Patient Assistance:
What You Should Know for Your Constituents

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Stephanie Hengst, Manager, Policy & Research, The AIDS Institute
Industry Patient Assistance: What Legislators Should Know

June 7, 2024

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Patient Assistance

What Legislators Should Know

AGENDA

1) PhRMA
   1) Overview of Members and Mission
   2) Supply Chain Complexities
   3) Patient Assistance and Threats

2) The AIDS Institute
   1) Overview of Mission/Policy Objectives
   2) Report on Patient Assistance

3) Resources for Legislators
Manufacturer Patient Assistance: How to access it and why it matters
Pharmaceutical Patient Assistance Helps Patients With Needed Financial Support (www.mat.org)

Despite more Americans having insurance, many are facing high cost-sharing that puts their ability to stay on a needed therapy at risk. Because of this, biopharmaceutical companies provide patient assistance in a variety of ways.

Building off the work of the Partnership for Prescription Assistance, PhRMA built the Medicine Assistance Tool (MAT) in 2019 to provide patients, caregivers, and providers with a streamlined point of access for information that can help them make more informed health care decisions.

**MAT INCLUDES**

- A search engine to connect patients with medicine-specific financial assistance programs
- Resources to help patients navigate their insurance coverage
Manufacturer Cost-Sharing Assistance reached almost $19B in 2022

Manufacturer cost-sharing assistance helps commercially insured patients who otherwise might struggle to afford their out-of-pocket costs.

### Share of Commercially Insured Patients Using Manufacturer Cost-Sharing Assistance for Brand Medicines, 2020¹

- **Using cost-sharing assistance:** 14%
- **Not using cost-sharing assistance:** 86%

### Total Manufacturer Cost-Sharing Assistance Has Grown in Recent Years²,³

- **2014:** $6.0 B
- **2022:** $18.7 B

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Coverage Trends

Utilization Management Imposed by Insurers and Pharmacy Benefit Managers Creates Barriers For Patients Attempting to Access the Medicines Their Doctors Prescribed

Commercial health plans apply utilization management restrictions to a large share of brand medicines. In a survey of physicians, about half said that utilization management policies rarely or never align with clinical evidence.¹

Share of Brand Medicines Subjected to Utilization Management in the Commercial Market, 2020²

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>11%</td>
</tr>
<tr>
<td>Diabetes GLP1</td>
<td>26%</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>31%</td>
</tr>
<tr>
<td>Diabetes SGLT2</td>
<td>35%</td>
</tr>
<tr>
<td>Depression</td>
<td>37%</td>
</tr>
<tr>
<td>Psoriasis</td>
<td>49%</td>
</tr>
<tr>
<td>Multiple myeloma</td>
<td>50%</td>
</tr>
<tr>
<td>Chronic myeloid leukemia</td>
<td>52%</td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
<td>53%</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>59%</td>
</tr>
</tbody>
</table>

Notes: Utilization management refers to medicines subjected to prior authorization and/or step therapy. Commercial insurance includes both employer-sponsored and health insurance marketplace plans. “Cholesterol” includes dyslipidemic brand medicines.

Cost Sharing Trends

Commercial Health Insurance Costs Are Rapidly Increasing for Both Employers and Employees

Employee contributions to health care have grown faster than wages for the past decade.

Cumulative Growth in Employer and Employee Contributions to Health Care and Employee Wage Growth, 2011–2021

EMPLOYER CONTRIBUTION to premiums increased 2.3x faster than inflation from 2011 to 2021.

Note: Employee figures represent the average cost of coverage for a single adult enrolled in an individual non-federal public or private employer-sponsored plan and includes only employers with 3 or more covered workers.

Patients Face Higher Out-of-Pocket Costs at the Pharmacy Counter Than in Other Parts of the Health Care System

Prescription drugs are the only type of health care where commercially insured patients’ cost sharing is based on the list price rather than the negotiated price their insurer pays.

Total hospital spending is much higher than retail prescription drug spending.

Yet, total patient out-of-pocket spending on retail medicines is more than on hospital care.

$1,324B

$378B

Total US all-payer health care spending

Hospital care  Retail prescription drugs

$34B  $50B

Total patient out-of-pocket spending

Hospital care  Retail prescription drugs

Without Cost-Sharing Assistance, Patients Would Pay More Out of Pocket

By helping commercially insured patients pay their out-of-pocket costs, manufacturer cost-sharing assistance can reduce prescription abandonment.

