have been from any cause). Late diagnoses can occur because health care providers may not always test older people for HIV infection, and older people may mistake HIV symptoms for those of normal aging and not consider HIV as a cause.

Many older people are sexually active, including those living with HIV, and may have many of the **same HIV risk factors as younger people**, including a lack of knowledge about HIV and how to prevent transmission, as well as multiple partners. Older people also face some unique issues:

- Many widowed and divorced people are dating again. They may be less aware of their risks for HIV than younger people, believing HIV is not an issue for their peer group. Thus, they may be less likely to protect themselves.
- Women who no longer worry about becoming pregnant may be less likely to use a condom and to practice safer sex. Age-related thinning and dryness of vaginal tissue may raise older women's risk for HIV infection.
- The availability of erectile dysfunction medications may facilitate sex for older men who otherwise would not have been capable of vaginal or anal intercourse.
- Although they visit their doctors more frequently, older people are less likely than younger people to discuss their sexual habits or drug use with their doctors. Also, doctors may be less likely to ask their older patients about these issues.

Stigma is a particular concern among older people because they may already face isolation due to illness or loss of family and friends. Stigma negatively affects people's quality of life, self-image, and behaviors, and may prevent them from seeking HIV care and disclosing their HIV status.

Aging with HIV infection also presents **special challenges for preventing other diseases** because older people with HIV may have an increased risk for cardiovascular disease, thin bones, and certain cancers. Older HIV patients and their care providers need to maximize prevention efforts against these conditions and remain vigilant for early signs of illness. They also need to be careful about interactions between the medications used to treat HIV and those used to treat common age-related conditions such as hypertension, diabetes, elevated cholesterol, and obesity.

What CDC Is Doing

CDC and its partners are pursuing a high-impact prevention approach to advance the goals of the National HIV/AIDS Strategy, maximize the effectiveness of current HIV prevention methods, and improve surveillance among older people in the United States. Activities include

- **Support and technical assistance** to health department and community-based organizations to deliver effective prevention and evidence-based interventions for antiretroviral therapy adherence for older Americans.
- ***Act Against AIDS***, a national communications initiative that focuses on raising awareness, fighting stigma, and reducing the risk of HIV infection among at-risk populations. *Act Against AIDS* includes *Let's Stop HIV Together* (approximately 40% of campaign participants are aged 50 and older); *HIV Screening. Standard Care.*, which encourages primary care physicians to screen patients of all ages for HIV infection; and *Prevention IS Care*, which provides continuing education and materials for physicians to address the complex issues of those living with HIV infection.
- **The Comprehensive HIV Prevention Programs for Health Departments Funding Opportunity Announcement,** a 5-year, $339 million HIV prevention initiative for health departments in states, territories, and select cities, including those serving clients at risk for HIV infection.

For additional information and resources, visit

Agency on Aging (www.aoa.gov/)
National Institutes of Health (www.nih.gov/)
Services & Advocacy for GLBT Elders (www.sageusa.org/)

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

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[a] HIV and AIDS diagnoses refer to the estimated number of people diagnosed with HIV infection, regardless of stage of disease at diagnosis, and the estimated number of people diagnosed with AIDS, respectively, during a given time period. The terms do not indicate when they were infected.

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

Aging with HIV: Responding to an emerging challenge

Aging with HIV: Responding to an emerging challenge

The development of highly active anti-retroviral therapy (HAART) for HIV infection in the 1990s is one of modern medicine's most dramatic success stories. Once effectively a death sentence, HIV infection can now be considered a serious, but largely manageable, chronic condition. Today, a person who begins HAART can reasonably expect to live another 30 to 50 years, and often well into older age.

This remarkable success has brought with it a new set of challenges, however, for patients and health professionals. Even when their disease is well controlled, people with HIV can develop aging-related conditions such as cardiovascular disease, certain cancers, kidney and liver disease, osteoporosis, and cognitive impairment decades ahead of their HIV-negative counterparts, and their life expectancy is significantly reduced. The health needs of the increasing number of HIV-positive Americans who are reaching older ages have become a significant public health issue.

The NIA supports research to help better understand and address the needs of older people with HIV, including basic studies comparing changes at the cellular, organ, system, and individual levels associated with both aging and HIV. Researchers believe such research may lead to improvements not only in the treatment of HIV but also in the treatment of other age-related diseases and conditions.

A growing concern

According to the Centers for Disease Control and Prevention (CDC), the ranks of those over age 50 living with HIV are rapidly increasing. In 2009, 32.7 percent of people with diagnosed HIV infection were age 50 and over, compared with 17 percent in 2001. As soon as 2015, the CDC projects, more than half of all HIV-infected Americans will be over 50 years old. The emergence of HAART is a major driver of this increase, but at the same time, the number of new HIV cases in this age group is increasing. According to the U.S. Administration for Community Living , some 17 percent of new cases of HIV are among older people.

“There's a certain misperception out there,” notes Dr. Basil Eldadah, acting chief of the Geriatrics Branch in NIA's Division of Geriatrics and Clinical Gerontology. “Older people may believe that HIV is a young person's disease. But older adults—and the healthcare providers who take care of them—should remember that the risk factors for getting infected with HIV are the same for older individuals as they are for younger adults. In addition, physical changes that naturally occur with age, such as compromised skin and mucous barriers and an altered immune system, may possibly increase susceptibility to infection in older age.”

Immune function

The reasons behind the increased risk for HIV-related comorbidities in older patients are not well understood. Researchers hypothesize that virally mediated changes in the immune system lead to a compression of the aging process, resulting in an earlier-than-average onset of age-related chronic disease and frailty. These changes to the immune system are similar to those seen in very old—but otherwise healthy—people.

“There are several similarities between the immune systems of very old individuals and those with HIV infection,” said Dr. Rebecca Fuldner, program officer in the NIA Division of Aging Biology. For example, T cells, which play a key role in immune function, become dysfunctional in both groups, meaning that the immune system has trouble recognizing and responding to invaders.

Like advanced age, HIV infection is also associated with chronic, low-level inflammation throughout the body, which is in turn related to a number of health conditions. HAART itself is associated with an increase in visceral fat, which secretes inflammatory proteins into the bloodstream, and damage to the mitochondria, also linked with increased inflammation.

“The link between aging, HIV, and inflammation is an interesting one,” said Dr. Fuldner. “It raises the possibility that a treatment for one of these conditions may have a positive effect on the others.” For example, anti-inflammatory drugs that are often prescribed to otherwise healthy older adults—including aspirin, omega-3 fatty acids, vitamin D, and statin drugs—are currently under study as adjuncts to antiretroviral therapy in younger HIV-infected individuals and may eventually be tested in older individuals as well.

NIA supports several projects on the immunology of aging and HIV. For example, one study is looking at the ability of HIV infection to induce cellular senescence, as well as the effects of HAART on cellular senescence; another study has identified several potential biomarkers of immune status in people infected with HIV.

Cognitive aging

HIV and its treatment can have profound effects on the brain. Although AIDS-related dementia, once relatively common among patients, is now rare, researchers estimate that more than 50 percent of patients with HIV have an HIV-Associated Neurocognitive Disorder (HAND). HAND may include deficits in attention, information processing, language, executive function, motor skills, memory, or sensory perception. These problems are usually not debilitating, but do have an adverse effect on the patient’s quality of life. Psychiatric symptoms such as depression and psychological distress are also common among these patients.

“HIV hits the brain early, continuously, and hard,” said Dr. Miroslaw Mackiewicz, program director for Integrative Neurobiology in the NIA Division of Neuroscience. “But an improved understanding of how the virus attacks the brain could suggest new pathways for prevention and treatment of the cognitive decline that so often comes with HIV infection.”

With the National Institute of Mental Health and other NIH Institutes, NIA has participated in a funding initiative on the pathophysiology of HAND in older persons on HAART. In addition, NIA supports a study of how HIV/AIDS affects both the heart and the brain, and whether this is important for the development of cognitive impairment.

These investigators, led by Dr. James Becker at the University of Pittsburgh, have used sophisticated brain imaging techniques to compare the brains of HIV-positive men undergoing HAART with those of uninfected men. They found brain atrophy in the HIV-positive men (but not in the control group) and noted that individuals who had been HIV-positive the longest had the greatest changes in the brain, in particular, in a section of the brain involved in movement and executive function. Dr. Becker postulates that a chronic, subclinical disease of small vessels in the brain underlies changes in the gray matter volume, white matter integrity, and changes in regional cerebral blood flow. The subclinical disease of small vessels in the brain continues even when the patient is undergoing treatment.

The investigators also conducted imaging and cognitive examinations on individuals who had recently had an initial positive test for HIV (within the past year, on average). They identified structural changes to the brain as well as deficits on neuropsychological tests in these individuals, suggesting that brain injury may occur very early in the course of infection with HIV.

New frontiers in medical management of HIV/AIDS

Several NIA and NIH-wide initiatives support research on the medical management of HIV/AIDS in older patients. For example, NIH is currently soliciting grant applications for clinical and translational studies of HIV infection and associated conditions, treatments, and biobehavioral and social factors in older adults. The National Institute of Allergy and Infectious Diseases has provided supplemental funding to several of its Centers for AIDS Research on HIV and aging. And, a trans-NIH Coordinating Committee on HIV and Aging coordinates various scientific efforts related to HIV and aging.

In 2011, the NIH Office of AIDS Research assembled a working group of experts on HIV and aging to assess the state of the science and identify research priorities. In a 2012 report, the working group listed several overarching themes, which will inform NIA’s efforts moving forward:

- Multi-morbidity, poly-pharmacy, and the need to emphasize maintenance of function
- The complexity of managing HIV infection in the context of treatment effects, aging, and concurrent disease
- The interrelated mechanisms of immune senescence, inflammation, and hypercoagulability
- The utility of multi-variable indices for predicting outcomes
- A need to emphasize human studies to account for complexity
- A need to focus on issues of community support, caregivers, and systems infrastructure

“In the early days, management of HIV focused on disease-specific measures like viral load and CD4 counts,” said Dr. Eldadah. “As the population of older people living with HIV increases, we need to continue to develop new paradigms that approach HIV infection and its treatment as a complex chronic condition interacting with aging changes, co-existing conditions, and the treatments for those conditions.”

Archive content: No

Source URL: https://www.nia.nih.gov/newsroom/features/aging-hiv-responding-emerging-challenge

HIV Among Youth

July 2015

Fast Facts

- Youth aged 13 to 24 accounted for an estimated 26% of all new HIV infections in the United States in 2010.
- Most new HIV infections among youth occur among gay and bisexual males; there was a 22% increase in estimated new infections in this group from 2008 to 2010.
- Over 50% of youth with HIV in the United States do not know they are infected.

Youth in the United States account for a substantial number of HIV infections. Gay, bisexual, and other men who have sex with men* account for most new infections in the age group 13 to 24; black/African American** or Hispanic/Latino[a] gay and bisexual men are especially affected. Continual HIV prevention outreach and education efforts, including programs on abstinence, delaying the initiation of sex, and negotiating safer sex for the spectrum of sexuality among youth—homosexual, bisexual, heterosexual, and transgender—are urgently needed for a new generation at risk.

** Referred to as gay and bisexual in this fact sheet. ** Referred to as black in this fact sheet.*

The Numbers

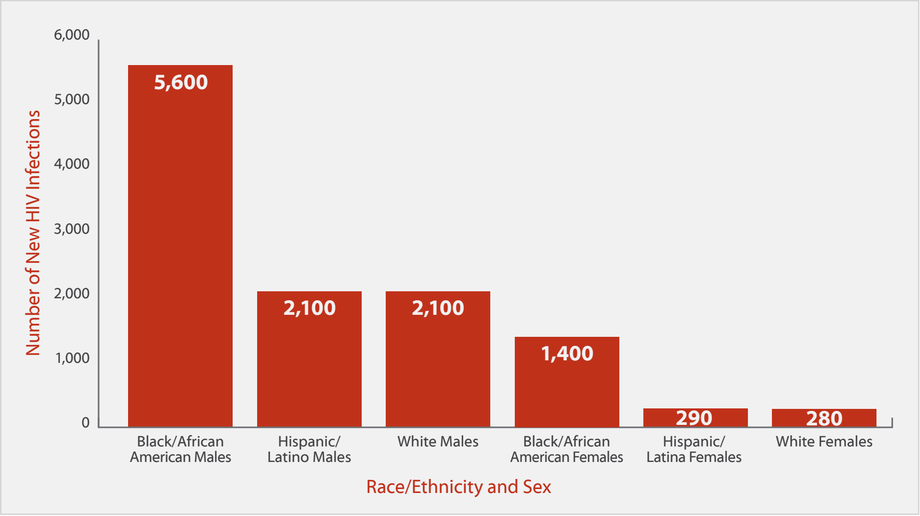
New HIV Infections[b] Among Youth (Aged 13-24)

- In 2010, youth made up 17% of the US population, but accounted for an estimated 26% (12,200) of all new HIV infections (47,500) in the United States.
- In 2010, young gay and bisexual men accounted for an estimated 19% (8,800) of all new HIV infections in the United States and 72% of new HIV infections among youth. These young men were the only age group that showed a significant increase in estimated new infections—22% from 2008 (7,200) through 2010 (8,800).
- In 2010, black youth accounted for an estimated 57% (7,000) of all new HIV infections among youth in the United States, followed by Hispanic/Latino (20%, 2,390) and white (20%, 2,380) youth.

HIV and AIDS Diagnoses[c] and Deaths Among Youth (Aged 13-24)

- An estimated 9,961 youth were diagnosed with HIV infection in the United States in 2013, representing 21% of an estimated 47,352 people diagnosed during that year. Eighty-one percent (8,053) of these diagnoses occurred in those aged 20 to 24, the highest number of HIV diagnoses of any age group.
- At the end of 2012, there were an estimated 62,400 youth living with HIV in the United States. Of these, 32,000 were living with undiagnosed HIV infection.
- In 2013, an estimated 2,704 youth were diagnosed with AIDS, representing 10% of the 26,688 people diagnosed with AIDS that year.
- In 2012, an estimated 156 youth with AIDS died, representing 1% of the13,712 people with AIDS who died that year.

Estimates of New Infections Among Youth Aged 13-24 Years, by Race/Ethnicity and Sex, United States, 2010



Source: CDC. Estimated HIV incidence among adults and adolescents in the United States, 2007–2010. *HIV Surveillance Supplemental Report* 2012;17(4).

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

[b] New HIV infections refer to HIV incidence, or the number of people who are newly infected with HIV within a given time frame (for example, 1 year), whether or not they are diagnosed.

[c] HIV and AIDS diagnoses indicate when a person is diagnosed with HIV infection or AIDS, but do not indicate when the person was infected.

Prevention Challenges

Low perception of risk. A majority of 15- to 24-year-olds in the United States responding to a Kaiser Family Foundation survey said they were not concerned about becoming infected with HIV, which means they may not take measures to protect their health.

Declining health education. The prevalence of having been taught in school about HIV infection or AIDS decreased from 92% in 1997 to 85% in 2013.

Low rates of testing. It is estimated that in 2010, about 50% of youth aged 13 to 24 with HIV in the United States were unaware of their infection, compared to 12.8% overall. In a 2013 survey, only 13% of high school students (22% of those who had ever had sexual intercourse), and in a 2010 survey, only 35% of adults aged 18 to 24 had been tested for HIV.

Low rates of condom use. In a 2013 survey in the United States, of the 34% of high school students reporting sexual intercourse in the previous 3 months, 41% did not use a condom.

High rates of sexually transmitted diseases (STDs). Some of the highest STD rates in the United States are among youth aged 20 to 24, especially those of minority races and ethnicities. The presence of an STD greatly increases a person's likelihood of acquiring or transmitting HIV.

Older partners. Young gay and bisexual men are more likely to choose older sex partners than those of their own age, and older partners are more likely to be infected with HIV.

Substance use. Nearly half (47%) of youth aged 12 to 20 reported current alcohol use in 2011, and 10% of youth aged 12 to 17 said they were current users of illicit drugs. Among the 34% of currently sexually active students nationwide, 22% had drunk alcohol or used drugs before last sexual intercourse. Substance use has been linked to HIV infection because both casual and chronic substance users are more likely to engage in high-risk behaviors, such as sex without a condom, when they are under the influence of drugs or alcohol.

Homelessness. Runaways, homeless youth, and youth who have become dependent on drugs are at high risk for HIV infection if they exchange sex for drugs, money, or shelter.

Inadequate HIV prevention education. Young people are not always reached by effective HIV interventions or prevention education—especially young gay and bisexual men, because some sex education programs exclude information about sexual orientation.

Feelings of isolation. Gay and bisexual high school students may engage in risky sexual behaviors and substance abuse because they feel isolated and lack support.

