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FY 2020 Houston EMA Ryan White Part A/MAI Service Definition Health Insurance Co-Payments and Co-Insurance Assistance	
HRSA Service Category Title:	Health Insurance Premium and Cost Sharing Assistance
Local Service Category Title:	Health Insurance Co-Payments and Co-Insurance
Budget Type:	Hybrid Fee for Service
Budget Requirements or Restrictions:	Agency must spend no more than 20% of funds on disbursement transactions. The remaining 80% of funds must be expended on the actual cost of the payment(s) disbursed.
HRSA Service Category Definition:	<i>Health Insurance Premium & Cost Sharing Assistance</i> is the provision of financial assistance for eligible individuals living with HIV to maintain a continuity of health insurance or to receive medical benefits under a health insurance program. This includes premium payments, risk pools, co-payments, and deductibles.
Local Service Category Definition:	<p>A program of financial assistance for the payment of health insurance premiums, deductibles, co-insurance, co-payments and tax liability payments associated with Advance Premium Tax Credit (APTC) reconciliation to enable eligible individuals with HIV disease to utilize their existing third party or public assistance (e.g. Medicare) medical insurance.</p> <p><u>Co-Payment</u>: A cost-sharing requirement that requires the insured to pay a specific dollar amount for each unit of service.</p> <p><u>Co-Insurance</u>: A cost-sharing requirement that requires the insured to pay a percentage of costs for covered services/prescription</p> <p><u>Deductible</u>: A cost-sharing requirement that requires the insured to pay a certain amount for health care or prescription, before the prescription drug plan or other insurance begins to pay.</p> <p><u>Premium</u>: The amount paid by the insured to an insurance company to obtain or maintain and insurance policy.</p> <p><u>APTC Tax Liability</u>: The difference paid on a tax return if the advance credit payments that were paid to a health care provider were more than the actual eligible credit.</p>
Target Population (age, gender, geographic, race, ethnicity, etc.):	All Ryan White eligible clients with 3 rd party insurance coverage (COBRA, private policies, Qualified Health Plans, CHIP, Medicaid, Medicare and Medicare Supplemental) within the Houston EMA.
Services to be Provided:	Provision of financial assistance with premiums, deductibles, co-insurance, and co-payments. Also includes tax liability payments associated with APTC reconciliation up to 50% of liability with a \$500 maximum.
Service Unit Definition(s): (RWGA only)	1 unit of service = A payment of a premium, deductible, co-insurance, co-payment or tax liability associated with APTC reconciliation for an HIV-infected person with insurance coverage.

Financial Eligibility:	Refer to the RWPC's approved <i>Financial Eligibility for Houston EMA/HSDA Services</i> .
Client Eligibility:	HIV-infected individuals residing in the Houston EMA meeting financial eligibility requirements and have insurance or be eligible to purchase a Qualified Health Plan through the Marketplace.
Agency Requirements:	<p>Agency must:</p> <ul style="list-style-type: none"> • Provide a comprehensive financial intake/application to determine client eligibility for this program to insure that these funds are used as a last resort in order for the client to utilize his/her existing insurance or be eligible to purchase a qualified health plan through the Marketplace. • Ensure that assistance provided to clients does not duplicate services already being provided through Ryan White Part B or State Services. The process for ensuring this requirement must be fully documented. • Have mechanisms to vigorously pursue any excess premium tax credit a client receives from the IRS upon submission of the client's tax return for those clients that receive financial assistance for eligible out of pocket costs associated with the purchase and use of Qualified Health Plans obtained through the Marketplace. • Conduct marketing with Houston area HIV/AIDS service providers to inform such entities of this program and how the client referral and enrollment processes function. Marketing efforts must be documented and are subject to review by RWGA. • Clients will not be put on wait lists nor will Health Insurance Premium and Cost Sharing Assistance services be postponed or denied without notifying the Administrative Agency. • Establish formal written agreements with all Houston HSDA Ryan White-funded (Part A, B, C, D) primary care, mental health and substance abuse provider agencies to enable clients of these agencies to enroll in Health Insurance assistance at his/her primary care, mental health or substance abuse provider site. (i.e. No need for client to physically present to Health Insurance provider.) • Utilize RWGA approved prioritization of cost sharing assistance, when limited funds warrant it. • Utilize consumer out-of-pocket methodology approved by RWGA.
Staff Requirements:	None
Special Requirements:	<p>Agency must:</p> <ul style="list-style-type: none"> • Comply with the Houston EMA/HSDA Standards of Care and Health Insurance Assistance service category program policies.

FY 2022 RWPC “How to Best Meet the Need” Decision Process

Step in Process: Council		Date: 06/10/2021
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: Steering Committee		Date: 06/03/2021
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: Quality Improvement Committee		Date: 05/18/2021
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
2.		
2.		
3.		
Step in Process: HTBMTN Workgroup #2		Date: 04/20/2021
Recommendations:	Financial Eligibility:	
1.		
2.		
3.		

2022-2023 Service Category Definition - Part B / DSHS State Services

Local Service Category:	Health Insurance Premium and Cost Sharing Assistance
Amount Available:	To be determined
Budget Requirements or Restrictions (TRG Only):	Contractor must spend no more than 20% of funds on disbursement transactions. The remaining 80% of funds must be expended on the actual cost of the payment(s) disbursed. ADAP dispensing fees are not allowable under this service category.
Local Service Category Definition:	<p>Health Insurance Premium and Cost Sharing Assistance: The Health Insurance Premium and Cost Sharing Assistance service category is intended to help people living with HIV maintain continuity of medical care without gaps in health insurance coverage or disruption of treatment. A program of financial assistance for the payment of health insurance premiums and co-pays, co-insurance and deductibles to enable eligible individuals with HIV disease to utilize their existing third party or public assistance (e.g. Medicare) medical insurance. For purposes of this service category, health insurance also includes standalone dental insurance.</p> <p><u>Co-Payment:</u> A cost-sharing requirement that requires the insured to pay a specific dollar amount for each unit of service.</p> <p><u>Co-Insurance:</u> A cost-sharing requirement that requires the insured to pay a percentage of costs for covered services/prescription</p> <p><u>Deductible:</u> A cost-sharing requirement that requires the insured pay a certain amount for health care or prescription, before the prescription drug plan or other insurance begins to pay.</p> <p><u>Premium:</u> The amount paid by the insured to an insurance company to obtain or maintain and insurance policy.</p> <p><u>Advance Premium Tax Credit (APTC) Tax Liability:</u> Tax liability associated with the APTC reconciliation; reimbursement cap of 50% of the tax due up to a maximum of \$500.</p>
Target Population (age, gender, geographic, race, ethnicity, etc.):	All Ryan White eligible clients with 3 rd party insurance coverage (COBRA, private policies, Qualified Health Plans, CHIP, Medicaid, Medicare and Medicare Supplemental plans) within the Houston HSDA.
Services to be Provided:	Contractor may provide assistance with: <ul style="list-style-type: none"> • Insurance premiums, • And deductibles, co-insurance and/or co-payments.
Service Unit Definition (TRG Only):	A unit of service will consist of payment of health insurance premiums, co-payments, co-insurance, deductible, or a combination.
Financial Eligibility:	<p>Affordable Care Act (ACA) Marketplace Plans: 100-400% of federal poverty guidelines. All other insurance plans at or below 400% of federal poverty guidelines.</p> <p>Exception: Clients who were enrolled prior to November 1, 2015 will maintain their eligibility in subsequent plan years even if below 100%</p>

2022-2023 Service Category Definition - Part B / DSHS State Services

	or between 400-500% of federal poverty guidelines.
Client Eligibility:	People living with HIV in the Houston HSDA and have insurance or be eligible (within local financial eligibility guidelines) to purchase a Qualified Health Plan through the Marketplace.
Agency Requirements (TRG Only):	<p>Agency must:</p> <ul style="list-style-type: none"> • Provide a comprehensive financial intake/application to determine client eligibility for this program to insure that these funds are used as a last resort in order for the client to utilize his/her existing insurance or be eligible to purchase a qualified health plan through the Marketplace. • Clients will not be put on wait lists nor will Health Insurance Premium and Cost Sharing Assistance services be postponed or denied due to funding without notifying the Administrative Agency. • Conduct marketing in-services with Houston area HIV/AIDS service providers to inform them of this program and how the client referral and enrollment processes function. • Establish formal written agreements with all Houston HSDA Ryan White-funded (Part A, B, C, D) primary care, mental health and substance abuse provider agencies to enable clients of these agencies to enroll in Health Insurance assistance at his/her primary care, mental health or substance abuse provider site. (i.e. No need for client to physically present to Health Insurance provider.) • Utilizes the RW Planning Council-approved prioritization of cost sharing assistance when limited funds warrant it (<u>premiums take precedence</u>). <ul style="list-style-type: none"> ○ Priority Ranking of Requests (in descending order): <ul style="list-style-type: none"> ▪ HIV medication co-pays and deductibles (medications on the Texas ADAP formulary) ▪ Non-HIV medication co-pays and deductibles ▪ Co-payments for provider visits (eg. physician visit and/or lab copayments) ▪ Medicare Part D (Rx) premiums ▪ APTC Tax Liability ▪ Out of Network out-of-pocket expenses <p>Utilizes the RW Planning Council –approved consumer out-of-pocket methodology.</p>
Special Requirements (TRG Only):	Must comply with the DSHS Health Insurance Assistance Standards of Care and the Houston HSDA Health Insurance Assistance Standards of Care . Must comply with updated guidance from DSHS. Must comply with the Eastern HASA Health Insurance Assistance Policy and Procedure.

