



**The Financial Burden of
PBM Benefit Design on
People Using Specialty
Medicines**

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Introduction

Healthcare policy is a complicated proposition. Unfortunately, the debate is being fought (in Congress, state legislatures, and the media) in partisan sound-bites. In the simplistic search for “good guys and bad guys,” what’s being overlooked (shockingly) is *what’s best for the patient*. Nowhere is this more crucial than when it comes to facilitating timely access to the right medicine for the right patient at the right time. The hue and cry of “drug prices are too high,” may be headline-friendly, but ignores the obvious foundational question of what actually constitutes the “price” of a drug? Is it the “list price” (featured in so many news stories) that nobody actually pays? Is it the discounted price paid to drug manufacturer by intermediaries such as insurance companies and prescription benefit managers – often reduced by 40% or more? Or is it the actual out-of-pocket cost coming out of the wallet of the patient? When it comes to “reform,” are we talking about reducing costs or allocating our healthcare resources more wisely? In this important new paper, Robert Goldberg puts aside the rhetoric and concentrates on the facts. And, as John Adams so aptly reminds us, “Facts are pesky things.”

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September 2017
New York City

The Financial Burden of PBM Benefit Design on People Using Specialty Medicines

Much of the debate over changes to the Affordable Care Act rightly highlighted the potential adverse impact of such changes on chronically ill people, especially those diagnosed with cancer, autoimmune disorders and rare diseases. Many were concerned about proposals that would override protections under the law for people with such pre-existing conditions.

While the failure to change the ACA was regarded as a victory for patients, it also meant that the most discriminatory features of health care system remained intact: The systematic effort to design drug coverage to maximize prescription drug rebates and patient cost sharing.

As this paper will show that pharmacy benefit management companies and health plans are generate nearly \$50 billion in revenue by collecting rebates (cash discounts) from the medicines such seriously ill patients use and requiring them to pay a large percentage of the retail price of such products. This study shows that such practices and prescription drug benefit designs discriminates against the sickest patients to limit access and maximize profit.

Targeting the Sickest

Under the ACA, health plans must cover at least one type of every different kind drug for each disease they can decide what drugs to offer and how much to charge. That compilation of medicines (the list of drugs your health plan offers, called a formulary) is developed by pharmacy benefit managers (PBMs).

As a study by economist Michael Geruso concludes, PBMs and health plans “use formulary benefit design — the arrangement of prescription drug coverage into various cost-sharing tiers — to screen out unprofitable patients by offering poor coverage for certain medications.”¹

Geruso looked at every health plan offered under the ACA (not including Medicaid) and found that “for the few therapeutic classes of drugs with the strongest insurer incentives to avoid the corresponding patients, drugs were 50 percent more likely to be placed on a specialty tier, relative to the same drugs in employer plans, where the patient avoidance incentives do not exist.”²

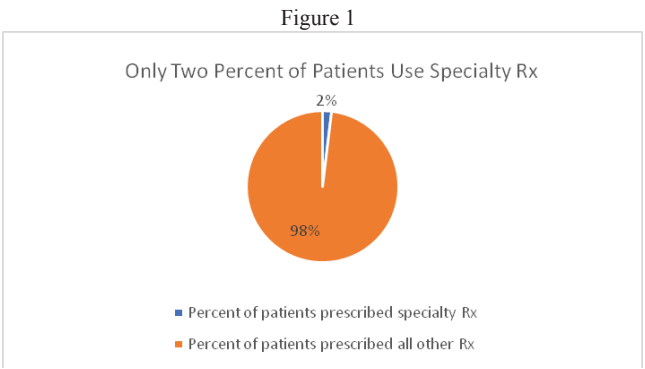
¹ Michael Geruso, Timothy J. Layton, Daniel Prinz, Working Paper 22832 SCREENING IN CONTRACT DESIGN: EVIDENCE FROM THE ACA HEALTH INSURANCE EXCHANGES
<http://www.nber.org/papers/w22832>

² Michael Geruso, Timothy J. Layton, Daniel Prinz, Working Paper 22832 SCREENING IN CONTRACT DESIGN: EVIDENCE FROM THE ACA HEALTH INSURANCE EXCHANGES
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In fact, individuals with Medicare and employer sponsored plans with people with cancer, HIV, hepatitis C, autoimmune conditions, multiple sclerosis and rare diseases are also much more likely to have to pay up to 40 percent of the retail price of a medicine. They comprise about 2 percent all insured consumers – 4.4 million people -- and less than 2 percent of all prescriptions.

