2019-20 Service Category Definition
Ryan White Part B and 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:	**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 continue 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. 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 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. Advance Premium Tax Credit (APTC) Tax Liability: 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 clients 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: Clients 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.
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)**:	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. • 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 (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** ~~and, pending the most current DSHS guidance, client must:~~ ~~• Purchase Silver Level Plan with formulary equivalency~~ ~~• Take advance premium credit~~ • ~~No assistance for Out of Network out-of-pocket expenses without prior approval of the Administrative Agent.~~ ~~Must comply with DSHS Interim Guidance.~~ Must comply with updated guidance from DSHS. Must comply with the Eastern HASA Health Insurance Assistance Policy and Procedure ~~(HIA-1701)~~.

FY 2020 RWPC "How to Best Meet the Need" Decision Process

Step in Process: **Council**		Date: **06/13/19**
Recommendations:	Approved: Y:_____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **Steering Committee**		Date: **06/06/19**
Recommendations:	Approved: Y:____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **Quality Improvement Committee**		Date: **05/14/19**
Recommendations:	Approved: Y:____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **HTBMN Workgroup #2**	Date: **04/23/19**
Recommendations:	Financial Eligibility: 0 - 400%, ACA plans: must have a subsidy
1.	
2.	
3.	

Houston EMA/HSDA Ryan White Part A/MAI Service Definition **Health Insurance Co-Payments and Co-Insurance Assistance** (Revision Date: 5/21/15)	
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 2020 RWPC "How to Best Meet the Need" Decision Process

Step in Process: **Council**		Date: **06/13/19**
Recommendations:	Approved: Y:_____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
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Step in Process: **Steering Committee**		Date: **06/06/19**
Recommendations:	Approved: Y:____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
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3.		

Step in Process: **Quality Improvement Committee**		Date: **05/14/19**
Recommendations:	Approved: Y:____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
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Step in Process: **HTBMN Workgroup #2**	Date: **04/23/19**
Recommendations:	Financial Eligibility: 0 - 400%; ACA plans: must have a subsidy
1.	
2.	
3.	

NASTAD

CO-PAY ACCUMULATORS: Considerations for HIV and Hepatitis

OCTOBER 2018

WHAT IS A CO-PAY ACCUMULATOR POLICY?

A co-pay accumulator policy is when an insurance plan or its pharmacy benefits manager refuses to count a manufacturer co-pay card or other third-party assistance (e.g., a charitable assistance program) towards that person's deductible or plan annual out-of-pocket maximum. Since the cost sharing for many HIV and hepatitis C (HCV) medications is very high, many insured people living with these conditions depend on manufacturer co-pay cards or charitable co-pay assistance programs to help defray their prescription drug cost sharing. Because manufacturer and charitable co-pay assistance programs have annual dollar limits per person, co-pay accumulator policies mean that people using co-pay cards will hit the annual limit on these programs earlier in the year. Once the co-pay assistance runs out, people may face steep and unexpected mid-year costs when they go to pick up their medications because they still have to meet their deductible and/or plan out-of-pocket maximum. Co-pay accumulator policies are more common in employer-sponsored insurance plans, but they are also appearing in individual market plans as well. The below example walks through the consumer impact of a co-pay accumulator policy on access to PrEP.

CASE STUDY FOR PREP

SILVER LEVEL HIGH DEDUCTIBLE PLAN (CO-PAY)

- Plan annual OOP maximum: $6,000; Deductible (combined medical and Rx): $3,000
- Drug cost sharing for preferred brand: $50 after deductible
- Industry co-pay assistance program (CAP) annual max: $7,200
- WAC monthly drug price: $1,676

COSTS WITHOUT CO-PAY ACCUMULATOR POLICY

Month	Consumer Pays	Co-pay Card pays
January	$0	$1,676
February	$0	$1,374
March	$0	$50
April	$0	$50
May	$0	$50
June-December	$0	$50
Total	**$0**	**$3,550**

Total plan payments (consumer and co-pay card) $3,550

COSTS WITH CO-PAY ACCUMULATOR POLICY

Month	Consumer Pays	Co-pay Card pays
January	$0	$1,676
February	$0	$1,676
March	$0	$1,676
April	$0	$1,676
May	$1,180	$496 (max co-pay assistance hit)
June	$1,676	$0
July	$194	$0
June-December	$50	$0
Total	**$3,300**	**$7,200**

Total plan payments (consumer and co-pay card) $10,500

DO CO-PAY ACCUMULATOR POLICIES AFFECT RYAN WHITE PROGRAM OR PREP DRUG ASSISTANCE PROGRAM INSURANCE ASSISTANCE?