2022-2023 Service Category Definition - Part B / DSHS State Services

FY 2022 RWPC “How to Best Meet the Need” Decision Process

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Step in Process: HTBMTN Workgroup #2		Date: 04/20/2021
Recommendations:	Financial Eligibility:	
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2.		
3.		

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**FY 2019 PERFORMANCE MEASURES
 RYAN WHITE GRANT ADMINISTRATION
 HARRIS COUNTY PUBLIC HEALTH (HCPH)**

Ryan White Part A
 HIV Performance Measures
 FY 2019 Report

Health Insurance Assistance
 All Providers

HIV Performance Measures	FY 2018	FY 2019	Change
75% of clients for whom there is lab data in the CPCDMS will be virally suppressed (<200)	1,421 (81.0%)	1,511 (80.6%)	-0.4%

HCPH is the local public health agency for the Harris County, Texas jurisdiction. It provides a wide variety of public health activities and services aimed at improving the health and well-being of the Harris County community.

Follow HCPH on Twitter [@hcph](https://twitter.com/hcph) and like us on [Facebook](https://www.facebook.com/hcph)

Insurance Coverage and Viral Suppression Among People with HIV in the United States, 2015-2018

Lindsey Dawson and Jennifer Kates
AIDS 2020



Filling the need for trusted information on national health issues.

Background

Health insurance coverage and access to care improve health outcomes, including viral suppression, for people with HIV in the United States. Prior research has demonstrated that implementation of the Affordable Care Act (ACA) in 2014 increased coverage among people with HIV and that certain forms of coverage are positively correlated with sustained viral suppression. We provide a 2018 update, the latest nationally representative data in this area, as well as trends over time.



Methods

This analysis is based on 2015-2018 data from the Medical Monitoring Project (MMP), a Centers for Disease Control and Prevention (CDC) surveillance system which produces nationally representative estimates of behavioral and clinical characteristics of adults with diagnosed HIV in the United States. We estimated weighted percentages of adults with the following types of health care coverage, grouping people into mutually exclusive categories, using the following hierarchy: Private coverage (with breakouts for employer coverage and marketplace coverage), Medicaid, Medicare, and other (including Tricare/CHAMPUS, Veteran's Administration, or city/county coverage). Rao-Scott chi-square tests were used for statistical comparisons to assess differences between groups.

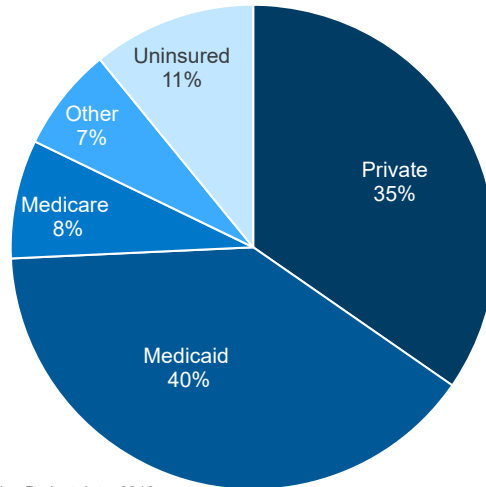


Findings – Coverage

- In 2018, Medicaid was the single largest source of coverage for adults with HIV, covering 4 in 10, followed by private insurance (35%). Just 1 in 10 are uninsured. (Fig. 1)
- Overall coverage rates have remained stable for this population since 2015, the year after full implementation of the ACA. (Fig. 2)



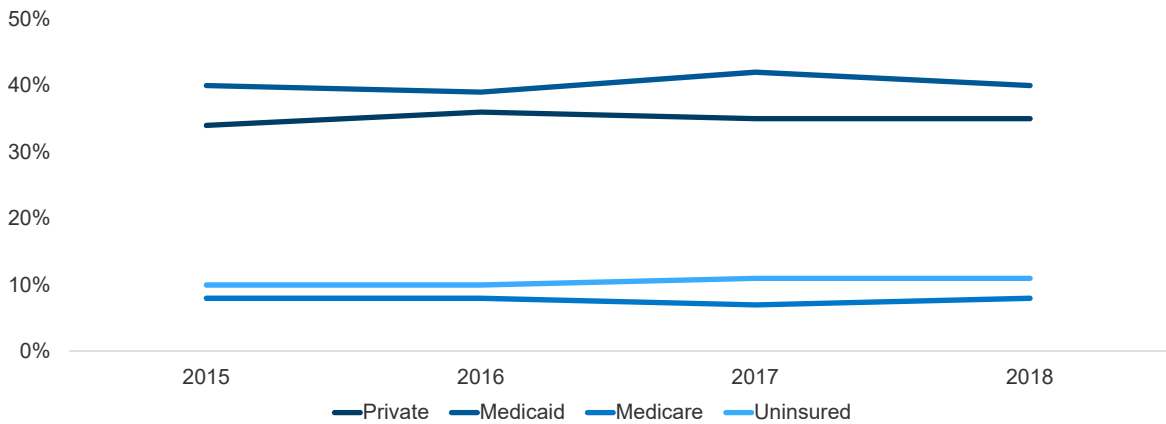
Figure 1: Insurance Coverage Among Adults with HIV, 2018



SOURCE: KFF/CDC Analysis of Medical Monitoring Project data, 2018.



Figure 2: Insurance Coverage Among Adults with HIV, 2015-2018



NOTE: No significant change between coverage groups in 2015 and 2018.
SOURCE: KFF/CDC Analysis of Medical Monitoring Project data, 2015-2018.

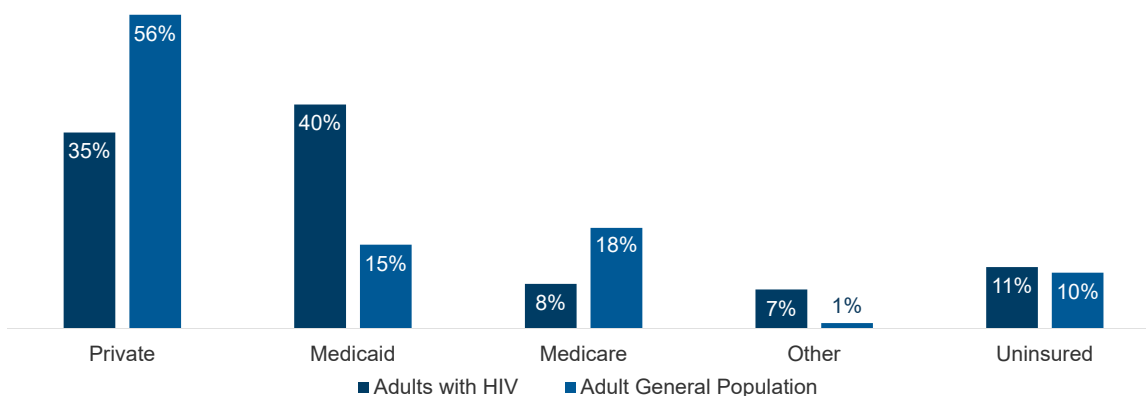


Findings – Coverage II

- Coverage patterns among adults with HIV differ from those of the general population. (Fig. 3)
 - Medicaid plays a much larger role for people with HIV (40% compared to 15%). Conversely, the general population is more likely to be privately insured (56% compared to 35%). Uninsurance rates are comparable between the two populations.
- In states that have expanded Medicaid under the ACA, people with HIV are significantly more likely to be covered by Medicaid than states that have not expanded (46% compared to 30%) and less likely to be uninsured (6% compared to 20%). (Fig. 4)



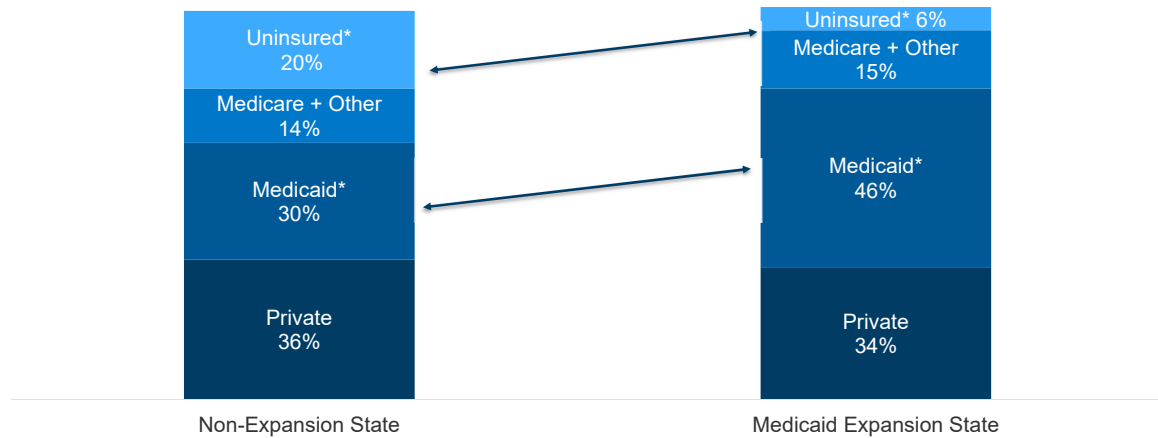
Figure 3: Insurance Coverage Among Adults with HIV Compared to Adults in the General Population, 2018



SOURCE: Coverage among people with HIV - KFF/CDC Analysis of Medical Monitoring Project data, 2018. Coverage among general population - Kaiser Family Foundation estimates based on the Census Bureau's American Community Survey, 2018. <https://www.kff.org/other/state-indicator/adults-19-64/>
NOTE: Data sources are different for people with HIV and the general population and statistical testing was not performed.