They also generate about 25 percent of all health care spending and – most important about 39 percent of all spending on medicines.⁴ Drugs for such conditions are more expensive than other brand and generic medicines for several reasons, the most important of which are the complex nature of the diseases they treat, the fact that the medicines often target specific subgroups of thousands of patients (as opposed to millions) and that such medicines often reduce the risk of death or expensive medical services.

The retail price of a generic drug is about \$300 a year, most brand drugs retail for \$3000. Medicines for the 2 percent of people with conditions such as cancer and rheumatoid arthritis the average annual cost of so-called specialty medicines for the small groups of people with cancer and rheumatoid arthritis is about \$53000.⁵



Source: [Express Scripts Drug Trend Report, 2016](#)

³ Express Scripts, Drug Trend Report, 2017 and Erin Trish, Jianhui Xu and Geoffrey Joyce Medicare Beneficiaries Face Growing Out-Of-Pocket Burden for Specialty Drugs While In Catastrophic Coverage Phase. Health Affairs 35, no.9 (2016):1564-1571

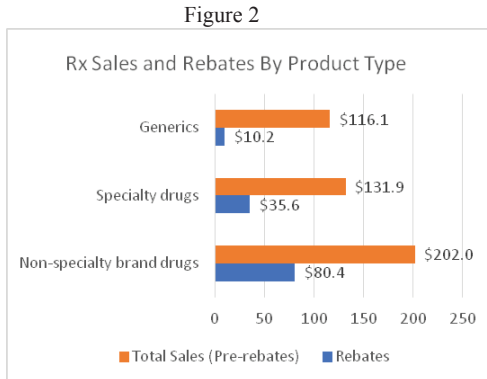
⁴ “Specialty medicines have been an increasing share of medicine spending over the past decade, rising from 21.8% of spending in 2007 to 39.6% in 2016 on an invoice-price basis.” Medicines Use and Spending in the U.S.: A Review of 2016 and Outlook to 2021, Quintiles IMS Institute May 2017

⁵ <http://www.cnbc.com/2016/02/29/aarp-price-hikes-doubled-average-drug-price-over-7-years.html>

Rebates Increase Revenue Instead of Reducing Drug Costs

PBMs and insurers claim they reduce the price of specialty medicines by negotiating cash rebates with pharma companies in exchange for covering their products.⁶ And by reducing the cost of medicines health plans in turn can increase the number of patients who receive important new medicines and limit out of pocket spending.

In 2016 \$450 billion was spent on prescription drugs (before rebates and discounts). Figure 2 (below) shows over \$130 billion of that amount was spent on specialty medicines which in turn generated \$35.6 billion in rebates.⁷ Figure 3 shows that specialty rebate revenue (\$35.6 billion) is derived from only two percent of patients.

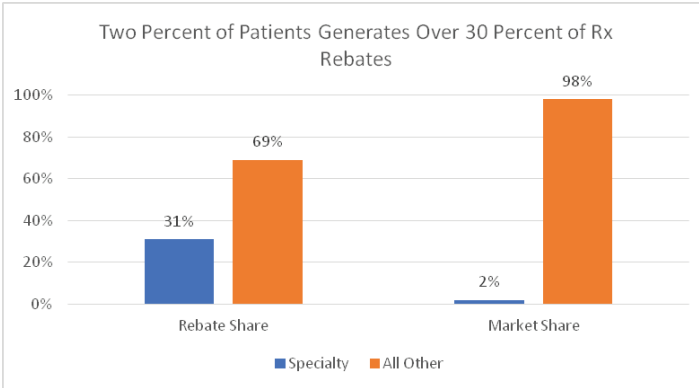


Source: Medicines Use and Spending in the U.S.: A Review of 2016 and Outlook to 2021, Quintiles IMS Institute May 2017

⁶ This includes rebates collected and passed on to Medicare and Medicaid.

⁷ Medicines Use and Spending in the U.S.: A Review of 2016 and Outlook to 2021, Quintiles IMS Institute May 2017

Figure 3



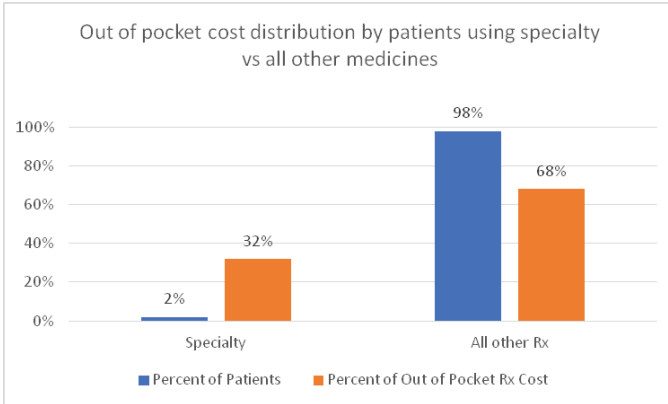
Source: Medicines Use and Spending in the U.S.: A Review of 2016 and Outlook to 2021, Quintiles IMS Institute May 2017

Do Rebates Reduce Copays?