Probably not. Even when plans and pharmacies use broad language stating that no third-party payments will count toward a person's deductible or out-of-pocket maximum, we believe that any payment made on behalf of a Ryan White HIV/AIDS Program or health department PrEP insurance assistance program should be covered by the federal third-party payment regulation, 45 CFR § 156.1250. The regulation requires issuers that sell Qualified Health Plans on the Marketplace to accept premium and other cost-sharing payments from Ryan White HIV/AIDS Program grantees as well as a qualified "local, state, or federal government program."

HOW DO I KNOW IF A PLAN HAS A CO-PAY ACCUMULATOR POLICY?

Unfortunately, plans and pharmacies/PBMs do not always make co-pay accumulator policies clear in plan documents. In a few cases, the information is found on a plan's Summary of Benefits and Coverage document, using language like the example below.

If you need drugs to treat your illness or condition **More information about prescription drug coverage is available at http://MolinaMarketplace.com/NMFormulary2019**	**Tier 1**	$10 copay/ prescription	Not Covered	Preauthorization may be required, or services not covered. Mail-order Prescription Drugs are available at up to a 90-day supply and is offered at two times the 30-day retail prescription Cost Sharing. Depending on Tier level this will be either a Copayment or a Coinsurance.
	Tier 2	$50 copay/ prescription	Not Covered	
	Tier 3	30% coinsurance	Not Covered	**Coupons or any other form of third-party prescription drug cost sharing assistance will not apply toward any deductibles or annual out-of-pocket limits.**
	Tier 4	30% coinsurance	Not Covered	Preauthorization is required, or services not covered. Mail order not available. Tier 5 (formulary preventative drugs) do not have any member Cost Sharing.

The pharmacy may also post information about the policy on its website or in letters to plan enrollees, particularly if the policy only applies to medications available through a specialty pharmacy. More often, the information about whether a plan has a co-pay accumulator policy is buried in plan documents and difficult to find. It is generally a good idea to call the number for pharmacy benefits on your insurance card to ask if there is a co-pay accumulator policy.

WHAT SHOULD I DO IF MY PLAN HAS A CO-PAY ACCUMULATOR POLICY?

If it is during open enrollment and your client depends on a manufacturer co-pay card or charitable assistance to afford medications, then it makes sense to stay away from plans with these policies.

If your client learns about the policy after open enrollment or the plan or pharmacy implements a co-pay accumulator policy in the middle of the year, consumers should review whether there are other assistance options (e.g., charitable assistance if that is not mentioned as part of the co-pay accumulator policy, local or state PrEP drug assistance programs, or clinic assistance programs). Sometimes, co-pay accumulator policies are only applied to medications accessed through a specialty or mail order pharmacy. Consumers should request to access their drugs at a brick-and-mortar, in-network, retail pharmacy instead, which is less likely to apply the co-pay accumulator policy. For most private insurance plans, consumers must have the option to pick up their medications at a brick-and-mortar pharmacy and should cite the federal regulation allowing for this option, 45 CFR § 156.122(e).

Assister Language to Help Clients Find Out if Their Plan Has a Co-pay Accumulator Policy

Do you use a drug manufacturer co-pay assistance card/coupon to help cover the cost of your medication?

If yes – when you choose an insurance plan, be sure to read the fine print or ask your insurance plan representative whether the copay assistance card/coupon will count toward your deductible and out-of-pocket maximum. If you are already enrolled in a plan, call your pharmacy benefits number to ask if your plan has a co-pay accumulator policy in place.

