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**:**	***Health Insurance Premium & Cost Sharing Assistance*** 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:	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. Co-Payment: A cost-sharing requirement that requires the insured to pay a specific dollar amount for each unit of service. Co-Insurance: A cost-sharing requirement that requires the insured to pay a percentage of costs for covered services/prescription Deductible: 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. Premium: The amount paid by the insured to an insurance company to obtain or maintain and insurance policy. APTC Tax Liability: 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.
Target Population (age, gender, geographic, race, ethnicity, etc.):	All Ryan White eligible clients with 3rd 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 *Financial Eligibility for Houston EMA/HSDA Services*.
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:	Agency must: • 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:	Agency must: • Comply with the Houston EMA/HSDA Standards of Care and Health Insurance Assistance service category program policies.

FY 2023 RWPC "How to Best Meet the Need" Decision Process

Step in Process: **Council**		Date: **06/09/2022**
Recommendations:	Approved: Y:_____ No: ______ Approved With Changes:______	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **Steering Committee**		Date: **06/02/2022**
Recommendations:	Approved: Y:_____ No: ______ Approved With Changes:______	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **Quality Improvement Committee**		Date: **05/03/2022**
Recommendations:	Approved: Y:_ ___ No: ______ Approved With Changes: _______	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **HTBMTN Workgroup #2**	Date: **04/19/2022**
Recommendations:	Financial Eligibility:
1.	
2.	
3.	

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:	**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 (PLWH) 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. <u>Co-Payment:</u> A cost-sharing requirement that requires the insured to pay a specific dollar amount for each unit of service. <u>Co-Insurance:</u> A cost-sharing requirement that requires the insured to pay a percentage of costs for covered services/prescription <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. <u>Premium:</u> The amount paid by the insured to an insurance company to obtain or maintain and insurance policy. <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.
Target Population (age, gender, geographic, race, ethnicity, etc.):	All Ryan White eligible PLWH with 3rd 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: • 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:	Affordable Care Act (ACA) Marketplace Plans: 100-400% of federal poverty guidelines. All other insurance plans at or below 400% of federal poverty guidelines. Exception: PLWH who were enrolled prior to November 1, 2015 will maintain their eligibility in subsequent plan years even if below 100% or between 400-500% of federal poverty guidelines.
Eligibility for Services:	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)**:	Agency must: • Provide a comprehensive financial intake/application to determine PLWH eligibility for this program to insure that these funds are used as a last resort in order for the PLWH to utilize his/her existing insurance or be eligible to purchase a qualified health plan through the Marketplace. • PLWH 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 PLWH 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 PLWH 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 PLWH to physically present to Health Insurance provider.) • Utilizes the RW Planning Council-approved prioritization of cost sharing assistance when limited funds warrant it (premiums take precedence). o **Priority Ranking of Requests (in descending order)**: ▪ 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 • Utilizes the RW Planning Council –approved consumer out-of-pocket methodology.
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.

FY 2023 RWPC "How to Best Meet the Need" Decision Process

Step in Process: **Council**		Date: **06/09/2022**
Recommendations:	Approved: Y:_____ No: ______ Approved With Changes:______	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **Steering Committee**		Date: **06/02/2022**
Recommendations:	Approved: Y:_____ No: ______ Approved With Changes:______	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **Quality Improvement Committee**		Date: **05/03/2022**
Recommendations:	Approved: Y:_ ___ No: ______ Approved With Changes: ________	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **HTBMTN Workgroup #2**	Date: **04/19/2022**
Recommendations:	Financial Eligibility:
1.	
2.	
3.	

FY 2020 Performance Measures Highlights

Ryan White Grant Administration

Harris County Public Health (HCPH)

Ryan White Part A
HIV Performance Measures
FY 2020 Report

Health Insurance Assistance
All Providers

HIV Performance Measures	FY 2019	FY 2020	Change
80% of clients for whom there is lab data in the CPCDMS will be virally suppressed (<200)	1,511 (80.6%)	1,367 (73.5%)	**-7.1%**

Insurance Coverage and Viral Suppression Among People with HIV, 2018

Lindsey Dawson (https://www.kff.org/person/lindsey-dawson/) (https://twitter.com/LindseyH_Dawson)

and **Jennifer Kates (https://www.kff.org/person/jennifer-kates/)** (https://twitter.com/jenkatesdc)

Published: Sep 24, 2020

DATA NOTE

Key Findings

- Health insurance and access to care improve health outcomes, including viral suppression, for people with HIV in the United States (U.S.). Our prior research documented (https://www.kff.org/health-reform/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/) an increase in insurance coverage among people with HIV, after implementation of the Affordable Care Act (ACA). In this update, we find that in 2018, just 1 in 10 (11%) nonelderly people with HIV were uninsured, a rate on par with that of the general population (10%).
- While the overall rate of uninsurance is now similar for people with HIV and the population overall, there are substantial differences in the type of coverage. Medicaid plays a much more significant role for people with HIV compared to the general population (40% v. 15%), and it is their single largest source of coverage, and people with HIV are much less likely to be covered by private insurance (35% v. 56%).
- The main driver of coverage increases for people with HIV has been the ACA's expansion of the Medicaid program (https://www.kff.org/health-reform/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/). As with our earlier research, in 2018, we continue to find that adults with HIV in sampled expansion states are significantly more likely to be covered by Medicaid (46% v. 30%) and less likely to be uninsured (6% v. 20%), compared to those in non-expansion states sampled.
- We observed coverage differences among adults with HIV by a range of demographic indicators. For example, men with HIV were almost twice as likely to have private coverage than women. Whites were also more likely to have private coverage compared to Blacks and Hispanics, who were more than three times as likely to be uninsured. We also noted differences by income, place of birth, and sexual orientation.
- The Ryan White HIV/AIDS Program plays a major role in providing outpatient care and support services to people with HIV, regardless of insurance coverage. In 2018, almost half of all people with HIV (46%) relied on Ryan White, including more than eight in ten (82%) of those who are uninsured.

Finally, we find that sustained viral suppression rates varied by payer, and were

- higher among those with private insurance or Medicare, compared to the uninsured. Viral suppression among those with Medicaid was not significantly different from the uninsured, a finding that could reflect the equalizing role of the Ryan White Program for the uninsured and lower incomes among individuals in these coverage groups. Additionally, those with Ryan White support were significantly more likely to have sustained viral suppression compared those without, regardless of payer.

Introduction

Health insurance coverage and access to care improve health outcomes, including viral suppression, for people with HIV in the United States. Our previous work, based (https://www.kff.org/health-reform/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/) on analysis of nationally representative data from the Centers for Disease Control (CDC) and Prevention's Medical Monitoring Project (MMP), demonstrated that implementation of the Affordable Care Act's (ACA) 2014 coverage provisions increased insurance coverage among adults with HIV. In this analysis, using the same data source and building on recent work (https://cattendee.abstractsonline.com/meeting/9289/Presentation/2850), we provide a detailed analysis of coverage in 2018, including by state Medicaid expansion status, race/ethnicity, gender, and income. For the first time, we include data on coverage among people with HIV by place of birth and sexual orientation.

Findings

Overall Coverage Findings

Our earlier research (https://www.kff.org/health-reform/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/) found that prior to the ACA's major coverage reforms, approximately 18% of people with HIV were uninsured in 2012. While not directly comparable to the current dataset, the share of people with HIV without insurance was just 11% in 2018, suggesting a substantial decline in uninsurance rates among this population. Indeed, implementation of the ACA resulted in a significant increase in coverage and since that time, rates have remained stable (Fig. 1). [1] (https://www.kff.org/hivaids/issue-brief/insurance-coverage-and-viral-suppression-among-people-with-hiv-2018/view/footnotes/#footnote-98765432-1) In 2018, Medicaid was the single largest source of insurance coverage for adults with HIV, covering 4 in 10. Private insurance was the second largest source of coverage, reaching more than one-third of the population (35%) and as noted, just 1 in 10 (11%) were uninsured (Fig. 2), on par with the general population).

