RESEARCH REPORT

ZS Research Center

Toward a comprehensive affordability agenda: How to end the drug price blame game

By Howard Deutsch and Megan Sadiua

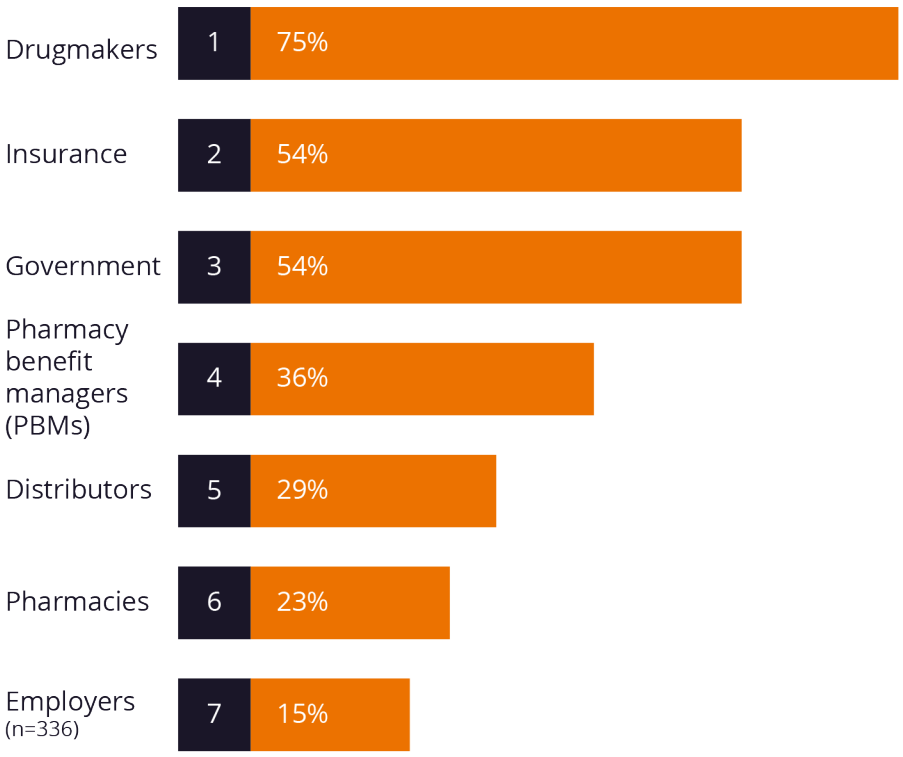
Prescription drug prices and affordability have been a hot-button topic in the U.S. for decades. And, like any other hot-button topic, there are some axioms about drug affordability repeated so often that "everyone knows" them and they are assumed rather than demonstrated. For example, U.S. Department of Health and Human Services Secretary Xavier Becerra starts his "Comprehensive Plan for Addressing High Drug Prices" introduction with the simple declaration "Americans pay too much for prescription drugs."

We also think we know exactly who is to blame for this state of affairs: the pharmaceutical companies that charge high prices. While there are plenty of places to point fingers, the public believes drugmakers are most blameworthy, with 75% of respondents to ZS's Patient Affordability Survey suggesting drugmakers are at fault for high prescription prices. This far outstrips all other entities in our study.

FIGURE 1:

Entity patients fault for the high cost of prescription drugs

(n=1,192)



Respondents were asked: "To what extent do you believe each of the following is at fault for the high cost of prescription drugs?"

The public and many policymakers have internalized a simple story:

1. Many patients struggle to afford their prescription drugs.
2. They struggle because drugmakers charge very high prices.
3. Policy action to limit what drugmakers can charge would address this.

While this story is simple, it is also mostly wrong. The reality of drug affordability is complex. The prices drugmakers charge are only sometimes related to the issues patients face. Policy action to limit list prices of branded drugs would address a small percentage of the affordability issues patients face (only about 13% based on our research) leaving an overwhelming majority of problems untouched. Efforts to address the very real struggles too many patients face must begin with a clearer understanding of the affordability landscape—the different forces that come together to create problems and the types of policy actions that might better address those problems.

The ZS Research Center has conducted groundbreaking research into prescription drug affordability in the U.S. that, for the first time, provides real context to the different situations in which patients struggle to access or afford their prescription drugs. We have gone beyond measuring the frequency of affordability troubles and have focused on the details of those problems in our patient survey—which drugs, what prices patients were asked to pay and what prices would have been acceptable. We have also studied a large claims data set to bring further quantitative grounding to the situations in which patients do not successfully fill the prescriptions written by their healthcare providers.