These policies should also be reported to your state department of insurance as potentially discriminatory against individuals with high-cost conditions who rely on co-pay assistance to afford their medications. There is a sample letter in the resources below to use when talking to your state department of insurance or other insurance regulators about this issue. Enrollees and advocates should also voice their opposition to these policies to employers and the plans themselves, citing adherence and access challenges when people cannot afford HIV and HCV medications.

RESOURCES

For questions about co-pay accumulator policies, contact Amy Killelea

HIV Health Care Access Working Group, Letter to Departments of Insurance and State Attorneys General on Co-pay Accumulator Policies.

National Hemophilia Foundation, Video: Co-pay Accumulator Adjustments - What Are They and How Can They Affect You

The AIDS Institute, examples of hidden copay accumulator policies in select health plans

Health Care on Bloomberg Law

Aging HIV Population Confronts High Drug Costs, Taxes Medicare

June 28, 2018

By Shira Stein

The first generation of AIDS crisis survivors is about to turn 65 and join the Medicare population, putting pressure on federal programs and spotlighting high prescription drug prices.

Over the next two decades, more than 600,000 people living with diagnosed HIV/AIDS will become eligible for Medicare, according to the Centers for Disease Control and Prevention. These individuals will not only be facing a disease that many expected to kill them years ago, but conditions that come with aging, and a complicated insurance system with high prices for the drugs they need to stay alive.

Medicare, too, could see financial problems as costs for the drugs grow. Gilead Sciences Inc. and Viiv Healthcare received over half of Medicare spending on antiretroviral drugs in 2016 while raising their prices significantly from 2012 to 2016. Analysts said these companies will face pressure not to raise prices, but that they will likely continue to do so anyway.

Medicare "is very ill-equipped to handle the needs of older HIV-positive adults," Perry Halkitis, dean of the Rutgers University School of Public Health, told Bloomberg Law June 21. Halkitis is also the author of "The AIDS Generation: Stories of Survival and Resilience" and an authority on long-term survivors of HIV.

Doctors are "only beginning to understand the complexity" of being HIV positive and elderly, Halkitis said.

Impact on Medicare

Medicare is already facing an earlier projection of its Hospital Insurance Trust Fund running out and attempts from Congress to cut Medicare and another government insurance program, Medicaid, to balance the budget.

But people who work in HIV/AIDS policy and advocacy disagree on how much the new population of Medicare beneficiaries will affect the financial stability of Medicare.

There will be an impact on Medicare, especially because introductory prices for new treatments are "usually quite high," Mark Hannay, director of Metro New York Health Care for All, told Bloomberg Law June 21. The organization is a health-care coalition that focuses on advocating for universal health care. Hannay has also previously worked at Act UP New York, an AIDS advocacy organization, and Gay Men's Health Crisis.

Although 45 percent of people diagnosed with HIV are over the age of 50, they would

only make up 2 percent of total Medicare beneficiaries when they reach 65, Mark Brennan-Ing, a senior research scientist at the New York City-based Brookdale Center for Healthy Aging at Hunter College, told Bloomberg Law June 22. The Brookdale Center for Healthy Aging is a research and advocacy organization that develops care for older adults.

According to a Kaiser Family Foundation analysis, approximately one-quarter of people with HIV are already on Medicare. The majority of those had been on social security disability insurance for two years and then were automatically enrolled in Medicare.

People who were first diagnosed with HIV in the 1980s are likely already on Medicare due to being disabled from not having antiretrovial drugs available to them, but people who were diagnosed later are likely not, so there are many people living with HIV who are not relying on Medicare yet, Halkitis said.

This is a "potential problem for the health-care industry," and Halkitis said he expects it will put more financial pressure on an "already strapped system."

Life Expectancy on the Rise

People living longer is a "major" success, but it adds to the burden on our health-care system, William McColl, vice president for policy and advocacy at Washington-based AIDS United, told Bloomberg Law June 22. AIDS United is an organization that aims to end AIDS through advocacy, awarding grants, and research.