### Annual Average Cost-Sharing Set by Health Plan and PBMs and Final Out-of-Pocket Spending Among Patients Using Cost-Sharing Assistance

<table>
<thead>
<tr>
<th>Year</th>
<th>Cost-sharing set by health plan/PBM</th>
<th>Final out-of-pocket spending</th>
<th>Savings from cost-sharing assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>2017</td>
<td>$629</td>
<td>$277</td>
<td>-$352</td>
</tr>
<tr>
<td>2019</td>
<td>$686</td>
<td>$282</td>
<td>-$404</td>
</tr>
<tr>
<td>2021</td>
<td>$850</td>
<td>$352</td>
<td>-$498</td>
</tr>
</tbody>
</table>

Notes: Includes out-of-pocket spending by commercially insured patients taking brand medicines. The difference between the health-plan- and PBM-set cost-sharing and final out-of-pocket spending represents the savings from use of cost-sharing assistance. Manufacturer cost-sharing assistance administered as debit cards are not captured in the data. As a result, the data may overestimate final out-of-pocket costs.

Without assistance, patients are more likely to abandon new prescriptions

Rate of Abandonment of Newly Prescribed Medicines by Final Out-of-Pocket Cost, 2022

Note: Includes new-to-product medicines filled by all patients across all payers. Newly prescribed medicines are those for which patients have not had a prescription for the specific brand or generic drug within the prior year. Pharmacies in the sample provide information on prescriptions that were prepared for dispensing and whether they were dispensed, with abandonment defined as the prescription in question not being dispensed to the patient within 14 days of the initial fill.

## Protecting Patient Assistance

Schemes exploiting patient assistance impact different markets and have different solutions

<table>
<thead>
<tr>
<th>AAPs (cost sharing assistance)</th>
<th>Maximizers (cost sharing assistance)</th>
<th>Alternative Funding Programs (patient assistance funds)</th>
</tr>
</thead>
</table>
| • AAP Bans passed in **20 states** (40.3 M lives)  
  • AAP bans can be legislative or regulatory | • Closing the EHB loophole mitigates the impact of maximizers | • Vendors focus on small to medium sized employers with employee incomes low enough to qualify for PAPs  
  • Mitigations difficult w/out strengthening EHB coverage requirements |
Since 2019, 20 states have passed AAP bans, with more than 40 million lives under state-regulated commercial insurance.

As of 3/27/24
Accumulator Adjustment Programs Can Make It Harder for Patients to Afford Their Medicines

Accumulator adjustment programs (AAPs) exclude the value of manufacturer cost-sharing assistance from patients’ deductibles and out-of-pocket maximums. This can result in increased patient costs and nonadherence.

Patients are increasingly subjected to AAPs.

AAPs can result in unexpected patient costs.

Note: Percentages show commercial market lives covered by plans that have AAPs; not all health plans choose to opt into AAPs.

2. IQVIA analysis for PhRMA. 2020.
Maximizers: Undermine the Intent of Manufacturer Assistance

Plans use maximizers to inflate patients' cost sharing for medicines to the maximum value of available manufacturer cost-sharing assistance, as much as thousands of dollars per prescription. Patients face high out-of-pocket costs unless they enroll in the maximizer program.

More health plans are subjecting patients to copay maximizers.¹

<table>
<thead>
<tr>
<th>Year</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>2018</td>
<td>6%</td>
</tr>
<tr>
<td>2020</td>
<td>23%</td>
</tr>
<tr>
<td>2022</td>
<td>41%</td>
</tr>
</tbody>
</table>

COPAY MAXIMIZER VENDORS profit from cost-sharing assistance intended for patients. Some ask health plans to pay administrative fees of 25% or more of the total amount of cost-sharing assistance they divert through copay maximizer programs to these companies.²

Alternative Funding Programs

AFPs drive patients to charitable or manufacturer patient assistance funds meant for uninsured and financially disadvantaged patients

- Target specialty medicines

- Encourage health plans to remove coverage for specialty drugs on premise that manufacturer PAPs will pay for them

- Patient must enroll in the vendor’s program or pay 100% of the cost of their medicines

- Once enrolled, vendor assists patient in applying for PAP

- If patient not eligible for PAP, they can appeal to have their medicine covered under the health plan
Three Prioritized Policy Areas

PhRMA State Legislative Engagement

- PBM Compensation & Fees
- Share the Savings
- Patient Assistance

Legislative & Regulatory Agenda
Patient Assistance: The Patient Perspective
For people with serious, complex, and chronic conditions, health insurance policies & plan design can help or hinder access to care.