Figure 4: Insurance Coverage Among Adults with HIV by State Medicaid Expansion Status, 2018



NOTES: * Coverage rates in Medicaid expansion vs non-expansion states significantly different (p>.001)
SOURCE: KFF/CDC Analysis of Medical Monitoring Project data, 2018.

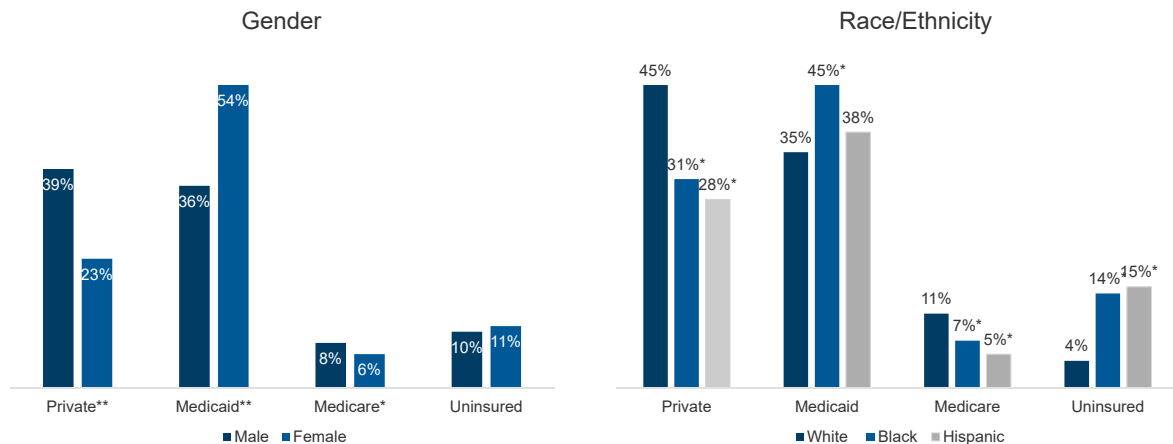


Findings – Coverage II

- There are also coverage differences by gender and race/ethnicity among people with HIV.
 - Male adults with HIV are more likely to have private coverage and Medicare while females are more likely to have Medicaid. Rates of uninsurance do not differ significantly by gender. (Fig. 5)
 - White adults with HIV are more likely than Blacks and Hispanics to have private insurance and Medicare and are less likely than Blacks to have Medicaid. Blacks and Hispanics are more than three times as likely as Whites to be uninsured. (Fig.5)



Figure 5: Insurance Coverage Among Adults with HIV, by Gender and Race/Ethnicity, 2018



NOTES: * Coverage rates significantly different between males and females (p<.05) **Coverage rates significantly different between males and females (p<.001)

NOTE: *Coverage rates significantly different compared to whites. (p<.001)

SOURCE: KFF/CDC Analysis of Medical Monitoring Project data, 2018.

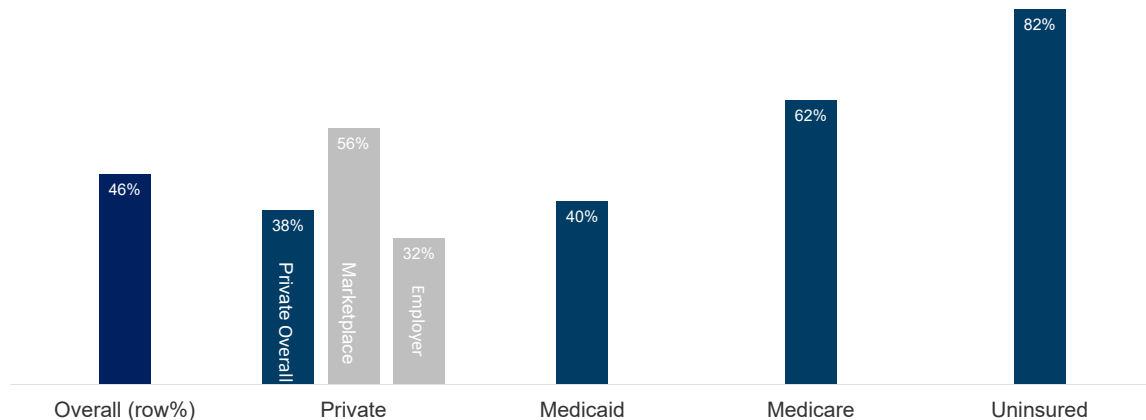


Findings – Ryan White

- The Ryan White HIV/AIDS Program continues to play an important role in providing outpatient care and support services to people with HIV, regardless of insurance coverage. In 2018, nearly half (46%) of adults with HIV found support through the program.
- Ryan White plays an especially important role for the uninsured, 82% of whom receive program services. Sixty-two percent (62%) of those on Medicare receive Ryan White support. Almost 4 in 10 of those with private insurance (38%) receive assistance through the program, a share that is significantly higher among those with marketplace coverage (56%) compared to employer-based coverage (32%). (Fig. 6)



Figure 6: Receipt of Ryan White Support Among Adults with HIV, by Insurance Coverage, 2018



NOTE: Ryan White support includes self attestation to receiving "coverage" through Ryan White, including ADAP.
SOURCE: KFF/CDC Analysis of Medical Monitoring Project data, 2018.

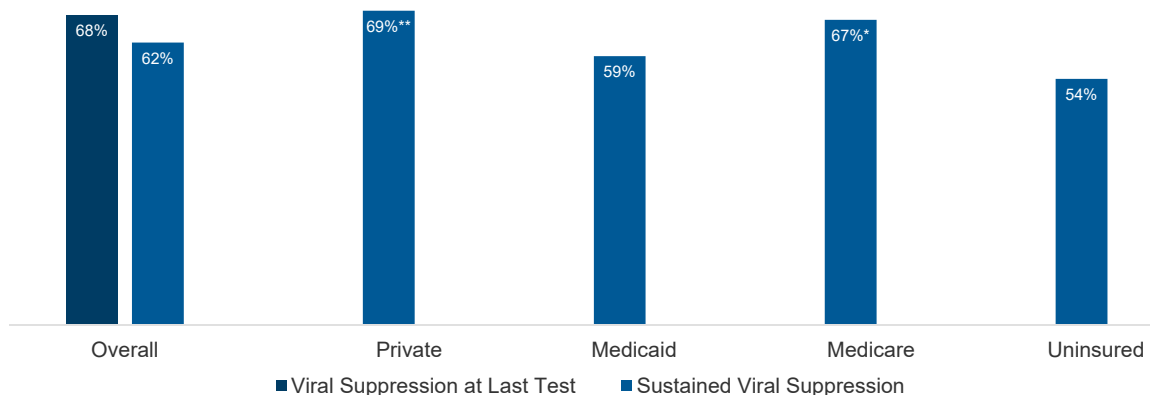


Findings – Viral Suppression

- Viral suppression, particularly sustained viral suppression (defined as having an undetectable viral load over all tests in the preceding 12 months), affords optimal individual health outcomes and provides substantial public health benefit. In 2018, 68% of people with HIV were virally suppressed at last test and 62% had sustained viral suppression. (Fig. 7)
- The proportion of people with sustained viral suppression was significantly higher among those with private insurance and among those with Medicare, compared to the uninsured. Other differences in viral suppression between those with coverage and the uninsured were not significant. (Fig. 7)



Figure 7: Sustained Viral Suppression Among Adults with HIV, by Insurance Coverage, 2018



NOTES: * Viral suppression rate greater than that of the uninsured (p>.05) ** Viral suppression rate greater than that of the uninsured (p>.001)
Sustained viral suppression is defined as having an undetectable viral load over all tests in the preceding 12 months.
SOURCE: KFF/CDC Analysis of Medical Monitoring Project data, 2018.