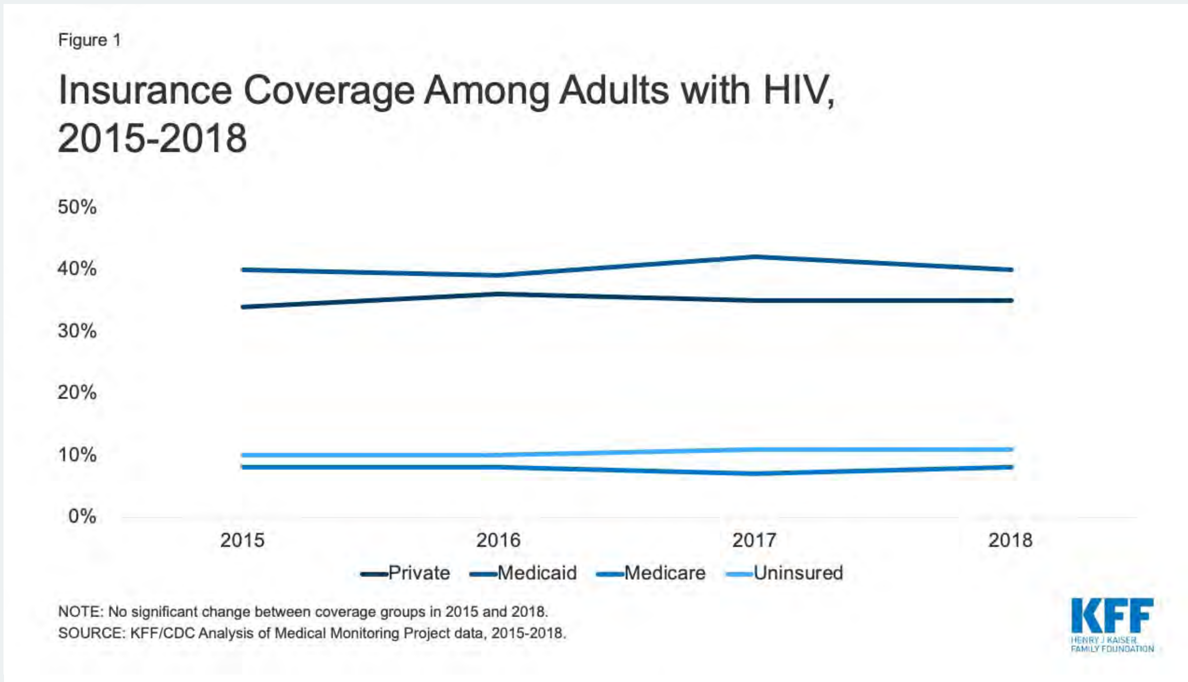


Figure 1: Insurance Coverage Among Adults with HIV, 2015-2018

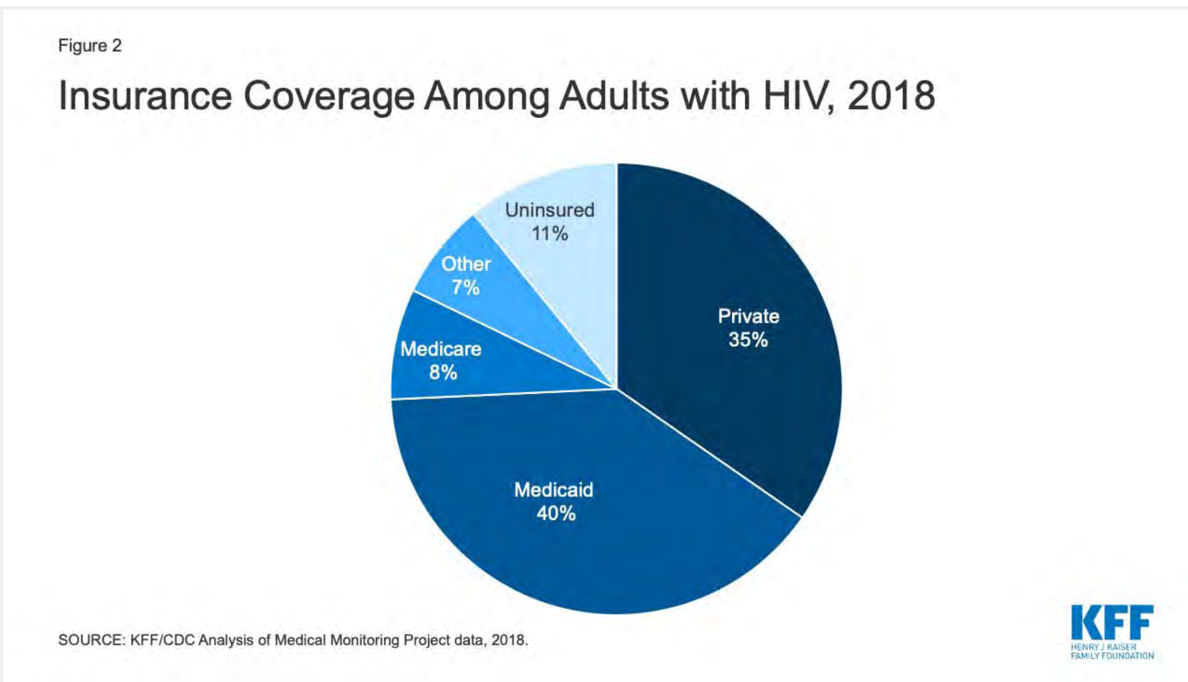


Figure 2: Insurance Coverage Among Adults with HIV, 2018

Coverage patterns among adults with HIV differ from those of the general population (Fig. 3). Medicaid plays a much larger role (40% v. 15%) and private insurance a smaller role (35% v 56%) among those with HIV compared to the general population. In addition, people with HIV are less likely to have private coverage through an employer (26% v. 49%) and more likely to have it through the individual market, including the ACA's marketplaces (7% v. 4%) (not shown). As noted above, uninsurance rates are comparable between the two populations (about 10%).

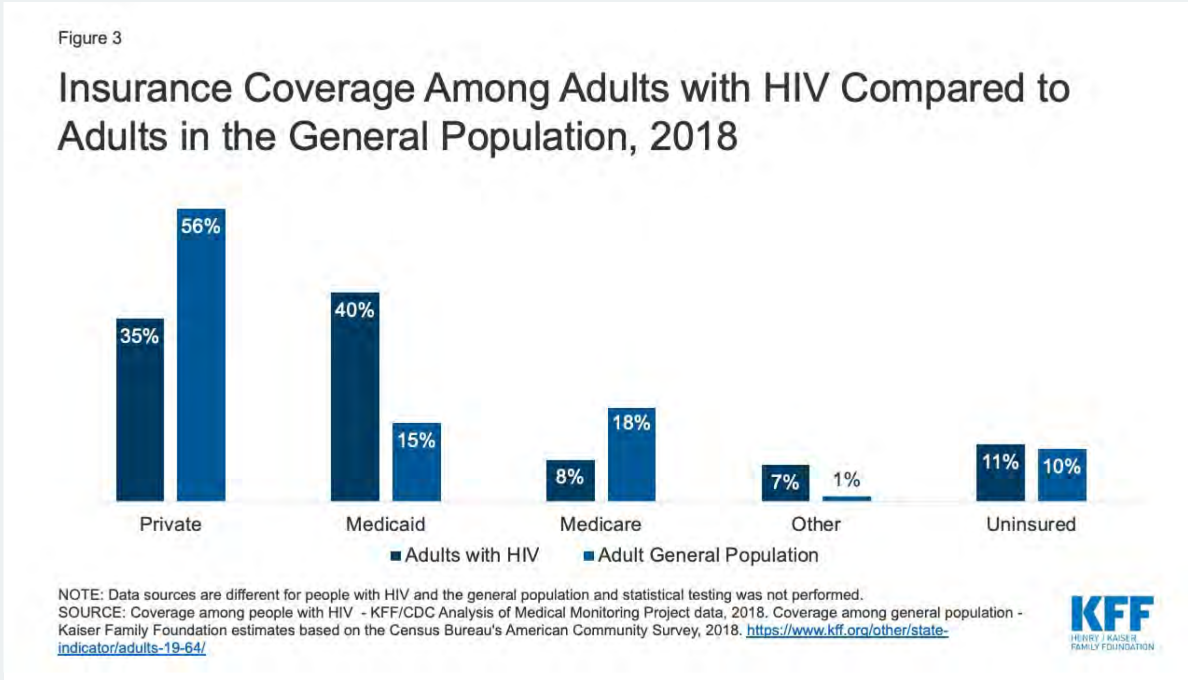


Figure 3: Insurance Coverage Among Adults with HIV Compared to Adults in the General Population, 2018

Coverage and Medicaid Expansion Status

Our earlier analysis (https://www.kff.org/health-reform/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/) found that Medicaid coverage among adults with HIV grew under the ACA and that this shift was driven by coverage gains in states that expanded their Medicaid programs. In 2018, the outsized role Medicaid plays in expansion states remains; adults with HIV in the expansion states sampled are significantly more likely to be covered by Medicaid compared to those in the sampled states that have not expanded (46% v. 30%). In addition, uninsurance rates in expansion states sampled are nearly three times lower than those in non-expansion states sampled (6% v. 20%). (Fig. 4)

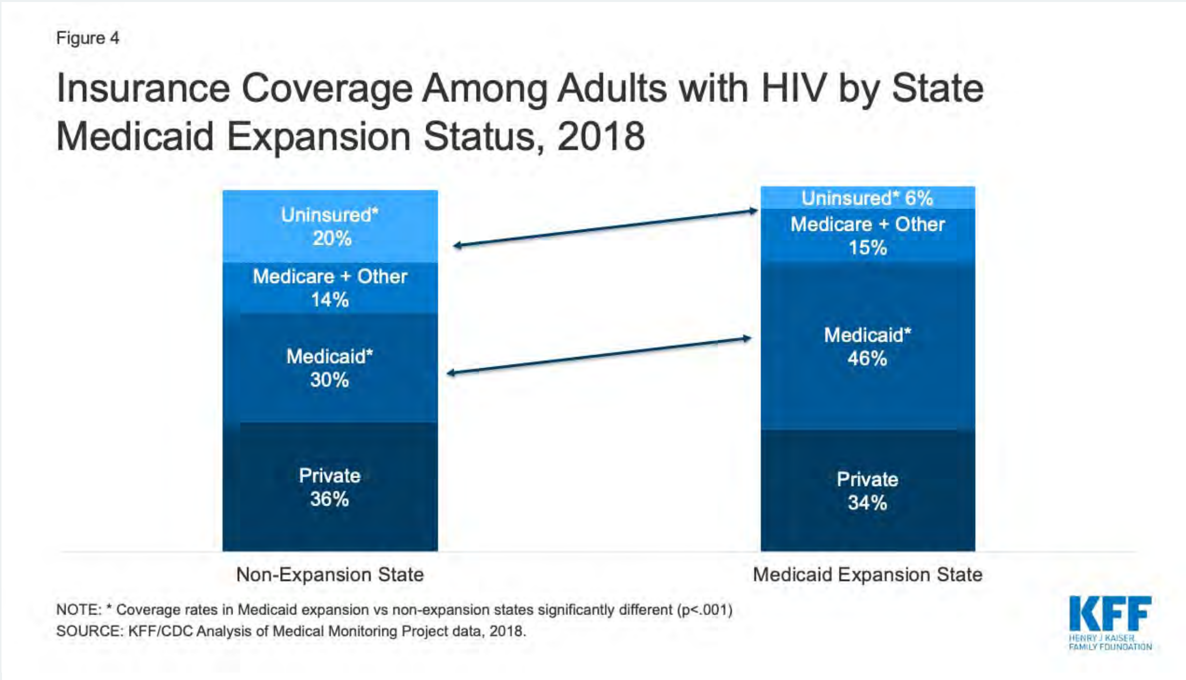


Figure 4: Insurance Coverage Among Adults with HIV by State Medicaid Expansion Status, 2018

Coverage by Key Demographics

We observed coverage differences among adults with HIV by a range of demographic indicators, including, race/ethnicity, gender, income, and, for the first time, place of birth and sexual orientation.