What CDC Is Doing

CDC uses a multifaceted approach to meet the goals of the National HIV/AIDS Strategy:

- In 2011, CDC awarded $55 million over 5 years to 34 community-based organizations (CBOs) to expand HIV prevention services for young gay, bisexual, and transgender youth of color.
- CDC funds health departments and CBOs to deliver effective behavioral interventions (www.effectiveinterventions.org).
- CDC's **Division of Adolescent and School Health** collects and reports data on youth health risk behaviors and supports many other projects (www.cdc.gov/yrbs). For example:
    - Funding 19 state and 17 local education agencies helps districts and schools deliver exemplary sexual health education emphasizing HIV and other STD prevention, increase adolescent access to key sexual health services, and establish safe and supportive environments for students and staff.
    - To meet the HIV/STD prevention needs of young men who have sex with men (YMSM), Advocates for Youth assists local education agencies with implementing multiple program activities and developing strategic partnerships and collaborations between schools and community-based, mental health, and social services organizations.
    - The National Coalition of STD Directors works with state education agencies and CAI works with local education agencies to increase adolescent access to key preventive sexual health services.
    - The American Psychological Association works with state education agencies and the Gay-Straight Alliance Network works with local education agencies to establish safe and supportive learning environments for students and staff.
- Through its *Act Against AIDS* campaigns (www.cdc.gov/actagainstaids), CDC aims to provide effective messages about HIV prevention and to reduce stigma, especially for high-risk groups. *Let's Stop HIV Together*, for example, fights stigma by showing that people with HIV are real people —including young people.

View the bibliography at www.cdc.gov/hiv/risk/age/youth.

Additional Resources

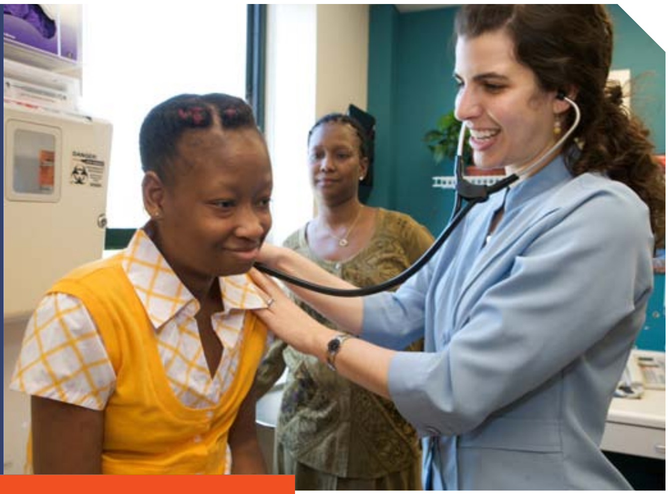
CDC-INFO
1-800-CDC-INFO (232-4636)
www.cdc.gov/info

CDC HIV Website
www.cdc.gov/hiv

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

U.S. Department of Health and Human Services
HRSA
Health Resources and Services Administration

Youth and Young Adults and the Ryan White HIV/AIDS Program

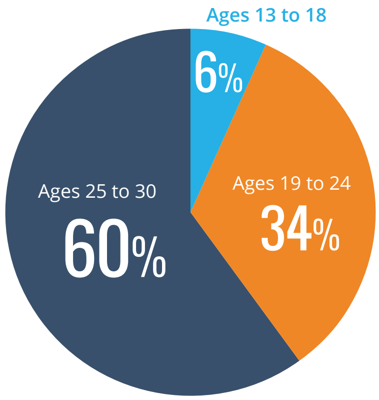


September 2015

To address the burden of HIV among young people and prevent further transmission of the virus, it is critical to strategically target prevention messages and to increase engagement of young people in HIV medical care. Youth represent a medically underserved population in the United States,[1] and successfully connecting with and caring for this population requires tailored approaches. Of the approximately 525,000 clients served by the Ryan White HIV/AIDS Program during 2013,[2] 15% were youth and young adults (hereafter referred to as "youth") aged 13–30 years (Figure 1). Consistent with national surveillance data and trends,[3] these youth, particularly those aged 19–30 years, were most likely to be black men who have sex with men (BMSM). Among female youth clients, 86% were racial or ethnic minorities.[2]

This report outlines the Health Resources and Services Administration's (HRSA) longstanding history serving youth, the health disparities that exist among this population, barriers youth face in engaging in care, data trends among Ryan White HIV/AIDS Program clients aged 13–30, and the ways in which grantees are overcoming challenges to successfully develop youth-centered programs.

Figure 1. Youth Served by the Ryan White HIV/AIDS Program, 2013
Ages 13–30, *N=79,050*



Source: Ryan White Services Report data, 2013

History of Youth-Focused Initiatives

The Ryan White HIV/AIDS Program has made a concerted effort throughout the years to focus attention on youth affected by HIV. In 1993, the Pediatric AIDS Service Demonstration Grants, administered by the HRSA for HIV-positive children and their families, were incorporated into the Ryan White HIV/AIDS Program, specifically the Part D program for women, infants, children, youth, and their families. Also beginning in 1993, the Special Projects of National Significance (SPNS) program funded 10 models of adolescent HIV care though the Adolescent Care Demonstration and Evaluation Initiative.[4] This multiyear project evaluated four categories of interventions:

- youth involvement
- outreach to bring youth into services
- case management and linkage to services
- a comprehensive continuum of care

Did You Know?

National statistics on youth and HIV

- According to national HIV incidence surveillance data from 2007 to 2010, individuals aged 13 to 24 accounted for 26% of new HIV infections.
- In 2012, nearly 45% of youth with HIV in the United States were unaware of their infection.

Sources:

CDC. Estimated HIV incidence in the United States, 2007–2010. HIV Surveillance Supplemental Report 2012;17(No. 4). http://www.cdc.gov/hiv/library/reports/surveillance/

CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas—2013. HIV Surveillance Supplemental Report 2015;20(No. 2). http://www.cdc.gov/hiv/library/reports/surveillance/

SPNS has also funded engagement and retention in care initiatives for high-risk youth populations. Specifically, the Outreach, Care, & Prevention to Engage HIV Seropositive Young Men who have Sex with Men (MSM) of Color Initiative focused on developing and evaluating innovative service models targeting HIV-infected men who have sex with men aged 13–24.[5] Other recent HRSA initiatives targeting young MSM (YMSM) include:

- UCare4Life: a mobile texting program that helps patients with HIV infection better adhere to medication regimens
- The Resource and Technical Assistance Center for HIV Prevention and Care for Black Men who have Sex with Men: a cooperative agreement that seeks to identify and disseminate best practices and models, particularly for BMSM aged 13–24.

HRSA publications focusing on youth in addition to this report include: newsletters focusing on the delivery of culturally competent care to young adult patients and transitioning adolescents from pediatric to adult care settings; and a population fact sheet on HIV and youth, detailing the critical issues faced by this population and featuring highlights of the Ryan White HIV/AIDS Program's response.

HRSA Data:

Where do they come from and how are they used?

The Ryan White HIV/AIDS Program Services Report (RSR) is the HRSA HIV/AIDS Bureau's (HAB) primary source of annual, client-level data collected from its nearly 2,000 funded grantees and providers.

These data are used to assess the number and type of non-AIDS Drug Assistance Program clients receiving services, as well as the quality of HIV care. Client-level RSR data collection has been in effect since 2010. Agencies that provide any Ryan White HIV/AIDS Program clinical or supportive services are required to submit data to HAB each year in a specified format. Those data contain an encrypted, unique identifier for each client and, depending on the type of agency reporting, additional demographic, service, and clinical data. Demographic data include the client's gender, race/ethnicity, health care coverage, poverty level, and housing status. Service data include the number and date of outpatient ambulatory medical care visits as well as visit counts for other core medical services, including mental health, substance abuse, and oral health. Providers of outpatient ambulatory medical care also report all viral load and CD4 test results and dates, as well as information concerning receipt of screening tests for hepatitis B, hepatitis C, and syphilis.

This array of data enables HAB to calculate important measures of performance, including viral load suppression and retention in HIV care—two central components of the National HIV/AIDS Strategy.

Health Disparities among Youth

Stigma and disclosure are two barriers to HIV care for clients, regardless of age. These issues, however, may be particularly acute among youth because adolescence and young adulthood are marked with self-identity exploration and sexual awakening.[6-8]

Adolescence is a psychologically complex time characterized by lowered inhibitions, increased risk-taking behavior, and decreased parental support and oversight.[9] Meanwhile, the establishment of romantic relationships, feelings of invulnerability, and choices regarding drug and alcohol use are distinct characteristics of this period.[9]

The U.S. Centers for Disease Control and Prevention (CDC) Youth Risk Behavior Survey found that 47% of high school students were sexually active and only 59% used a condom during their last sexual encounter. Of sexually active students, only 13% had been tested for HIV.[10] These factors, individually and in combination, place youth at increased risk for sexually transmitted infections (STIs), including HIV.

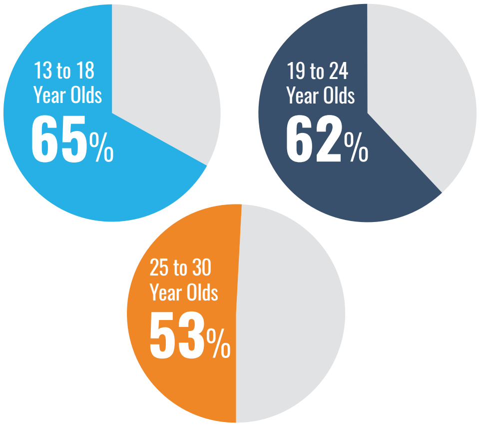
Fear of violence, rejection, discrimination, and confidentiality related to HIV status and sexual orientation are among the leading causes of delayed initiation into care and treatment by youth.[6-8] Compounding these factors are the structural challenges youth face when accessing and navigating the health care and insurance landscapes, regardless of whether they were perinatally or behaviorally infected. These barriers range from cost for care or co-pays, lack of transportation, low health literacy, competing priorities, and limited educational attainment.[6] In fact, among Ryan White HIV/AIDS Program clients, only 40% of youth aged 13–18 utilized outpatient/ambulatory medical care during 2013, compared to 56–63% among clients in other age groups.[2]

Disparities among Racial/Ethnic Minority Youth

HIV infection is inextricably linked to a host of health, social, and structural issues that are more pronounced within communities of color. These include poverty, psychological comorbidities, substance use, sexual victimization, stigmatization, and discrimination, all of which undermine the health and well-being of infected persons, including youth. Vulnerabilities such as these are cumulative and support the notion of a *syndemic,* or set of mutually reinforcing epidemics driven by cultural marginalization, that heightens the risk for acquiring HIV.[11-14] In the United States, communities of color, particularly black, non-Hispanic communities of color, are most severely affected by HIV infection; the highest rate of new infections is among young, black, non-Hispanics,[15] which underscores a need to strategically reach a new generation of people.

Figure 2. Black, Non-Hispanic Youth Served by the Ryan White HIV/AIDS Program

by Age Group, 2013



Source: Ryan White Services Report data, 2013

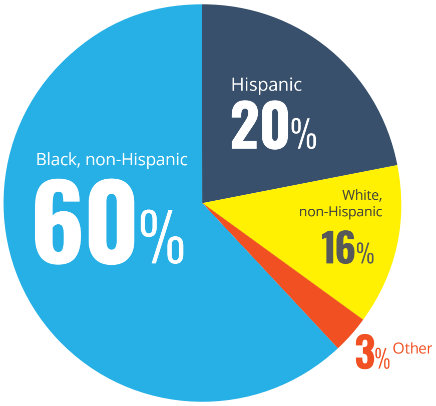
Consistent with the burden of HIV among youth in the United States, black, non-Hispanic youth represent the largest racial/ethnic group among Ryan White HIV/AIDS Program clients aged 13–30. As Figure 2 illustrates, black, non-Hispanics represent the majority of young clients served by the Ryan White HIV/AIDS Program across all age cohorts of young people.

Young Women

Young women of color are also disproportionately affected by HIV and are well represented in the Ryan White HIV/AIDS Program: during 2013, approximately 86% of female Ryan White HIV/AIDS Program clients aged 13–30 were women of color.

Figure 3. Young Women of Color Served by the Ryan White HIV/AIDS Program

Ages 13–30, by Race/Ethnicity, 2013



Source: Ryan White Services Report data, 2013

Heterosexual contact was the leading cause of transmission among young women and accounted for 26% of all infections among Ryan White HIV/AIDS Program clients aged 13–30. Figure 3 illustrates the distribution by race and ethnicity of young women aged 13–30 who received Ryan White HIV/AIDS Program services during 2013.

Young women have several risk factors for HIV infection. Male-to-female transmission of HIV is approximately 2 to 4 times more efficient than female-to-male transmission, due to the permeable mucous membranes of female reproductive organs.[16] In addition to anatomical risk factors, beliefs about gender roles, knowledge of sex and sexuality, and gender inequality in relationships all play important roles in determining girls' risk factors and risk behavior.[17-19] Trauma and intimate partner violence (IPV), as well as associated post-traumatic stress disorder (PTSD), are also significantly higher among HIV-positive women and girls, than among the general population of women. Risk associated with IPV and HIV is two-sided: Women and girls are at increased risk for violence because of their HIV status, and those who experience violence are at increased risk for being infected with HIV.[20,21] Among women and girls who have experienced IPV in the United States, 69% experienced this violence at age 25 or younger, and 22% experienced IPV for the first time between the ages of 11 and 17 years old.[22]

Trauma and IPV are linked to poorer health outcomes along the HIV Care Continuum.[21] For many women and girls, engagement in care and medication adherence cannot be separated from painful reminders of violence or betrayal. As "Tammy," a Ryan White HIV/AIDS Program Part D client, says, "I know I need to take my meds. It's just so hard some days. I thought we were in love. I thought he was monogamous. Now, every day from here until forever I have to live with a reminder of what he's done. I can never escape it."

Young MSM

Gay, bisexual, and other men who have sex with men have particularly high rates of HIV infection and face their own unique set of challenges. For example, social networking sites for sex-seeking are particularly popular among YMSM and contribute to an increased number of sex partners and increased risk for STIs.[23] As one Ryan White HIV/AIDS Program YMSM client states, "It's easier to find a hook-up online now than it is to order Chinese takeout." He adds, "It's the reverse order of a relationship. We hook up first and then if there is chemistry and real connection, then maybe you'll date. Quite honestly, we only see heterosexual relationships in the media. I don't know what a healthy, black, gay relationship looks like. I've never seen it."

Among Ryan White HIV/AIDS Program clients aged 13–30, MSM was the transmission category for 60% of infections. The racial/ethnic distribution among YMSM in 2013 was 54% black, non-Hispanic; 22% Hispanic; 20% white, non-Hispanic; and 4% other races.

Black, non-Hispanics were particularly overrepresented among YMSM aged 13–24.* This is consistent with national trends: from 2009 to 2013, young, black MSM aged 13–24 had the largest increase in diagnoses of HIV infection compared to other racial/ethnic groups of YMSM —from 3,895 diagnoses in 2009 to 4,643 diagnoses in 2013.[24]

MSM of color, including YMSM of color, tend to select sexual partners who are of the same race/ethnicity. Higher HIV prevalence, coupled with a smaller dating community, place these individuals at increased risk.[25-27] MSM, especially YMSM, may also underestimate their risk or make inaccurate assumptions about their partner's HIV status. For example, the National HIV Behavioral Surveillance System conducted HIV testing in 20 cities and found that only 49% of HIV-positive YMSM aged 18–24 knew of their infection.[28] For black YMSM, partnering with older black men (among whom HIV prevalence is high) may also lead to increased risk, particularly as HIV prevalence is found to increase with age among the MSM population.[27]

*Among RSR clients, approximately 68% of YMSM aged 13–18 were black, non-Hispanic, and 62% of YMSM aged 19–24 were black, non-Hispanic

Transitioning into Adulthood: Behaviorally Infected Youth and Perinatally Infected Youth

The efficacy of HIV antiretroviral therapy (ART) has greatly improved life expectancy for HIV-positive individuals and, as a result, many adolescents are making the transition into adult care systems. By the age of 21, HIV-positive young adults should make a planned, purposeful switch from child-centered to adult care.[29] The differences between these care models are well-documented, and the primary difference is fragmentation of services. While child-centered care facilities utilize multidisciplinary teams of pediatricians, nurses, social workers, psychologists, child life therapists, and other dedicated caregivers, adult-oriented care often fails to include both medical and psychosocial services.[29] These services are especially important as HIV-infected young people have higher rates of mental health issues like anxiety, depression, and PTSD than their HIV-negative peers.[7]

Perinatally infected youth account for 9% of Ryan White HIV/AIDS Program clients aged 13–30, compared to 87% of behaviorally infected youth, and 4% other transmission modes. Perinatally infected youth often experience drug resistance after many years of ART therapy and, in some cases, inconsistent treatment adherence. Because of this, they are more likely to have complex, intolerable medication regimens and to be in advanced stages of HIV disease compared to behaviorally infected youth.[30] The most common barriers to care experienced by both groups are forgetting to take medication and consciously deciding to take a break. A higher number of identified barriers is also associated with poorer medication adherence.[31]

Many youth, particularly those perinatally infected, establish strong emotional attachments to their pediatric health care providers and are reluctant to break these bonds. Consequently, transitions can be very challenging, and 50% of perinatally infected youth report adherence difficulties post-transition.[32] As "Luisa," a perinatally infected Ryan White HIV/AIDS Program client explains of the transition, "I'm not scared of leaving [pediatric care], and I know I can come back and visit. But it'll be different. I can't open up to everybody and have them walk out of my life," she says. "I've had that my whole life going in and out of foster homes. I've finally found people I trust and I don't want to start over."