"I doubt it's going to balloon Medicare in ways that are unapproachable or unattainable by the Medicare system," McColl said. "In some ways Medicare is well set-up for this" because they are able to negotiate the lowest possible cost for treatments, although they are unable to negotiate lower drug prices.

Dan Tietz, CEO of New York City-based Bailey House, told Bloomberg Law June 19 that he doesn't think it's going to make a "meaningful" impact on Medicare because of the small percentage of people with HIV/AIDS that will be on Medicare compared with the total Medicare population. Bailey House is an organization that provides support through housing and health services to people with or at risk of HIV/AIDS.

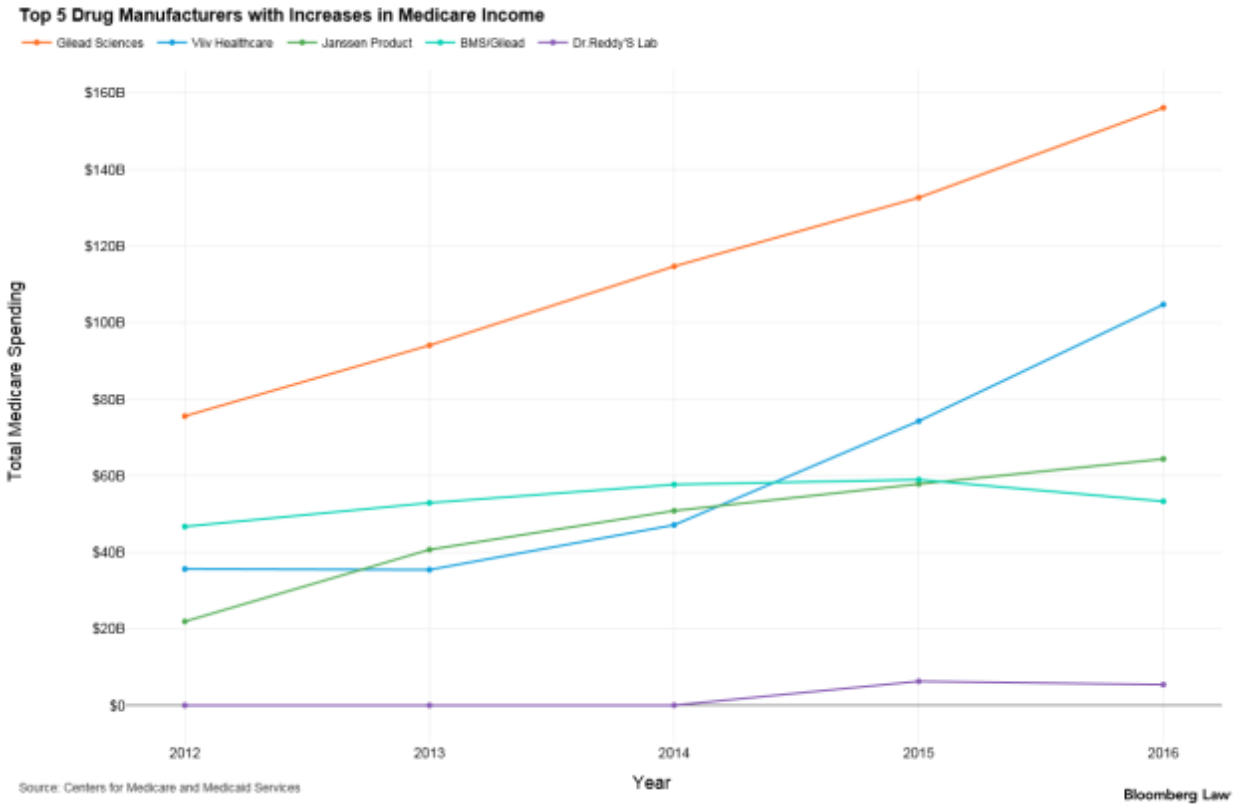
The cost of each individual to Medicare is driven by life expectancy, Ruth Finkelstein, executive director of the Brookdale Center for Healthy Aging, told Bloomberg Law June 25.