PBMs claim that the rebates are reflected in lower co-pays for drugs. According to government health expenditure data, Americans were charged \$46.6 million in out of pocket drug costs or about 9 percent of all retail drug spending. To be sure, on average, out of pocket spending for medicines has declined over the past decade. People using specialty drugs wind up paying more. A recent IMS study found that “specialty prescriptions are set based on list prices 34% of the time and that accounts for 91% of out-of-pocket spending by patients.”⁸

⁸ Medicines Use and Spending in the U.S. A Review of 2016 and Outlook to 2021. Report by the QuintilesIMS Institute. page 24.

Figure 4



Medicines Use and Spending in the U.S. A Review of 2016 and Outlook to 2021. Report by the QuintilesIMS Institute. Page 25

Since 2 percent of all patients use specialty drugs, it follows that they were also responsible for \$15 billion in out of pocket costs (\$46.6 billion x .32).

Because such individuals pay a share or the full amount of the retail price of specialty drugs, the rebates do not reduce cost sharing. Both rebates and cost sharing is a source of revenue. If we divide the number of patients (4.4 million) that comprise the 2 percent by the rebate revenue (\$35.6 billion) and copays (\$15 billion) we find that each person ‘generates’ over \$12000 in rebate and copayments which in turn are shared by PBMs and insurers. (Figure 5)

Figure 5

	\$ Per Patient
Average out of pocket per specialty patient	3410
Average rebate per specialty patient	8886
Total 'tax' on sickest 2 percent of Americans	12296

Medicines Use and Spending in the U.S. A Review of 2016 and Outlook to 2021. Report by the QuintilesIMS Institute.

The Prescription Drug Poll Tax

This analysis confirms the conclusion of the Geruso study and demonstrates that far from making medicines affordable PBMs and insurers design benefits in ways to at once discourage patients from using specialty medicines and maximize revenue from those that do. Nearly every ACA and Medicare drug plan put specialty medicines on the highest cost sharing tier. Half of all drug coverage provided to employer sponsored health plans impose the same burden only on the two percent.⁹

As a result, people who use specialty medicines are 10 times more likely to pay full price for the most expensive medicine. On average, they are 10 times more likely to pay over \$2500 out of pocket for medicines than other consumers.¹⁰

While high cost sharing discourages enrollment, it is also true that no one can be denied coverage. So, the combination of withholding rebates and retail priced based cost sharing – in addition to other ways PBMs (on behalf of insurers) use to reduce access –discourages a large percent of people from simply not picking up prescriptions or refilling them.

One study showed that 50% to 60% of privately insured patients abandoned anti-inflammatory biologics and MS specialty drugs when faced with \$2000 or more in monthly OOP costs (compared with 5% to 6% abandonment rates among patients facing less than \$50 in monthly costs. Even for oral cancer agents, approximately one-fourth of privately insured and Medicare patients abandoned their specialty medication when OOP cost on the claim was greater than \$500 compared with less than 5% to 6% abandonment rates with less than \$100 in OOP costs.¹¹ Abandonment and reduced use of medicines because of an increase in cost sharing is associated with higher health care costs and increased sickness.¹²

⁹ 2016 Employer Health Benefits Survey Sep 14, 2016

“Among covered workers at large firms whose largest plan has a separate tier for specialty drugs, 43% have a copayment for specialty drugs and 46% have a coinsurance requirement ([Exhibit 9.15](#)). The average copayment is \$89 and the average coinsurance rate is 26% ([Exhibit 9.16](#)). Seventy-eight percent of those with a coinsurance requirement have a maximum dollar limit on the amount of coinsurance they must pay.”

¹⁰ Source: Medicines Use and Spending in the U.S.: A Review of 2016 and Outlook to 2021, Quintiles IMS Institute May 2017

¹¹ [Doshi JA](#)¹, [Li P](#), [Ladage VP](#), [Pettit AR](#), [Taylor EA](#).