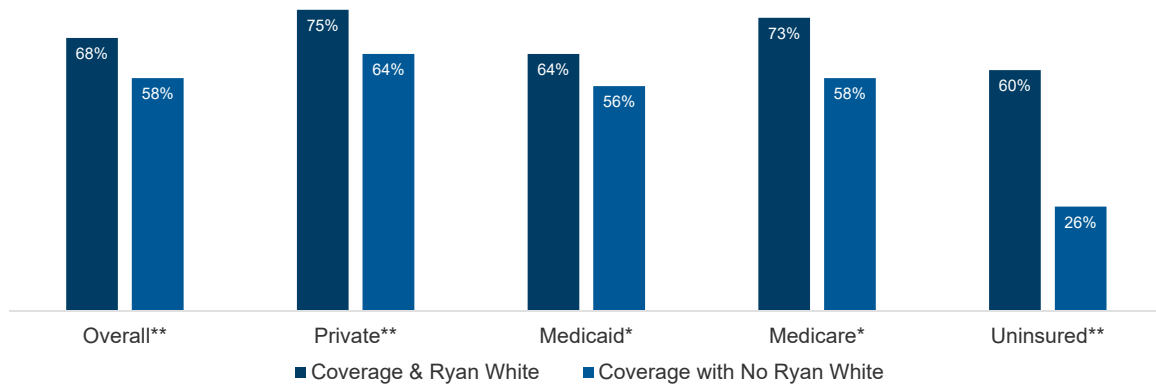


Findings – Viral Suppression II

Ryan White support appears to make a significant difference in achieving sustained viral suppression. Overall, those with Ryan White support were significantly more likely to have sustained viral suppression compared to those without and this trend was observed across all coverage types, and was especially apparent among the uninsured. (Fig. 8)



Figure 8: Ryan White Support and Sustained Viral Suppression Among Adults with HIV, by Insurance Coverage



Notes: * Rate of viral suppression significantly different between those with coverage source & Ryan White vs. those with coverage source and no Ryan White, (p<.05). ** Rate of viral suppression significantly different between those with coverage source & Ryan White vs. those with coverage source and no Ryan White, (p<.001). Sustained viral suppression is defined as having an undetectable viral load over all tests in the preceding 12 months. Source: KFF/CDC Analysis of Medical Monitoring Project data, 2018.



Conclusion

The ACA has made a significant difference in expanding insurance coverage among people with HIV. In 2018, the uninsurance rate among people with HIV was similar to that of the public at large. Medicaid represented the single largest source of coverage for people with HIV, particularly in Medicaid expansion states, followed closely by private insurance. We observed significant differences in coverage by gender and race/ethnicity, with notable disparities related to rates of uninsurance by race/ethnicity. The Ryan White Program is a critical source of care, treatment, and support for people with HIV, especially for the uninsured but also for a substantial share of those with coverage. Certain insurance sources and support from Ryan White were associated with sustained viral suppression, a crucial indicator of optimizing the individual and public health benefits associated with antiretroviral treatment.



Acknowledgments

The authors wish to thank Dr. Sharoda Dasgupta, Dr. Linda Beer, and Dr. Yunfeng Tie of the CDC, who were instrumental in this work in providing access to data, guidance, and conducting statistical analysis.



The Lifetime Cost of HIV

Balancing the Relationship Between Cost and Quality Care

By [James Myhre & Dennis Sifris, MD](#) | Medically reviewed by [a board-certified physician](#) |

Updated on July 26, 2020

A number of studies have not only looked into the lifetime cost of HIV therapy but its cost-effectiveness during different states of infection.

One such study from the *Journal of Acquired Immune Deficiency Syndromes* aimed to estimate the average lifetime cost of HIV—both for individuals starting [antiretroviral therapy \(ART\)](#) early ([CD4 count](#) of 500 cells/mL or less) and those starting late (200 cells/mL or less).

The results confirmed what many smaller studies have long suggested: that early initiation of ART correlates to far lower lifetime costs.

According to the research, for those starting treatment at higher CD4 counts, the estimated average lifetime cost is roughly \$250,000. By contrast, those starting at 200 cells/mL or less were likely to spend twice that amount—from anywhere between \$400,000 and \$600,000.



Andy / Getty Images

Among the reasons cited for the higher costs are the increased risk of both HIV-related and non-HIV-related illnesses in those with compromised immune systems. Moreover, the likelihood that a person will be able to restore immune function to near-normal levels (i.e., CD4 counts of 500-800 cells/mL) becomes less likely the later one starts treatment.

Retrospective analyses from Weill Cornell Medical College further supported the conclusions. tracking individuals with HIV from the age of 35 until death. While the cost of treatment for those who started treatment on diagnosis (\$435,200) was significantly higher than those who delayed therapy (\$326,500), the saving in terms of disease and hospitalization avoidance was considered substantial.

The investigators were further able to conclude that the lifetime cost savings of avoiding HIV infection in a single person was between \$229,800 to \$338,400.

Putting Lifetime Cost of HIV Into Perspective

While the lifetime cost of treatment may, on the surface, appear exorbitant—suggesting inflated [HIV drug prices](#) or American healthcare costs—it's important to look at the costs in relation to other attributable health concerns.

Consider, for example, that the average lifetime cost of smoking for a 24-year-old male is \$183,000, while a 24-year-old female can expect to spend an average of \$86,000. Beyond the cost of the cigarettes themselves, the social costs to Medicare, Medicaid, Social Security, and health insurance are seen to be far greater—whether due to smoking cessation, emphysema, lung cancer, etc.

(These figures are exacerbated by the fact that smoking, as an independent factor, is known to [reduce life expectancy by as much as 12.3 years](#) in people with HIV.)

Meanwhile, the lifetime cost of drinking three alcoholic beverages a day comes to a startling \$263,000 over a lifetime, which correlates to a 41% increased [risk of cancer](#) in men, whether HIV-positive or HIV-negative.

Cost Containment Strategies

None of this, of course, is meant to diminish the financial impact of HIV, both on the individual and the healthcare system as a whole.

From an individual perspective, the cost of HIV care directly relates to how well a patient is retained in care and how effectively that person can adhere to a prescribed therapy. In their May 2014 revision of the U.S. HIV treatment guidelines, the Department of Health and Human Services (DHHS) addressed these concerns by recommending that clinicians "minimize patients' out-of-pocket drug-related expenses whenever possible."

This includes the use of generic drug alternatives whenever possible or reasonable. However, the decision should be accompanied by a careful assessment as to whether the reduced costs might increase the pill burden for the patient. In such cases, the use of generics may reduce overall costs but at the expense of patient adherence. Furthermore, the generic components of a multi-drug regimen could lead to higher insurance co-pay, increasing rather than decreasing out-of-pocket expenses.

In a similar vein, the DHHS has recommended a reduction in the frequency of CD4 monitoring for patients who have been on ART for at least two years and have had consistent, undetectable viral loads. While this is seen to be less impactful in terms of actual cost containment, associated tests such as CD8 and CD19 are, in fact, costly; have virtually no clinical value; and are not recommended as a course of managed HIV care.

For those who have exhibited long-term viral suppression on ART, the DHHS currently recommends that:

- CD4 monitoring be performed every 12 months for those with CD4 counts between 300 and 500 cells/mL, and;
- CD4 monitoring is considered optional for those with CD4 counts over 500 cells/mL.

According to the guidelines, CD4 counts direct when to start or stop prophylactic therapy designed to prevent [opportunistic infections](#), or to assess whether the patient's immunological response to ART is adequate. (An "adequate" response is defined as an increase in the CD4 count by 50 to 150 cells during the first year of therapy, with similar increases every year until a steady state is achieved.)

By contrast, [viral load testing](#) should be considered the key barometer for treatment success. As such, the DHHS recommends viral load monitoring every 3-4 months for patients with consistent, stable viral suppression.

Article Sources

Verywell Health uses only high-quality sources, including peer-reviewed studies, to support the facts within our articles. Read our [editorial process](#) to learn more about how we fact-check and keep our content accurate, reliable, and trustworthy.


1. Farnham PG, Gopalappa C, Sansom SL, et al. [Updates of lifetime costs of care and quality-of-life estimates for HIV-infected persons in the United States: late versus early diagnosis and entry into care](#). *J Acquir Immune Defic Syndr*. 2013;64(2):183-9. doi:0b013e3182973966
2. Schackman BR, Fleishman JA, Su AE, et al. [The lifetime medical cost savings from preventing HIV in the United States](#). *Med Care*. 2015;53(4):293-301. doi:10.1097/MLR.0000000000000308
3. Sloan FA, Ostermann, J, Conover c, Taylor, Jr. DH, Picone G. [The Price of Smoking](#). Cambridge, MA: MIT Press; 2006.
4. U.S. Department of Health and Human Services (DHHS). [Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents](#).

Additional Reading

- U.S. Department of Health and Human Services (DHHS). ["Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents."](#) Bethesda, Maryland.