People who believe that Medicare beneficiaries with HIV will be expensive for the system fail to recognize that, "while life has been extended a lot, HIV is still a life-shortening condition," Finkelstein said, and therefore people with HIV will likely not be on Medicare as long as other beneficiaries.

Rising Cost of Antiretrovirals

Antiretroviral drugs are a protected class of Medicare Part D drugs, which means that all Medicare Part D plans have to provide coverage for the drugs in that class. That means that pharmacy benefit managers and insurers aren't able to negotiate "meaningful" rebates, Brian Rye, a senior health-care analyst at Bloomberg Intelligence, told Bloomberg Law June 20. Access to different medications is helpful

for patients, but the costs to Medicare can be a source of frustration.



Manufacturer Medicare spending

Thirty-two percent of all Medicare spending on antiretroviral drugs in 2016 went to Gilead Sciences, Inc., an increase of 8 percent from 2012, according to a Bloomberg Law analysis. An additional 12 percent of Medicare spending on antiretroviral drugs in 2016 went to a joint HIV venture between Gilead and Bristol-Myers Squibb Co. to develop and commercialize fixed-dose combinations of HIV medications, an increase.

Gilead raised prices on their antiretroviral drugs covered by Medicare by an average of 34 percent between 2012 and 2016.

Viiv Healthcare received the next highest amount of Medicare spending in 2016, 22 percent. Viiv Healthcare raised prices on its antiretroviral drugs covered by Medicare by an average of 23 percent.

The two companies made up the largest portion of Medicare spending on antiretroviral drugs in 2016.

“There will continue to be pushback on pricing,” Bob Kirby, lead analyst for Fitch Ratings on pharmaceuticals and medical devices, told Bloomberg Law June 27. “Manufacturers are going to have to demonstrate the value of their medicines.”

“The pressure is not going away, it just puts more impotence on the RD efforts of these companies to make better drugs that meaningfully improve outcomes,” Kirby said.

Gilead Sciences, Inc. and Viiv Healthcare “probably will get some pressure” to stop

raising prices, Rye said, but he said they will likely "continue with whatever strategy they wanted to, irrespective of criticisms from Congress."

Drug Pricing

People with HIV are taking at least one pill on a daily basis, which can cost "well over $20,000 per year per person," Kenneth Mayer, medical research director and co-chair of the Boston-based Fenway Institute, told Bloomberg Law June 21. The Fenway Institute is a research center within Fenway Health that focuses on ensuring access to health care for traditionally underserved communities

Prior to 2006, people with HIV/AIDS were paying for most of their prescriptions through Medicaid, the Ryan White HIV/AIDS Program, or state assistance programs. The Medicare Part D benefit, which covers prescription drugs, went into effect Jan. 1, 2006, and began covering part of those prescription costs.

The Ryan White HIV/AIDS Program is a federally funded and operated program that funds medical care and support services for people with HIV/AIDS. The program also funds the AIDS Drug Assistance Program (ADAP), which provides medications to low-income people living with HIV who have limited or no health coverage, including people on Medicaid or Medicare. ADAP also purchases health insurance for eligible people.

A 2018 study published in the journal Medical Care looked at the population eligible for Medicaid and Medicare and found that the transition from prescription drug coverage under Medicaid to Medicare in 2006 was associated with increased out-of-pocket spending for people with HIV/AIDS. The study also found that the transition was associated with an increase in ADAP use, which didn't result in negative care outcomes for people with HIV.

Out-of-pocket costs for people with HIV can be "steep" with traditional Medicare, Hannay said.

Being on Medicare Part D can be scary for anyone who isn't dual Medicare/Medicaid eligible or on ADAP because they might have to pay thousands of dollars for their prescriptions, Alexandra Remmel, the director of client and legal advocacy at the New York City-based Gay Men's Health Crisis, told Bloomberg Law June 18. Gay Men's Health Crisis is a nonprofit that works to provide HIV/AIDS care, advocacy, and prevention.