We hope our research findings will help shape a more productive discourse on drug pricing and affordability—one geared toward aligning policy solutions to the real issues patients face. Their problems are too important to be so poorly served by the oversimplified story we are all told.

Study design

To understand what is happening "under the hood" with patient affordability, we conducted a survey of 2,977 consumers in September 2021. All 2,977 consumers were asked a battery of questions regarding the perceptions of drug prices. For the 500 respondents who experienced affordability issues, we probed for specific details about their situations. We asked them to: name the most recent drug with which they had a problem, describe the nature of that problem and characterize the impact this difficulty had on them. We also asked them to provide the price they were asked to pay for the prescription and the price they would have been willing to pay.

In addition, we studied a Symphony Health Integrated Dataverse (IDV®)[1] patient claims data set, which included data from January 2016 through December 2019, with a focus on all prescriptions patients did not successfully fill at the pharmacy, either due to insurance rejection or patient choice. The claims analysis enabled quantitative validation of the consumer research findings.

Key affordability findings

Drug prices are a salient political issue because prescription drugs are a necessity for many and difficulties affording those medicines can disrupt patients' lives in several ways. We asked those who experienced affordability issues about what happened when they couldn't afford a drug and the impact that had on their health and wellbeing. These realities serve as a reminder as to why it's so important we find ways to address patient affordability.

Affordability problems are highly disruptive

Twenty-five percent of the 500 respondents who experienced an affordability issue reported never taking or discontinuing the medication they were prescribed. Of those who did end up filling the prescription, 65% reported taking a week or longer to receive that medication. As one patient reported, "I eventually saved enough to fill the prescription, but I only use it when I have to, making it last longer."

Impact on health and wellbeing

We asked survey respondents about their disease symptoms and the level of hassle they faced as a consequence of their affordability problem. Of the 500 respondents with an affordability issue, 43% of them indicated a negative impact to their health, while 99% of respondents described their level of "stress, frustration or inconvenience" as moderate or high. In characterizing these impacts, one patient stated "It has an impact not only on my diabetes, but on my depression and general stamina in dealing with life."

Consumers overestimate scale of affordability challenges

According to a poll conducted by the Kaiser Family Foundation, 24% of adults taking a prescription drug say they are hard to afford. This figure was cited by the Biden administration in their drug pricing materials. Consumer perception is quite different. In our survey, 62% of the 2,977 respondents expressed strong agreement with the statement "most of the U.S. population struggles to afford prescription medicine." Among those who have not personally had those difficulties, 56% still expressed strong agreement with the statement.

[1]Symphony Health is an ICON plc Company, IDV®, January 1, 2016, to December 31, 2019.

Generic drugs account for half of affordability problems

Generic drugs are often assumed to be inexpensive. It is therefore striking that in our survey, drugs with generic versions available comprised 52% of the cases where consumers faced affordability challenges.

This result was consistent with our analysis of prescription claims. Over 70% of all prescriptions patients chose not to fill at the point of sale in 2019 were for generic drugs. There can be many reasons beyond affordability that result in a patient being unable or unwilling to fill their prescription. When we focused solely on higher-priced claims in that data set, we noted 50% of all unfilled claims with co-pays of at least $30 were for generic drugs. Forty-four percent of all unfilled claims of at least $50 were for generics.

Generic drug markups are a key driver of affordability issues

While some generic drugs have very high wholesale prices, most of the drugs consumers cited in our survey as difficult to afford are available at substantially lower prices than they were asked to pay at the pharmacy. Since consumers told us exactly which drugs gave them problems, we looked up prices for those medicines on the GoodRx homepage and compared those to what the patients were asked to pay. GoodRx prices are based on negotiations between retail pharmacies and benefit managers, so they represent price points at which a retail pharmacy is perfectly willing to sell the drugs—plus a cushion for the cut that GoodRx takes.

For example, one patient listed a co-pay of $40 for a prescription for gabapentin. When we queried GoodRx in January 2022, the homepage showed prices under $15 for that drug at eight different pharmacies. Looking across the full set of generic drugs that surveyed consumers considered difficult to afford, we found dramatically lower prices available in 76% of those cases.