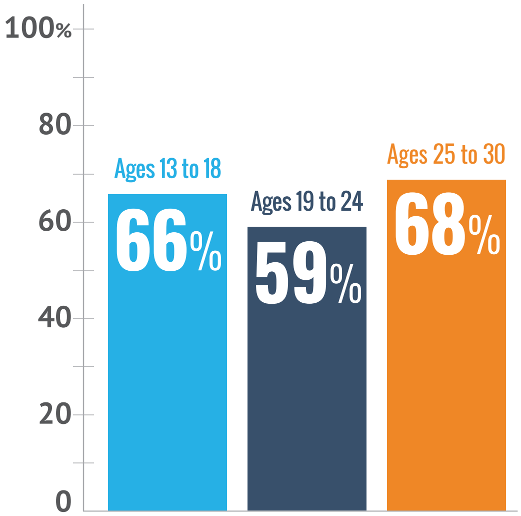
While Luisa's story is unique, her concerns are not. Creating a supportive environment for youth transitioning to adult care requires understanding the circumstances surrounding where these clients are coming from and who they are. The vast majority of Ryan White HIV/AIDS Program clients are racial and ethnic minorities, and almost all are dealing with the effects of poverty and lack of private insurance. For most of these clients, life has been filled with uncertainty and has been anything but easy. Many youth received little or no medical care or access to information about their health prior to becoming HIV-positive and entering care at a Ryan White HIV/AIDS Program-funded facility. For youth facing developmental, security-related, and mental and physical health-related challenges, these challenges do not necessarily disappear when clients enter adult care and, thus, providers need to create a welcoming environment where youth feel safe and supported.

Viral Suppression and Retention in Care

Knowledge of HIV infection, retention in HIV care, and viral suppression are key pieces of the HIV Care Continuum and carry both individual and public health benefits.[33] Having access to caring and culturally competent staff within a welcoming environment can mean the difference between youth engaging in services and moving along the HIV Care Continuum or walking out the door. "Why would I go across town to have a receptionist give me attitude and then sit in some cold, sterile waiting room for 30 minutes just to be seen for 10?" asks "DaShawn," a Ryan White HIV/AIDS Program youth client. "It's got to be a place I'd want to hang out. Even better if the people working there look like me."

Figure 4. Viral Suppression among Youth Served by the Ryan White HIV/AIDS Program

by Age Group, 2013

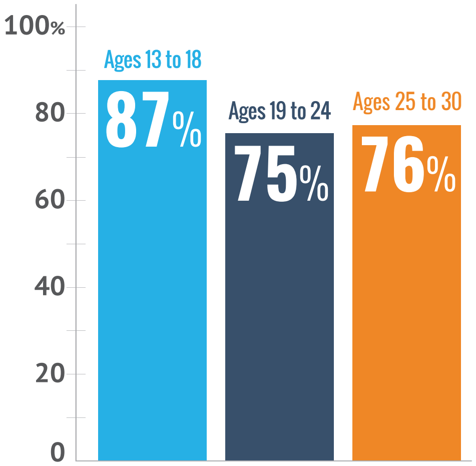


Source: Ryan White Services Report data, 2013

Ryan White HIV/AIDS Program grantees and providers have found ways to successfully connect with youth, and better viral suppression outcomes have been seen among youth in Ryan White HIV/AIDS Program settings compared to national estimates.[34] But there is room for improvement: for example, among Ryan White HIV/AIDS Program clients of all ages, approximately 79% were virally suppressed in 2013; youth clients, however, had lower percentages of viral suppression than the average, as illustrated in Figure 4.

Figure 5. Retention in HIV Care among Youth Served by the Ryan White HIV/AIDS Program

by Age Group, 2013

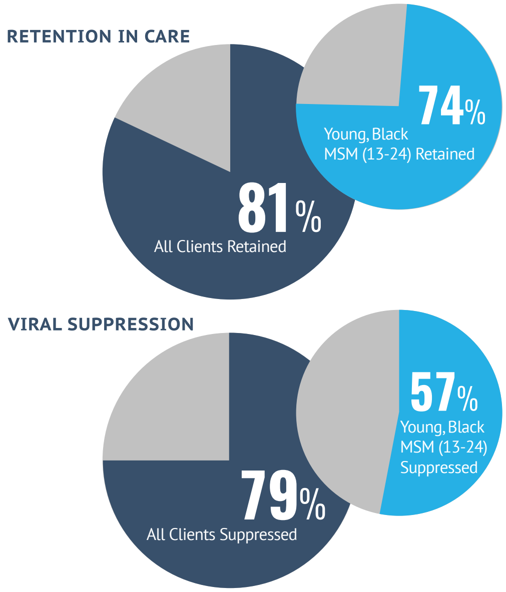


Source: Ryan White Services Report data, 2013

Lack of viral suppression among HIV-positive youth—a sexually active population with inconsistent condom use—may lead to increased HIV transmission.[35,36] Black, non-Hispanic clients are the least likely of any racial/ethnic group to be virally suppressed. This is particularly noteworthy given high rates of HIV infection among black, non-Hispanic YMSM and black, non-Hispanic young women.

Retention in care is a critical component supporting viral suppression. Youth served through the Ryan White HIV/AIDS Program in 2013 achieved significantly better retention in care than national estimates,[34] although gaps continue to exist between percentages of youth retained in care and those who achieve viral suppression. Figure 5 shows the percentages of retention in care among youth in the different age groups; these percentages are particularly higher than the viral suppression percentages in Figure 4.

Figure 6. Retention in Care and Viral Suppression among Young, Black MSM Served by the Ryan White HIV/AIDS Program, 2013



Source: Ryan White Services Report data, 2013

When examining young, black MSM aged 13–24—the most at-risk youth population—retention and viral suppression are both lower than Ryan White HIV/AIDS Program clients overall (Figure 6) and lower than the averages among youth clients. Continued efforts to better reach this population and deliver the services and adherence information they need remains critical to curtailing new infections and moving closer to an AIDS-free generation.

Examples of Successful Interventions

Grantee sites are using a variety of innovative methods to successfully facilitate engagement in care and leadership development among youth and young adults with HIV. Although each operating model is unique, successful programs are striving to be as youth-friendly and accommodating as possible while encouraging youth to take an active role in the HIV community.

Howard Brown Health Center

Mary Brewster and Beto Soberanis of Howard Brown Health Center in Chicago, IL, believe it is critical to engage youth in overall health care, not just HIV care. To facilitate this, all case managers at Howard Brown are certified Affordable Care Act enrollment counselors, allowing them to help clients obtain insurance and learn how to utilize it. "We try to break down any of those barriers you see in more traditional medical settings and make it as accessible to our youth as possible," says Brewster, the youth program director.

At Howard Brown, a lesbian, gay, bisexual, transgender, and queer-friendly facility, this may entail combining hormonal therapy and HIV treatment into one appointment, absorbing the cost of HIV treatment for youth who are unable to access insurance, or meeting youth off-site. Case managers working specifically with the youth population strive to make their facility a one-stop health center where patients can access all of the medical services they need in one location. If needed, appointments are provided on a walk-in basis, especially for those who are transient or street-based, to make HIV care as simple and accessible as possible.

New York State AIDS Institute

To encourage leadership among youth with HIV, the AIDS Institute in New York has formed a Young Adults Consumer Advisory Committee (YACAC). Youth aged 13–24 meet periodically to discuss relevant and timely issues, including pre-exposure prophylaxis (PrEP), stigma, discrimination, and emotional attachment to pediatric providers. They have the opportunity to provide feedback and recommendations to AIDS Institute staff, as well as to speak directly with clinical providers to voice any concerns. Participants are often paired with older mentors from the AIDS Institute's adult advisory committee to support their engagement in YACAC, and both encourage and facilitate the subsequent transition to the adult consumer advisory board.

Dan Tietz, the AIDS program manager for consumer affairs, stresses the importance of meeting youth at their level. Logistically, this entails flexible scheduling to accommodate school and other activities, communicating with youth informally through social media and text messages, and hiring dedicated staff that are as young or peer-like as possible. "These youth understand that when they give recommendations, they see tangible results. One of the keys is to let it be their process and respect that process." Youth seeing their recommendations readily implemented within the clinic has a two-fold result: a more youth-friendly clinic overall, and development of the next generation of HIV leaders. Youth are additionally provided with opportunities to be involved in their care, with the goal of promoting improved self-management and an easier transition into the adult care system.

Children's Hospital & Research Center Oakland

Because the transition from child-centered to adult care systems is often difficult for HIV-infected youth, patients at the Oakland Children's Hospital begin preparing early. From ages 17–21, young adults are led through a transition program to ensure they have a full understanding of the HIV disease process, their own medical history, and the importance of medication adherence and engagement in care. "A successful youth program incorporates a pediatric program that has a dedicated HIV youth program for the kids to transition through," says Stephanie Montgomery at Oakland Children's Hospital.

Youth at Oakland Children's Hospital are also encouraged to attend the One Love Conference, a 3-day youth-created, youth-led conference held at a local California college campus. It gives adolescents and young adults an opportunity to engage in discussions and workshops on issues such as finances, relationships, and medication adherence, as well as providing an opportunity to develop leadership skills. The hospital-affiliated Downtown Youth Clinic also focuses on the transition from pediatric to adult systems of care by employing peer advocates to work with youth to identify key goals for not only their health but also for school and careers, thereby critically thinking about their futures and setting themselves up for success.

Characteristics of a Successful Youth Program

While programs vary, certain shared characteristics across sites can help providers refine their work to better reach—and engage—HIV-positive youth. These include:

- An LGBTQ-friendly environment
- One-stop shops with health, hormone therapy, and social support services in one location (if not feasible, active referrals to youth-friendly social support settings)
- Employment of youth-dedicated, youth-friendly staff
- Accessible location with walk-in appointments and flexible scheduling
- Uses informal modes of communication, like texting and social media
- Creates a warm, welcoming environment with social interaction and entertainment in waiting areas
- Active communication with youth
- Opportunity for youth to give feedback and have opinions heard
- Creation of leadership opportunities for youth
- Access to youth peer support groups
- Incentives, where possible, such as bus tokens to alleviate the financial burden of transportation
- Navigators to help youth understand the health care system and enroll them into Affordable Care Act coverage (if applicable)
- Development of individualized transition plans
- Early transition planning for adult care
- Health education
- Goal-setting (for health, school, career)
- Connection to youth-friendly activities and conferences to support social networking and skills building

Conclusion

HRSA focuses efforts on youth in a myriad of ways and equips providers with best practices for reaching this population. Through the Integrating HIV Innovative Practices (IHIP) Project, SPNS has created training manuals and curricula around hard-to-reach populations, including youth. Other ways SPNS is evaluating and addressing the needs of HIV-positive youth include a BMSM initiative focused on youth:

> The Ryan White HIV/AIDS Program Part B-funded Resource and Technical Assistance Center for HIV Prevention and Care for Black Men who have Sex with Men Cooperative Agreement has a special focus on YMSM youth aged 13–24. This project is working to synthesize strategies for reaching and engaging this population and creating technical assistance materials to help the broader Ryan White HIV/AIDS Community.

Additionally, publications such as this report underscore issues among youth as well as strategies for reaching them. Similarly, a forthcoming HRSA CAREAction newsletter on social media includes tips on reaching youth via various online platforms and how to literally meet youth "where they are."

HRSA encourages grantees to increase their communication and collaboration with one another to create an even stronger safety net for high-risk populations such as youth. For example, the National Quality Center, in conjunction with HRSA's Division of Community HIV/AIDS Programs, created a Part C and D Collaborative to establish sustainable clinical quality management programs, share best practices across Part C- and D-funded sites, and ultimately improve health outcomes. The Ryan White HIV/AIDS Program has a rich history and a depth of knowledge to share with the broader health care community, just as grantees have much to share with one another.

Ultimately, effectively addressing challenges requires knowing where a need exists, understanding how to address it, and staying the course to see it through. For HRSA, the RSR data highlight client needs and challenges. As the HRSA Living History website essay on youth[37] illustrates, the Bureau has a longstanding and unwavering commitment to addressing HIV among young people in the United States. HRSA remains committed to proactively tackling barriers to care to bring HIV-positive youth into care, provide them a seat at the table, and ensure that they have a bright future.

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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).

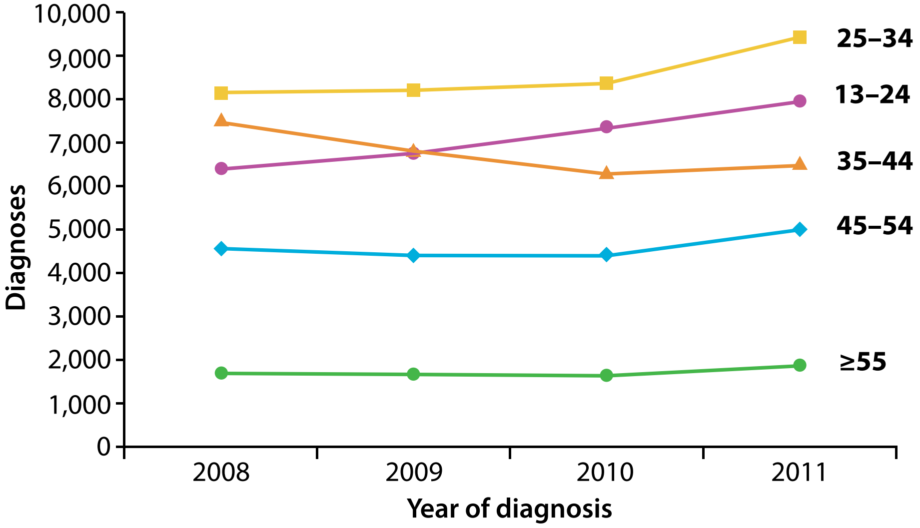
YMSM:

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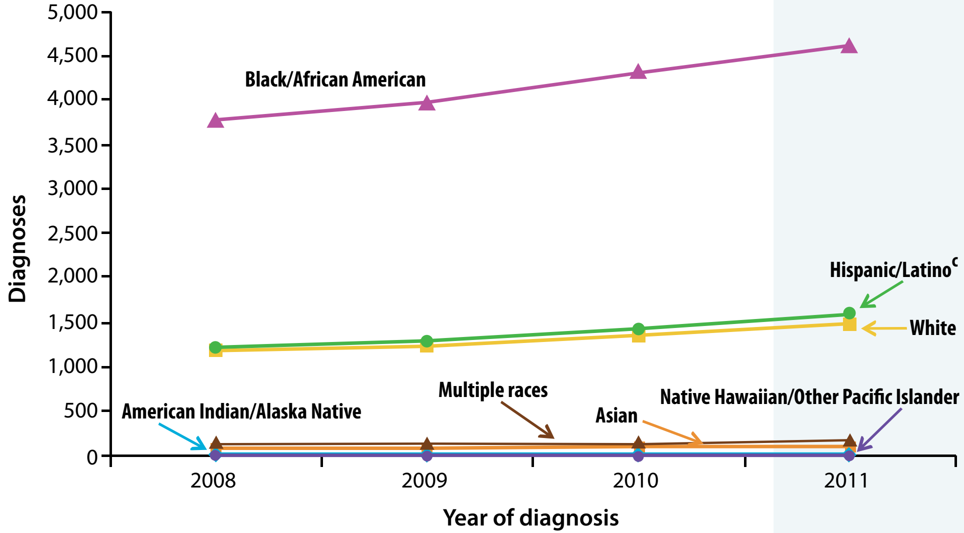
[a] CDC uses the term men who have sex with men (MSM) in its surveillance systems. MSM indicates the behaviors that transmit HIV infection, rather than how individuals self-identify in terms of their sexuality.

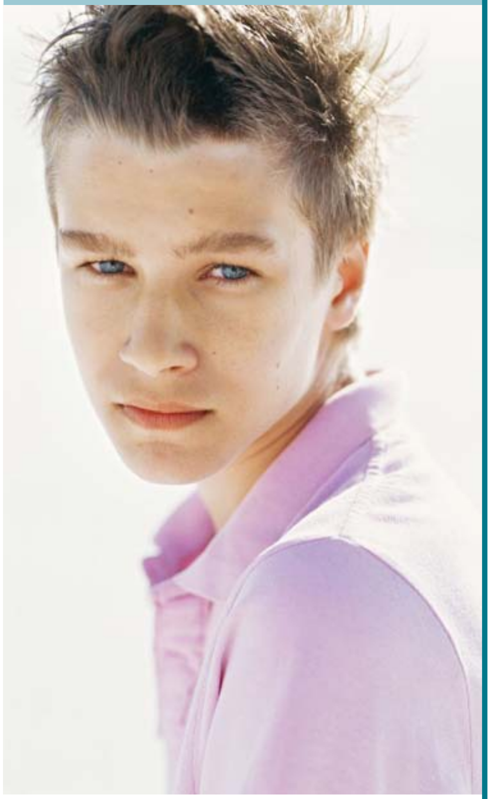
[b] Black/African American: Referred to as black in this fact sheet.

[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]

[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.

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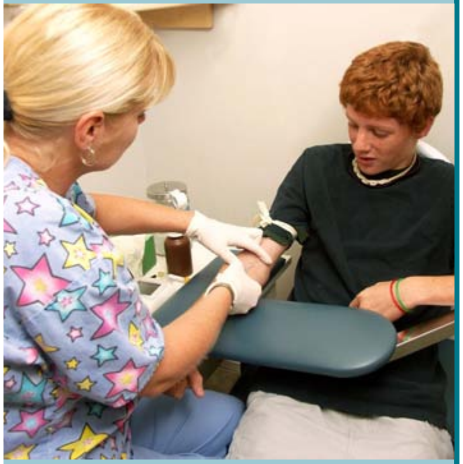
[e] Sexual health education programs that are medically accurate, consistent with scientific evidence, and tailored to students' contexts; and that use effective classroom instructional methods.