Gender: Male adults with HIV were almost twice as likely to have private coverage (39% v. 23%) and more likely to have Medicare than females (8% v. 6%), while females were more likely to have Medicaid (54% v. 36%). Women's greater likelihood of Medicaid coverage could reflect eligibility based on lower incomes and categorical eligibility based on being pregnant, parent of a dependent child, higher rates of disability. Rates of uninsurance do not differ significantly by gender. (Fig. 5)

Race/ethnicity: White adults with HIV were more likely than Blacks and Hispanics to have private insurance (45% v. 31% and 28%, respectively) and Medicare (11% v. 7% and 5%, respectively) and less likely than Blacks to have Medicaid (35% v 45%). Notably, Blacks and Hispanics were more than three times as likely as Whites to be uninsured (14% and 15%, respectively vs. 4%). These trends reflect in part, disparities seen in coverage by race/ethnicity nationwide, including that people of color are more likely than White to live in non-expansion states, (Fig. 5)

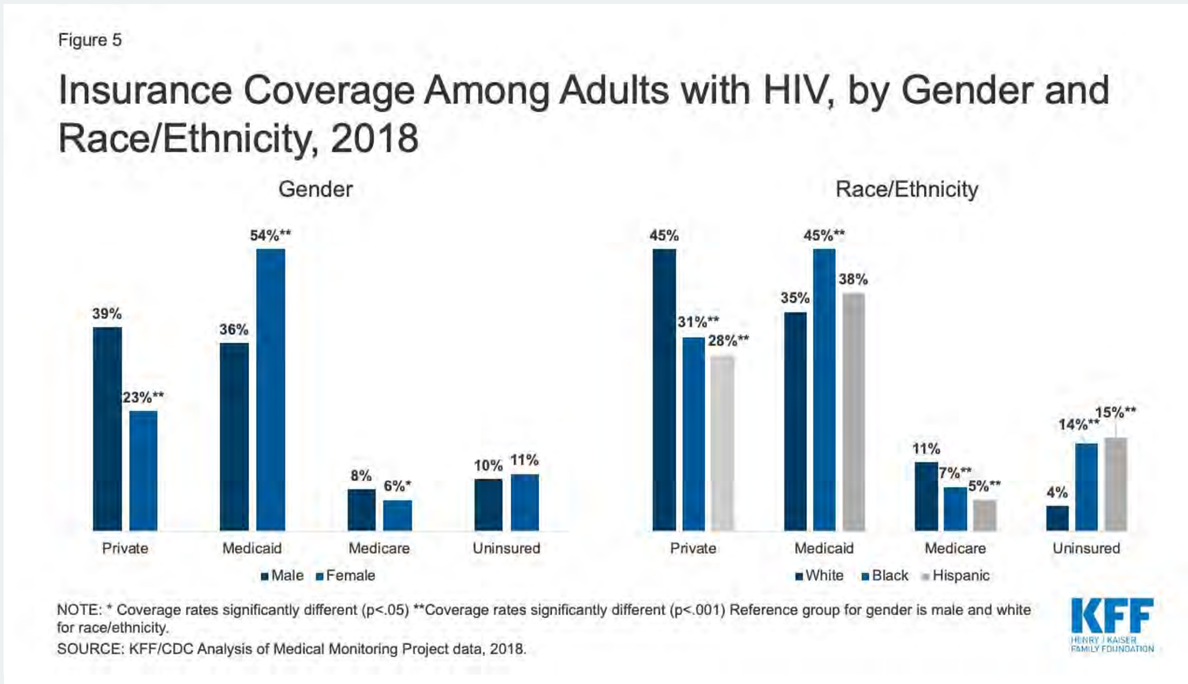


Figure 5: Insurance Coverage Among Adults with HIV, by Gender and Race/Ethnicity, 2018

Income. Those with household incomes <100% of the federal poverty level (FPL) ($12,140 for an individual in 2018 (https://aspe.hhs.gov/2018-poverty-guidelines)) were significantly less likely to have private coverage compared to all other income groups and most likely to have Medicaid coverage. This likely reflects the association between income and access to employment benefits and marketplace subsidies. The percentage of people with HIV with private healthcare coverage increased, and Medicaid coverage decreased, with increasing household income. (Fig. 6)

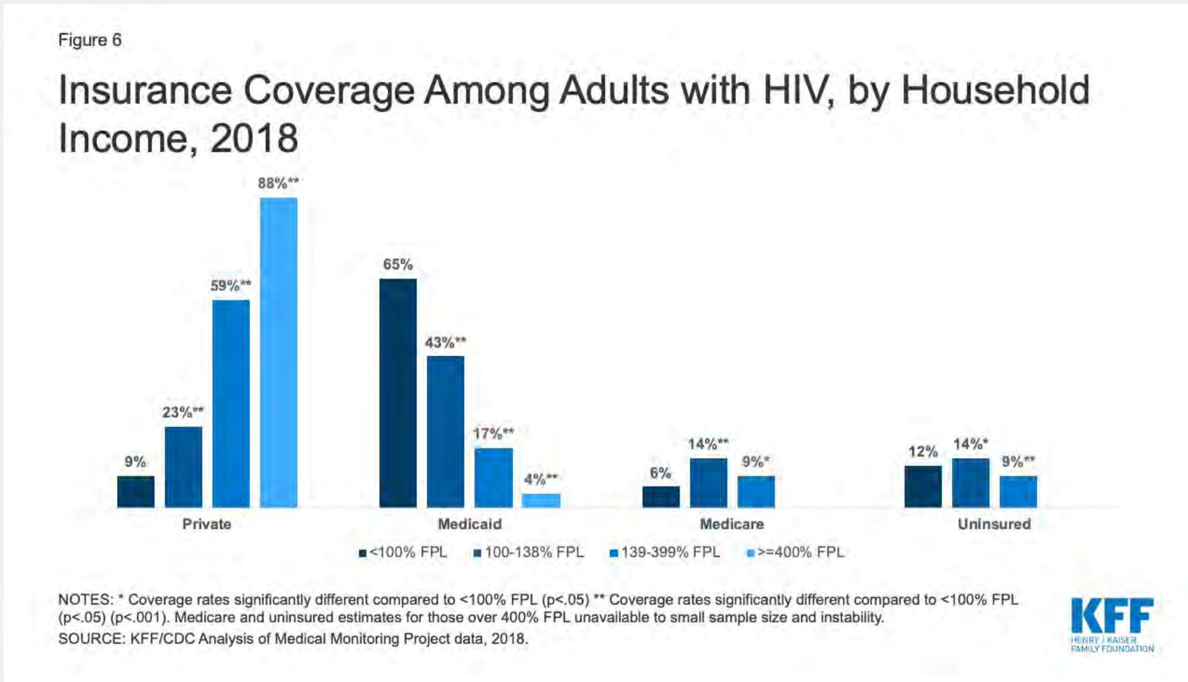


Figure 6: Insurance Coverage Among Adults with HIV, by Household Income, 2018

U.S. Born. Nine in 10 adults (86%) with HIV in the U.S. were born in country whereas 15% were born abroad.[2] (https://www.kff.org/hivaids/issue-brief/insurance-coverage-and-viral-suppression-among-people-with-hiv-2018/view/footnotes/#footnote-98765432-2) These individuals were significantly less likely to have the publicly funded health coverage sources, Medicaid and Medicare, than those born in the U.S (28% v. 42% and 4% v. 8%, respectively), potentially reflecting citizenship and residency requirements in public coverage. This group was also three times as likely to be uninsured compared to U.S. born counterparts (24% v. 8%). (Fig. 7)

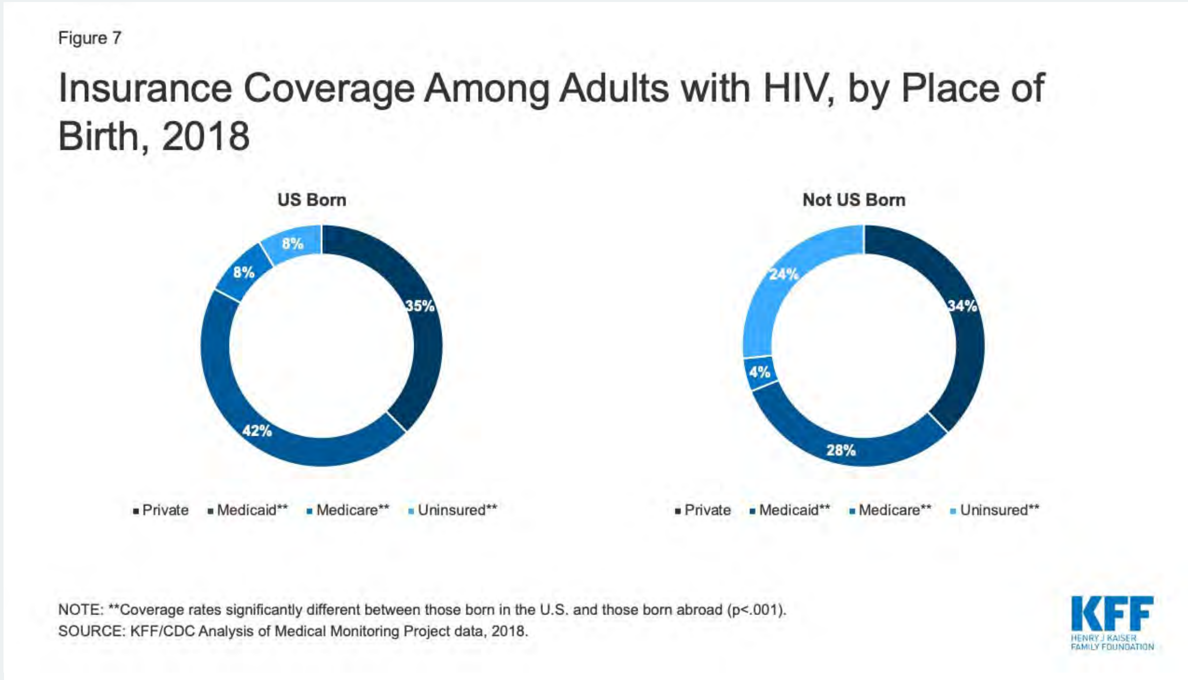


Figure 7: Insurance Coverage Among Adults with HIV, by Place of Birth, 2018

Sexual Orientation. Overall, 47% of adults with HIV identify as heterosexual and 41% as lesbian or gay. Smaller shares identify as bisexual (9%) or as “something else” (3%). Heterosexual adults with HIV, who are disproportionally Black and Latina women, were less likely than lesbian and gay adults with HIV to have private insurance coverage (25% v. 48%) and more likely to have Medicaid (49% v. 30%). Bisexual adults with HIV were less likely to have Medicaid (40% v. 49%) and more likely to be uninsured than heterosexuals (17% v. 11%). (Fig. 8)