Large differences between what patients were asked to pay for generic drugs and what retail pharmacies were willing to accept are the single biggest driver of affordability challenges patients experienced, accounting for about 40% of all such issues. Marketplace players like GoodRx and the new Mark Cuban Cost Plus Drug Company pharmacy have stepped in to address this problem, but many patients with affordability issues are not yet successfully availing themselves of these offerings.

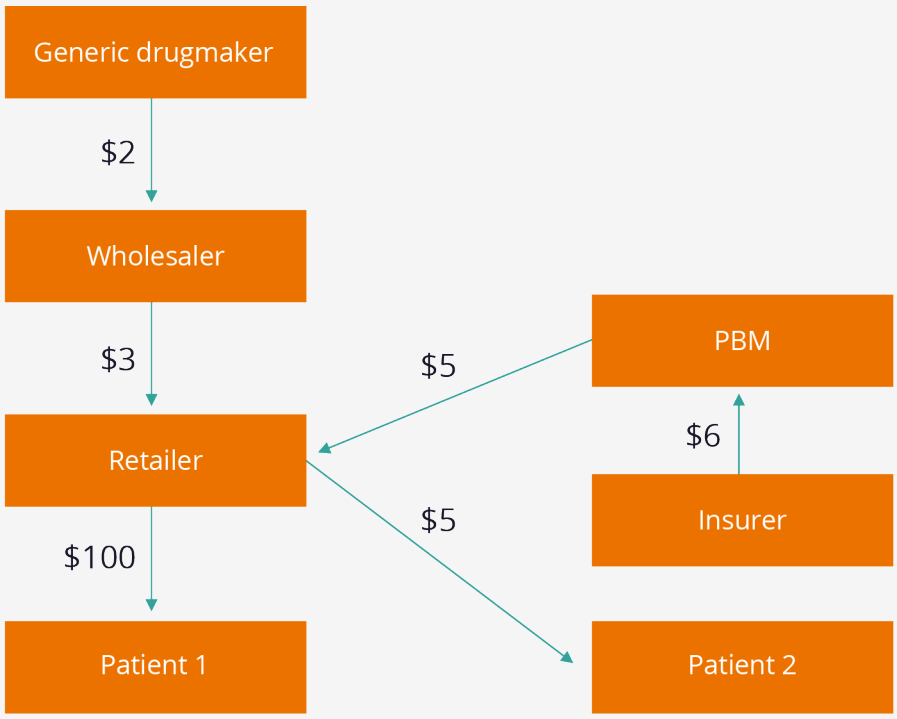
CASE STUDY: Flow of money for generic drug prescriptions

There are a host of scenarios in which a patient ends up paying a high price for a generic medication that has been on the market for several years. The diagram below illustrates one such case. In this example, a retail pharmacy is selling a drug it acquired for $3 from a wholesaler.

- The retail pharmacy has a contract with a PBM for this drug for a price of $5.
- An insured patient with access to this price pays $5, which gives the retailer a profit of $2 on this transaction.
- However, a patient who doesn't have access to this price, due to their health plan, pays the "usual and customary" price set by the retailer at $100, giving the retailer a profit of $97 on this transaction.

FIGURE 2:

Generic drug transaction



Consumers level greatest blame on drugmakers for high prices

We asked 2,977 consumers whether they considered prescription drug prices reasonable. For those who considered prices unreasonable (n=1,192), we asked which entities they blamed for that situation. The pharmaceutical industry was cited most commonly (75% of responses), far ahead of insurance (54%), the government (54%), pharmacies (23%) and employers (15%).

These figures don't change materially based on the consumer's situation. Consumers who haven't experienced affordability problems and those who have both fault the pharmaceutical industry equally. Consumers who have experienced affordability problems with generic drugs—a situation usually caused by a combination of insurance, pharmacies and employers, rather than drug manufacturers—also held the pharmaceutical industry most responsible.

Branded drug price controls would only address 13% of the problem

Most prescription claims follow a co-pay structure in which the patient's out-of-pocket payment is only loosely related to the drug's list price. Higher or lower list prices might affect the patient's co-pay indirectly by shifting the drug to a different cost sharing tier on their drug formulary. However, when a patient is in the deductible phase of their health benefit or when a drug is on a co-insurance formulary tier, the relationship between a drug's list price and cost to the patient is direct. Absent any other policy changes, price controls on branded drugs will provide cost relief in those deductible and co-insurance situations, but not in co-pay situations.