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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HIV Among Women

March 2016

Fast Facts

- Around 1 in 4 people living with HIV in the United States are women.
- Most new HIV diagnoses in women are attributed to heterosexual sex.
- Between 2005 and 2014, the number of new HIV diagnoses among women declined 40%.

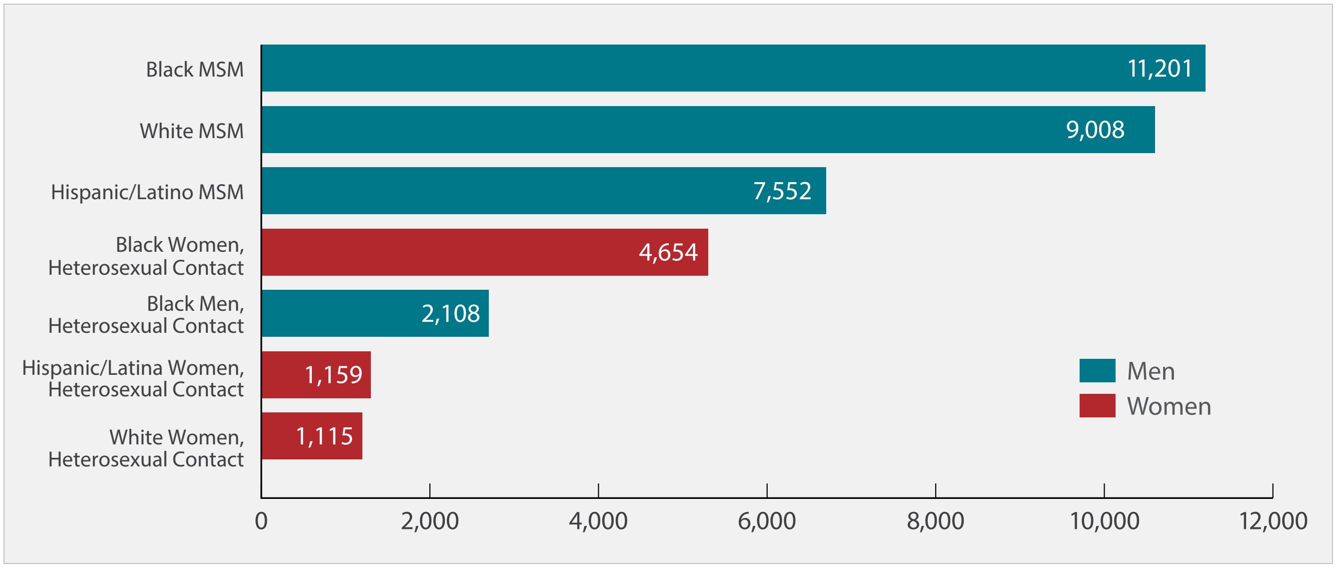
Black/African American[a] and Hispanic/Latina[b] women continue to be disproportionately affected by HIV, compared with women of other races/ethnicities. Of the total estimated number of women[c] living with diagnosed HIV at the end of 2013, 61% (137,504) were African American, 17% (39,177) were white, and 17% (38,664) were Hispanics/Latinas.

The Numbers

HIV and AIDS Diagnoses[d]

- Women made up 19% (8,328) of the estimated 44,073 new HIV diagnoses in the United States in 2014. Of these, 87% (7,242) were attributed to heterosexual sex,[e] and 13% (1,045) were attributed to injection drug use.
- Among all women diagnosed with HIV in 2014, an estimated 62% (5,128) were African American, 18% (1,483) were white, and 16% (1,350) were Hispanic/Latina.
- New HIV diagnoses declined 40% among women from 2005 to 2014. They declined 42% among African American women, 35% among Latina women, and 30% among white women.
- Women accounted for 25% (5,168) of the estimated 20,792 AIDS diagnoses among adults and adolescents in 2014 and represent 20% (246,372) of the estimated 1,210,835 cumulative AIDS diagnoses in the United States from the beginning of the epidemic through the end of 2014.

Estimated New HIV Diagnoses in the United States for the Most-Affected Subpopulations, 2014



Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2014 (http://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-us.pdf). *HIV Surveillance Report* 2015;26. Subpopulations representing 2% or less of HIV diagnoses are not reflected in this chart. Abbreviation: MSM = men who have sex with men.

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

[b] Hispanics/Latinas can be of any race.

[c] Adult and adolescent females aged 13 and older.

[d] HIV and AIDS diagnoses indicate when a person is diagnosed with HIV infection or AIDS, but do not indicate when the person was infected.

[e] Heterosexual sex with a person known to have, or be at high risk for, HIV infection.

[f] In 27 states and the District of Columbia (the areas with complete lab reporting by December 2014).

[g] A person with a suppressed viral load has a very low level of the virus. That person can stay healthy and has a dramatically reduced risk of transmitting the virus to others.

Living With HIV and Deaths

- An estimated 284,500 women were living with HIV at the end of 2012, representing 23% of all Americans living with the virus. Of women living with HIV, around 11% do not know they are infected.
- Of women diagnosed with HIV in 2013, 84% were linked to HIV medical care within 3 months. But only 55% of women living with HIV were retained in care (receiving continuous HIV medical care).[f] Only 39% of women living with HIV at the end of 2012 were prescribed antiretroviral therapy (ART), the medicines used to treat HIV, and only 30% had achieved viral suppression.[g]
- An estimated 1,859 women died from HIV or AIDS during 2013.

Prevention Challenges

- The greater number of people living with HIV (prevalence) in African American and Hispanic/Latino communities and the fact that people tend to have sex with partners of the same race/ethnicity mean that women from these communities face a greater risk of HIV infection with each new sexual encounter.
- Some women may be unaware of their male partner's risk factors for HIV (such as injection drug use or having sex with men) and may not use condoms.
- Assuming no prevention methods (http://www.cdc.gov/hiv/basics/prevention.html) (such as condoms or medicines to prevent HIV [http://www.cdc.gov/hiv/risk/prep/index.html]) are used, the risk of getting HIV during vaginal sex is higher for women than it is for men. Anal sex is riskier for getting HIV than vaginal sex, and the risk is much greater for the receptive partner than for the insertive partner in anal sex. In a behavioral survey of heterosexual women at increased risk of HIV infection, 25% of HIV-negative women reported having anal sex without a condom in the previous year.
- Some sexually transmitted diseases, such as gonorrhea and syphilis, greatly increase the likelihood of getting or spreading HIV.
- Women who have been sexually abused may be more likely than women with no abuse history to engage in sexual behaviors like exchanging sex for drugs, having multiple partners, or having sex without a condom.

What Is CDC Doing?

Through its high-impact prevention approach, CDC is working with state and local partners throughout the United States to identify and implement the most cost-effective and scalable interventions in the geographic areas and populations most affected by HIV. Activities include:

- Funding to health departments and community-based organizations:
  - Awards of $339 million over 5 years (2012-2016) to health departments to direct resources to the geographic areas of greatest need and prioritize the HIV prevention strategies that will have the greatest impact on the US epidemic.
  - Awards of approximately $130 million over 5 years (2014-2019) to provide training and technical assistance for staff of health departments, community-based organizations, and health care organizations to help them link HIV-positive people to care, retain or reengage them in care, and help them achieve viral suppression.
- The *Act Against AIDS* (http://www.cdc.gov/actagainstaids/index.html) campaigns, including
  - *Doing It* (http://www.cdc.gov/actagainstaids/campaigns/doingit/index.html), a new national HIV testing and prevention campaign that encourages all adults to know their HIV status and protect themselves and their community by making HIV testing a part of their regular health routine;
  - *Let's Stop HIV Together* (http://www.cdc.gov/actagainstaids/campaigns/lsht/index.html), which raises HIV awareness and fights stigma among all Americans and provides many stories about people living with HIV;
  - *One Test. Two Lives.* (http://www.cdc.gov/actagainstaids/campaigns/ottl/index.html), which provides resources to help obstetric providers test their patients.
- *Partnering and Communicating Together (PACT) to Act Against AIDS* (http://www.cdc.gov/actagainstaids/partnerships/pact.html), a new 5-year partnership between CDC and leading national organizations representing the populations hardest hit by HIV and AIDS, to intensify HIV prevention efforts in these populations.
- Research on microbicides—creams or gels that could be applied vaginally or anally before sexual contact to prevent HIV transmission.
- Support and technical assistance to health departments and community-based organizations to deliver effective behavioral interventions (https://effectiveinterventions.cdc.gov/en/Home.aspx).

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

SECURING THE FUTURE OF WOMEN-CENTERED CARE:

Findings from a Community-Based Research Project by Women Living with HIV

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POSITIVE WOMEN'S NETWORK - USA

www.pwn-usa.org /pwnusa @uspwn

EXECUTIVE SUMMARY

Women currently account for nearly a quarter of the domestic HIV epidemic[1]. In 2013, an estimated 9,278 women aged 13 years or older were newly diagnosed with HIV in the United States[2]. An overwhelming majority of these new HIV diagnoses resulted from heterosexual contact[3]. Women of color, especially Black women, bear a particular burden of the HIV epidemic, representing the majority of US women living with HIV as well as the majority of new infections[4]. Although women with HIV are more likely to be linked to care, they are also more likely to be initially diagnosed late and more likely to die than men with HIV. The majority of women with HIV are not engaged in regular care and only a third are virally suppressed[5]. Among people living with HIV in the US, women, Black Americans, and residents of the South have the poorest health outcomes[6,7].

These poor health outcomes have been overwhelmingly correlated with socioeconomic and structural barriers in the literature[8,9]. In addition, stigma, discrimination, and racism have been linked with lower engagement in care systems, worse provider-patient relationships, and worse health outcomes[10]. As the US HIV epidemic has become increasingly an epidemic which impacts those living in poverty, people of color, and communities facing multiple forms of discrimination, a spectrum of non-medical services has become progressively necessary to reduce barriers to medical care for people living with HIV.

For the past 25 years, the Ryan White Program has served as a critical gap-filler in helping to deliver these services. Although medicalization of the HIV response has been underway for decades, Ryan White has retained the flexibility to provide services that facilitate access to care, known as “supportive” services. The implementation of the Patient Protection and Affordable Care Act (the “Affordable Care Act” or “the ACA”) presents tremendous opportunities to expand access to healthcare for low-income people and those living with chronic health conditions. However, due to state discretion in adopting some ACA provisions, geographic disparities in access persist. As a crucial source of essential health coverage for people living with HIV, the Ryan White Program is likely to undergo reauthorization within the next several years. This marks a pivotal moment to understand which supportive services are most needed today, opportunities to fortify the HIV response through additions of new service categories, and how best to construct a Ryan White system that will support and leverage other existing resources.

The last several years have seen an increased biomedicalization of the HIV response, and a declining federal commitment to addressing the needs of women living with HIV(WLHIV) in the context of the domestic epidemic. Care continuum models which narrowly focus on medical visits, prescription refill status, and CD4 and viral suppression measures mask the actual experiences of women living with HIV in their attempts to engage with care as well as their experiences of wellness and quality of life. In the face of these changing healthcare needs, quality of life concerns, coverage availability, service delivery infrastructure, and political landscape, Positive Women’s Network – USA (PWN-USA), a national membership body of women living with HIV, facilitated a community-based participatory research project led and executed by women living with HIV to inform advocacy efforts around women-centered care. A 14-member team of women living with HIV conducted 180 surveys to assess availability and quality of medical and supportive services.

Findings indicated that women with HIV, by and large, are actively engaged in maintaining their health and seeking to live with dignity.

The Ryan White system is largely working well for women with HIV and should be maintained. However, given the changing landscape of the epidemic and demographics of those impacted, there are areas where improvement is possible. In particular, provision and quality of sexual and reproductive healthcare is inconsistent and differently affects women of reproductive and non-reproductive age. In addition, there is a high level of unmet need for mental health services. Finally, inadequate financial resources, family responsibilities and transportation challenges present ongoing structural barriers to engaging in consistent care for respondents.

BACKGROUND

THE RYAN WHITE PROGRAM

In 1990, Congress passed the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act, most recently reauthorized as the Ryan White HIV/AIDS Treatment Extension Act of 2009 (the "Ryan White Program," or "RWP"), to address the domestic crisis of the HIV epidemic. The Ryan White Program remains the nation's largest safety net program for HIV care and treatment, serving approximately half a million people living with HIV annually. In 2014, the RWP served 144,982 women living with HIV (WLHIV), comprising 28.3% of the total number of clients receiving services[11].

Ryan White-funded medical care is widely viewed as an early and effective "medical home model"[12,13,14] and has been held up for its multidisciplinary approach as an exemplar of comprehensive and coordinated patient-centered care.[15,16] The Ryan White Program is broken down into a number of legislative Parts aimed at addressing the specific medical, emotional, mental, and social support needs of people living with HIV.

THE RYAN WHITE PROGRAM – PART D

Within Ryan White, the Part D program stands out as one of a handful of collaborative models that have developed an evidence-based approach for intervening to improve HIV clinical outcomes[17] and as "epitomiz[ing] the CARE Act's overall mission."[18] Part D is known for its integrated, network-based models, which rely on collaboration and communication among a multidisciplinary group of providers, including community-based organizations. During the 2006 Ryan White reauthorization, the legislation was expanded to explicitly permit coverage of a range of non-medical services by Part D funding. These services included family-centered case management, referrals for substance use, mental health services, other social and support services and other services needed to support the patient and patient's family's participation in Part D services.

The flexibility under which services supporting engagement in care can be funded by Part D grants contrasts sharply with Parts A, B and C of the Ryan White legislation, each of which have been bound by a requirement to spend a minimum of 75% of their funds on "core medical services," such as medical, pharmaceutical, mental health, and insurance premium cost-sharing, since the 2006 reauthorization.[19] Remaining funds in Parts A, B and C may be used to resource the provision of "supportive services"*1 that help meet HIV-related medical outcomes. These services facilitate engagement in medical care by reducing barriers to access or by providing emotional, psychological, and other forms of support. To be an allowable cost under the RWP, all services must relate to HIV diagnosis, care and support, and must adhere to established HIV clinical practice standards reflecting HHS treatment guidelines[20].

Importantly, Part D is the only place in the entire Ryan White program where grantees are required to describe their plans to address a range of issues for female clients, including provision of family planning services, domestic violence awareness, health needs of perimenopausal and menopausal WLHIV, and coordination of medical care for pregnant WLHIV, including care after delivery.

In FY 2011, Ryan White Part D provided comprehensive services, including services to reduce perinatal transmission of HIV, to 60,621 female clients, and served a total of 187,819 clients[21]. For three consecutive years, the President's budget has proposed consolidating Part D into Part C of the Ryan White Program, asserting that because two-thirds of Part D grantees are also funded by Part C, such a consolidation will reduce administrative burden on co-funded grantees.

THE PROMISE OF THE AFFORDABLE CARE ACT

Signed into law in March 2010, the Affordable Care Act offers tremendous opportunity to improve access to healthcare for people living with HIV. The ACA prohibits health plans from charging higher premiums, or placing lifetime and annual benefit limits on individuals with preexisting conditions and Section 1557 protects individuals from discrimination on the

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*1 Supportive services are defined as services "needed for individuals with HIV/AIDS to achieve their medical outcomes (such as respite care for persons caring for individuals with HIV/AIDS, outreach services, medical transportation, linguistic services, and referrals for health care and support services."

basis of race, sex, disability, or age[22]. The legislation also expanded Medicaid eligibility, established state Health Insurance Marketplaces (exchanges), and created new benefit standards with prevention enhancements[23]. Qualified health plans in the state-based insurance marketplaces are required by law to include essential community providers serving low-income and underserved communities, including RWP providers.

Under the ACA, all new health plans are required to provide certain prevention services at no cost. This emphasis on prevention shows promise for improving quality of care for women: covered prevention services for women include well-woman visits, counseling and screening for intimate partner violence, HIV screening, and contraception counseling and dispensing.[24]

The expansion of state Medicaid coverage to individuals up to 138% of the Federal Poverty Level remains one of the most important reforms for WLHIV, who tend to be low income. However, in June of 2012, a Supreme Court decision challenging the law limited the authority of the Department of Health and Human Services Secretary to enforce the expansion throughout the states, effectively making the eligibility expansion optional[25]. Despite the fact the federal government will pay virtually all of the costs of associated with expansions through 2016, many Southern states remain opposed, using resistance to Medicaid expansion as a political football. Non-expansion states declined an estimated 32 billion dollars of federal funding by electing not to expand[26]. Refusal to implement this cornerstone of the reform presents a missed opportunity to confront racial, economic, and HIV-related health disparities prevalent in the South.

In non-expansion states and elsewhere, the Ryan White Program will remain critical to filling in gaps as a "payer of last resort" and for providing comprehensive and quality HIV care.

Approximately three quarters of RWP clients are insured but rely on the program to supplement their coverage and to provide critical support services that are not typically covered under insurance plans, such as case management, that can facilitate engagement in care.[27, 28]

METHODS

The Project was grounded in community-based participatory research methods (CBPR), which engage those most affected by an issue to conduct research on and analyze that issue, with the goal of devising strategies to resolve it[29]. CBPR is frequently conducted in collaboration with those who have formal training in research methods, fusing resources and technical skills derived from an academic setting with the invaluable insight of community members of an affected population who may be more likely to design meaningful questions and elicit participation from others who share similar circumstances.