Research Article

A Cross-Sectional Study on the Affordable Care Act from the Perspective of People Living with HIV: The Interplay between Knowledge, Stigma, Trust, and Attitudes

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Background. Many AIDS Drug Assistance Programs (ADAPs) purchased Affordable Care Act (ACA) Qualified Health Plans (QHPs) for low-income people living with HIV (PLWH). To date, little has been published about PLWH's perspective on the ACA. We explored ACA knowledge, HIV stigma, trust in the healthcare system, and ACA attitudes among PLWH with ADAP-funded QHPs in Virginia. **Methods.** Participants were surveyed about demographic characteristics, ACA knowledge, HIV stigma, trust in various healthcare and government entities, and attitudes toward the ACA. Descriptive statistics were used. We assessed for associations (1) between baseline characteristics and correct ACA knowledge, HIV-related stigma, trust, and ACA attitudes and (2) between correct ACA knowledge and the following data: sources of ACA knowledge, HIV stigma, and trust. **Results.** Participants ($n = 53$) were a vulnerable population based on the assessment of social determinants of health, and 30% had correct ACA knowledge. Almost three-fourths of participants used HIV clinic case managers for ACA information. Participants who used websites for ACA information had correct ACA knowledge more often compared to those that did not (71% vs. 15%; $p = 0.001$). Those with correct ACA knowledge had lower stigma scores compared to those without correct ACA knowledge (93.8; SD: 15.4 vs. 108; SD: 20.3; $p = 0.01$). Participants trusted HIV clinicians more than general clinicians and insurance companies. No association was found between having correct ACA knowledge and endorsing having enough information about the ACA to understand how it will impact their HIV care. **Conclusions.** Websites imparted accurate ACA information. HIV clinic case managers were the most used source, and HIV clinicians were a trusted source of information. HIV clinicians and case managers should consider disseminating information about the ACA and its impact on HIV care delivery via internet videos. Lack of internet and stigma are a threat to PLWH gaining actionable healthcare information.

1. Introduction

With the implementation of the Affordable Care Act (ACA), HIV healthcare delivery and health insurance coverage for many people living with HIV (PLWH) in the United States (US) changed [1]. Across the US, many PLWH with low incomes gained insurance coverage through expanded

Medicaid [1]. Additionally, even for those who did not receive Medicaid due to income restrictions or living in a Medicaid nonexpansion state, many aspects of HIV care changed [2]. Almost all state AIDS Drug Assistance Programs (ADAPs) offered to purchase ACA Qualified Health Plans (QHPs) for PLWH with low incomes [2, 3]. Virginia ADAP paid the insurance premiums, deductibles, and

medication copayments, so most of the possible financial costs related to coverage through the ACA were covered by the state [2]. Our group and others have published studies demonstrating that PLWH with ADAP-funded QHPs are more likely to achieve viral suppression compared to PLWH who receive medications directly from a state ADAP [4–6].

In addition to the available quantitative data suggesting the importance of comprehensive insurance coverage for PLWH, the Kaiser Family Foundation has performed two focus groups with PLWH in urban centers to understand their experience with the ACA [7, 8]. These studies' participants with QHP coverage reported putting a lot of trust in case managers to help them make QHP enrollment decisions and prioritizing being able to continue to see their established HIV clinician [7, 8]. Our group also published a qualitative study about the perspectives and opinions of nonurban PLWH in Virginia who enrolled in ADAP-funded QHPs [9].

Besides the previously mentioned work, little else has been published about the ACA from the perspective of PLWH. We aimed to add more from the patient perspective. Additionally, with this descriptive, hypothesis-generating study, our group sought to understand the interplay of ACA knowledge, stigma, trust, and attitudes about the ACA, which have not been examined together, to our knowledge. In terms of knowledge, previous studies had demonstrated knowledge gaps about the ACA for PLWH in Nebraska [10]. We examined this topic in a nonurban southern population and added the examination of associations between ACA knowledge and stigma, trust, and attitudes about the ACA. These three patient-centered topics were chosen based on the review of previous research. We hypothesized that these could influence PLWH's decisions about healthcare and might be important areas to consider in thinking about how to convey information about changes in healthcare delivery to PLWH more effectively. For stigma, it has been identified as one of the most significant barriers to ending the HIV epidemic worldwide [11] and has been shown to mediate the relationship between self-efficacy and HIV medication adherence and quality of life [12]. We wondered if stigma may be associated with less self-efficacy in making decisions about the ACA. For trust, the Kaiser Family Foundation's work in urban focus groups has highlighted trust in HIV clinicians as important sources of knowledge within the changing healthcare system [7, 8]. Given this, we wanted to explore trust in HIV clinicians for a nonurban southern population, as well as trust in other clinicians, insurance companies, and governmental bodies. For attitudes, it has been shown that better ACA knowledge is associated with increased favorability of the ACA [13, 14].

The specific objective of this study was to explore ACA knowledge, HIV-related stigma, trust in various healthcare and governmental bodies, and attitudes toward healthcare and the ACA among PLWH covered by ADAP-funded QHPs in Virginia. This current work adds to the literature by offering more perspectives from PLWH who live in the nonurban US, as they likely have different experiences than those in urban centers. Moreover, the surveys were conducted with individuals, so participants were not influenced

by dominant respondents as can happen in focus groups. Exploring knowledge, stigma, trust, and attitudes towards new healthcare policies and their interactions may help guide future interventions in designing health policy or education related to health system delivery changes.

2. Methods

2.1. Study Enrollment. This prospective study's goal for recruitment was to enroll at least 5% of people who were eligible for ADAP-funded QHPs in two Virginia Department of Health planning regions (Northwest and Southwest). The University of Virginia Institutional Review Board (IRB) for Social and Behavioral Sciences and the Centra Health IRB approved this study. Participants recruited for the study were English-speaking people living with HIV (PLWH) and were eligible for a Virginia ADAP-funded QHP. They were recruited face to face before or after an HIV medical visit in a medical exam room to ensure privacy and confidentiality. Recruitment took place at three Ryan White HIV/AIDS Program (RWHAP) clinics between December 2015–May 2016 and January 2017–February 2017. Participation in the study took an average of 45 minutes, and participants received compensation for their time. The study included a survey and an interview, both of which were administered verbally to minimize any barriers related to low literacy. Findings from the interviews are published elsewhere [9].

2.2. Cohort Characteristics. Participants were surveyed with validated measurement tools, when possible. Baseline characteristics collected included demographic, socioeconomic, and HIV-related information. Characteristics included age, self-reported gender, race/ethnicity, financial status (annual income as a percentage of the federal poverty level (FPL)), highest level of education completed, housing stability using methods from Montgomery et al. [15], transportation difficulties, internet access, and mental health including depressive symptoms assessed using the 5-item MHI scale from Berwick et al. [16], problem drinking assessed using the AUDIT-C questionnaire from Bush et al. [17], and a single-question screening test for illicit drug use [18]. Other information related to HIV care that was collected included self-reported current antiretroviral prescription status (yes/no) and self-reported current viral suppression status (virally suppressed, not virally suppressed, and unsure).

2.3. Variables

2.3.1. Sources of ACA Knowledge. Participants were provided with a list of possible sources of information about the ACA, which included physician, nurse, clinic case managers, clinic social workers, clinic support staff, other hospital staff, television or magazines, websites, social networking sites, radio, mail, your health insurance company, and friends or family. From this list, they were asked to select their primary

source of information and then all sources of information used.

2.3.2. *ACA Knowledge.* Adapted from a previous study, the following questions were used to assess ACA-related knowledge with the answer options yes, no, and I don't know [19]:

- (1) Does the Affordable Care Act provide subsidies for people with low incomes to purchase health insurance?
- (2) Does the Affordable Care Act make it illegal to exclude a person from an insurance plan due to a pre-existing condition?
- (3) Does the Affordable Care Act eliminate the Ryan White HIV/AIDS Program?
- (4) Did Virginia decide to move forward with the Affordable Care Act's optional Medicaid expansion?

Answering "I don't know" as an answer choice was considered an incorrect answer. Correct ACA knowledge was defined as getting the first three questions correct, as there was a very low correct response rate about Virginia's Medicaid expansion status.

2.3.3. *Stigma.* Information regarding HIV-related stigma was collected using the Berger HIV Stigma Scale [20], and the total score was reported. A higher score means that the person is experiencing more stigma.

2.3.4. *Trust.* Additionally, participants' trust in their main HIV clinician, non-HIV clinician, and health insurance companies was captured by asking their agreement with five statements about each entity [21]. Likert scales were used for these statements, with options including strongly agree, agree, neutral, disagree, and strongly disagree. These were each associated with a numeric score from 5 to 1, and a maximum total score of 25 was possible. Participants' trust in the US federal government and the Virginia state government was also assessed [22]. The questions assessing trust in the US federal government and Virginia state government asked "how often can you trust the governmental body to do what is right," with answer choices that included always, most of the time, about half the time, some of the time, never, and don't know [22]. The "don't know" answer choice was removed during analysis due to ambiguity.