In our consumer survey, we identified cases where the unaffordable prices shared were likely tied to deductible or co-insurance situations. Since consumers also shared prices they would have been willing and able to pay, we were able to assess how changes in list price might shift a drug price from unaffordable to affordable. We found that in about 13% of cases in our sample, a policy change that slashed branded drug list prices in half would address the patient's affordability issue. It is striking that such an aggressive action would go such a small way toward the problems it would purportedly address.

Some patients still experience affordability issues at lower prices

We asked consumers who experienced affordability problems to characterize the reasons for their difficulties. Of the 500 respondents with affordability issues, 73% cited multiple factors. While the most common factor was that the "co-pay or co-insurance was too high," at 44%, the second most common factor was "burden from other financial obligations," at 32%. In addition, a small but meaningful proportion of consumers described affordability problems even at modest co-pay levels. Fifteen percent of our survey respondents indicated a co-pay

level would only be acceptable at prices of $10 or less. Such cases will be very difficult to address with direct policy interventions on drug economics and will likely require a different type of societal action.

Why so many patients struggle with affordability

From a patient's perspective, every affordability issue looks about the same. The patient receives a prescription, tries to fill it at a pharmacy, and determines that it is too expensive. However, the specific reasons behind the scenes for this outcome can vary significantly. These factors fuel a blame game that characterizes much of today's discourse on drug prices, costs and affordability. The reality is every stakeholder in the healthcare ecosystem is at least sometimes somewhat responsible for patient affordability problems:

- **The pharmaceutical industry** sets list prices on branded drugs that often form the basis for patient co-pay levels. If their prices were lower, patients would often pay less.
- **PBMs** manage and profit from the infrastructure that drives drug manufacturers to charge high list prices with offsetting rebates rather than offering lower prices. They have also developed "innovative" methods to redistribute money from patients and drugmakers to plan sponsors and themselves. These methods are frequently opaque including, for example, adding new group purchasing organization intermediaries headquartered in Europe that take part in price negotiations. The connection between such actions and patient health are difficult to comprehend.
- **Employers and other plan sponsors** have, in an effort to reduce plan premiums, chosen to adopt various mechanisms offered by health plans and PBMs that shift the burden of payment onto patients, rather than onto the broader insurance pool. Tactics such as high deductibles, the adoption of co-pay accumulators, aggressive use of co-insurance for specialty medications, declining to share negotiated rebates with patients at point of sale and declining to adopt a preventive drug list all serve to make drugs more expensive for more patients than they should be.
- **Pharmacies** often add tremendous retail markups on generic drugs, harming the uninsured or under-insured who may not be aware of available discount options.
- **The government** allows each of the private sector players to act the ways they do. Further, the government has chosen a narrow definition of "essential health benefits" available at a $0 co-pay that doesn't include many prescription drugs that truly are essential.

In other words, every time one healthcare entity points the finger of blame at another healthcare entity over drug costs, they're at least partly right! The extent to which those entities are responsible varies by situation.

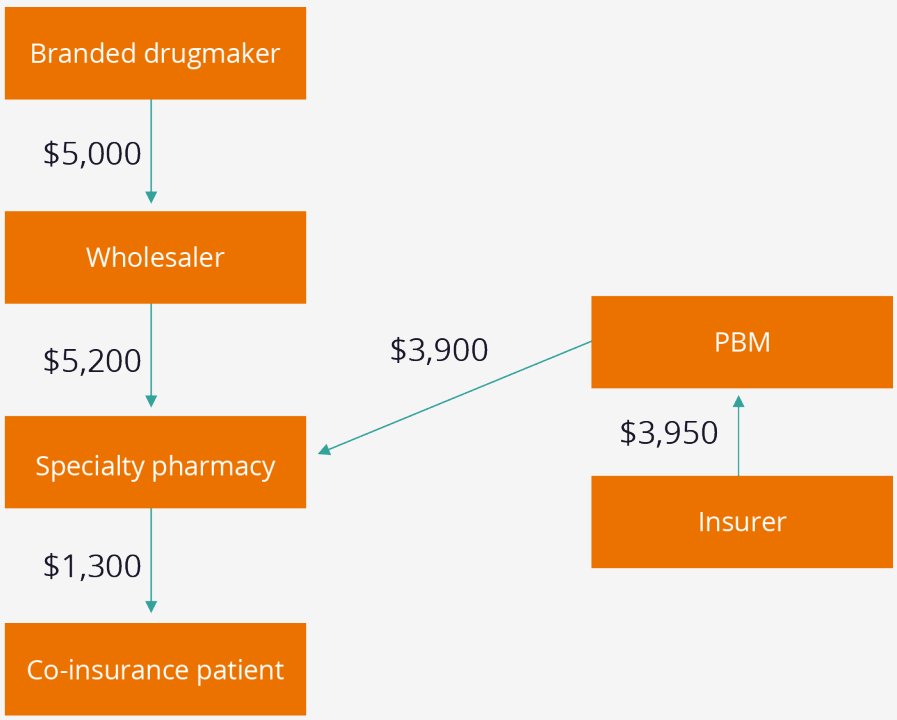
CASE STUDY: Flow of money when a branded drugmaker is selling a specialty drug