For the Project, 14 women living with HIV ("the research team") were recruited and trained in CBPR research values and methods by Dr. Sonja Mackenzie, based at Santa Clara University. Training was conducted via a webinar series; webinars were recorded for later viewing and listening as needed. The research team was also provided with reading materials to support their understanding of CBPR processes.

Following the trainings, the team met regularly via phone and webinar, generating a set of research questions related to the quality and accessibility of care for WLHIV. Based on those questions and areas of interest, domains for an online survey instrument were developed. The survey was developed with support from PWN-USA staff, piloted by the team members, and went through several rounds of revisions with input from the researchers. Researchers then worked in teams of two to survey WLHIV in their respective communities. Researchers recruited survey respondents through their social and personal networks, local clinics, community-based organizations (CBOs), AIDS service organizations (ASOs) and other social service agencies. The survey instrument was administered online through SurveyMonkey. Researchers obtained signed informed consent from survey takers before administering the survey and participants received a $20 Target or Walmart gift card for their participation in the survey. Due to varying levels of literacy, in some instances researchers read the questions aloud to participants and recorded responses in the survey instrument.

In addition to survey data, researchers collected surveillance, epidemiological, and Ryan White service

utilization data in their seven geographic locations across the United States. Regions were: Baton Rouge, LA; San Francisco Bay Area, CA; Chicago, IL; San Diego, CA; Orangeburg area, SC; Tampa Bay, FL; and Southern Michigan. PWN-USA staff provided support to the research team through monthly calls for the full team, regular check-in calls with regional teams as needed, and ongoing development of materials to support the project.

Survey data were analyzed by PWN-USA staff in collaboration with the research team. Findings were presented to the research team for analysis and discussion in three stages. A webinar was held to present initial data, generate discussion and create opportunity for the research team to pose new questions about the data. Subsequently, a second webinar attempted to address those questions through data introduced and presented for discussion and analysis. Finally, the research team provided comments on the draft report, which were incorporated prior to release.

The research team consisted of 14 women living with HIV, all cisgender, including nine black women, three white women and two Latina women. Five researchers were under the age of 40, while the remaining nine were between the ages of 51 and 63.

FINDINGS

The majority of respondents were long-term HIV survivors. Mean time since diagnosis was 16 years. 76.7% of respondents had been diagnosed with HIV for 10 years or longer and 36.3% reported they had been diagnosed with HIV for 20 years or more. 11% of respondents had been diagnosed with HIV for less than five years.

Table 1. Selected Demographic Characteristics of Survey Respondents

	Percentage of HIV epidemic in US	**Percentage of survey respondents**
Race		
Black/African-American	63%	67%
Caucasian/White	18%	16%
Latina/Chicana	18%	9%
Age		
44 and under	45.8%	40.8%
45 or over	54.1%	59.2%
		Mean: 46.7 years
Sexual Orientation		
Heterosexual	unknown	78%
Lesbian or Gay		6.1%
Bisexual		4.9%
Residence		
Urban		65.2%
Rural		22%
Suburban		12.8%
South	48%	43%
Non-South	52%	57%

According to the 2014 Ryan White Services report, 83.1% of female clients were at ≤138% of the FPL, while 72.5% of female clients were at ≤100% FPL, compared with 76.3% and 64.2% of Ryan White clients overall respectively. Our sample thus tended to be even lower income than women in the Ryan White client population, at 89.7% of respondents below 138% of the FPL and 73.8% below 100% of the FPL. 45% of our sample was living on less than $10,000 per year. 24% of

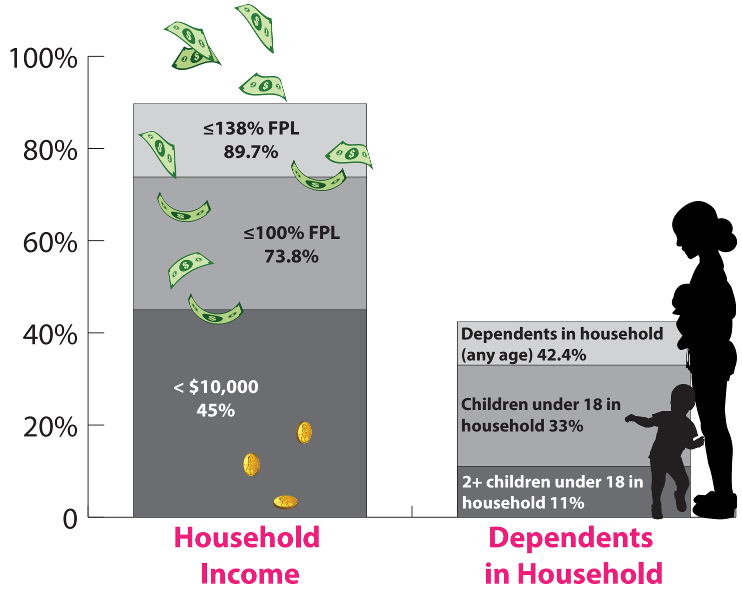

Figure 1. Household Income and Number of Dependents in Household

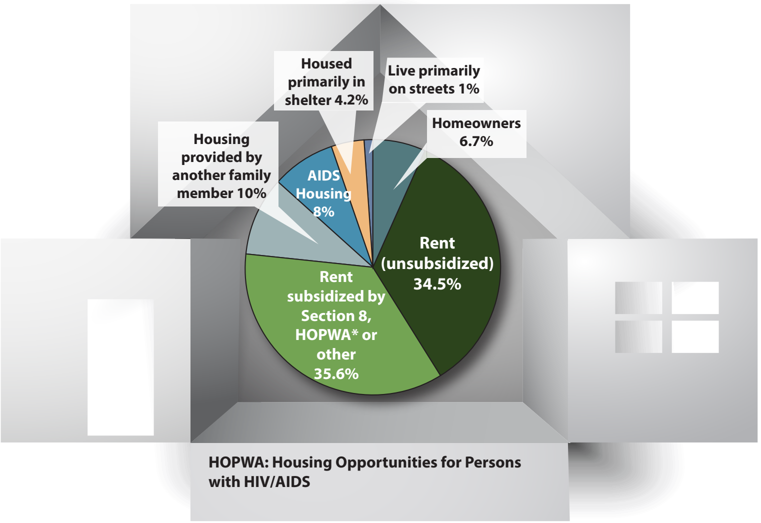

Figure 2. Housing Status

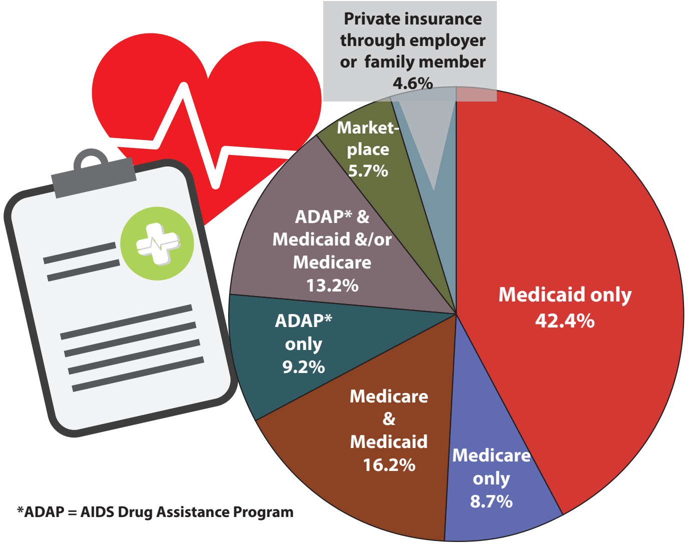

Figure 3. Healthcare Coverage

respondents in our sample were being paid for work (performed part of time or full time). 80% of survey respondents reported that their income was the sole source of income in their households.

Table 2. Diagnosed Co-morbidities Reported by Respondents

Co-Morbidity	% of Respondents Diagnosed
Hypertension	30%
Hepatitis C	21.6%
Diabetes	17.2%
Chronic lower respiratory disease	12.7%
Cervical cancer	9%
Chronic liver disease	7%
Heart disease	6%
Another form of cancer	5%

WOMEN ON THE CARE CONTINUUM

MEDICAL CARE

The success of the Ryan White Program in providing a spectrum of high quality care and services should not be understated. Because our researchers recruited respondents primarily through Ryan White clinics, ASOs and other HIV service providers, it is unsurprising that our engagement in care picture appears more favorable than national statistics on the care continuum for all US women living with HIV.

Most respondents reported a high level of confidence in their provider's expertise on HIV care (86%), and a high level of trust in their providers to maintain confidentiality of their medical information (82%). 51% of respondents reported they had not missed a medical appointment in the past year. 96% of respondents reported medical or supportive receiving services through community based organizations or clinics funded by Ryan White.

The survey inquired about all medications prescribed to respondents. Survey participants reported an average of three prescriptions, with 12% of respondents indicating they had five or more

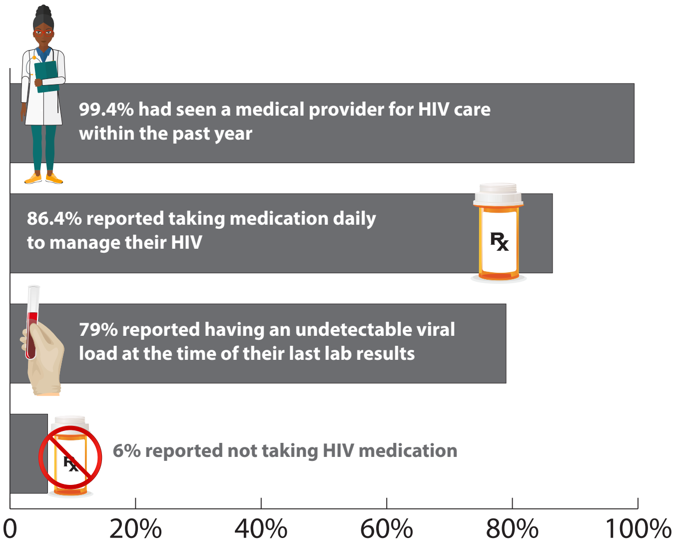

Figure 4. Engagement in Care

prescriptions. 30% were prescribed a single tablet daily HIV regimen.

Over 14% of respondents reported that their out-of-pocket medication costs for copayments had increased over the past year, with 37% of those reporting increases of $11-20 and an additional 15% reporting increases of $21-40 a month.

SEXUAL AND REPRODUCTIVE HEALTHCARE

While a majority of respondents reported having received a pap smear within the last 3 years as recommended by current cancer screening guidelines, age disparities were apparent in screening rates, with women of reproductive age (44 and younger) more likely to be screened than women 45 years of age and older. Additionally, most respondents of reproductive age had not been asked in the past year whether they wanted to get pregnant or needed birth control.

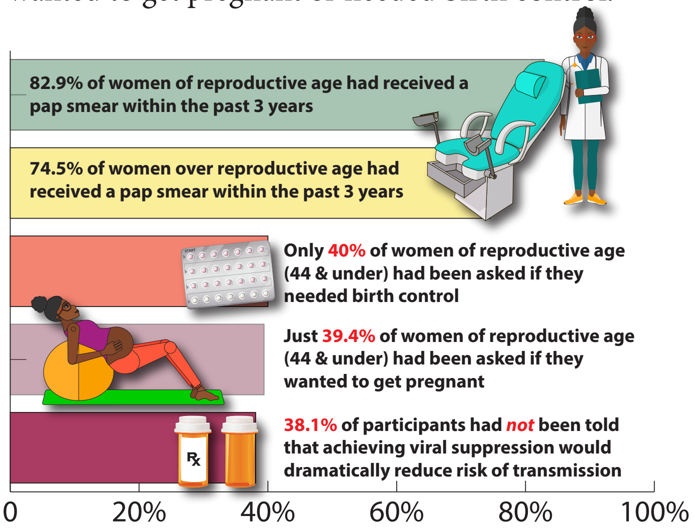

Figure 5. Sexual and Reproductive Healthcare Needs

MENTAL HEALTH

Respondents demonstrated a high need for mental health services. 17% of respondents reported they had been diagnosed with post-traumatic stress disorder (PTSD). In addition, an alarming 64.9% had been diagnosed with depression. Nearly two-thirds (64.6%) of respondents reported that they would like to see someone for counseling or therapy, of those, 59% reported being able to access these services as often as they needed. A quarter of those who reported needing group therapy had been unable to access these services.

SUPPORTIVE SERVICES

While the survey found overall high levels of engagement in care, adherence to medication, and robust support systems, barriers to care were significant and respondents often reported facing multiple obstacles.

CASE MANAGEMENT AND TREATMENT ADHERENCE

Most respondents (76.2%) reported they were receiving case management services at the time the survey was administered, and the majority receiving such services were satisfied with them. However, 15% of respondents reporting that they needed medical case management had not received any in the past year, and respondents reported a particular need for support with treatment literacy and medication adherence.

Nearly a fifth of respondents who said they needed help understanding their prescribed medications and how to take them did not receive such support.

CHILDCARE

14.8% of respondents reported needing childcare services on-site at their HIV medical service provider in the past year; however, of those who needed this service over half (52%) did not receive it. Women who had not received this service tended to be older (mean age 36, compared with 32 for those who had received this service). Over half of respondents who needed childcare services on site at a non-medical HIV service provider had not received those services. An age disparity was visible here as well: the mean age of those who had received childcare services was 32.2 years, and of those who had not, 39.5 years.

TRANSPORTATION

Over a third of respondents (34.2%) reported an unmet need for rides to medical appointments in the past year. 38.5% of respondents who needed transportation vouchers to get to medical appointments in the past year had not been able to get such vouchers. Of the 88 respondents who had missed at least one medical appointment in the 12 months prior, 50% of this group cited lack of transportation as the primary reason, and a quarter of respondents reported that transportation to and from medical appointments was the single biggest factor that would improve their ability to remain in HIV care. Another 18% of respondents (mean age = 36.3 years) reported they specifically needed medical transportation that would allow dependent children to travel with them. Respondents who reported being unable to access transportation that would allow dependent children to travel with them tended to be older (mean age = 40.3 years).

Nearly a third of respondents reported they had missed filling a prescription for HIV medications within the past year, with the primary reasons being lack of transportation (24%) and cost of copays (15%). All respondents who reported they had missed filling a prescription due to copay cost in the past year also reported that they had missed a medical appointment due to lack of transportation. Each of these respondents was on Medicaid.

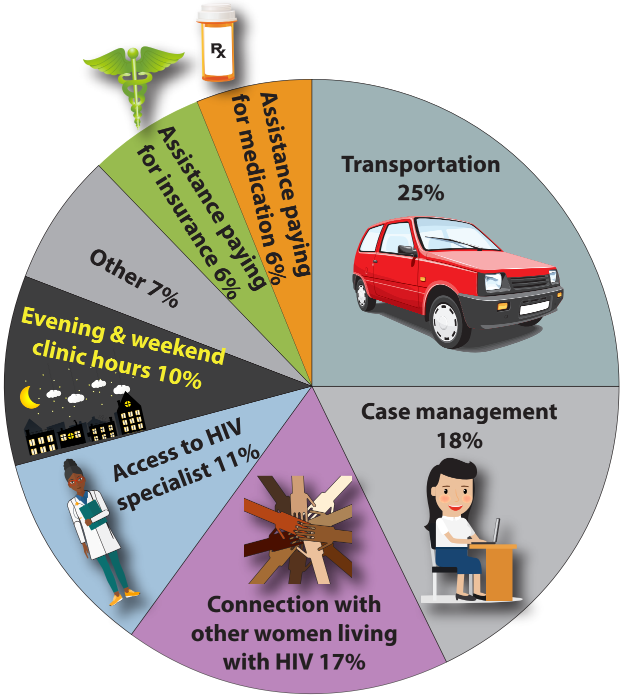

Figure 6. What One Thing Would Improve Your Ability to Stay in Care?

DISCUSSION

Significant advances have been made in medical treatment for HIV and in our understanding of the potential of viral suppression to prevent onward transmission of HIV. However, the findings from this community-based participatory research project indicate that women with HIV face significant barriers to engaging in care and living life with dignity. Many of these challenges are related to a system that has not adequately evolved to address the needs of a population who are simultaneously aging with HIV, living in extreme poverty, managing co-occurring health conditions, coping with the impacts of lifetime trauma and structural racism, and continuing to face stigma, discrimination, and microagressions. These barriers may impede unfettered access to healthcare delivered in any setting.

ECONOMIC INSECURITY PRESENTS AN OBSTACLE TO ACCESSING MEDICAL CARE AND PRESCRIPTIONS

It is well documented that women with HIV tend to be lower-income than the overall population of people living with HIV in the US[30]. Although 31% of respondents were either volunteering or working full-time, nearly three-quarters of respondents reported incomes at or below 100% of the FPL. Severely limited economic resources were directly or indirectly linked with many of the reported barriers to care. Despite respondents' commitment to their care, lack of financial flexibility to manage copayments, transportation, childcare, and other basic needs presented a challenge.

Strikingly, transportation presented the single largest barrier to women of all ages accessing healthcare and filling their prescriptions, independently of urban/rural residence. 8% of respondents who had missed a medical appointment in the past year reported that it was because they were too sick to go. Navigating public transportation to go to an appointment may be much more formidable than getting in the car to drive when one is sick.

In addition, facing poverty while occupying the role of primary caretaker complicates several aspects of engagement in care. Many respondents needed but could not get transportation access to medical appointments that would allow children to travel with them.