- 50% of population have 1 or more chronic condition.
- 2-5% of population on specialty drugs.

Patient out-of-pocket costs are becoming untenable. Average silver plan costs:
- Premium: $477 per month; Deductible: $5,101; MOOP: $9,450.
- Copayments & Coinsurance: more tiers = more money.
  - Specialty tier: 69% of individual marketplace plans apply 40% coinsurance *after* deductible is met.
People with chronic illnesses are more likely to have medical debt.

- Average savings: approx. $3,000.
- 45% of single-person, non-elderly household cannot pay over $2,000.

### Percent of adults reporting delaying or going without care due to costs, 2020

<table>
<thead>
<tr>
<th>Category</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delayed Care</td>
<td>8%</td>
</tr>
<tr>
<td>Did Not Get Care</td>
<td>7%</td>
</tr>
<tr>
<td>Yes to Either</td>
<td>9%</td>
</tr>
</tbody>
</table>
### INDIANA

#### Copay Assistance Diversion Programs

**Copay Accumulators 101**

Millions of Americans endure long and expensive medical journeys to get the medications that best treat their needs. Copay accumulators are policies that allow insurers and pharmacy benefit managers (PBMs) to collect copayments on an enrollee’s behalf without counting those payments toward the enrollee’s annual deductible or out-of-pocket limit. These policies undermine access to lifesaving prescription drugs for people living with serious, complex, chronic illnesses.

#### Findings for Indiana 2024 Marketplace Plans

Indiana received a C because 4 out of 6 plans have copay assistance diversion policies.

<table>
<thead>
<tr>
<th>These plans have copay assistance diversion policies:</th>
<th>These plans do not have copay assistance diversion policies:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aetna CVS Health</td>
<td>Ambetter from MHS*</td>
</tr>
<tr>
<td>Anthem Blue Cross and Blue Shield</td>
<td>CareSource</td>
</tr>
<tr>
<td>Cigna</td>
<td>US Health &amp; Life (Ascension)</td>
</tr>
</tbody>
</table>

#### Need for Action

Indiana legislators can further protect Hoosiers with chronic illnesses in Indiana, D.C., and Puerto Rico and enacting legislation to protect residents of all insurance companies and PBMs. Such legislation would ensure that plans are protected.

A federal rule requires all private health insurance plans, including Medicare Advantage plans, to court copay assistance toward patient cost-sharing. The rule above have copay diversion policies contrary to this rule. Indiana insurers and pharmacy benefit managers comply with federal rules.

The HELP Copays Act of 2023 (SB 680 and SL 1273) would ensure that Hoosiers receive help with copay assistance on employer-sponsored health plans living with chronic illnesses.

* = plan applies copay assistance for brand drug with no generic equivalent
+= Plan utilizes as copay max out or alternative funding program

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Unchecked: Copay Accumulator Adjustment Policies in 2024
<table>
<thead>
<tr>
<th>Grade</th>
<th>% of Plans with CAAPs</th>
<th>State</th>
</tr>
</thead>
<tbody>
<tr>
<td>A*</td>
<td>0%</td>
<td>HI, DC *AR, AZ, CT, DE, GA, IL, KY, LA, ME, NC, NM, NY, OK, PR, TN, TX, VA, WA, WV</td>
</tr>
<tr>
<td>B</td>
<td>1% - 25%</td>
<td>MA, NJ</td>
</tr>
<tr>
<td>C</td>
<td>25% - 50%</td>
<td>AK, CA, IN, KS, MD, ND, RI, VT, WY</td>
</tr>
<tr>
<td>D</td>
<td>50% - 75%</td>
<td>AL, CO, FL, MS, NE, NH, NV, OH, SD</td>
</tr>
<tr>
<td>F</td>
<td>75% - 100%</td>
<td>IA, ID, MI, MN, MT, MO, OR, PA, SC, UT, WI</td>
</tr>
</tbody>
</table>

*States that have laws in effect received a Grade A*
With this program, a variable copayment may apply, which takes into account coupon assistance available to pay your cost for the prescription drug. The copayment for program prescription drugs may be set to the maximum of either the copayment associated with the tier placement of the prescription drug on our formulary, or the amount determined by the manufacturer-funded copayment assistance program.