In this case where a patient is asked to pay a high price, a branded drugmaker is selling a specialty drug with a wholesale price of $5,000 per month.

- The specialty pharmacy has set a retail price of $5,200.
- The patient, who is on Medicare, is not able to use a manufacturer co-pay discount and pays a 25% co-insurance of $1,300.
- The PBM reimburses the pharmacy for the remaining $3,900 of the retail price. The insurer pays that amount to the PBM plus a small added fee.

FIGURE 3:

Specialty drug transaction



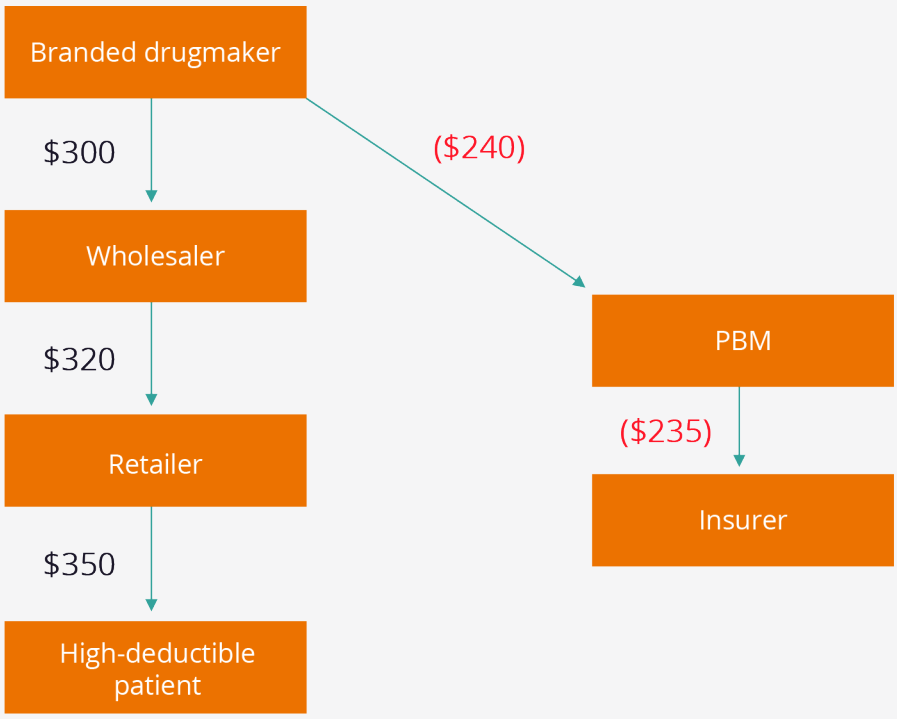
CASE STUDY: Flow of money when a patient has a high deductible

This diagram details what happens in instances where a patient with a chronic condition, such as diabetes, is asked to pay a high price for a treatment while on a high-deductible insurance plan. In this example, a branded drugmaker is selling a medication at a heavily discounted wholesale price of $300. They have a contracted rebate of $240 back to the PBM, which yields a net price of $60 back to the drugmaker.

- A patient with a high-deductible plan pays the full retail price of $350 even though the drugmaker receives a net price of $60.
- The PBM passes most of its $240 rebate to the patient's insurer.
- The insurer collects $235, but neither the PBM nor the insurer use the rebate to offset the patient's cost.

FIGURE 4:

High-deductible transaction



Toward a comprehensive affordability agenda

Since the underlying reasons for drug affordability issues are multifaceted, there is no single simple solution that will address the real-world problems patients face. If we seek to address patient affordability comprehensively, reforms will be required that target each driver. What might comprise such a comprehensive agenda? Below, we summarize its core elements.