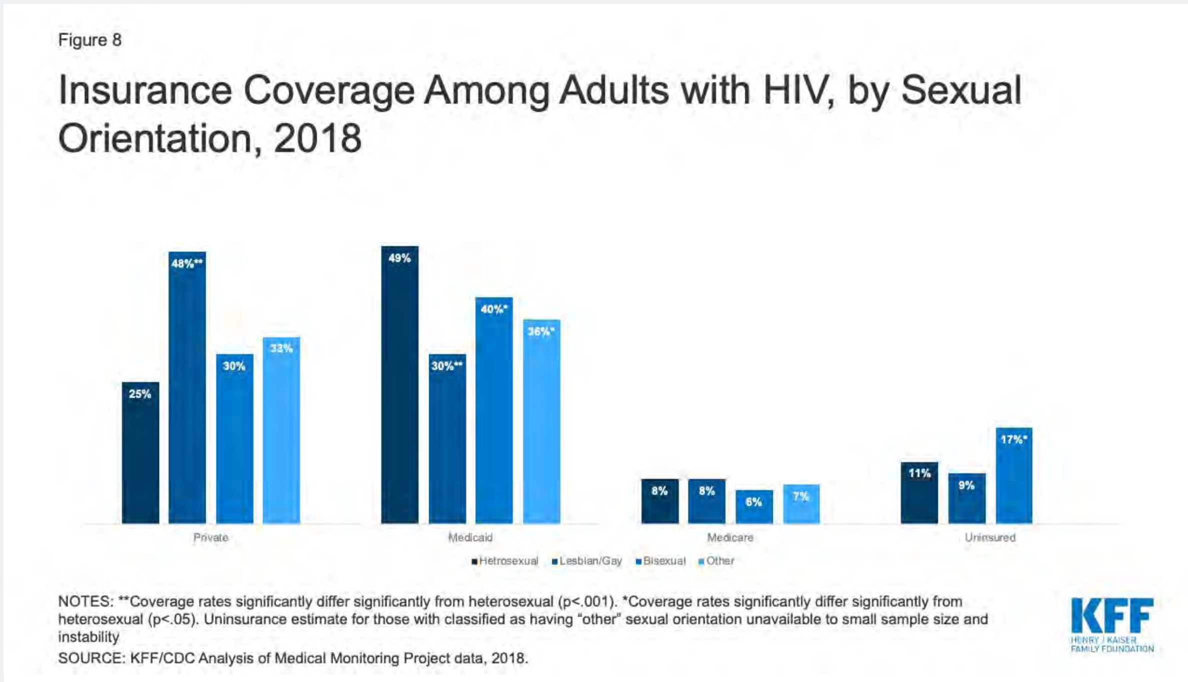


Figure 8: Insurance Coverage Among Adults with HIV, by Sexual Orientation, 2018

Coverage and Ryan White

The federal Ryan White HIV/AIDS Program provides outpatient HIV care, treatment, and support services to people with HIV who are underinsured and uninsured. In 2018, nearly half (46%) of adults with HIV received support from the program. The program provides assistance to those with and without coverage but plays an especially significant role for the uninsured, 82% of whom receive program services. Those who are uninsured may receive direct medical care and prescription drugs through the program, as well as support services. Ryan White also plays a meaningful role for those with insurance coverage, addressing gaps in coverage (e.g. providing support services not included in traditional coverage) and assisting with costs associated with insurance (e.g. insurance premiums and out-of-pocket costs related to HIV medication). Sixty-two percent (62%) of those with Medicare receive Ryan White support. Among those with private insurance, almost 4 in 10 (38%) receive assistance through the program. This share was significantly higher among those with marketplace coverage (56%) compared to employer-based coverage (32%), potentially reflecting the role Ryan White plays in helping clients purchase individual insurance (https://www.kff.org/report-section/the-ryan-white-program-and-insurance-purchasing-in-the-aca-era-introduction/) coverage. It could also reflect higher cost-sharing for many in individual insurance (Fig. 9).

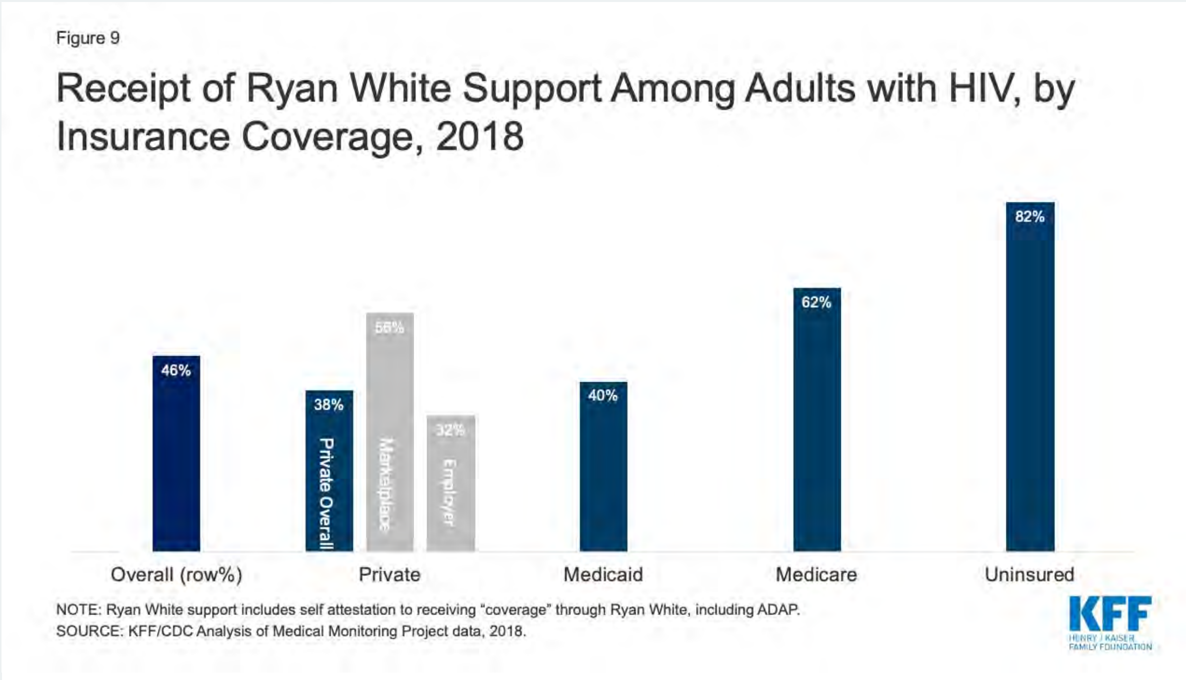


Figure 9: Receipt of Ryan White Support Among Adults with HIV, by Insurance Coverage, 2018

Coverage and Viral Suppression

Viral suppression (defined as having an undetectable viral load at the time of last available laboratory data) is a critical health indicator, affording optimal health outcomes at the individual level and, because when an individual is virally suppressed they cannot transmit HIV, significant public health benefit (https://aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-arv/0). However, because viral suppression can change over time, especially depending on treatment adherence, it is particularly important to look at sustained viral suppression (defined as having an undetectable viral load over all tests in the preceding 12 months), a stronger indicator of long-term adherence antiretroviral treatment and its associated preventive benefits. In 2018, 68% of people with HIV were virally suppressed at last test and 62% had sustained viral suppression, the same share as in 2015. (Fig. 10)

Certain insurance types were positively associated with sustained viral suppression. The proportion of people with sustained viral suppression was significantly higher among those with private insurance, including those with employer-sponsored and marketplace coverage, and among those with Medicare, compared to the uninsured. Viral suppression rates among those with Medicaid were not significantly different from the uninsured, a finding that could reflect the equalizing role of the Ryan White Program for the uninsured. Lower viral suppression rates among those with Medicaid and the uninsured compared to those with other coverage types, could be accounted for by lower household income, among other, largely related, factors. (Fig. 10)

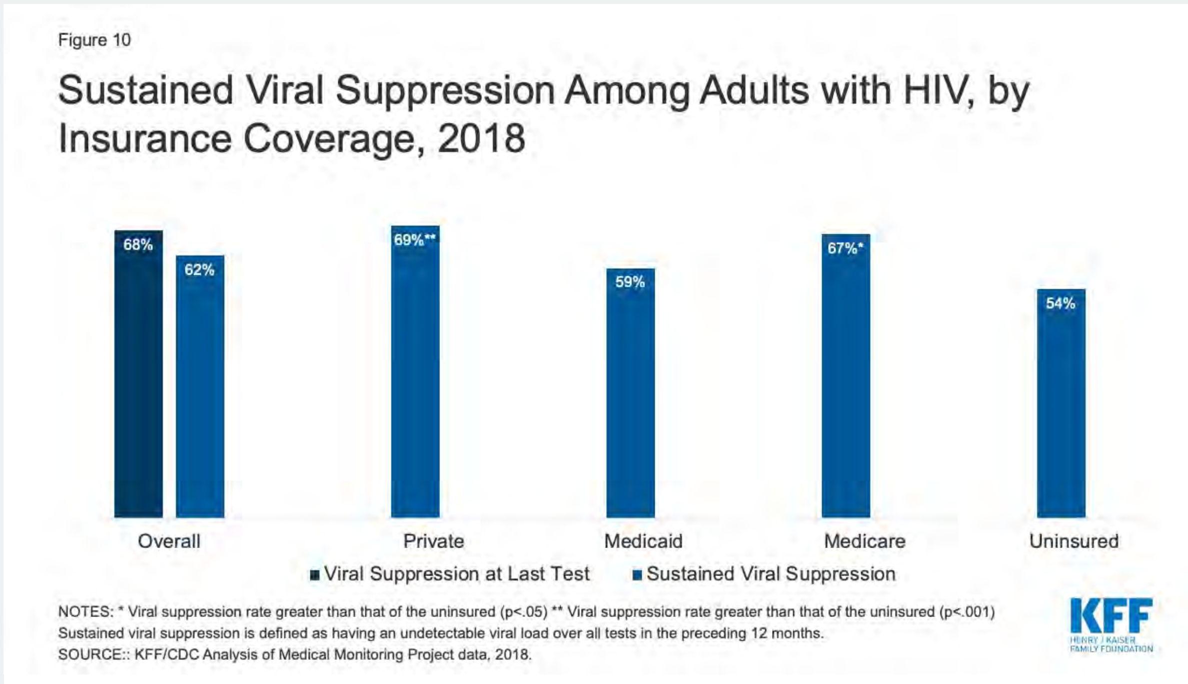


Figure 10: Sustained Viral Suppression Among Adults with HIV, by Insurance Coverage, 2018

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 (68% v. 58%) and this pattern was observed across all coverage types, and was especially apparent among the uninsured (60% v 26%). (Fig. 11)