In addition, because certain Specialty Drugs are not classified as essential health benefits under the plan in accordance with the Affordable Care Act, any member cost share payments for these specialty drugs will not count towards the plan's deductible or out-of-pocket limit.

Coverage for certain specialty medications is only applicable if our CareLink Assist program fails to provide a solution. Included in the network, the plan offers an option to access certain medications at a discount through our CareLink International Global Sourcing program.
Kristen, MS, Ohio
When suddenly faced with a $3,800 bill, Kristen’s medication was held hostage. She feared her MS would rebound and she wouldn’t be able to work.

Robin, Blood Cancer, Kentucky
Her family savings was drained when they suddenly had to cover the $10,000 out-of-pocket cost for the medicine that prevents Robin’s rare blood disorder from becoming leukemia.

David, Hemophilia, Florida/Illinois
When access to his medication was threatened by a copay accumulator, David moved from Florida to Illinois.

Jason, HIV, Utah
After the copay assistance is exhausted, he cannot afford the $3,200 copay and stops his meds until the first of the next plan year. He’s worried about becoming Rx-resistant.

Brian, Cystic Fibrosis, Florida
Brian worked as an advocate, helping cash-strapped families get the treatment they needed. Then he became a cash-strapped patient.

Tami, Psoriasis & Psoriatic Arthritis, Pennsylvania
It took 10 years to find the right treatment. Without the help of the copay assistance, she has ~$26 dollars in her budget for all other medical expenses.
Advocates are working to advance policy solutions at multiple levels.

- **State Legislation**
  - 21* states, DC and PR have enacted laws prohibiting copay accumulators.
    - AR, AZ, CO, CT, DC, DE, GA, IL, KY, LA, ME, NC, NM, NY, OK, OR, PR, TN, TX, VA, VT, WA, WV
  - Advocacy campaigns continue
    - MD, MO, MI, UT, PA, RI, and more

- **Federal Legislation**
  - The HELP Copays Act
    - HR. 830, 135 Cosponsors
    - S. 1375, 18 Cosponsor

*CO, DC, OR, VT laws go into effect in 2025
Arizona HB.2166
This law requires that financial assistance from outside parties, including drug manufacturers, count towards an enrollee’s total out-of-pocket maximum when there is no generic version of their prescription medication available, or when the patient has received permission to take the name brand drug through prior authorization, step therapy, or an issuer’s appeals process.

Delaware SB.267
Cost-Sharing Calculation. When calculating an enrollee contribution to any applicable cost sharing requirement, a carrier shall include any cost-sharing amounts paid by the enrollee or on behalf of the enrollee by another person. If under federal law, application of this requirement would result in Health Savings Account ineligibility under § 223 of the federal Internal Revenue Code, this requirement shall apply for Health Savings Account-qualified High Deductible Health Plans with respect to the deductible of such a plan after the enrollee has satisfied the minimum deductible under § 223, except with respect to items or services that are preventive care pursuant to § 223(c)(2)(C) of the federal Internal Revenue Code, in which case the requirements of this paragraph shall apply regardless of whether the minimum deductible under § 223 has been satisfied.

Virginia SB.1596
When calculating an enrollee’s overall contribution to any out-of-pocket maximum, deductible, copayment, coinsurance, or other cost-sharing requirement under a health plan, a carrier shall include any amounts paid by the enrollee or paid on behalf of the enrollee by another person.
In an analysis of premium changes in states with copay accumulator adjustment bans and those without, we found no evidence that enacting a copay accumulator adjustment ban has a meaningful impact on average premiums.
### Resources

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<tr>
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<tbody>
<tr>
<td>All Copays Count Coalition</td>
<td><a href="http://Allcopayscount.org">Allcopayscount.org</a></td>
</tr>
<tr>
<td>Social Media</td>
<td>@AIDSadvocacy, @CopaysCount</td>
</tr>
<tr>
<td>Stephanie Hengst</td>
<td>Manager, Policy &amp; Research</td>
</tr>
<tr>
<td></td>
<td><a href="mailto:Shengst@taimail.org">Shengst@taimail.org</a></td>
</tr>
</tbody>
</table>
Q&A for Legislator Attendees

Please step up to the standing microphones in the room. Please keep your remarks in the form of a question.