FIGURE 5:

An independent view of potential solutions for patient affordability

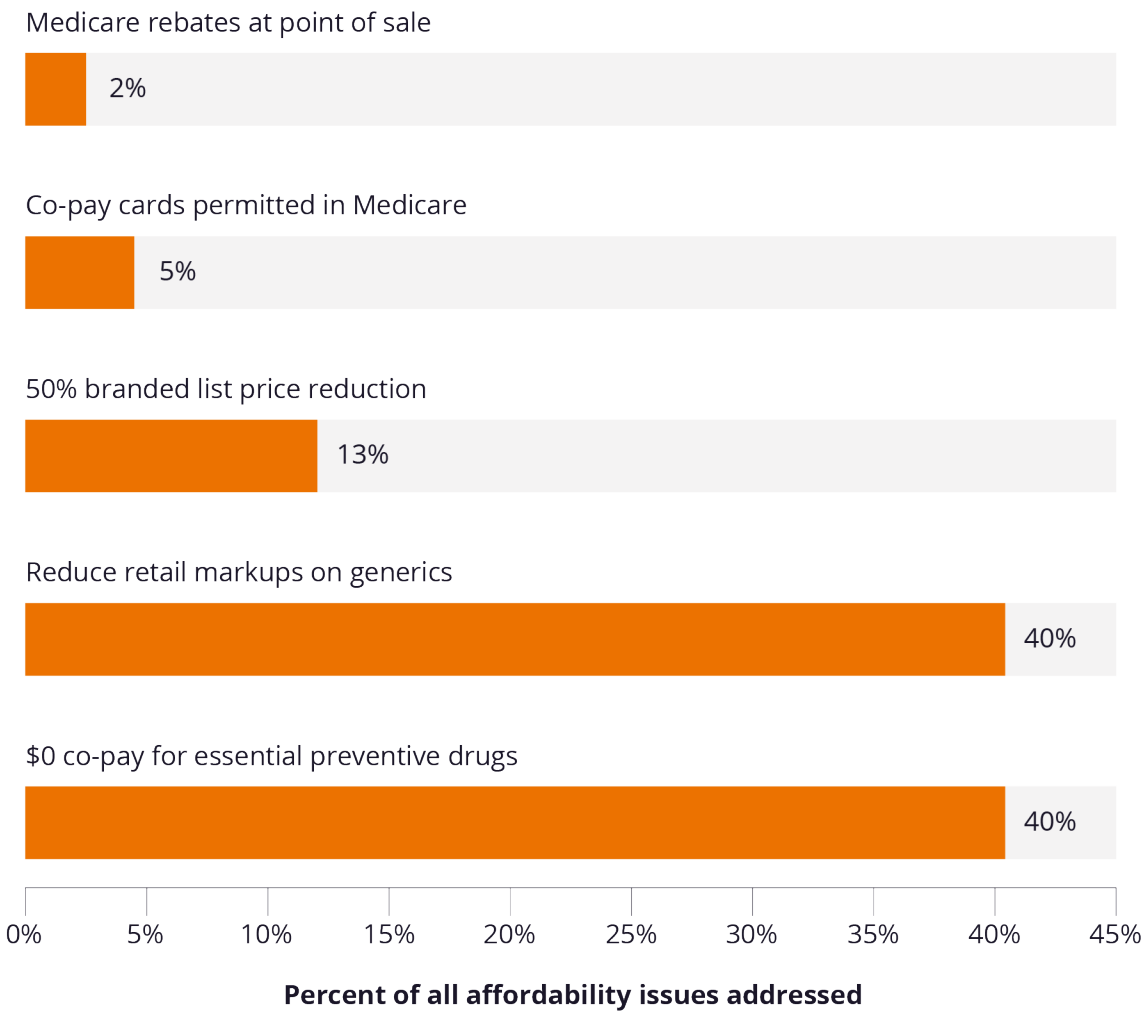


Figure 5 looks at several different interventions aimed at improving patient affordability issues if each one were implemented individually.