2.3.5. *Attitudes towards the ACA.* Participant attitudes were assessed about five topics using a Likert scale as described above: (1) if health insurance helps improve health outcomes, (2) whether the ACA will improve US health outcomes, (3) if they believe they have enough information about the ACA to understand how it will affect their HIV care, (4) if they think the ACA will improve their HIV-related health, and (5) if they believe the ACA will improve their non-HIV-related health. The majority of these questions was adapted from a previous study [19]. The question

about having enough information was converted to a binary variable (Strongly Agree/Agree vs. Neutral/Disagree/Strongly Disagree) so that its association with correct ACA knowledge could be studied.

2.4. *Data Analysis.* For statistical testing, all baseline characteristics were collapsed into two or three categories to avoid sparse data bias: age (≤ 45 vs. > 45), gender (cis male vs. noncis male), race/ethnicity (white vs. nonwhite), financial status ($\leq 100\%$ FPL vs. $> 100\%$ FPL), education level (beyond high school vs. high school and less), housing stability (stable housing, concern for future housing instability, or current unstable housing), transportation difficulties (yes/no), internet access (access to the internet via a computer and a phone, access via only one source point, and no internet access), presence of depression (yes/no, using the MHI-5 scale with 70 points as the cutoff [16]), problematic alcohol use (yes/no, using the AUDIT-C scale with 4 points as the cutoff [17]), and illicit drug use during the past year (yes/no [18]).

Data analysis was performed using R (R Foundation for Statistical Computing, Vienna, Austria) and RStudio (RStudio Inc., Boston, MA). Each question was analyzed with the available data. Any missing data are noted in the results. Descriptive statistics were used to evaluate baseline characteristics, correct ACA knowledge, sources of ACA knowledge, HIV-related stigma, trust in the medical system and government, and attitudes towards the ACA. Mann-Whitney *U* tests or Kruskal-Wallis tests were used to assess for an association between baseline characteristics (age, gender, race/ethnicity, years since HIV diagnosis, financial status, education level, housing stability, transportation difficulties, internet access, depressive symptoms, problem drinking, and illicit drug use) and each of the following: correct ACA knowledge, HIV-related stigma, trust in the medical system and government, and attitudes towards the ACA.

Additional analyses were performed to investigate if there are any associations between correct ACA knowledge and the following data: sources of ACA knowledge, HIV stigma, and trust. A Kruskal-Wallis test was used to assess if any source of knowledge, which was used by at least 5 participants, was associated with a different distribution of correct ACA knowledge questions. Mann-Whitney *U* tests were used to assess the association between correct ACA knowledge and average HIV Stigma Scale overall score and all trust scores. The interaction of participants' perception of having enough information to understand how the ACA will affect their healthcare and performance on the ACA knowledge questions was studied using a Fisher's exact test.

3. Results

3.1. *Participant Characteristics.* Characteristics of the participants ($n = 53$) are included in Table 1. We achieved the study enrollment goal of enrolling $\geq 5\%$ of the PLWH who were eligible for ADAP-funded QHPs in two Virginia Department of Health planning regions (Northwest and

Southwest, $n = 696$). The participants all enrolled in an ADAP-funded QHP in the first (2014) or second (2015) year that the option was available. No data were collected on people who did not elect to participate in the survey. The median participant age was 43 years (interquartile range (IQR): 30, 50), and the median time since diagnosis was 10.2 years (IQR: 4.1, 19.7). The majority of participants (66.0%) was male, and just over half (56.6%) were black race/ethnicity. Most participants (69.8%) made less than 133% FPL, and two-thirds completed education equivalent to a high school diploma or less. Nearly 20% of participants reported concerns related to housing stability, about 30% endorsed transportation difficulties, and 17.0% reported having no reliable internet access point. Almost a quarter of participants reported problem drinking or illicit drug use within the past year, while two-thirds endorsed depressive symptoms. More than 90% of participants (92.5%) reported being prescribed ART, and 78.8% of participants reported being virally suppressed.

3.2. ACA Knowledge. Almost 80% of participants correctly knew that the ACA provides for low-income subsidies (Table 2). Just over 40% knew that the ACA provides protection for people with pre-existing conditions. Over two-thirds knew that the RWHAP would continue under the ACA. Thirty percent of all participants had correct ACA knowledge. 11% of participants who correctly knew about Virginia's Medicaid expansion status also had correct ACA knowledge. Participants with higher incomes were more likely to demonstrate correct ACA knowledge than those with lower incomes (48% vs. 19%; $p = 0.03$). No other baseline characteristics were associated with correct ACA knowledge.

3.3. Sources of ACA Knowledge. Participants reported that their primary source for obtaining ACA information was clinic case managers (47%) followed by using websites (13%), television (11%), clinic social workers (11%), and newspapers or magazines (4%) (Figure 1). In terms of all sources of information about the ACA, the most common sources were learning from clinic case managers (70%), using television (42%), learning from clinic social workers (36%), learning from an attending physician in charge of their care (30%), and learning from friends or family (28%) (Figure 1). The mean number of reported sources was 3.6 (standard deviation (SD): 2.1; range: 1–10).

Participants who used websites for ACA information were more likely to have correct ACA knowledge compared to those that did not (71% vs. 15%; $p = 0.001$). While not statistically significant, participants who learned ACA information from clinic social workers were more likely to have correct ACA knowledge compared to those that did not (47% vs. 21%; $p = 0.09$). Use of other sources of ACA information (physician, nurse, clinic case managers, clinic support staff, other hospital staff, television or magazines, social networking sites, radio, mail, health insurance companies, and friends or family) was also not associated with correct ACA knowledge.

TABLE 1: Baseline characteristics.

Cohort characteristics	Total: n (%) ($n = 53$)
Age (years)	
Median (IQR)	43 [30, 50]
Gender	
Male	35 (66.0%)
Noncis male	18 (34.0%)
Race	
Black	30 (56.6%)
White	19 (35.8%)
Others	4 (7.5%)
Years since HIV diagnosis	
Median (IQR)	10.3 [4.8, 19.7]
Financial status ¹	
<50% FPL	16 (30.2%)
51–100% FPL	16 (30.2%)
101–133% FPL	5 (9.4%)
134–200% FPL	7 (13.2%)
>201% FPL	9 (17.0%)
Education	
Less than high school	5 (9.4%)
High school or equivalent	30 (56.6%)
Vocational	5 (9.4%)
College degree	11 (20.8%)
More than college degree	2 (3.8%)
Housing stability ¹	
Unstable housing	3 (5.7%)
Stable housing with future concern	7 (13.2%)
Stable housing without future concern	43 (81.1%)
Transportation access	
Difficulty	15 (28.3%)
No difficulty	38 (71.7%)
Internet access	
Neither	9 (17.0%)
Smartphone only	6 (11.3%)
Computer only	2 (3.8%)
Computer and smartphone	36 (67.9%)
Depressive symptoms ²	
Yes	35 (66.0%)
No	18 (34.0%)
Problem drinking ³	
Yes	12 (22.6%)
No	41 (77.4%)
Drug use within the past year ⁴	
Yes	12 (22.6%)
No	41 (77.4%)
Currently prescribed ART	
Yes	49 (92.5%)
No	4 (7.5%)
Current viral suppression status	
Virally suppressed	41 (78.8%)
Not virally suppressed	6 (11.5%)
Unsure	5 (9.6%)

¹Housing stability assessed using methods from Montgomery et al. [15].

²Depressive symptoms assessed using the 5-item MHI scale from Berwick et al. [16].

³Problem drinking assessed using the AUDIT-C questionnaire from Bush et al. [17].

⁴Drug use assessed using a single-question screening test from Smith et al. [18].

Abbreviations: IQR: interquartile range, FPL: federal poverty level, and ART: antiretroviral therapy.

TABLE 2: Respondents' Affordable Care Act (ACA) knowledge, HIV stigma, trust in the healthcare system and government, and ACA attitudes.

ACA knowledge ¹ : <i>n</i> (%)	Overall <i>n</i> = 53
ACA subsidies	
Correct	41 (77%)
Not correct	12 (23%)
Pre-existing conditions	
Correct	23 (43%)
Not correct	30 (57%)
ACA/Ryan White interaction	
Correct	37 (70%)
Not correct	16 (30%)
Virginia Medicaid expansion	
Correct	6 (11%)
Not correct	47 (89%)
Correct ACA knowledge ²	
Yes	16 (30%)
No	37 (70%)
HIV Berger Stigma Scale ³ : mean (SD)	
Total stigma	104 (20.0)
Trust in clinicians/insurance companies ⁴	
Mean (SD)	
Trust in HIV clinicians	21.8 (2.5)
Trust in general clinicians	19.5 (3.6)
Trust in insurance companies	13.6 (3.8)
Trust in governmental bodies ⁵ : <i>n</i> (%)	
How often can you trust the federal government to do what is right?	
Always	2 (3.8%)
Most of the time	8 (15.1%)
About half the time	12 (22.6%)
Some of the time	15 (28.3%)
Never	8 (15.1%)
Don't know	8 (15.1%)
How often can you trust the Virginia state government to do what is right?	
Always	3 (5.7%)
Most of the time	9 (17.0%)
About half the time	13 (24.5%)
Some of the time	12 (22.6%)
Never	8 (15.1%)
Don't know	8 (15.1%)
Attitudes toward the ACA ¹ : mean (SD)	
Does insurance improve healthcare?	3.9 (1.0)
Will the ACA improve US health outcomes?	3.5 (0.9)
Will the ACA improve your HIV health outcomes?	3.7 (1.0)
Will the ACA improve your non-HIV health outcomes?	3.4 (0.9)
Do you have enough information on the ACA to understand its impact on your HIV care?	
Agree	28 (53%)
Disagree	25 (47%)

¹ACA knowledge and attitudes toward the ACA were assessed using questions from McManus et al. [19]. ²Correct ACA knowledge was defined as getting the first three questions correct (ACA subsidies, pre-existing conditions, and ACA/Ryan White interaction) as there was a very low correct response rate about Virginia's Medicaid expansion status. ³Stigma was assessed using the Berger HIV Stigma Scale [20]. ⁴Trust in clinicians and insurance companies was assessed using methods from Dugan et al. [21]. ⁵Trust in governmental bodies was assessed using methods from the American National Election Studies [22].