As housing costs in large urban areas continue to rise, people living with HIV in major metropolitan areas may face displacement, having to move further from accessible services and public transportation options.

In addition, inconvenient hours—the reason given by 19% of those who had missed appointments and by 11% of those who had not filled a prescription—generally present the largest barrier to those with inflexible work hours, lack of transportation or who have family responsibilities.

WOMEN WITH HIV ARE AGING AND HAVE SIGNIFICANT FAMILY RESPONSIBILITIES

Women in our sample, as in the general epidemic among women, are aging with HIV, due to treatment advances. This has implications for individual health, family structures, and healthcare access needs. As women with HIV cope with long-term medication side effects as well as other co-morbidities, their healthcare needs become increasingly complex. A lack of dedicated treatment education support may undermine abilities of WLHIV to manage co-morbidities and long-term HIV care, including side effects, particularly as they are living longer with HIV and with other co-occurring conditions. However, the robust availability of case management services may provide a ready opportunity to expand treatment education services.

Despite challenges to accessing culturally relevant and comprehensible treatment education, our respondents were committed to their health and very active in their lives, families and communities. Most were able to name all medications they were taking and were actively making an effort to stay in care.

As women age with HIV, family structures are changing. Older women living with HIV often serve as family matriarchs and may be coping with feeding their families, as well as the effects of community violence, intergenerational effects of racist policing and incarceration, diminishing availability of social services, HIV, and myriad other health issues. As a result, they may find themselves physically and emotionally responsible for the wellbeing of multiple generations simultaneously - younger and older generations. With these added family and household responsibilities, severely limited financial resources are often stretched and ultimately affects their ability address their overall health, including HIV.

Traditionally, childcare and family services to support engagement in care have been available primarily or solely to women with HIV of reproductive age. However, as older women with HIV find themselves handling a host of evolving family responsibilities, they may require access to childcare, transportation support that allows family members to travel with them, and flexible clinic, pharmacy, and health consultation hours, in order to effectively engage in care.

QUALITY OF SEXUAL AND REPRODUCTIVE HEALTHCARE SERVICES IS INCONSISTENT AND VARIES BY AGE

Changing age demographics of WLHIV may also be a factor in securing access to sexual and reproductive healthcare services. Although significant scientific advances have occurred that provide an opportunity to expand sexual and reproductive health and rights (SRHR), project data reflect a persistent and significant communication breakdown between health providers and women living with HIV regarding sexual behavior, fertility choices and family planning, as similarly reported in previous studies[31].

Treatment as prevention, including viral suppression and pre-exposure prophylaxis (PrEP), combined with developments in reproductive health technologies have made having sex and building families safer, easier and less expensive for WLHIV. Yet respondents had not consistently been informed by their providers that viral suppression decreases the likelihood of passing HIV to a partner, many had not been asked whether they were interested in conceiving, and over half of reproductive age had not been offered birth control. Women over the age of 45 were less likely to have received essential preventive screenings such as pap smears.

Thus, the data show that WLHIV may still be experiencing sex negativity and reproductive stigma in healthcare settings and are too often denied the full range of sexual and reproductive health options. Stigma about sexual behavior may particularly affect provision of services for women who were diagnosed earlier in the epidemic and women with HIV over 44. Such stigma may be internalized, which can contribute to depression and other mental health issues.

NEED FOR MENTAL HEALTH AND PEER SUPPORT SERVICES

WLHIV are more likely to suffer from depression and post-traumatic stress disorder than women in the general population, prevalence which may derive from a history of abuse and/or living with a chronic stigmatized illness itself.[32] In addition, mental health of WLHIV is almost certainly negatively affected by racial discrimination and the persistent stress of poverty.

Our data show an inadequacy of available mental health services, with participants reporting high levels of unmet need for individual counseling, group therapy, and peer-based support groups.

Our data also demonstrate that many women with HIV would choose to participate in support groups with other WLHIV if available.

Geographic disparities are apparent in access to peer support services. Nearly all Michigan respondents reported they were unaware of any support groups in their area. By contrast, in Louisiana, respondents tended to be aware of support groups but reported that support groups available were not convenient for them. Among Southern respondents, 29% of those who were unable to access support groups reported not knowing of any such groups in their area, while 42.9% reported that support groups were inconvenient or hard to get to.

RECOMMENDATIONS

Care for women with living HIV in the Ryan White system is generally working, when they are able to access it. However, given the growing correlation between extreme poverty and HIV diagnosis, as well as increased longevity complicated by co-occurring conditions and mental health concerns, there is significant room for improvement in the following areas:

I. Mandate meaningful involvement of women living with HIV in community planning processes:

The Health Resources and Services Administration HIV/AIDS Bureau (HRSA HAB) and the Centers for Disease Control and Prevention (CDC) must make a joint commitment to mandate and support meaningful involvement of women living with HIV in integrated HIV prevention and care planning processes.

Meaningful involvement of people living with HIV/AIDS (MIPA) is a globally recognized principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives.[33] Mandating and supporting involvement is essential to ensuring communities receiving services have a say in how service priorities are determined, designed and implemented.

WLHIV should not only be passively consulted in such processes, but should be engaged in leadership in decision making bodies that govern the administration of care.

This will require dedicated support, training, and capacity building so that communities most impacted are prepared to participate in decision-making. Networks of people with HIV can serve as resources on the ground to prepare, support, and organize input from their constituents.

II. Implement interventions that improve the fundamental economic conditions of women's lives

Integrating access to services that support a pathway out of poverty is a critical next step for the future of HIV care and service delivery. Interventions such as micro-enterprise projects and building proficiency in financial management, budgeting, banking, and associated life skills should be institutionalized as part of HIV service delivery to support long-term financial security.

Healthcare systems, including the Ryan White Program, should consider ways to structurally incorporate linkages to job readiness and training, vocational rehabilitation, computer and Internet literacy and other services that provide opportunities for integration into the workforce.

Case managers and peer advocates have the potential to play a critical role in successful implementation of such programs. However, cross-training, linkage and coordination between HIV care systems, vocational rehabilitation, and workforce participation at the local level is necessary and should be resourced through structured funding opportunities.

There is not a one-size-fits-all approach to the issue of economic insecurity. Steady wages may present a new obstacle to healthcare coverage and ability to meet basic needs because women with HIV are required to maintain incomes below eligibility requirements in order to qualify for lifesaving benefits, such as ADAP, food and housing assistance, and Medicaid. Thus, individual level benefits advisement is needed to support informed decision-making as people with HIV attempt to transition into the formal workforce or to increase taxable wages earned.

To ensure success, structural barriers to employment should be eliminated, including but not limited to hiring practices that discriminate against people with criminal records.

Increasing technological literacy and Internet access also offers the potential to extend the success of telemedicine delivery in regions where transportation presents a major barrier to access, as well as enhancing the ability for people to manage, utilize and maximize their own electronic health records.

III. Improve the quality of HIV care provided, with a focus on mental health services, sexual and reproductive health, and addressing co-morbidities

Comprehensive HIV care must address the prevalence of co-morbidities and co-occurring conditions for WLHIV. Our data on Hepatitis C prevalence among women with HIV is consistent with national estimates that approximately a quarter of US people living with HIV are also living with Hepatitis C.

The President's FY2017 budget, released in February 2016, includes $9 million in funding for a Special Projects of National Significance initiative to identify and treat Hepatitis C among people living with HIV in the Ryan White care system. Such a focus on Hepatitis C should become a consistent priority within the Ryan White Program as long as it is necessary and we fully support this model as an example of leveraging an existing care system that is working well to cure and treat other co-morbidities and/or chronic conditions impacting people with HIV on a mass scale. In addition, as managing long-term life with HIV increasingly requires managing multiple complex health concerns, there is a growing need for treatment literacy programs and medication adherence support which address HIV along with other health concerns.

Similarly, given the high prevalence of depression and post-traumatic stress disorder among women living with HIV, implementation of trauma-informed primary care[34] in care settings serving WLHIV should be a priority.

Trauma-informed care offers tremendous potential to improve quality of services and the care environment for clients as well as providers.

Availability of mental health services and interventions that promote healing from trauma for people with HIV should be scaled up, starting with but not limited to Ryan White settings. Peer support structures, including support groups and peer advocacy programs, remain vital to support wellness and life goals of women with HIV, and should be consistently resourced.

Incredible progress has been made in our understanding of the potential for viral suppression to support HIV prevention goals. Despite a significant body of compelling data, it is unclear that providers serving people with HIV are up to date on the current state of the "treatment as prevention" (TasP) science.

To support accurate counseling on sexual health and reproductive rights, all healthcare and social service providers at clinical and community-based institutions serving people with HIV should receive regular trainings on the current state of the science around treatment as prevention and pre-exposure prophylaxis (PrEP).

Such trainings should be grounded in sex positivity and human rights, reproductive justice principles, and provide accurate, up-to-date information on the state of the science. Trainings should be directed to a range of professionals who engage with people living with HIV, including doctors, nurses, social workers, case managers, peer advocates, mental health professionals, and other providers. AIDS Education Training Centers (AETCs) should be utilized as an existing resource to create and deliver such trainings, in meaningful collaboration with local, regional or national networks of people living with HIV.

Ryan White Part D has historically provided high-quality, non-stigmatizing sexual and reproductive health (SRH) care to women with HIV of reproductive age and youth and adolescents living with HIV. Given the disparities in access to quality SRH care, we should build on Part D's successes by leveraging best practices and implementing standards for culturally relevant, non-stigmatizing, sex positive sexual and reproductive healthcare services for all people with HIV, independent of gender, gender identity, age, clinic type or payer source.

IV. Invest in supportive and facilitative services and reduce structural barriers to care

Transportation presents a clear barrier to consistent engagement in healthcare for women with HIV in urban, rural, South, and non-South settings. Medical transportation access should be improved and should consider the needs of women of all ages with family responsibilities. To further promote accessibility of care and treatment, clinics and pharmacies should consider extending or diversifying hours.

Childcare should be available for women with HIV who need it, both at clinics and at service delivery access points such as support groups, independently of the age of the client.

Lifting the AIDS Drugs Assistance Program (ADAP) restriction which bars provision of more than a month's supply of medication at once may reduce barriers to filling prescriptions, particularly where transportation and/or schedule are a factor.

In addition to medical case management, the RWP allocates funding for non-medical case management services (NMCM) to provide clients with guidance and assistance in accessing medical, social, community, legal, financial and other services, as well as fostering links between institutional and personal systems of support for their clients and key family members[35]. Redefining the spectrum of services covered by both medical and non-medical case management may be important future considerations for the Ryan White Program.

V. Addressing stigma, including institutionalized stigma and discrimination

WLHIV continue to experience the negative consequences of HIV related stigma and discrimination. HIV stigma is further compounded by oppression and discrimination experienced on the basis of race, class, gender, sexuality, and gender identity. These multiple and intersecting stigmas may perpetuate internalized stigma and have negative consequences for the physical and mental health of WLHIV.

Interventions that reduce stigma, including internalized stigma, should be resourced and prioritized. In addition, providers, healthcare workers, case managers, outreach workers, health educators and peer counselors must be equipped with the tools and training to deliver non-judgmental and affirming care.

Laws that criminalize, unfairly target, or more harshly penalize people on the basis of their HIV positive status create a hostile environment and should be eliminated.

STUDY LIMITATIONS AND FUTURE CONSIDERATIONS

Study limitations include the overall sample size (n=180) and recruitment strategy. The research team recruited participants from points of entry in the health service delivery system including AIDS service organizations (ASOs), local clinics, or other social service providers and support groups. As a result, our sample was far more likely to be engaged in care than the national average, and data reflecting our sample's overall engagement and maintenance in care may not reflect national trends.[36]

We did not access medical records for this study, so data on health conditions, viral suppression and other lab tests, prescriptions, and other health information is based on self-report, which may be inaccurate in some cases. Further, it is possible that responses may have been affected by respondent bias if some participants feared negative repercussions answering questions related to adherence to medical treatment and their medication regimens.[37, 38, 39, 40, 41]

The survey was only administered in English due to funding constraints; this is the likely reason for relatively low participation of Latina-identified WLHIV. Also, this report does not adequately address specific health and access to care concerns of lesbian, bisexual and transgender women living with HIV or young people with HIV transitioning to adult care. Over 10% of our respondents identified as lesbian, gay, or bisexual (LGB) and there is inadequate research considering how LGB women with HIV may experience healthcare settings and quality of care differently. These populations require specific attention and focus in future research. Further, many issues which may affect engagement in care were not addressed in this study, such as food insecurity, which is likely to play a significant role in medication adherence and health outcomes.[42]

CONCLUSION

Women living with HIV are deeply committed to their health, their families, and their communities. As women are living longer and aging with HIV, they are managing multiple health challenges and family responsibilities while living in poverty. Over thirty years into the epidemic, HIV stigma continues to take a toll on health and well-being of people living with HIV, impacting engagement in care and quality of care provided, particularly in the arena of sexual and reproductive health.

The Ryan White Program is a medical home model that is working well for women with HIV and will continue to be urgently needed to fill gaps in other healthcare systems and other payer sources. However, the RWP should be updated to address the needs of a population living long term with a chronic, stigmatized illness. Supportive services that have historically been available primarily to women of reproductive age, such as childcare and medical transportation that allows transportation for minors, should be expanded to women with HIV of all ages. Our data demonstrates a continued necessity for existing supportive services[*2], which facilitate engagement and retention in care, and indicates new or reframed service categories may be necessary to support living with HIV long-term.

Specifically, future iterations of Ryan White should: i) ensure meaningful involvement of women with HIV: ii) reduce structural and cost-related barriers to care, especially transportation iii) support women with HIV to get out of poverty iv) prioritize stigma reduction, and v) expand the scope of service provision, with a focus on trauma-informed service delivery and affirming sexual and reproductive healthcare for all people of all ages and genders living with HIV.

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*2 Supportive services include AIDS Drug Assistance Program Treatment (ADAP) pharmaceutical assistance; child care services; early intervention services (EIS) emergency financial assistance; food bank/home delivered meals; health education/risk reduction; health insurance premium and cost sharing assistance for low income individuals; home- and community-based health services; home health care; hospice; housing; legal services; linguistic services; medical case management, including treatment adherence services; medical nutrition therapy; medical transportation; mental health services; non-medical case management services; oral health care; other professional services; outpatient/ambulatory health services; outreach services; permanency planning; psychosocial support services; referral for health care and support services; rehabilitation services; respite care; and substance abuse services. The specific list of allowable services varies by Ryan White Part.

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HIV Among Transgender People

April 2015

Fast Facts

- Transgender women are at high risk for HIV infection.
- By race/ethnicity, black/African American transgender women have the highest percentage of new HIV-positive test results.
- Efforts are under way to improve the quality of HIV data collected on transgender communities.

Transgender communities in the United States are among the groups at highest risk for HIV infection. The term *gender identity* refers to a person's basic sense of self, and transgender refers to people whose gender identity does not conform to a binary classification of gender based on biological sex, external genitalia, or their sex assigned at birth. It includes gender-nonconforming people with identities beyond the gender binary who self-identify as: male-to-female or transgender women; female-to-male or transgender men; two-spirit; and people who self-identify simply as women or men.

The Numbers

Because data for this population are not uniformly collected, information is lacking on how many transgender people in the United States are infected with HIV. However, data collected by local health departments and scientists studying these communities show high levels of HIV infection and racial/ethnic disparities.

- In 2010, more than half of the HIV testing events among transgender people occurred at non-healthcare facilities (55.1%). The Centers for Disease Control and Prevention (CDC) reported that the highest percentage of newly identified HIV-positive test results was among transgender people (2.1%). For comparison, the lowest percentages of newly identified HIV-positive test results were among females (0.4%), followed by males (1.2%). Among transgender people in 2010, the highest percentages of newly identified HIV-positive test results were among racial and ethnic minorities: blacks/African Americans comprised 4.1% of newly identified HIV-positive test results, followed by Latinos (3.0%), American Indians/Alaska Natives and Native Hawaiians/Other Pacific Islanders (both 2.0%), and whites (1.0%).
- In New York City, from 2007-2011, there were 191 new diagnoses of HIV infection among transgender people, 99% of which were among transgender women. The racial/ethnic disparities were large: approximately 90% of transgender women newly diagnosed with HIV infection were blacks/African Americans or Latinas. Over half (52%) of newly diagnosed transgender women were in their twenties. Also, among newly diagnosed people, 51% of transgender women had documentation in their medical records of substance use, commercial sex work, homelessness, incarceration, and/or sexual abuse as compared with 31% of other people who were not transgender.
- Findings from a meta-analysis of 29 published studies showed that 27.7% of transgender women tested positive for HIV infection (4 studies), but when testing was not part of the study, only 11.8% of transgender women self-reported having HIV (18 studies). In one study, 73% of the transgender women who tested HIV-positive were unaware of their status. Higher percentages of newly identified HIV-positive test results were found among black/African American transgender women (56.3%) than among white (16.7%) or Latina (16.1%) transgender women; and self-reported HIV infection in studies made up of predominantly of black/African American transgender women (30.8%) was higher than positivity reported in studies comprising mainly white transgender women (6.1%). Studies also indicate that black transgender women are more likely to become infected with HIV than non-black transgender women.
- A review of studies of HIV infection in countries with data available for transgender people estimated that HIV prevalence for transgender women was nearly 50 times as high as for other adults of reproductive age.