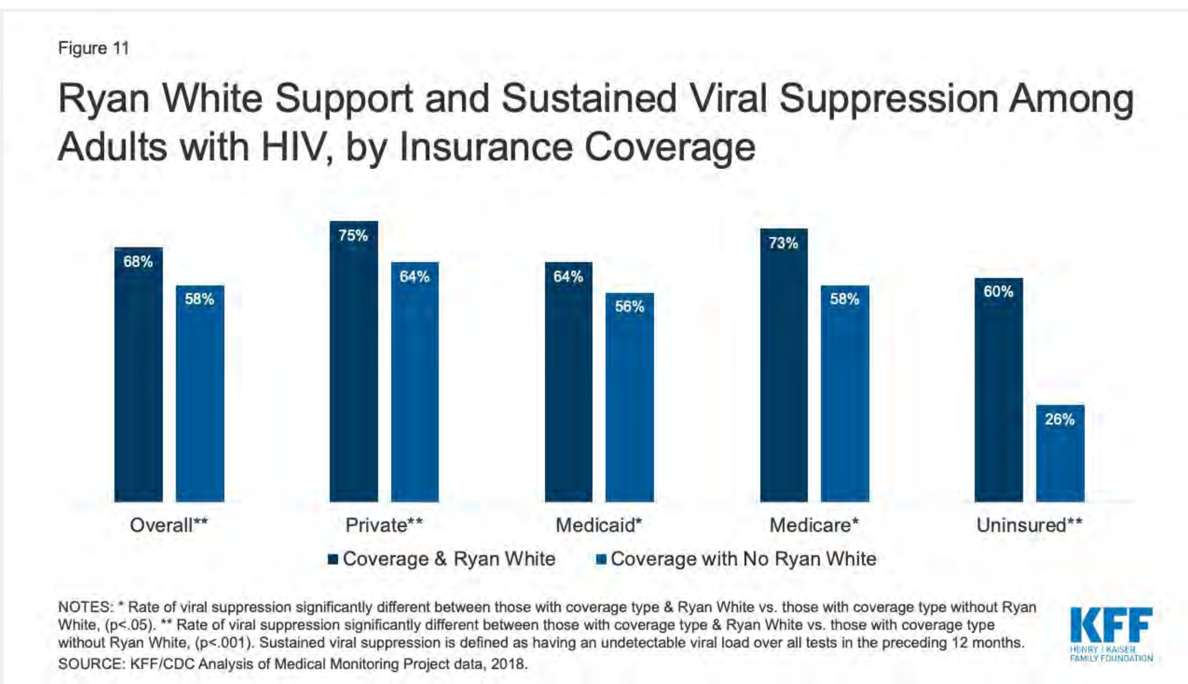


Figure 11: Ryan White Support and Sustained Viral Suppression Among Adults with HIV, by Insurance Coverage

Discussion

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, income, and race/ethnicity, with notable disparities related to rates of uninsurance by race/ethnicity. We also provide the first national data on adults with HIV and insurance coverage by place of birth and sexual orientation. The Ryan White Program is a significant 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 greater rates of sustained viral suppression, a crucial indicator of optimizing the individual and public health benefits associated with antiretroviral treatment.

The ACA has made a significant difference in expanding insurance coverage for people with HIV, yet its future continues to be contested terrain. On the one hand, the Trump Administration is seeking to invalidate the law before the Supreme Court, while on the other hand, states, including states with leadership that has opposed the ACA, continue to adopt Medicaid expansion through voter led ballot initiatives; as of September 2020, 39 states (including D.C.) have adopted Medicaid expansion. In addition, health care could be a major issue in the 2020 elections with candidates President Trump and Democratic nominee Joe Biden holding deeply diverging views on the issue (https://www.kff.org/slideshow/health-care-and-the-2020-presidential-election/). Their different policy perspectives and positions stand to significantly impact coverage, and likely care outcomes, for people with HIV, as well as the success of the administration's "Ending the HIV Epidemic" initiative (https://www.kff.org/hivaids/issue-brief/the-u-s-ending-the-hiv-epidemic-ehe-initiative-what-you-need-to-know/).

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.

This work was supported in part by the Elton John AIDS Foundation. We value our funders. KFF maintains full editorial control over all of its policy analysis, polling, and journalism activities.

The Lifetime Cost of HIV

Balancing the Relationship Between Cost and Quality Care

By James Myhre & Dennis Sifris, MD | Updated on April 10, 2022

Medically reviewed by Ronald Lubelchek, MD

Human immunodeficiency virus (HIV) affects around 1.2 million people in the United States.[1] Great strides have been made to improve life expectancy with HIV infection, especially when the virus is diagnosed early. However, there is no cure. A lifetime of doctor's appointments, testing, and treatments are needed to manage HIV. And aside from being vital for survival, these treatments are expensive.

This article discusses the relationship between the cost and the effectiveness of HIV treatment. It also examines how lifetime cost varies depending on when treatment begins.

What Is Lifetime Cost?

Lifetime cost is the total cost of healthcare and treatment spent between the time a person is diagnosed with an illness until their death.

YakubovAlim / Getty Images

HIV Care Expenses

HIV is a virus that attacks the immune system. It it's not treated, it will advance through all three of the following stages without exception:

1. **Acute HIV infection:** The virus begins to attack the immune system, causing flu-like symptoms between two and four weeks after a person is infected.
2. **Chronic HIV infection:** The virus multiplies in the body, but there are often no symptoms. This stage may last for a decade or more.
3. Acquired immune deficiency syndrome **(AIDS):** HIV has severely damaged

HIV treatment begins as soon as the diagnosis is made. It's also from this point that HIV-care costs begin.

Your lifetime cost for HIV care is the total amount you can expect to pay for the following:

1. **Lab tests:** Close, routine monitoring to help determine your treatment plan and to assess how well it is working
2. **Antiretroviral therapy (ART):** A combination of medications you will take consistently to slow the progression of HIV
3. **Medical care:** Including any medical bills from doctor's appointments or visits to the ER

Your bills may vary from year to year, depending on how stable your condition is, how often your doctor orders tests, what your insurance covers, and more.

Lab Tests

There are two types of lab tests that you will need to take regularly: a test that measures your CD4 count, and a test that measures your viral load.

CD4 tests: Your CD4 count will be monitored regularly to see how far the infection has advanced and if treatment is working to protect your CD4s.[3]

In the first two years after your diagnosis, your CD4 count will be measured every three to six months with a simple blood test. After that, it may be measured every six to 12 months.[4]

HIV viral load tests: These blood tests measure how many HIV particles are treatment whose viral load has been suppressed for more than two years and whose clinical and immunologic status is stable.[5]

> A good sign that HIV treatment is working is when CD4 count is high and viral load is low.

Estimated costs for lab tests: Expect to pay around $45 per CD4 count test and $107 per viral load test.[6]

Medication

HIV is treated with antiretroviral therapy (ART)—a combination of three or more drugs that stops the virus from multiplying and destroying CD4 cells.[7]

You will be prescribed ART medication shortly after your diagnosis. In most cases, ART is taken every day.

This regimen may be adjusted based on your specific needs. For example, your ART regimen may be changed if you become pregnant, or if your health insurance does not cover the cost of your medications.[8]

Estimated cost for ART: $36,000 a year[9]

Most insured people pay between 9% and 14% of this out of pocket, while insurance pays up to 24%. The rest may be covered by Medicare and discounts provided by ART manufacturers.[10]

If you qualify for the state AIDS Drug Assistance Program (ADAP), you may not pay any co-payments for HIV medications, though some people who have insurance (or Medicare) will still pay some reduced co-payments. If you have Medicaid, you will typically not need to pay co-payments to receive ART.

Medical Care

Because HIV damages the immune system, people with HIV are more vulnerable to AIDS-related cancers, pneumonia, HIV-wasting syndrome, and more. These illnesses are known as opportunistic infections.[11]

Each time you visit your doctor, you and/or your insurance provider will be billed. In addition to regular doctor's appointments for lab tests and HIV-related checkups, you may incur more medical bills if you develop an opportunistic infection.

For this reason, the total cost of your medical bills can vary quite a bit from year to year.

Recap

HIV medication makes up the bulk of lifetime care expenses. Lab tests and medical visits can add up, though.

Total Lifetime Cost

According to the Centers for Disease Control and Prevention, currently, the lifetime treatment cost of an HIV infection is estimated at $379,668.[12]

Research shows that early HIV diagnosis and treatment improves health outcomes and life expectancy.

The following chart compares life expectancy and lifetime cost of care based on CD4 count at the time of diagnosis:[6]

CD4 Count at Diagnosis	Additional Life Expectancy	Lifetime Cost
200 or less	30.73 years after HIV diagnosis	$253,222
201–350	36.57 years after HIV diagnosis	$326,705
351–500	37.94 years after HIV diagnosis	$372,344
501–900	38.08 years after HIV diagnosis	$402,238

Note: A person is diagnosed with AIDS when their CD4 count drops below 200 CD4 cells per cubic millimeter of blood (200 cells/mm). For comparison, a healthy CD4 count for an HIV-negative person ranges between 500 and 1600 cells/mm.[13]

Researchers in one study made several conclusions:[6]

Life expectancy: People who were diagnosed with HIV in an early stage of infection lived 24% longer than people who were diagnosed in a later stage.

AIDS diagnosis: HIV progressed to AIDS twice as fast in people who received treatment late compared to people who began treatment early.

Quality of life: People who began treatment early had a 44% higher quality of life score than people who began treatment late.

HIV transmission: People who began treatment early passed HIV along to 50% fewer people than those who began treatment late.

Lifetime cost: People who began ART early had a 60% higher lifetime cost than people who began ART after their HIV infection was advanced.

The results show that people diagnosed with HIV at an early stage—and who begin ART promptly—live longer and have better health outcomes. For some people, the lifetime cost can be higher due to more years taking ART.[6]

In another study, the average lifetime cost of healthcare and treatment was $291,000 after insurance and financial aid, with ART accounting for 68% of the total cost.[14]

Many people live with HIV for several years before they are diagnosed. In fact, an estimated 13% of people with HIV do not know they have it.[1]

While undiagnosed people with HIV obviously don't have ART expenses, the study found that they pay nearly as much for doctor's appointments and emergency medical care as those who are diagnosed.[14]

Recap

The lifetime cost of HIV medication is higher for a person who begins ART early. Undiagnosed people don't have the burden of ART expenses, but their lifetime medical bills are still high and their health outcomes are poorer.[14]

Related: What Can Cause Your Immune System to Be Suppressed?

Early Treatment, Better Outcomes

The effectiveness of healthcare and ART for an HIV-positive person depends on three main factors:[6]

How advanced the infection is when they are diagnosed: Since HIV symptoms can remain hidden for a long time, evaluation can be delayed.
The quality of the initial healthcare they receive
How soon they begin ART and how effective the therapy is

According to Anthony Fauci, MD, Director of the National Institute of Allergy and Infectious Diseases, "We now have clear-cut proof that it is of significantly greater health benefit to an HIV-infected person to start antiretroviral therapy sooner rather than later."[15]

In one study, for example, researchers followed 4,685 HIV-positive adults, all of whom began the study with a normal CD4 count above 500 cells/mm.[16] The adults were placed in two groups: one began ART immediately, while the other group delayed ART until their CD4 counts dropped below 350 cells/mm.

After three years, researchers found that the adults who began ART immediately were 72% less likely to develop serious AIDS-related events and 57% less likely to die as a result of them.