Impact of Cost Sharing on Specialty Drug Utilization and Outcomes: A Review of the Evidence and Future Directions *Am J Manag Care*. 2016;22(3):188-197

¹² [Doshi JA](#)¹, [Li P](#), [Ladage VP](#), [Pettit AR](#), [Taylor EA](#).

Impact of cost sharing on specialty drug utilization and outcomes: a review of the evidence and future directions. *Am J Manag Care*. 2016 Mar;22(3):188-97.

[JAMA](#). 2012 Mar 28;307(12):1284-91. doi: 10.1001/jama.2012.340.

PBMs and plans protest that they have no choice because the price of medicines keeps rising. However, the net price of medicines has been falling for the past seven years (the PBMs and plans pocket the spread.) And studies show that eliminating cost sharing would add little to monthly premiums.¹³ It is more likely that the combination of rebates and cost sharing is calibrated to produce the most revenue while discouraging as many patients with serious illnesses as possible. Indeed, in addition to collecting rebate and copay revenue from the sickest patients, PBMs and health plans are more likely to require such individuals to obtain prior authorization for the dispensing of a drug and impose step or quantity limits as well.

Indeed, even if PBMs were capturing rebates and increasing cost sharing to reduce (rather than profit from) drug prices, imposing a tax or an obstacle that has disparate impact on a small group of people because of their condition is discriminatory. In the South, after Reconstruction, states imposed a poll tax that needed to be paid as a condition for voting. It was used to circumvent the 14th amendment which promised equality under the law for African Americans. The taxes had to be paid in cash, at a time when many black southerners had extremely low cash incomes. Hence the out of pocket expense discouraged a minority from voting.

Similarly, the cost sharing at full price (along with not passing along rebates) has the same effect as did the poll tax. In the South, out pocket costs – in addition to complicated regulations such as literacy tests and residency requirements -- reduced voting. In health care, they are used to discourage the use of medicines and require people to pay a much steeper price than others.

Conclusion: PBMs and Pre-Existing Conditions

In a recent change in the ACA regulations, HHS regarded “placing most or all drugs that treat a specific condition on the highest cost tiers, a potentially discriminatory practice.”¹⁴ HHS went out of its way to note the if a plan does seek to put most or all drugs on the higher cost sharing level “further investigation by the enforcing entity may be required. We strongly caution issuers that the examples cited appear discriminatory in their application when looking at the totality of the circumstances, and may therefore be prohibited.”¹⁵

Ironically, the perennial critics of prescription drug prices have embraced policies that limit access to new medicines to maximize health insurer ‘value.’ They claim limiting coverage of

Out-of-pocket medication costs and use of medications and health care services among children with asthma. [Karaca-Mandic P¹](#), [Jena AB](#), [Joyce GF](#), [Goldman DP](#).

¹³ Pharmacy Cost Sharing Limits for Individual Exchange Benefit Plans: Actuarial Considerations. Prepared by. Milliman, Inc., NY. Bruce Pyenson <http://www.lls.org/>

¹⁴ Summary of HHS's Final Rule on Nondiscrimination in Health Programs and Activities Jul 14, 2016 | [Elizabeth Cornachione](#), [MaryBeth Musumeci](#), and [Samantha Artiga](#)

¹⁵ Ibid.

drugs, forces companies to reduce their prices and that we should remove regulations (such as the HHS nondiscrimination requirement) to free “insurers and government programs from the requirement to include all expensive drugs in their plans as we explain to the public that some drugs are not effective enough to justify their price.”¹⁶

This study suggests that letting PBMs and health plans decide what drugs are no effective to justify their price is used to exploit the vulnerability of the sickest 2 percent of Americans to maximize profit. Health system ‘value’ comes from designing prescription drug benefits to impose a special burden on people with pre-existing conditions. Whether the ACA is left intact, replaced or reformed, such discrimination will endure and deepen unless the medical segregation of the two percent is extinguished.

¹⁶ Bach, Peter “Why Drugs Cost So Much” New York Times, January 14, 2015

Appendix

Source data for percent and number of patients using specialty medicines

	Employer	Non-Group	Medicaid	Medicare	Other Public	Uninsured
By coverage source	155965800	21816500	62384500	43308400	6422300	28965900
Estimated percentage of patients using specialty Rx	0.009	0.009	0.009	0.05	0.009	
Number using specialty Rx	1403692.2	196348.5	561460.5	2165420	57800.7	4384721.9

Sources:

Kaiser Family Foundation estimates based on the Census Bureau's March 2014, March 2015, and March 2016 Current Population Survey (CPS: Annual Social and Economic Supplements).

CMPI

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