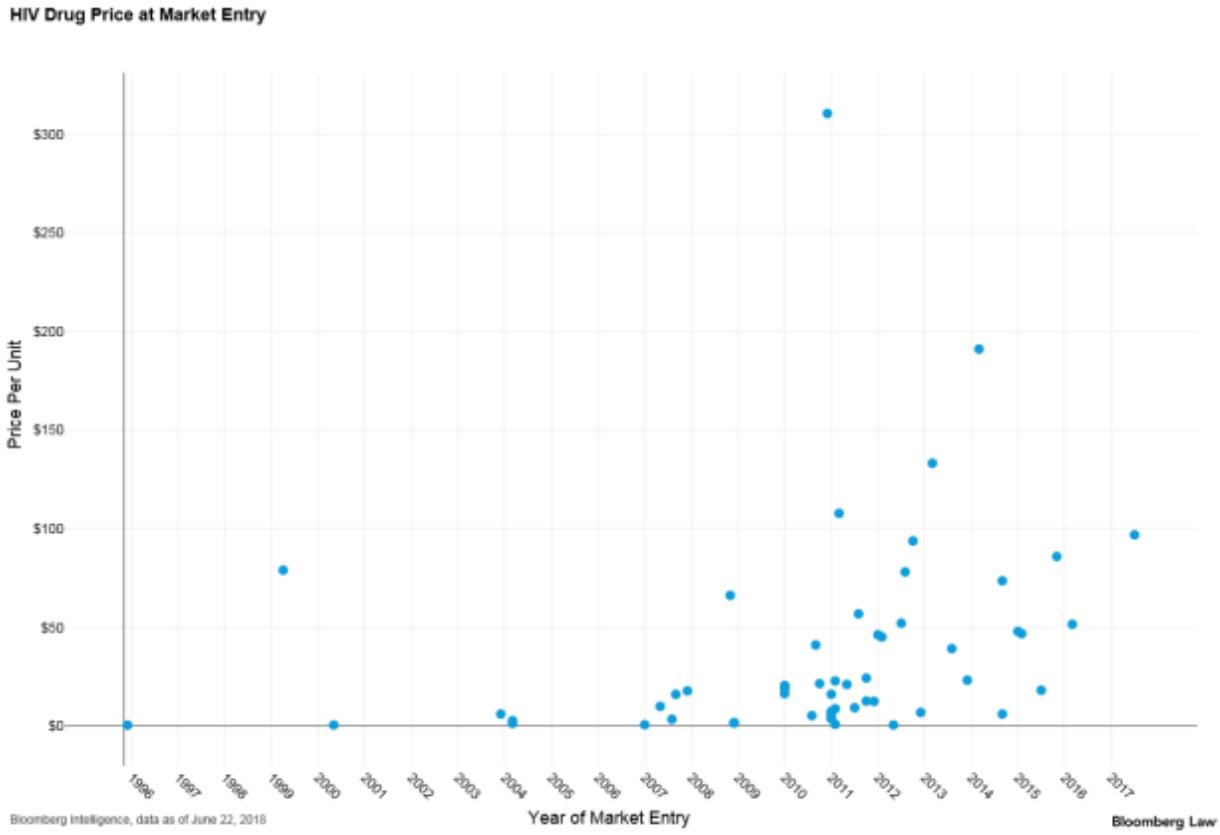
"There's no way you can afford the meds and still exist" without Medicare, McKenna said.

Antiretroviral drugs are "not the biggest component of Medicare Part D drug spending," Aaron Tax, director of advocacy at New York City-based SAGE USA, told Bloomberg Law June 21. SAGE USA is an organization that provides resources and support to elderly LGBT people and their caregivers. However, "the impact on out-of-pocket spending and individual drugs that aren't getting those rebates are coming under more of a microscope."

The biggest concern for older people living with HIV is their prescription drug costs. This population is "used to being in an employer-based plan or other plan where the costs were covered," and they're having to figure out how to pay for them now, Scott Schoettes, counsel and HIV project director at Lambda Legal, told Bloomberg Law

June 25. Lambda Legal is a civil rights organization that focuses on protecting LGBT communities and people with HIV/AIDS through litigation, education, and policy.

An additional concern for long-term survivors of HIV/AIDS is the cost of newer, more expensive antiretroviral drug regimens.