Cost-Saving Strategies

Since 2012, the cost of ART has increased by at least 30%.[17] This made an already expensive regimen that much more so.

People who cannot afford ART are far less likely to stick with it, according to the Department of Health and Human Services (DHHS). The agency urges clinicians to "minimize patients' out-of-pocket drug-related expenses whenever possible."[17]

If you are having trouble keeping up with the cost of your HIV-related healthcare, talk to your doctor about options.

Generic Drug Options

Taking generic ART drugs rather than name brand drugs may lower your lifetime cost by thousands of dollars.

One team of researchers looked at the price difference between generic and brand-name ART drugs. They found that taking generic drugs could lower the lifetime cost by an estimated 20%.[14]

The U.S. Food and Drug Administration (FDA) has approved multiple generic options for each class of ART drugs. They cost less than their brand-name counterparts and are equally as effective.[18]

The full list of generic drug options is available on the official National Health Institute website for HIV.

In some cases, switching to a generic ART regimen may increase the number of pills you have to take at a time. But it should not increase how many times per day you need to take those pills.[17]

> When discussing a generic ART regimen with your doctor, be sure to mention if having to take more pills would prevent you from sticking with your treatment. If so, a single-tablet ART may be a better option for you.

Single-Tablet ART Regimens

A single-tablet regimen (STR) combines multiple drugs into one tablet. STRs allow people with HIV to take fewer pills with each dose, making it easier and simpler to maintain their ART regimen long-term.

There is always a chance that a drug will be temporarily or permanently discontinued from the market. Or, prescriptions for each drug in an ART regimen may not be refilled at the same time. STRs solve these problems, as there is only one tablet to keep track of.[17]

The FDA has also approved Cabenuva, a complete ART regimen that is taken via injection once per month or every other month.[19] It combines the drugs cabotegravir and rilpivirine into one treatment, allowing it to replace a multiple-pill ART regimen.[20]

Fewer Lab Tests

To reduce lifetime cost, the DHHS recommends that doctors limit CD4 tests for people who have been on ART at least two years and have undetectable viral loads.

They state that viral load testing should be considered the primary measure of treatment success, and it should be tested every three to four months or every six months.[5]

For people with an undetectable viral load, the DHHS also recommends that:[5]

CD4 count should be tested every 12 months for people with CD4 counts between 300 and 500 cells/mm

CD4 monitoring should be optional for people with CD4 counts over 500 cells/mm

Even when your CD4 count and viral load are considered stable, you should see your doctor any time you develop a new or worsening symptom.

AIDS Drug Assistance Programs

If you are a U.S. citizen and you do not have insurance, or your insurance does not cover your HIV care, you may qualify for the Ryan White HIV/AIDS program. This AIDS drug assistance program (ADAP) funds free or low-cost medications, healthcare, and support services for low-income people affected by the disease. [21]

Over half of Americans with HIV are covered by Ryan White. Since the program began in 1990, its coverage has helped millions of people slow the progression of their disease. One study even found that people covered by Ryan White have significantly better health outcomes than people covered by private insurance, medicaid, or medicare.

You can find out if you are eligible by calling your state's Ryan White program hotline. An agent will point you toward healthcare providers in your area who participate. Upon receiving care at one of those facilities, you will be assigned a case worker who will work with you to apply for coverage.

You can also find Ryan White healthcare providers in your area by using an online locator hosted by the Health Resources and Services Administration.

Patient Assistance Programs

If you are not eligible for medicare, medicaid, or ADAPs, you may apply for patient assistance programs (PAPs).

PAPs are programs funded by pharmaceutical companies that help uninsured and under-insured people with HIV get low-cost or free ART medications.

Different PAPs have different eligibility requirements, but it usually depends on your income level. To apply for a PAP, you and your healthcare professional will each fill out separate paperwork, then a caseworker will mail your application to the pharmaceutical company for consideration.

A common PAP form for HIV is available, and many PAP programs may accept it. Individual manufacturers may also have their own forms, so it's worth checking their websites.

Clinical Trials

The search for ways to prevent, treat, and cure HIV is ongoing. To evaluate the safety and effectiveness of new medical approaches, drug manufacturers and researchers conduct clinical trials.

Depending on the trial, you may be able to participate. Clinical trials often offer free medication and medical care in exchange for your time and help. You may also receive money or gift cards, or be reimbursed for meals and transportation.[22]

If you are interested in participating in clinical trials, you can contact the National Institute of Health at 1-800-448-0440, or email ContactUs@HIVinfo.NIH.gov to learn more.

Know that participating in a clinical trial may require you to take new and experimental drugs or participate in tests that can be uncomfortable. Understand going in that there may be risks involved, including unpleasant side effects. Discuss the prospect of enrolling with your doctor.

Integrative HIV Care

Research shows that HIV-positive people who receive supportive care for mental health, substance use disorders, and sexual health may have better health outcomes and lower lifetime cost.[17] Care programs like these are known as integrative HIV services.

Integrative care is available for HIV-positive people with substance use disorders, transgender people with HIV, older adults with HIV, and more.

These services can help remove barriers to HIV care and treatment through financial assistance, counseling, and other means of support.[17]

If you are interested in an integrative care service, talk to your doctor. Your doctor may also be able to point you toward an integrated HIV care clinic in your community.

Recap

HIV care is expensive and out of reach for most people without some assistance. There are a variety of cost-saving programs and strategies that can help you reduce your lifetime cost. You may be eligible for more than you might expect, so they are worth exploring.

Summary

The total lifetime cost for HIV care includes doctor's appointments, lab tests, and ART. The bulk of the cost comes from ART, but starting ART early can increase your life expectancy and improve your quality of life.

If you are concerned about the cost of your HIV treatment, talk to your doctor. With their OK, you may be able to lower your lifetime cost with generic medications, participating in a clinical trial, or other money-saving strategies.

A Word From Verywell

Living with HIV can be isolating at times, but there is no need to feel alone. Chances are there is an HIV support group online or in your community that you can join. Support groups provide opportunities to connect with people who understand what it's like to live with HIV—from overcoming stigma to managing symptoms and dealing with money matters.

These judgment-free zones are a great place to express your concerns (financial or otherwise), ask for advice, and learn how to cope with HIV.

22 Sources ⊕

Americans' Challenges with Health Care Costs

Audrey Kearney (https://www.kff.org/person/audrey-kearney/) (https://twitter.com/audrey__kearney) ,

Liz Hamel (https://www.kff.org/person/liz-hamel/) (https://twitter.com/lizhamel) ,

Mellisha Stokes (https://www.kff.org/person/mellisha-stokes/) , and

Mollyann Brodie (https://www.kff.org/person/mollyann-brodie/) (https://twitter.com/Mollybrodie)

Published: Dec 14, 2021

FINDINGS

As the COVID-19 pandemic has dragged on and much of the national health care discussion has focused on hospital capacity, health care worker burnout, COVID-19 vaccination, and other measures to protect public health, the high cost of health care continues to be a burden on U.S. families. As KFF polling has found for many years, health care costs factor into decisions about insurance coverage and care seeking, and rank as a top financial worry. This data note summarizes recent KFF polling on the public's experiences with health care costs. Main takeaways include:

- **Many U.S. adults have difficulty affording various health care and dental costs.** These difficulties are comparable to – and in many cases higher than – the shares who have difficulty affording other household costs, such as rent, transportation, and food. Furthermore, substantial shares of adults older than 65 report difficulty paying for various aspects of health care, especially services not generally covered by Medicare, such as hearing services, dental and prescription drug costs.
- **The cost of health care often prevents people from getting needed care or filling prescriptions.** Half of U.S. adults say they put off or skipped some sort of health care or dental care in the past year because of the cost. Three in ten (29%) also report not taking their medicines as prescribed at some point in the past year because of the cost.
- **High health care costs disproportionately affect uninsured adults, Black and Hispanic adults, and those with lower incomes.** Larger shares of U.S. adults in each of these groups report difficulty affording various types of care and delaying or forgoing medical care due to the cost.
- **However, those who are covered by health insurance are not immune to the burden of health care costs.** Nearly half (46%) of insured adults report difficulty affording their out-of-pocket costs, and one in four (27%) report difficulty affording their deductible.
- **Difficulty paying medical bills can have significant consequences for U.S. families.** In March 2019, about one-fourth of U.S. adults (26%) reported that they

or a household member have had problems paying medical bills in the past year, and about half of this group (12% of all adults) said the bills had a major impact on their family. Medical bill problems also disproportionately affect those without health insurance, those with lower household incomes, and adults in households where they or a member of their household has a serious health condition.

Difficulty Affording Medical Costs

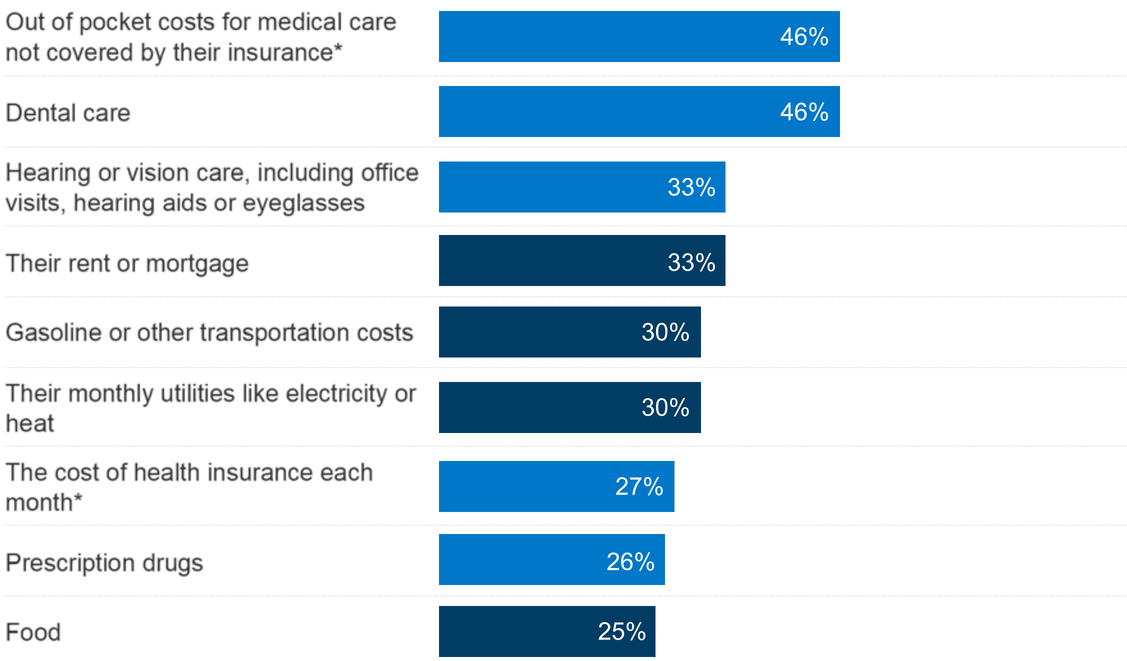
Health care costs top the list of expenses that people report difficulty affording. Substantial shares of adults in the U.S. report difficulty paying for various aspects of health care including nearly half who report having difficulty paying for dental care (46%) and a similar share of insured adults who report difficulty affording out-of-pocket costs not covered by their insurance (46%). These shares are substantially higher than the shares who report difficulty affording other household expenses such as rent or mortgage, gasoline, monthly utilities, or food and groceries. In addition to these costs, one-third report difficult paying for hearing or vision care (33%), while about one-quarter say the same about their prescription drugs (26%). Among the insured, about one-quarter (27%) say their monthly premium is difficult to afford. Those with lower incomes, Black and Hispanic adults are more likely to report difficulty affording some medical costs. *See Appendix table A.1 for breaks by socioeconomic and health status.*

Affording dental, hearing, and vision care is also an issue among adults 65 and older as those benefits are not generally covered by Medicare.[1] (https://www.kff.org/health-costs/issue-brief/americans-challenges-with-health-care-costs/view/footnotes/#footnote-542892-1) See the October 2021 Health Tracking Poll (https://www.kff.org/health-costs/poll-finding/kff-health-tracking-poll-october-2021/) for a deeper dive into health care costs and challenges among older adults.