3.4. Stigma. Fifty-one out of 53 participants completed all 40 questions of the Berger HIV Stigma Scale. The overall average stigma score was 104 (SD: 20.0; maximum score: 160; Table 2).

The mean overall stigma scores were higher for participants who were older than 45 years (115.0; SD: 21.2; Table 3) compared to those under 45 years old (97.1; SD:

16.0; $p = 0.003$). They also differed for those who had transportation difficulties (115.0; SD: 17.2) compared to those who had stable transportation (99.4; SD: 19.4; $p = 0.01$). Mean stigma scores were higher for those who did not have internet access (122.0; SD: 16.9) compared to those who had internet access on a computer or a phone (105; SD: 14.8) and those who had access on both a computer and a

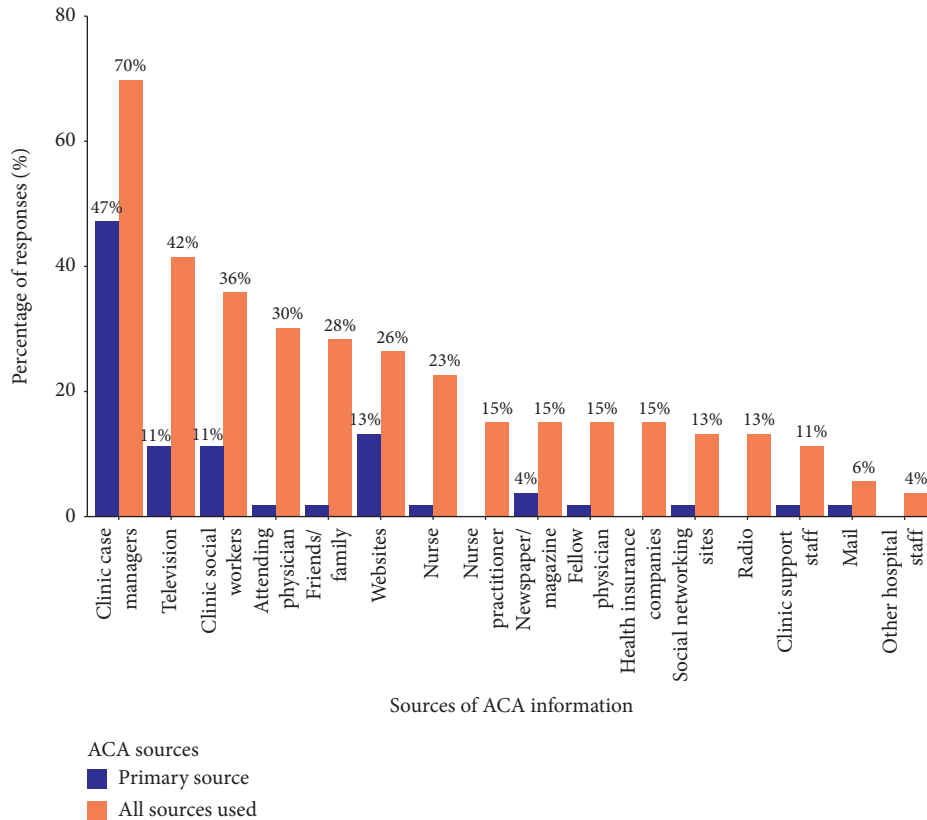


FIGURE 1: Frequency of participants' sources and main sources of Affordable Care Act knowledge. The labels for bars less than 5% are not shown.

phone (99.2; SD: 19.5; $p=0.01$). Lastly, participants with depressive symptoms had higher mean stigma scores (111.0; SD: 19.2) than those who did not have depressive symptoms (90.8; SD: 14.3; $p=0.001$). Gender, race/ethnicity, financial status, education level, housing stability, problem drinking, and illicit drug use were not associated with differences in overall HIV-related stigma.

Those with correct ACA knowledge had decreased overall stigma scores (93.8; SD: 15.4) compared to those without correct ACA knowledge (108; SD: 20.3; $p=0.01$).

3.5. Trust. The overall average trust score in HIV clinicians was 21.8 (SD: 2.5; max score: 25; Table 2). Overall, the average trust score for general clinicians was 19.5 (SD: 3.6; max score: 25). The overall average score for participant trust in insurance companies was 13.6 (SD: 3.8; max score: 25).

Differences in trust in HIV clinicians were not associated with any baseline characteristics or with correct ACA knowledge. Correct ACA knowledge was associated with lower trust in general clinicians (18.1; SD: 3.8) compared to participants with incorrect ACA knowledge (20.1; SD: 3.3; $p=0.01$). No other baseline characteristics were associated with differences in trust in general clinicians. Participants who had an education level of high school or less trusted health insurance companies more (14.7; SD: 3.4) than those who had education beyond high school (11.6; SD: 3.9; $p=0.008$). Other baseline characteristics and correct ACA

knowledge were not associated with differences in trust in health insurance companies.

In terms of trust in the federal government, 3.8% said they could "always" trust the federal government, 15.1% said "most of the time," 22.6% said "about half the time," 28.3% said "some of the time," 15.1% said "never," and 15.1% said "don't know" (Table 2). In terms of trust in the Virginia state government, 5.7% said they could "always" trust the Virginia state government, 17.0% said "most of the time," 24.5% said "about half the time," 22.6% said "some of the time," 15.1% said "never," and 15.1% said "don't know."

Differences in trust in the federal government were not associated with any baseline characteristics or with correct ACA knowledge. Participants with depressive symptoms had less trust in the Virginia state government (2.43 points; SD: 1.1) compared to those without depressive symptoms (3.27; SD: 1.2; $p=0.02$). Other baseline characteristics and correct ACA knowledge were not associated with differences in trust in the Virginia state government.

3.6. Attitudes towards the ACA. The mean response for the statement "You believe that having health insurance improves one's healthcare" was 3.9 (SD: 1.0; Table 2). The mean score for the question "Do you think that the Affordable Care Act will improve US health outcomes?" was 3.5 (SD: 0.9). Participants' mean response to "Do you think that the Affordable Care Act will improve your HIV-related health?"

TABLE 3: Stigma score compared to selected baseline characteristics and correct Affordable Care Act knowledge.

	Total stigma score Mean (SD)	<i>p</i> value
All participants (<i>n</i> = 52) ¹	104 (20.0)	
Age (years)		
≤45 (<i>n</i> = 32)	97.1 (16)	0.003
>45 (<i>n</i> = 20)	115 (21.2)	
Income		
≤100% FPL (<i>n</i> = 32)	108 (20.4)	0.1
>100% FPL (<i>n</i> = 20)	97.0 (17.7)	
Stable transportation		
Yes (<i>n</i> = 38)	99.4 (19.4)	0.01
No (<i>n</i> = 14)	115 (17.2)	
Internet access		
Both (<i>n</i> = 35)	99.2 (19.5)	0.01
Computer or phone (<i>n</i> = 8)	105 (14.8)	
Neither (<i>n</i> = 9)	122 (16.9)	
Depression		
Yes (<i>n</i> = 35)	111 (19.2)	0.001
No (<i>n</i> = 17)	90.8 (14.3)	
Correct ACA knowledge		
Yes (<i>n</i> = 16)	93.8 (15.4)	0.01
No (<i>n</i> = 35)	108 (20.3)	

Differences in stigma scores for baseline characteristics were examined with Mann-Whitney *U* tests or a Kruskal-Wallis test (internet access). Differences between stigma scores and correct Affordable Care Act knowledge were evaluated with a Mann-Whitney *U* test. ¹One participant did not fill out a sufficient number of questions to be included.

was 3.7 (SD: 1.0). The mean response for the question “Do you think that the Affordable Care Act will improve your health?” was 3.4 (SD: 0.9). Over half of participants (53%) agree that they believe that they have enough information about the ACA to understand its impact on their HIV care.