A Bloomberg Law analysis found an upward trend of antiretroviral drugs coming onto the market at a higher price in recent years.

Many people who were infected with HIV prior to the advent of antiretroviral drugs "have resistance or are unable to use the most common drug regimens," McColl said, which means that they have to use "much more expensive" regimens.

Impact on Care

People with HIV/AIDS "are trying to figure out how to survive with a changing insurance world," Remmel said.

The biggest issues for people with HIV/AIDS is the cost of drugs and high copays in Medicare, Finkelstein said.

People with HIV need to choose their Medicare plan "carefully" to prevent large out-of-pocket costs, Tietz said.

The care of long-term survivors of HIV will be "costly," especially because they typically die from complications related to AIDS, not AIDS itself, Charlie Ferrusi, program manager at the New York State Department of Health AIDS Institute, told Bloomberg Law June 21.

It is not a guarantee that dual eligibility for Medicare and Medicaid makes care affordable, Finkelstein said. For people who are dual-eligible, Medicare is their primary insurance and Medicaid helps fill in some of the financial gaps, but they don't necessarily pay all the costs of HIV/AIDS care.

Long-term survivors are "experienced in their care and can advocate for themselves with their doctors," so they should be able to transition to Medicare without having a lot of problems, Luigi Ferrer, community relations manager at Miami-based Pridelines, told Bloomberg Law June 20. Pridelines is a nonprofit that provides resources, including health services, for the LGBTQ community.

Some providers have heard concerns from people with HIV that moving to Medicare might force them to change their doctor. For long-term survivors of HIV, their doctor might be the person they see as having kept them alive for so many years, so it can be an important relationship to keep. It's more common for providers to refuse Medicaid patients than those with Medicare, so having to change providers is less of a concern for people on Medicare, Tietz said.

"There's a certain level of certainty that comes with Medicare that you know you're going to get coverage," Hannay said.

Care can differ on a state-by-state basis, Ferrer said, especially if people with HIV/AIDS choose a Medicare Advantage managed care plan. "It really depends upon which HMOs are licensed to work with the Medicare programs in the state."

Efforts to change Medicare and/or Medicaid "have an outsized impact" on people with HIV/AIDS because so many of them are on one or both systems, McColl said.

"The threat of losing Medicare hovers over our head like another dark cloud," Sean McKenna, who has been living with HIV for over 30 years, told Bloomberg Law June 21. "We really learn to depend on [Medicare]."

McKenna said he feels that he's getting the same care through Medicare as he was while on private insurance. McKenna has been on Medicare since 1996 and is one of the long-term survivors who was automatically enrolled after being put on disability.

Long-term survivors also face the issue of continuing to receive care as they age. "Lots of long-term survivors have cognitive issues," so they need help with understanding how to fill out the paperwork for Medicare, Medicaid, and ADAP, McKenna said. Some advocacy organizations are involved in helping fill out that paperwork, like Gay Men's Health Crisis, but not all long-term survivors have assistance in doing so.

Aging

People with HIV/AIDS are also experiencing aging earlier than expected. Tax said older people with HIV are developing aging-related conditions earlier than uninfected people of the same age.

"People living with HIV, while they're living longer and healthier, they're experiencing conditions associated with aging," McColl said. Doctors who are used to treating elderly people in their 70s are now needing to treat people in their 50s who have "complex treatment regimens."

Some of the people who have been living with HIV since antiretroviral drugs were

first released started treatments with medications that had high levels of toxicity and doctors don't know the full implications of how that can affect their health now, Mayer said.

Older adults who've had HIV for an extended period of time can also have other health conditions that come with having HIV, and their health challenges tend to be around those other conditions, Tietz said.

Advanced HIV can cause chronic inflammation, which leads to an increased risk for heart disease and cancer, Mayer said.

Doctors are finding these aging issues out now because they weren't able to study the effects of aging on people with HIV until recent years.

"No one knew we were going to get that far" to need doctors who could care for elderly people with HIV, McKenna said.

---With assistance from Christina Brady in Washington.