Figure 1

About Half Of Adults Say It Is Difficult To Afford Out-Of-Pocket Health Care Costs, Dental Care

Percent who say it is very or somewhat difficult for them to afford to pay for each of the following:



NOTE: *Items asked only of those who are insured. See topline for full question wording.
SOURCE: KFF Health Tracking Poll (Sept. 23-Oct. 4, 2021) • PNG

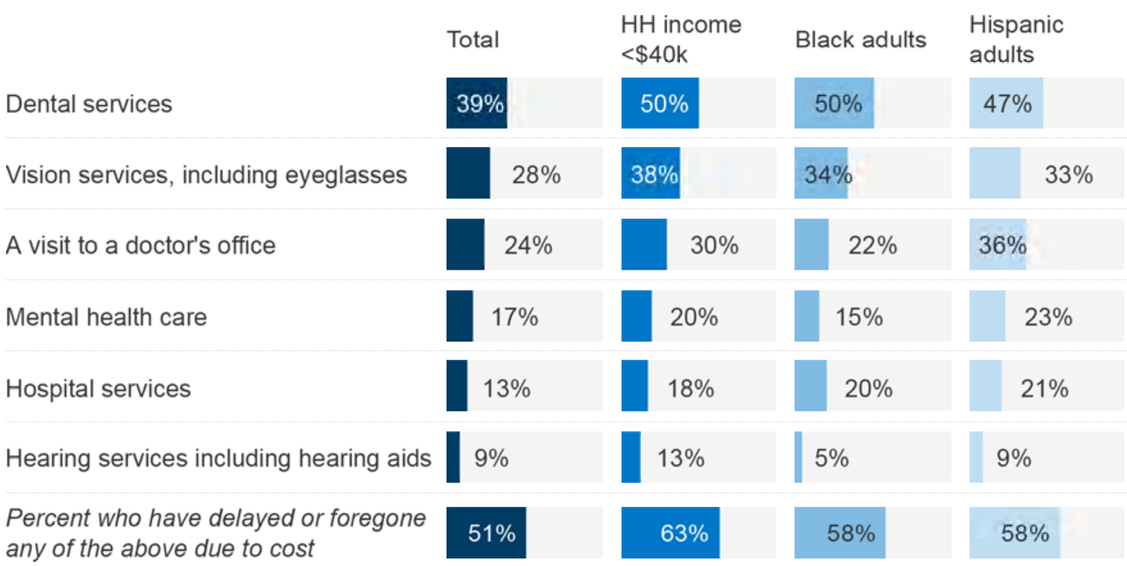
The cost of care can also lead some adults to skip or delay seeking services. Half of adults (51%) report they have delayed or gone without certain medical care during the past year due to cost. Dental services are the most common type of medical care that people report delaying or skipping, with 39% of adults saying they have put it off in the past year due to cost. This is followed by vision services (28%), visits to a doctor's offices (24%), mental health care (17%), hospital services (13%), and hearing aids (9%).

About six in ten Black and Hispanic adults (58% each) report delaying or skipping at least one type of medical care in the past year due to cost, compared to half (49%) of White adults. Similarly, about six in ten (63%) adults with household incomes under $40,000 and 55% of those with incomes between $40,000 and $89,999 report delaying some sort of care due to cost, compared to three in ten (31%) of those in hoseholds making $90,000 or more annually. *See Apendix table A.2 for additional breaks by socioeconomic and health status.*

Figure 2

Half Of U.S. Adults Report Skipping Or Delaying Medical Care Due To Cost, Including About Six In Ten Lower Income, Black and Hispanic Adults

Percent who say they have delayed or gone without each of the following in the past year due to the cost:



NOTE: See topline for full question wording.

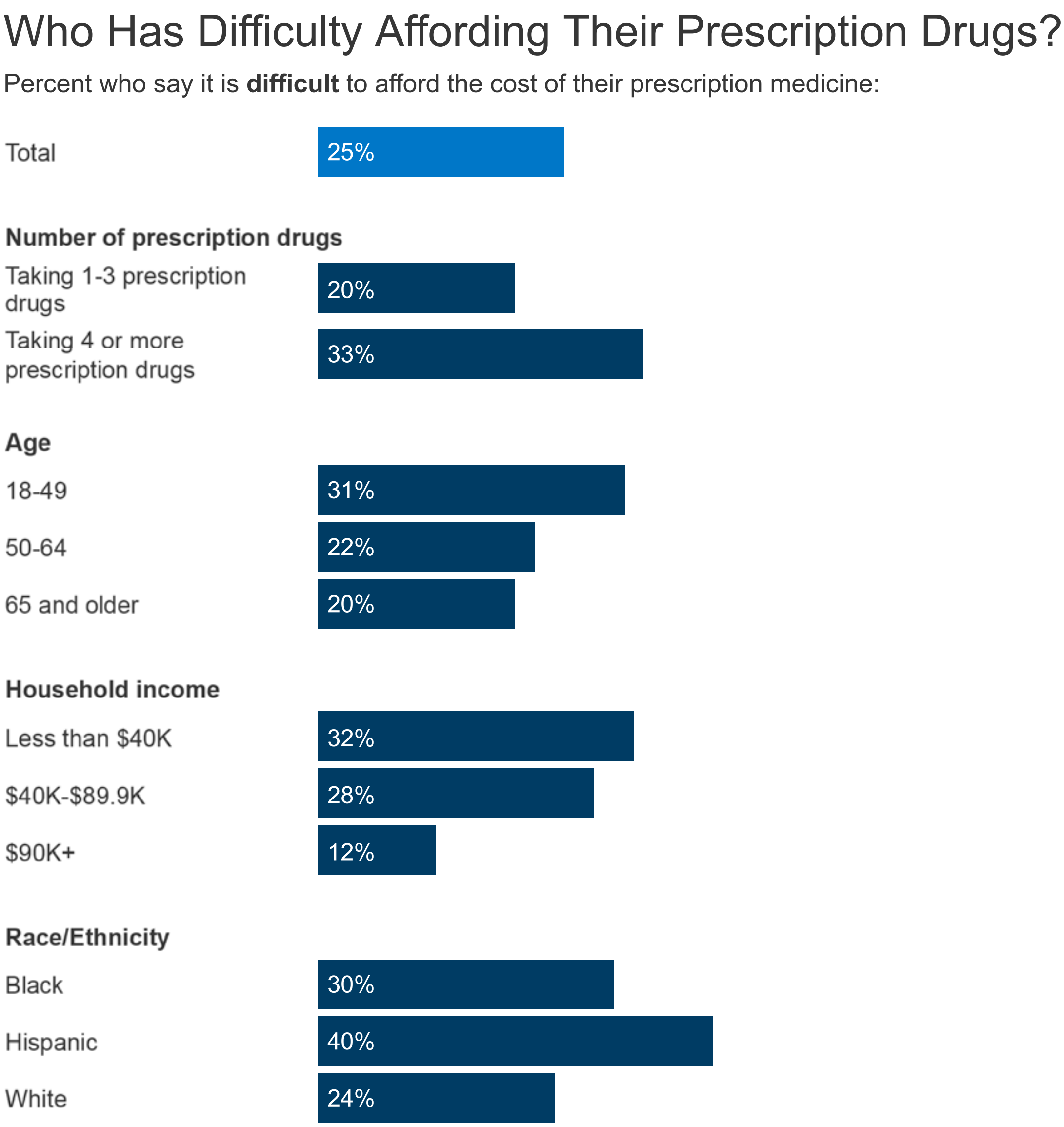
Besides differences by income and race or ethnicity, a [KFF report from 2019 (https://files.kff.org/attachment/Topline-KFF-Health-Tracking-Poll-March-2019)] found that people without health insurance were disproportionately likely to put off or skip medical care or take over-the-counter medicines instead of prescription drugs due to costs. Three-fourths of adults 18-64 (76%) without health insurance reported this, compared to half (52%) of adults with health insurance.

Insurance does not offer ironclad protection, however. Among people with employer-sponsored health insurance, KFF research in 2018 found that workers in higher deductible plans were more likely to report problems paying medical bills and skipping or delaying care due to cost compared to those with lower deductibles. See this [KFF/LA Times Survey Of Adults With Employer-Sponsored Insurance (https://www.kff.org/private-insurance/report/kaiser-family-foundation-la-times-survey-of-adults-with-employer-sponsored-insurance/)] for a more in depth look.

Prescription Drug Costs

For many U.S. adults, prescription drugs are another component of their routine care. Among those currently taking prescription drugs, one in four say they have difficulty affording their cost, including at least one third (33%) who take four or more prescription drugs, those in households with annual incomes under $40,000 (32%) and Hispanic adults (40%).