Prevention Challenges

Individual behaviors alone do not account for the high burden of HIV infection among transgender people. Many cultural, socioeconomic, and health-related factors contribute to the HIV epidemic and prevention challenges in US transgender communities.

- **Identifying transgender people within current data systems can be challenging.** Some transgender people may not identify as transgender due to fear of discrimination or previous negative experiences. Since some people in this community do not self-identify as transgender, relying solely upon gender to identify transgender people is not enough. Gender expression may fluctuate for some transgender people due to issues such as perceived safety or reluctance to identify as transgender in certain situations. The Institute of Medicine has recommended that behavioral and surveillance data for transgender men and women should be collected and analyzed separately and not grouped with data for men who have sex with men. Using the 2-step data collection method of asking for sex assigned at birth and current gender identity increases the likelihood that all transgender people will be accurately identified.

- It is important to avoid making assumptions about **sexual orientation** and **sexual behavior** based on gender identity because there is great diversity in orientation and behavior in this population, and some identify as both transgender and gay, heterosexual, bisexual, or lesbian. For example, transgender men claim a variety of sexual orientations and have sexual partners that include gay men and transgender women.
- **Transgender men's sexual health has been understudied.** Compared to transgender women, little is known about HIV risk and sexual health needs among transgender men. One meta-analysis of 29 studies involving transgender people showed that only 5 of them had separate data concerning transgender men.
- **Behaviors and factors that contribute to high risk of HIV infection** among transgender people include higher rates of drug and alcohol abuse, sex work, incarceration, homelessness, attempted suicide, unemployment, lack of familial support, violence, stigma and discrimination, limited health care access, and negative health care encounters.
- **Police policies can conflict with public health initiatives.** For example, some law enforcement officers and agencies view the presence of condoms as evidence of sex work, even though public health initiatives identify condoms as a way to prevent HIV infection.
- **Discrimination and social stigma** can hinder access to education, employment, and housing opportunities. In a study conducted in San Francisco, transgender people were more likely than men who have sex with men or heterosexual women to live in transient housing and be less educated. Discrimination and social stigma may help explain why transgender people who experience significant economic difficulties often pursue high-risk activities, including sex work, to meet their basic survival needs.
- Interventions that address multiple **co-occurring public health problems**—including substance use, poor mental health, violence and victimization, discrimination, and economic hardship—should be developed and evaluated for transgender people.
- **Health care provider insensitivity** to transgender identity or sexuality can be a barrier for HIV-infected transgender people seeking health care. Although research shows a similar proportion of HIV-positive transgender women have health insurance coverage as compared with other infected people who are not transgender, HIV-infected transgender women are less likely to be on antiretroviral therapy.
- **Additional research is needed to identify factors that prevent HIV in this population.** Several behavioral HIV prevention interventions developed for transgender people have been reported in studies, generally involving relatively small samples of transgender women. Most have shown at least modest reductions in HIV risk behaviors among transgender women, such as fewer sex partners and/or unprotected anal sex acts, although none have involved a control group. Behavioral HIV prevention interventions developed for other at-risk groups with similar behaviors have been adapted for use with transgender people; however, their effectiveness is still unknown.

What CDC Is Doing

CDC and its partners are pursuing a **high-impact prevention** approach to advance the goals of the *National HIV/AIDS Strategy* and maximize the effectiveness of current HIV prevention methods among transgender people. Activities include:

- Providing support and technical assistance to providers that help community-based organizations enhance structural interventions for transgender people (condom distribution, community mobilization, HIV testing, and coordinated referral networks and service integration).
- Funding researchers to develop groundbreaking HIV prevention interventions for transgender people. Examples include *Life Skills* (for young transgender women aged 16-24) and *Girlfriends* (for adult transgender women).
- Releasing campaigns under the *Act Against AIDS* umbrella, such as *Let's Stop HIV Together* to address HIV-related stigma and raise awareness, and *HIV Treatment Works* to encourage people living with HIV to overcome barriers to get in care and stay on treatment.
- Issuing awards of $55 million for *HIV Prevention Projects for Young Men of Color Who Have Sex with Men and Young Transgender Persons of Color* (**FOA PS11-1113**; September 2011), to provide effective HIV prevention services over 5 years to young transgender people of color and their partners regardless of age, gender, and race/ethnicity.
- Revising the fields used to identify transgender people in the National HIV Surveillance System, which is used for reporting diagnoses of HIV infection. In addition, CDC has developed guidance for state and local health departments that collect these data. Some city or state health departments include data on diagnosed HIV infection among transgender people in annual, quarterly, or special reports.

For more information, visit CDC's Lesbian, Gay, Bisexual, and Transgender Health website at www.cdc.gov/lgbthealth/index.htm.

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

Why Transgender Women Have the Country's Highest HIV Rates

There are a lot of factors behind this invisible epidemic, none of them good.

By Sunnivie Brydum April 02 2015 4:57 PM EDT

Transgender women are the fastest-growing population of HIV-positive people in the country, according to Miss Major, a 70-year-old transgender woman of color and the executive director of TGI Justice Project, a San Francisco–based advocacy organization that fights for the rights of transgender, intersex, and gender-variant people who are in prison or have served jail time.

Most experts agree with Major's assertion, but hard data backing up that reality is hard to come by since HIV data collection methods often either mistakenly categorize transgender women as men who have sex with men, or don't distinguish between transgender and nontransgender women.

This kind of systematic mislabeling and ignorance is a grim reality for many trans women, says Major. Medical professionals, police officers, and even gay and lesbian communities "go out of their way to crush us so that we feel ignored and rejected, and that our wishes and desires don't count," Major says. "There is no care for who we are and what we do."

The data validates Major's concerns. A 2009 report from the National Institutes of Health found that nearly a third of transgender Americans are HIV-positive. The study also indicated that many transgender women may not know their HIV status, due to a series of cultural, social, and economic barriers.

Transgender women of color are at an even greater risk for HIV infection than their white peers. The NIH study noted that African-American and Latina transgender women had the highest infection rates; among those transgender women of color surveyed, more than 56% of black trans women were HIV-positive, and Latina trans women had an HIV infection rate of 16%.

Transgender women often require regular hormone therapy, and many of those who can afford the out-of-pocket expense undergo various forms of gender-reassignment surgery. But with multiple medications necessary already (such as estrogen, which must be taken weekly), HIV-positive trans women are less likely to regularly use antiretroviral medication than are their nontransgender peers. The NIH study, which focused on a clinic in New York City, reported that transgender women were often concerned that HIV medication would interfere with their hormone therapy. One woman told NIH researchers that many of her fellow HIV-positive trans women prioritized hormone therapy over HIV medication: "They feel that the HIV meds would mess with the hormones, and by them being transgender, they want the hormones to work OK."

A great deal of the medication and treatment these women need is not covered by insurance, and is often costly and difficult to obtain. To make matters worse, antidiscrimination laws rarely cover transgender women.

“In the majority of the states in the U.S., it’s legal to discriminate on the basis of gender identity,” says JoAnne Keatley, director of the Center of Excellence for Transgender Health at the University of California, San Francisco. “You can deny a person employment or you can terminate someone who is transitioning on the job merely because they are transgender.”

That kind of discrimination has a devastating effect on the economic well-being of transgender people. According to a 2011 report from the National Center for Transgender Equality, transgender people were four times more likely than the general population to live in extreme poverty, with a household income less than $10,000 a year, and more than twice as likely as the general population to be homeless. A staggering 90% of the 6,450 transgender people surveyed nationwide reported being the target of harassment, mistreatment, or discrimination at work.

This complex web of intertwining oppression and discrimination leaves many transgender women with no option to support themselves but to turn to underground employment—most frequently by engaging in sex work.

“We have to scrounge for housing, and it puts us in the street at night to cover what we need to cover during the day,” explains Major. “It’s kind of like a merry-go-round that we’re on, and it’s difficult to stay [HIV-] negative.”

Cyd Nova, the harm reduction coordinator at San Francisco’s St. James Infirmary, a clinic for current and former sex workers, agrees that trans women are often forced to turn to sex work to support themselves.

“Sex work is a form of labor available to people who may not have many other options,” says Nova. “Sex work is also a means of empowerment for a community that often has high financial needs.”

But the effort to meet those needs runs into problems with the criminalization of sex work, which hits transgender women particularly hard. Police officers sometimes target trans women, and in several major U.S. cities, use the presence of multiple unused condoms as evidence of prostitution.

“Trans women are disproportionately profiled and targeted by law enforcement for harassment and arrest,” says Nova. “And because of policies like [using] condoms as evidence, trans women often face a choice between protecting themselves and their partners from HIV and risking arrest.”

Incarceration also plays a role in the high HIV rates. When a trans woman is arrested and jailed for prostitution—or any other crime—many prisons will house her with male inmates. Other jails keep trans prisoners in solitary confinement, often only releasing the inmate from her cell for an hour or so each day, presumably for her protection.

“Once a trans person becomes part of that cycle of criminal injustice, it’s hard to break out of that,” says Keatley.

While sex workers in general are more likely to be HIV-positive than those who do not engage in sex work, transgender female sex workers are at four times greater risk for contracting HIV than other female sex workers, according to an international analysis published in 2008 in the Journal of Acquired Immune Deficiency Syndromes.

Further complicating efforts to combat HIV among transgender people is that population’s basic lack of access to medical care. The 2009 NIH study examined one community-based health clinic in New York City and identified a number of reasons that transgender women aren’t seeking preventive health care, including limited access to low-cost care and safe, trans-inclusive medical environments, along with the incompetence of many doctors about basic transgender health care, which results in trans women feeling unsafe to disclose their HIV status.

The combination of social stigma, institutional discrimination, economic hardship, and distrust of medical professionals creates a major barrier to connecting transgender women with HIV-related care.

“Not much HIV-prevention messaging is aimed toward or accessible to trans people,” says Nova. Noting that most HIV-prevention programming is for gay and bisexual men, Nova argues that current prevention efforts don’t meet the needs of HIV-positive trans women.

When this reality is layered with the medical profession’s lack of understanding around transgender health care, the result is an identity that is stigmatized and often treated as psychiatric illness. Given that, Nova says, “it is no wonder that trans people are hesitant to come into contact with HIV care, which in turn multiplies the risk of transmission.”

Tags: Stigma

THINKSTOCK

Transgender Issues in HIV

Providers need accurate, current information to provide optimal care

BY JAE SEVELIUS, PH.D.

AS AWARENESS ABOUT THE EXISTENCE OF TRANSGENDER PEOPLE GROWS in mainstream consciousness, so does our knowledge about their unique strengths, needs, and vulnerabilities. Providers of HIV care need accurate and current information about transgender people living with HIV, including potential barriers and facilitators to engagement and retention, as well as strategies for optimizing HIV care and treatment for transgender patients. ►

Terminology

'Transgender' is an umbrella term for individuals whose gender identity differs from the sex they were assigned at birth.

'Transgender women', sometimes referred to as 'male-to-female' (or 'MTF') are individuals who were assigned male sex at birth, but who identify as women or as transgender women.

Similarly, 'transgender men' ('female-to-male' or 'FTM') were assigned female sex at birth, but identify as men or as transgender men. Some transgender people do not identify within the male/female binary at all.

Furthermore, current literature is moving away from the MTF and FTM terminology for a variety of reasons; a summary of selected common terms is provided in Table 1. Terminology used to describe transgender identities varies widely by geographic region, age, ethnicity, and other factors. When serving transgender patients, providers can build trust by asking for and using the terminology preferred by each patient and by ensuring that the patient's preferred name and pronoun is recorded in his/her medical record and used by every staff person who interacts with the patient.

Stigma and Discrimination

Transgender people often experience stigma and discrimination, resulting in social marginalization and negative health outcomes. Because their gender identity and/or presentation differs from the sex they were assigned at birth, transgender people challenge society's most basic assumptions about the binary nature of sex and gender and the stability of identity.

The discrimination, rejection, and violence experienced by transgender people are often referred to as 'transphobia'. Just as homophobia negatively affects lesbians and gay men, transphobia affects transgender people in a multitude of deleterious ways. Experiences of discrimination and victimization negatively impact mental health by increasing anxiety, depression, and suicidality.[1-3]

Transphobic discrimination, victimization, and lack of social support consistently are associated with attempted suicide, substance use, dropping out of school, and unprotected sex among transgender youth[4]. Transgender people have shockingly high rates of suicidal ideation and suicide attempts compared to the general population (31 percent vs. 2 percent),1 and often report using substances to cope with the intense stressors associated with the stigma of being transgender.[5]

HIV in Transgender Populations

Transgender women are one of the most highly impacted groups in the HIV epidemic to date, yet they are disproportionately under-researched and underserved by current treatment efforts. Transgender women have 49 times higher odds of HIV infection compared to other groups, a disparity that exists across race, culture, and socioeconomic boundaries.[6] Disparate prevalence rates of HIV are particularly pronounced for African American transgender women when compared with transgender women of other races and ethnicities.[7] Furthermore, HIV+ transgender women have an almost three-fold higher community viral load than non-transgender HIV+ adults in San Francisco (64,160 vs. 22,376),[8] and likely elsewhere. HIV-related mortality and morbidity rates have also been found to be higher among transgender women.[9]

In addition, there is evidence that current efforts to provide effective treatment to transgender women living with HIV are not as successful as with other populations. In the only study of its kind to date, transgender women living with HIV were less likely to be receiving antiretroviral therapy than a control group of non-transgender men and women.[10] Furthermore, transgender women living with HIV who were on antiretroviral therapy demonstrated worse adherence than non-transgender people, reported less confidence in their abilities to integrate treatment regimens into their daily lives, and experienced fewer positive interactions with their healthcare providers.[11]

To date, there are few studies of HIV incidence among transgender men in the literature. Transgender men at risk for HIV are those that report sex with non-transgender men (trans MSM), a subgroup that has only recently begun to receive attention in public health research. The few research studies focused on trans MSM to date have found relatively high levels of reported risk behavior, but lower levels of HIV prevalence (0-3 percent).[12] Some trans men who are on cross sex hormone therapy (i.e. testosterone, or 'T') self-report a link between testosterone use, increased sex drive, increased interest in engaging in sexual activity, and exploration of sexual behaviors that may include sex with non-trans men. For trans men on testosterone, the masculinization of the body may lead to increased access to non-trans MSM partners, and a willingness to take sexual risks that could potentially place trans MSM at risk for STI and HIV infection.

Engagement and Retention in HIV Care

Because transgender women are extremely disproportionately affected by HIV, and because the vast majority of HIV-related research has focused on transgender women, this discussion will focus on what we know about transgender women's experiences with seeking HIV care. Much of this information may be applicable to transgender men as well, but transgender men are likely to face qualitatively different issues as well.

Transgender women living with HIV face culturally unique and substantial challenges to adhering to HIV care and treatment regimens, such as limited access to and avoidance of healthcare due to stigma and past negative experiences, prioritization of gender-related healthcare, and concerns about adverse interactions between antiretroviral therapy and hormone therapy. Issues that affect other marginalized populations, such as mental health issues, substance use, and poverty, are barriers to care among transgender women as well, but additional transgender-specific barriers exist as a result of transphobia, as well as needs for gender affirmation and transition-related healthcare.

Importance of Gender Affirming Health Care

"Gender affirmation" is the process by which individuals feel socially validated in their gender identity through interpersonal

Table 1. Selected common terms used to describe transgender identities

Term	Definition
Transgender	An umbrella term used to describe individuals whose gender identity differs from the sex they were assigned at birth
Trans	Shorthand term for 'transgender'
Transgender woman/Trans woman	Transgender person assigned male at birth, identifies as female
Transgender man/ Trans man	Transgender person assigned female at birth, identifies as male
Transvestite/ Cross-Dresser	A person who dresses in gendered clothing that differs from their own identity for entertainment or sexual purposes but does not necessarily identify as transgender
Genderqueer	Gender nonconforming person, a term increasingly used by youth
Transsexual	A term that is sometimes used to refer to transgender individuals who have undergone medical procedures to affirm their gender; currently a less favored term in trans-related literature

interactions, such as interactions with a healthcare provider. The Model of Gender Affirmation is a transgender-specific model developed to examine the role of gender affirmation in risk-taking, self-care, and healthcare-seeking behavior.[13] It posits that when a transgender woman places a high level of importance on gender affirmation, she will seek out opportunities to receive this affirmation and avoid experiences in which she is not affirmed in her gender.

A gender affirming healthcare experience would include, for example, a transgender patient being called by the correct name and pronoun by all staff throughout the healthcare encounter without unnecessary attention being drawn to her transition status. Gender affirmation also includes having access to and support for transition-related health care, such as hormones and surgeries, as desired by the patient. Evidence of the associations between access to gender affirmation and improved quality of life, mental health, and self-care behaviors among transgender people is growing rapidly.[14,15]

Gender affirmation is of paramount importance to many transgender women at every stage of the HIV care continuum. Transgender sensitivity and knowledge on the part of providers and clinics can be a crucial barrier when absent, and a powerful facilitator when present. Studies have reported that when transgender women do seek healthcare, patients' trust in their provider is compromised when they encounter insensitivity and low levels of knowledge. Diminished trust subsequently impairs patient-provider communication and can affect participants' decisions to initiate and/or adhere to antiretroviral therapy.

Multiple negative experiences can ultimately result in avoidance of healthcare settings altogether. Gender affirming healthcare, however, can support engagement and retention in HIV care among transgender women by increasing patient-provider trust, fostering positive interactions, and supporting a collaborative relationship.