Participants who reported a history of problematic alcohol use were less likely to believe that the ACA would improve their non-HIV-related health (2.9; SD: 1.1) compared with those who did not have problematic alcohol use (3.5; SD: 0.9; *p* = 0.04). Those who reported using an illicit substance in the past year were more likely to say that they did not have enough information about the ACA to understand how it will impact their HIV care (75% vs. 39%; *p* = 0.03). No other baseline characteristics were associated with differences in attitudes towards the ACA. No association was found between a participant having good ACA knowledge and saying they have enough information about the ACA to understand how it will impact their HIV care.

4. Discussion

This study highlights that participants had knowledge gaps related to the ACA. Like many PLWH, especially in the south, a significant portion of participants in this study had major barriers to healthcare access including unstable housing, transportation difficulties, a lack of internet access, and high HIV-related stigma scores. There was no association between a participant having correct ACA knowledge and their feeling as though they had enough ACA

information to understand how it will affect their HIV care. In light of this finding, HIV clinicians and HIV clinic staff should consider that PLWH may not recognize their own knowledge gaps.

Nearly one-third of the study participants did not know that the RWHAP would be continuing under the ACA, and just over 10% of participants correctly knew that Virginia had not expanded Medicaid at the time of the survey. A 2013-2014 Nebraska study investigating a similar population of PLWH found that only 25% knew about the preservation of the RWHAP, and 63% did not know about whether Nebraska decided to expand Medicaid [10]. This suggests that lack of knowledge about specific aspects of the ACA may be common among PLWH. Our team performed a 2015 study assessing national HIV clinician knowledge of the ACA that showed that a majority of HIV clinicians knew about the preservation of the RWHAP (91%) and their state’s Medicaid expansion status (73%). We performed a follow-up study in 2018 that demonstrated HIV clinicians’ improved knowledge on these topics as well [23]. This suggests that HIV clinicians can share with PLWH about these topics [19] as well as about the association between ACA Qualified Health Plans and viral suppression [4–6]. From this study, it seems that only one-third of PLWH received any ACA information from their HIV clinician, so this is an area for improvement. Increasing dissemination of this information to PLWH is an important goal for HIV clinicians and HIV clinic staff, such as medical case managers, so that PLWH will have actionable and correct knowledge about the ACA and can advocate for themselves. Excellent skills in system-based medicine have been noted to be an important skill for infectious diseases clinicians [24]. The Accreditation Council for Graduate Medical Education defines system-based medicine as an awareness of and responsiveness to the larger context and system of healthcare, including the social determinants of health, as well as the ability to call effectively on other resources in the system to provide optimal healthcare [25]. Skills in this area may be even more important for HIV clinicians given the barriers that their patients face issues related to social determinants of health that have only been exasperated by COVID-19 [26] and the known impact of social determinants of health on HIV outcomes [27].

Our study population demonstrated high levels of trust in both their HIV clinicians and general clinicians, relative to their trust in health insurance companies. Additionally, for this study population, no baseline characteristic was associated with the difference in trust in HIV clinicians, suggesting that the HIV clinicians are maintaining the trust of PLWH of different ages, genders, race/ethnicity groups, and socioeconomic groups. Previous studies have demonstrated that African Americans may trust their HIV clinicians less than those of other race/ethnicity groups [28]. Trust in clinicians has been shown to be an important factor in care for PLWH, including that it is associated with adherence to antiretroviral therapy [29] and improved retention in HIV care [30]. Trust in clinicians can allow them to become key information brokers related to healthcare, public health, and research [31].

Given the observed trust in the HIV clinician relationship in this population, it seems that there may be an opportunity for education about the ACA to be brokered through HIV clinics by HIV clinicians or case managers [32]. We did not find any association between correct ACA knowledge and learning ACA information from HIV clinicians and HIV clinic staff. However, future strategies to combine trusted and commonly used sources, HIV clinicians and case managers, with websites, which were the only source of ACA knowledge in this study that was associated with correct ACA knowledge, should be explored. While there will be variable health insurance literacy [33], HIV clinics could develop low-cost websites with videos to share accurate and actionable ACA knowledge with PLWH. Videos could be disseminated via a private YouTube channel or a clinic-specific mobile health application. For example, an HIV clinic-based mobile health application utilized its platform to share how the ACA was going to impact HIV care in Virginia [34]. Sharing information electronically reaches PLWH outside of their busy HIV clinic visits, and if it is asynchronous, it could be viewed at a time that is convenient for them. AIDS Education and Training Centers are poised to organize these efforts, as they have a track record in creating changes in clinician practices and changes to the care system [35].

Additionally, given that using websites was associated with correct ACA knowledge, access to the internet is important for PLWH to gain accurate knowledge about healthcare system changes. Internet access is being increasingly recognized as a social determinant of health, and this has been supported by the Federal Communications Commission [36]. Advocating for increased broadband in rural areas and access to smartphones for all PLWH is essential to ensure equitable access to health information [37]. In addition to knowledge benefits, HIV stigma scores were lower with increasing access to the internet.

Additional work needs to be done to understand the interaction between internet access, stigma, and correct knowledge. As mentioned previously, stigma has been called one of the most significant barriers to ending the HIV epidemic [11]. Participants with higher stigma scores were less likely to demonstrate correct ACA knowledge. This raises the question of whether having good knowledge of the healthcare system helps decrease stigma, or if factors that contribute to higher stigma scores are also barriers to accessing knowledge of the healthcare system. Our data revealed similar patterns about what characteristics (increased age, lower incomes, and mental health challenges) are associated with HIV-related stigma as many previous studies [38].

Compared with HIV clinicians and general clinicians, there was lower trust for health insurance companies. This is not surprising given that, before the ACA was passed in 2010, HIV was essentially an uninsurable pre-existing condition in the private marketplace [39]. Due to this issue, having health insurance is relatively new for many PLWH. After the full implementation of the ACA in 2014, the percentage of PLWH with private insurance was estimated to double [1]. It was surprising that the entities that support

the RWHAP and ADAP, the federal and state government, did not seem to have much trust from the participants. The RWHAP clinics, ADAP, and ADAP-supported QHPs were generally viewed as beneficial or necessary in the qualitative analysis of this same population's interviews [9] and in the Kaiser Family Foundation's focus group studies [7, 8]. Based on the findings from these participants, it is possible that any goodwill accorded to the governmental bodies for these programs is outweighed by other laws or policies. Looking at trust overall, this study's results suggest that new initiatives or changes to how healthcare is delivered to PLWH may be better accepted if they are communicated from HIV or general clinicians, rather than coming directly from insurance companies or the government. Given the constraints of clinic flow and timing, these messages may need to be electronically delivered, as discussed above.

In terms of looking at specific groups that may need more educational outreach, participants who engaged in illicit drug use reported that they did not feel that they had enough information about the ACA to make informed decisions about their health. When examining ACA attitudes, participants with a history of problem drinking were less likely to believe that the ACA will improve their non-HIV-related healthcare. This could be due to them factoring in their own personal experience or the historically low treatment rates (10%) for people with alcohol use disorder [40]. However, due to the ACA, QHPs must cover Essential Health Benefits which include substance use disorder treatment. There is some leeway at the state level to mandate what exact services must be covered, but this is the first time that any treatment for substance use disorder has to be covered in the US [41].

This study has several limitations including that there was no information collected on those who chose not to participate and the possibility of unmeasured confounding. Moreover, ACA knowledge was measured with only 4 questions. The findings may not be representative of the US given the limited geographic scope. Additionally, all participants were enrolled in ADAP-funded QHPs and received care at RWHAP clinics, which means there was homogeneity in how participants' care was being supported and delivered. The study also has a small sample size. Additional research is needed in larger groups. Participants were recruited from HIV clinic visits, so this population is likely more engaged with the healthcare system and may have a more positive view of the healthcare system than people who are not regularly seeking care. Lastly, as a hypothesis-generating study, we did not use a Bonferroni correction, given that it is a conservative test that protects from type I error, but increases type II errors [42]. Results were presented as they were calculated, and readers should interpret the results in the context of the overall descriptive study.

Since this survey was completed, Virginia has expanded Medicaid [43], so it is possible that people's method or ability to access healthcare, attitudes toward the ACA, or correct ACA knowledge may have changed. Nevertheless, the healthcare system will continue to shift and change. PLWH may not be aware of their knowledge gaps, as systems change. HIV clinicians are a trusted source, HIV case

managers are a highly utilized source, and websites are associated with correct ACA knowledge. Combining these three, internet-based videos of HIV clinicians and case managers could help to educate PLWH about the ACA and its impact on HIV care delivery. Lack of internet and stigma pose threats and need to be addressed. Future larger studies should examine how knowledge, stigma, trust, and attitudes may impact the healthcare decisions of PLWH.

Data Availability

Access to the survey data used for this study is restricted by the University of Virginia Institutional Review Board in order to protect patient's privacy. Data are available from Dr. McManus for researchers who meet the criteria for access to confidential data.

Disclosure

The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Conflicts of Interest

Dr. McManus reports an investigator-initiated research grant from Gilead Sciences, Inc., and stock ownership in Gilead Sciences, Inc. Dr. Dillingham reports an investigator-initiated research grant from Gilead Sciences, Inc, and consulting for Warm Health Technology, Inc.

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