Figure 3



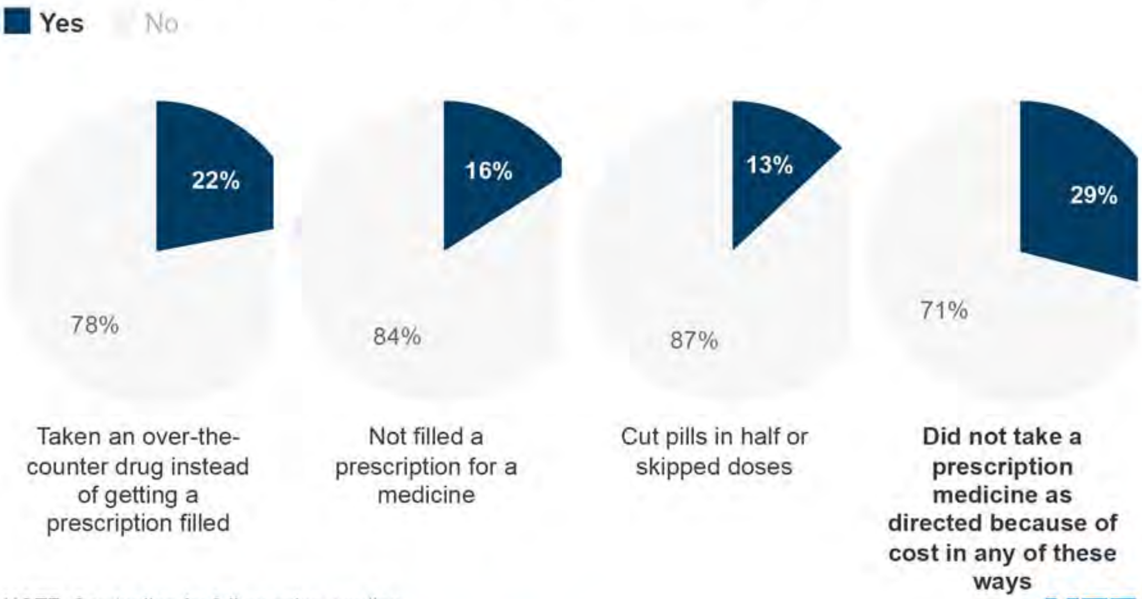
NOTE: Among those who currently take any prescription medicines. See topline for full question wording.
SOURCE: KFF Health Tracking Poll (Sept. 23-Oct. 4, 2021) • PNG

The high cost of prescription drugs also leads some people to cut back on their medications in various ways. About three in ten (29%) U.S. adults say they have not taken their medicines as prescribed at some point in the past year because of the cost. This includes about one in five who say they took an over-the counter drug instead (22%), one in six who report that they haven't filled a prescription (16%), and 13% who say they have cut their pills in half or skipped a dose of a prescribed medicine due to cost.

Figure 4

Three In Ten Say They Have Not Taken Their Medicine As Prescribed Due To Costs

In the past 12 months, have you done any of the following due to cost?



NOTE: See topline for full question wording.
SOURCE: KFF Health Tracking Poll (Sept. 23-Oct. 4, 2021) • PNG

Problems Paying Medical Bills, and Their Consequences

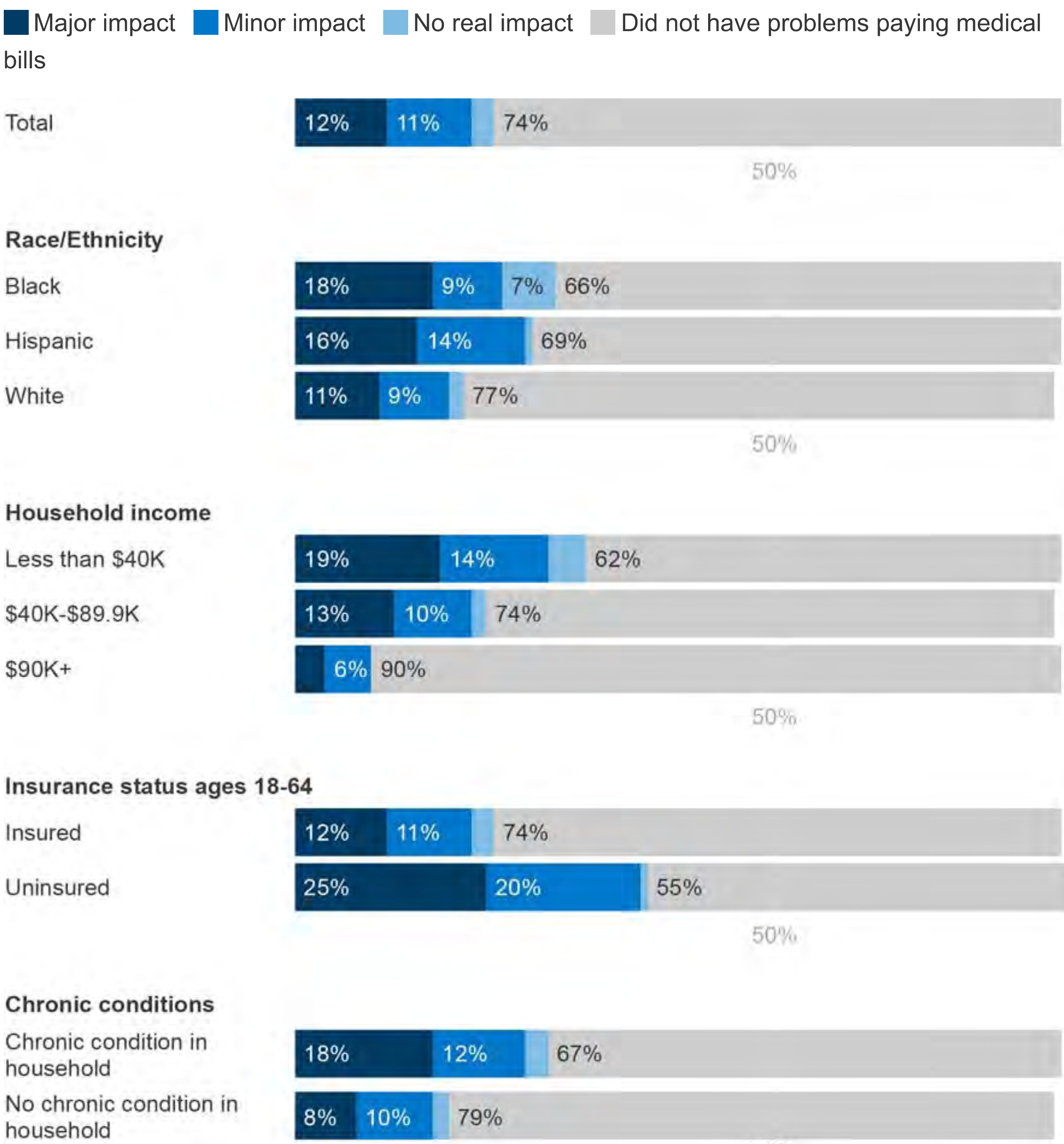
Health care costs also impact some American households after an individual receives care. A KFF survey from March 2019 (https://files.kff.org/attachment/Topline-KFF-Health-Tracking-Poll-March-2019) found that about one-fourth of U.S. adults (26%) said they or a household member have had problems paying medical bills in the past year, and half of this group saying the bills had a major impact on their family (48% of those who had medical bill problems, or 12% of all adults). The share reporting their household has had problems paying medical bills has remained steady between about 25% and 30% for the past decade.

Adults in households with incomes under $40,000, those without health insurance coverage, and those in households where someone has a chronic condition are more likely than their counterparts to report negative impacts from their inability to pay for medical bills. Adults in households with incomes under $40,000 are nearly four times as likely to report problems paying medical bills as those who have annual incomes of $90,000 or more (38% vs. 10%). Nearly half (45%) of uninsured adults ages 18-64 report issues paying medical bills, and one in four (25%) say it has had a major impact on them and their families. Among those under age 65 *with* health insurance, one in four report issues paying medical bills, and 12% say it has had a major impact on their lives. In addition, one-third of adults in households with a serious medical condition report problems paying medical bills, compared to one in five in households without such a condition.

Figure 5

Larger Shares Of Adults With Lower Incomes, The Uninsured, And Those In Households With Chronic Conditions Report Negative Impacts Due To Problems Paying Medical Bills

In the past 12 months, did you or anyone in your household have problems paying or an inability to pay any medical bills?
IF YES: Overall, how much of an impact have these medical bills had on you and your family?

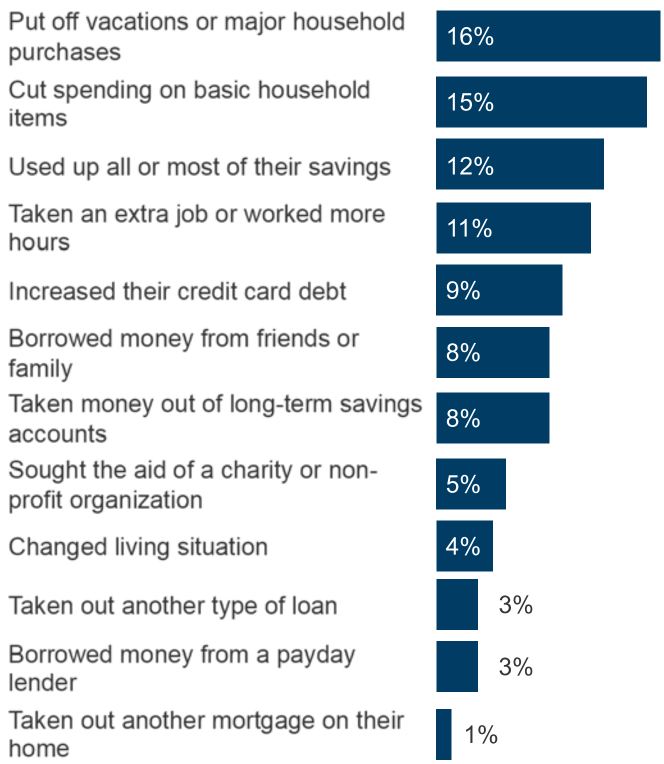


In 2019, those who reported problems paying for medical bills indicated cutting costs in other areas to pay for them. Most commonly, 16% of all adults say they had problems paying medical bills that led them to put off vacations or major household purchases (16%) and a similar share reported bill problems that led them to cut spending on basic household items (15%). Slightly fewer say they have used up all or most of their savings (12%) due to medical bills, taken an extra job or worked more hours (11%), increased their credit card debt (9%), borrowed money from friends or family (8%), or taken money out of long-term savings accounts (8%) in order to pay medical bills.

Figure 6

About One In Six Say They Have Put Off Vacations Or Household Expenses, Cut Spending To Pay Off Medical Bills

Percent who say they or someone in their household did each of the following in the past 12 months in order to pay medical bills:



APPENDICES (HTTPS://WWW.KFF.ORG/REPORT-SECTION/AMERICANS-CHALLENGES-WITH-HEALTH-CARE-COSTS-APPENDICES/) ›