Intake forms should permit transgender patients to identify themselves and their records should correctly identify their preferred name and pronoun to all providers and staff that interact with them. This documentation should be handled as sensitive and confidential health information. This increases trust in the provider and clinic by ensuring that patients are not called by the wrong name and/or pronoun, an experience commonly reported by transgender people as highly detrimental to their health care experience.

Efforts are currently underway to allow for the identification of transgender patients using electronic medical records.[16] In the meantime, clinics should revise local systems to be inclusive and respectful of transgender patients. The UCSF Center of Excellence for Transgender Health's Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care, and Services offer guidelines for clinics and have been implemented by agencies across the US.[17]

Currently, few formal medical education programs include transgender-specific medical care in their training of providers. Providers who serve transgender patients should be comfortable with transgender people at all stages of transition. Training providers to conduct thorough yet respectful health assessments, including mental health and sexual health, will help build trust and rapport with transgender patients. In addition, creating a safe clinic space, including respectful front line staff, sends the message that transgender patients are welcome and is more likely to yield positive health care experiences.

Integration of Hormone and Antiretroviral Therapy

Transgender women living with HIV often juggle a variety of demands on their time and energy due to trauma, addiction, and the deleterious effects of transphobia in their day-to-day lives. Once they initiate antiretroviral therapy, transgender women often experience barriers to integrating the regimens into their daily lives.

One method for starting to address this barrier is the integration of hormone therapy and antiretroviral therapy in HIV primary care settings, a strategy that has been employed successfully and recommended by primary care clinics that serve transgender patients.[18]

Seeing the same provider (or at the very least, being seen at the same clinic) for both hormones and antiretroviral therapy may facilitate patient management of their appointments and medications, increase the likelihood that they keep their appointments (augmented by a high level of motivation to adhere to their hormone regimen), and increase trust in their provider.

Several resources are available to guide the provision of hormones for providers who are new to treating transgender patients. The UCSF Center of Excellence for Transgender Health has an online Primary Care Protocol for Transgender Patient Care that provides peer-reviewed guidelines and additional resources for review.[19] In addition, the World Professional Association for Transgender Health recently revised its Standards of Care document that has long served as a resource for those wishing to increase their expertise and receive guidance in the provision of health care to transgender patients.[20]

Additional Recommendations

- **Increase visibility of transgender people in peer and professional support roles.** Transgender patients often feel most comfortable with outreach and program staff who are also transgender. Transgender staff who already have established relationships with the community that the program seeks to serve can be indispensable in terms of recruitment and retention. In addition, transgender staff who have personal experience with many of the same issues that clients face can offer unparalleled support, guidance, and mentorship. Transgender staff who are openly living with HIV can model disclosure about status to help reduce stigma and can serve as an invaluable resource in peer navigation programs.
- **Attend to transgender-specific needs.** Interventions specific to transgender patients are ideal. Programs such as a transgender-specific portal to a larger health clinic, use of peer health navigators, and transgender-specific clinic hours are exemplar models that have been successful. In areas where it is not possible to create transgender-specific services, explore aspects of existing programs that can be tailored to the transgender community, such as adding a transgender-specific support group to substance abuse treatment programs or housing programs.
- **Maintain current referral resources.** While some areas may not have many transgender-specific referral resources, identifying services that are informed and sensitive can help patients avoid negative experiences in the community. This may also increase the likelihood that they will access support services that may help them stay engaged in their treatment, such as complementary and alternative therapies that help alleviate side effects of HIV medications and spiritual and/or meditation groups that help promote healthy coping strategies. When possible, create a centralized, up-to-date, and comprehensive transgender resource guide that can be given to patients.

Conclusion

Engagement and retention of transgender patients in HIV care and treatment will be optimized by services that are gender affirming and integrate transition-related healthcare needs. Such interventions must fully attend to the social, economic, and psychological context of transgender patients' lives and address the multiple barriers to healthcare engagement, treatment adherence, and empowerment that serve to create, maintain, and deepen HIV-related health disparities, particularly among transgender women living with HIV. HIV

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THE LINK

*News About HIV Prevention, Care,
and Treatment for Key Populations*

JULY 2015 | Issue 3

TRANS-forming: DATA FOR DECISION MAKING

Throughout this edition of The LINK, our guest authors are brimming with optimism about the world's increased attention to the human rights and health needs of transgender people—thanks to decades of advocacy by the trans community. Internationally, the transgender movement has been particularly strong in Asia and Latin America, where trans men and women are celebrating their identity and fighting for social change. In Bangladesh, hijras, who identify as neither male nor female, led Dhaka's first pride parade in 2014. More than 1,000 Bangladeshi hirjas marched to mark a year since their official recognition as a third gender. In 2012, Argentina's government passed transgender rights regulations that are considered to be some of the world's most progressive, and in 2013, Chile began to cover sex reassignment surgery under the government plan.

Certainly, we should celebrate these and other hard-won reforms. But the trans community and its allies also remember that trans men and women continue to face stigma, discrimination, violence, and, particularly for trans women, a disproportionate rate of HIV infection. Most of what we do know about trans women and HIV comes from studies in the United States and other western countries, though that has begun to change. (See Tonia Poteat's article on page 4 for more information about trans women in the HIV cascade.) Even less is known about trans men, though according to a Lancet analysis,[1] those who have sex with men are likely to experience a "heightened vulnerability" to HIV.

This dearth of information is not surprising. Few countries issue identification documents in which a person's self-identified gender differs from his or her assigned sex. Also, the way data are collected contributes to trans people's relative invisibility. When trans women are diagnosed with HIV, they are often coded as "male," which makes it difficult to gather reliable data on HIV in these communities. LINKAGES advisory board member JoAnne Keatley, in her article on page 3, provides a more in-depth look at the need to count trans people in public health measurements.

Beyond failure to officially recognize trans people, many countries criminalize "impersonations of the opposite sex," effectively forcing the transgender community underground. And in 2014, only 39 percent of countries reported that their national AIDS strategies specifically addressed transgender people.

Though their need for health services is great, their experiences in the health system are not. In a 2010 survey of 7,000 transgender people in the United States, 19% reported being refused care because of their transgender or gender

ARTICLE CONTINUED ON PAGE 2

IN THIS ISSUE

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USAID FROM THE AMERICAN PEOPLE
PEPFAR U.S. President's Emergency Plan for AIDS Relief
LINKAGES

Thank you to the following for submitting photos for the LINKAGES banner:
FHI 360's Asia-Pacific Regional Office (Ian Taylor and Mr. Naysokhim); Global Forum on MSM & HIV; Global Network of Sex Work Projects; and the International Network of People who Use Drugs

nonconforming status and 28% said they were subjected to harassment in medical settings.[2] Even trans-friendly health care providers often are not "trans-competent"; that is they lack training to address trans-specific medical issues. In this study, 50% of those surveyed reported having to teach their medical providers about transgender care.

Despite these often formidable obstacles, the trans community has shown resilience and strong leadership. Trans-led grassroots organizations are challenging the barriers that transgender people face, advocating for their rights, fighting stigma and discrimination, and demanding improved health care. For example, LINKAGES partner Sisters is a Thai organization run by and for trans women. Sisters employs community-based peer educators to help trans women navigate HIV treatment, care, and services. (Read more about Sisters on page 5.) Transgender constituency groups have been partners in the development of the *Transgender Implementation Tool* and the *Asia Pacific Trans Health Blueprint* which, as Darrin Adams discusses in his article on page 6, will be foundational guides to improving health services for transgender people.

Until recently, the world's response to HIV has largely overlooked trans people. But due to the hard work of the trans community and their partners, the tide has begun to turn. We must all continue to support these efforts, for trans people need and deserve to be counted. Health care providers must become trans-friendly *and* trans-competent. Researchers must study the needs of trans men and trans women specifically and collect data in a way that correctly captures gender identity. Governments and policymakers must codify the rights of trans people into law and then see that laws are enforced. For through combined efforts made at many levels, health care and social justice can really be transformative.

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PROMISING STRATEGIES FOR STIGMA REDUCTION

The *Transgender Implementation Tool (TRANSIT)* operationalizes the trans-specific recommendations in the WHO's *Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations.* (For more information about the *TRANSIT,* see page 6). Among other topics, the tool discusses promising strategies for building empowerment in the trans community and preventing and responding to stigma, discrimination, and violence. Following is a sample of the recommendations.

- Foster and support programs and advocacy led by the trans community. Areas that have a history of trans people organizing to advocate for their own rights tend also to have the highest standards of care and the most community-based organizations meeting transgender people's needs.
- Reform laws so that trans people are allowed a legal identity, and all associated identity documents, based on the gender of their choosing.
- Increase the use of information and communication technologies, especially in languages other than English, to reach global trans audiences.
- Develop and improve strategies for measuring, documenting, and monitoring stigmatizing and discriminating events and experiences.
- Implement trans-specific trainings of health care workers on a systematic basis, with buy-in and participation by the ministries of health and in-country educational systems.

Photo Credit: © Ian Taylor

Ms. Popy is a hijra community leader in Bangladesh.

COUNT ME IN!

It is an amazing time in transgender (trans) health. Never before has there been this level of interest and attention being paid to my community. Steadily there is progress being made toward health policy and human rights inclusion. Yet, for all the progress we've made, there remains a challenge in adequately addressing our health and wellness needs. Trans people cannot be fully accounted for in health policy if we are not counted in surveillance and public health measurements. Data used by governments and global health organizations to describe epidemics and allocate funds to steer public health responses do not consistently include measures that capture gender identity. As a result, trans people continue to be included in data describing gay men and other men who have sex with men. This practice leads to erroneous equating of gender identity with sexual orientation and a serious undermining of trans peoples' ability to take leadership of our own public health approaches. In spite of the lack of standardized measures capturing gender identity, studies that have intentionally sampled trans women have consistently shown them to have among the highest HIV prevalence rates of any population. In some instances, public health data reflect that in addition to high HIV rates, trans women have to deal with a lack of trained, culturally aware providers. As a result trans women who are disproportionately affected by HIV also reflect lower percentages of being linked to and retained in ARV therapy.

Even when public health officials have good intentions and make attempts at inclusion, they often get it wrong. The use of inappropriate measures forces trans people to choose among male, female, and transgender options as if trans people do not have male and female identities. In the best case scenario, this practice captures the existence of a trans identity but does not distinguish between trans male and female identities. In fact many of the issues we deal with have to do with societal views of gender. For example, trans women face problems common to non-trans women, such as gender-based violence, lower pay for equal work, and more. In order to adequately describe the public health status of all trans people one must distinguish between trans men, trans women, and people who are non-binary. Public health approaches cannot simply be reduced to a "one size fits all" model. We must tailor our efforts to account for the specificities within our community in order to be able to make an impact that is sustainable and that respects our bodies, minds, and identities.

At the Center of Excellence for Transgender Health (www.transhealth.ucsf.edu) we advocate the use of a two-step model to capture both gender identity and sex assigned at birth. We believe that this approach is the most efficient way to delineate differences in identity and anatomy, both crucial for making health care decisions. The model can be used in surveillance as well and will more accurately describe not only issues affecting trans people but also distinguish them from non-trans people such as MSM. If this model is used consistently, we believe it will lead to greater clarity and understanding of the issues we have in common and the differences that make us distinct. At the end of the day, when you are not counted, you don't count.

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Photo Credit: © Cameron Wolf

Members of Swing Thailand pose outside the transgender networking zone at the International AIDS conference, wearing costumes they made of condoms.

HIV CARE AND TRANSGENDER WOMEN: WHERE DO WE LOSE THEM ALONG THE CONTINUUM?

With the goal of ending the AIDS pandemic by 2030, UNAIDS has set ambitious intermediate targets: by 2020, 90% of people living with HIV will know their status, 90% of people diagnosed with HIV will be on treatment, and 90% of people on treatment will have a suppressed viral load. Ultimately, the ability to end AIDS depends on reaching key populations—the people who bear a disproportionate burden of HIV.

Transgender women are a highly vulnerable group among key populations; they have a global HIV prevalence of 19% and 49 times the odds of HIV infection compared to the general population.[1] Since these data suggest that about one in five transgender women worldwide may be living with HIV, it's critical to understand what the HIV care continuum looks like for them. The data to answer this question are limited, but what we do know tells us we have much work to do.[2]

One study among a probability-based sample of transgender women in San Francisco found that while 95% were previously aware of their HIV status and 87% had accessed care in the prior 6 months, only 65% of those living with HIV were on antiretroviral therapy (ART) and only 44% had suppressed viral loads.[3]

However, a nationally representative sample of people in HIV care in the United States suggests that the news may not be all bad. In this study of more than 36,000 people in HIV care, 80% of the 285 transgender participants were retained in care, 76% received ART, and 68% achieved viral suppression, and their outcomes were not significantly different from nontransgender men and women.

Another population-based study from the Medical Monitoring Project in the United States and Puerto Rico compared transgender women in HIV care to nontransgender people in care. The authors found no difference in the proportion receiving a prescription for ART; however, transgender women were less likely to report 100% adherence and less likely to have durable viral suppression than nontransgender men.[4] These differences took place in the context of significant structural disparities. The same study found that transgender women had a greater need for supportive services ranging from mental health and domestic violence services to meals, transportation, and housing.[4] The need for meals and housing services were significantly less likely to be met for transgender women compared to nontransgender men.

All of these studies took place in the United States, a high-income country with some of the best health care resources in the world. While we don't yet have data about the HIV care continuum for transgender women from other countries, it is likely that transgender women living in countries with greater resource constraints will have more difficulty accessing HIV testing, care, and treatment services. When developing programs to better engage transgender women along the HIV care continuum, it will be important to keep in mind lessons learned from data. We know that it is possible to engage transgender women in HIV testing and care. However, once they are in care, we must address housing instability, food insecurity, and other structural barriers to ART adherence and viral suppression.

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THE WHAT, WHERE, AND HOW: MAPPING THE HIV AND COMPREHENSIVE HEALTH IMPLEMENTATION STRATEGY FOR TRANS PEOPLE GLOBALLY

"This is the year for trans," said a donor representative at the kick-off consultation for the *Asia and the Pacific Trans Health Blueprint* (or *AP Blueprint*) in October 2014. In many respects, this was a reading of the tea leaves about what would indeed transpire in the months following—what many trans advocates and their allies have been working toward for years. As trans people have generally become more visible and some have achieved mainstream fame (read: Lavern Cox and Caitlyn Jenner), trans people have become a part of the public discourse.

Now, a collection of global and regional documents (see text box) is emerging that, together, will shift discourse into action to improve the health and human rights of trans people and their communities. Two of these documents are the *AP Blueprint* and the *Trans Implementation Tool (TRANSIT).*

The *AP Blueprint* is being developed through a collaboration of the Asia Pacific Transgender Network, United Nations Development Programme, and the United States Agency for International Development (USAID)-funded Health Policy Project. The purpose of the document is to provide a contextual map about where the gaps and points of intervention lie for the realization of comprehensive trans health. The document is grounded in the World Health Organization (WHO) *Consolidated Guidelines for Key Populations* and developed with regional input from trans people, trans health medical providers, WHO, and other stakeholders.

The *TRANSIT* is one of a series of global implementation tools for key populations—sex workers, men who have sex with men, transgender people, and people who use drugs. The *TRANSIT* is a programming guidance document that demonstrates *how* to implement the trans-related recommendations from the WHO *Consolidated Guidelines*. With chapters written by trans people who are members of regional and country-level initiatives, the *TRANSIT* compiles promising practices and evidence-based approaches in five key areas: community empowerment; stigma, discrimination, violence, and human rights; services; service delivery approaches; and program management.

A FAMILY OF DOCUMENTS FOR TRANS HEALTH

A core set of documents has emerged to advocate for the implementation of HIV-specific and comprehensive trans health. They include, but are not limited to:

- The PAHO 2011 Latin America and 2014 English-speaking Caribbean Trans Health Blueprints
- WHO's 2014 HIV Consolidated Guidelines for Key Populations and a policy brief on trans people and HIV
- The forthcoming Trans Implementation Tool and the Asia and the Pacific Trans Health Blueprint

Photo Credit: © Rose Wilcher, FHI 360

Beyonce Karungi, founder and executive director of Transgender Equality Uganda, participated in a TRANSIT consultation in Bangkok earlier this month.

On its own, the *AP Blueprint* could serve as an advocacy tool to demonstrate what is needed for comprehensive health services for trans people and their communities. This demonstration could be further highlighted in technical briefs that feature chapters or sections of interest in a particular region or country. Furthermore, the blueprint could be adapted to develop modular health provider trainings that might be instituted as part of a national curriculum and other pre-service training points of entry. Used together, the *TRANSIT* and the *AP Blueprint* could make an even larger impact in the region. The *Blueprint* could complement the *TRANSIT* by showing *where* to implement the *how*. Additionally, the *TRANSIT* is a global document that has been synthesized from regional approaches. The *AP Blueprint* could provide the cultural context needed to begin localizing the *TRANSIT* into implementation and adoption at the national and sub-national levels in the Asia-Pacific region.

The *AP Blueprint* and the *TRANSIT*—developed through the hard work of so many people passionate about these issues—will pave the way for trans health and human rights in the Asia-Pacific region and around the world.

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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.

National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
Division of HIV/AIDS Prevention

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 (http://www.cdc.gov/hiv/pdf/risk_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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