FIGURE 6:

A combined view of potential patient affordability solutions

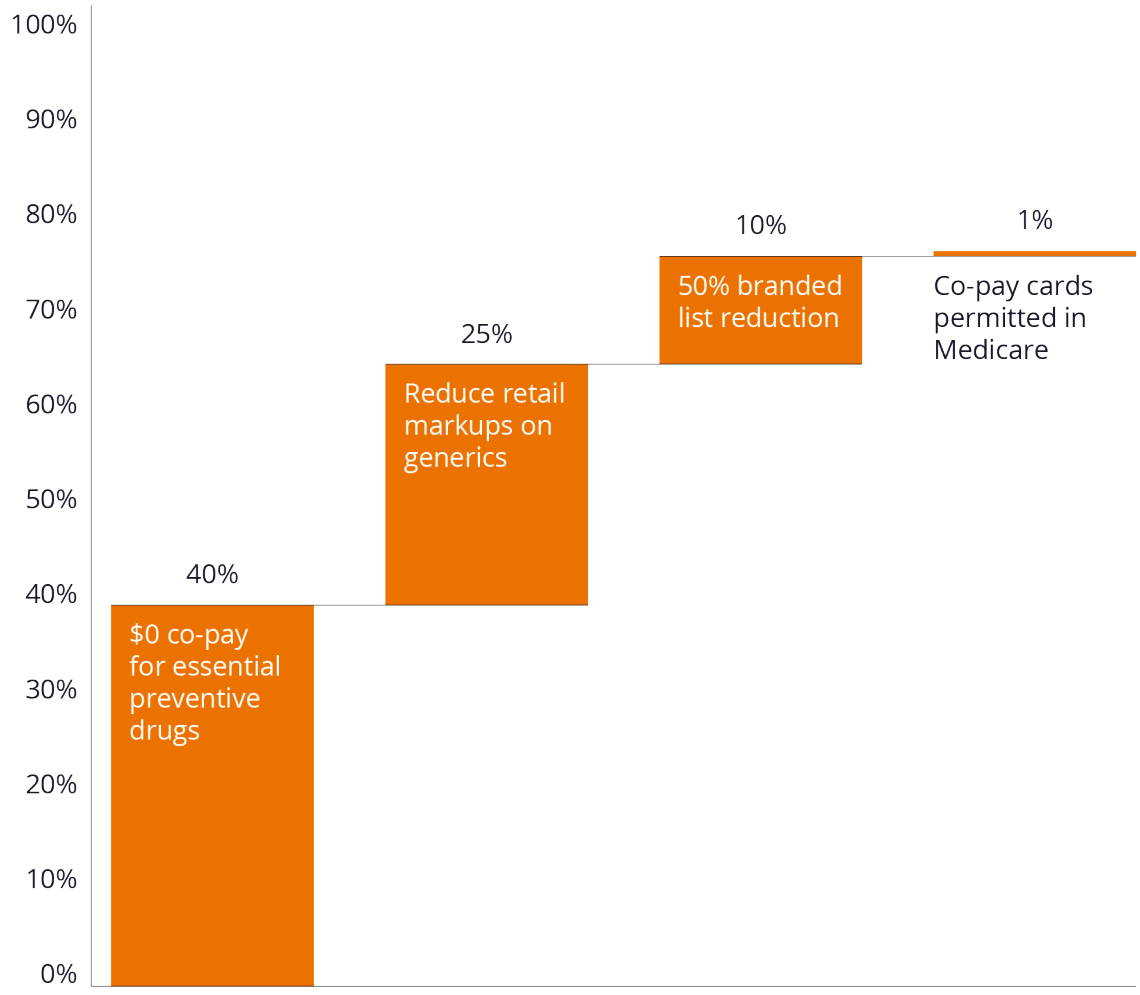


Figure 6 reflects what would happen if more than one intervention was implemented at the same time. The figures look different because of overlap. For example, reducing retail markups on generics will help some of the same patients as having a national preventive drug list. Medicare point-of-sale rebates were excluded from this view because enacting that would add 0% to the impact.

Benefit design reform

Benefit designs in both the private commercial insurance market and in the Medicare market create an array of situations where patients face unaffordable co-pays for prescription drugs. The most prominent cause is the ubiquity of deductibles in Medicare Part D (up to $480 in 2022) and the nearly 30% of covered workers who are enrolled in high-deductible plans according to Kaiser Family Foundation's 2021 Employer Health Benefits survey. When patients have a significant deductible, they may be subject to an unaffordable co-pay on a prescription drug before that deductible is satisfied.

While deductibles are a valid tool for managing insurance premium levels, it is counterproductive to require patients to pay high costs to access many essential therapies. Some forward-thinking employers have recognized this and have adopted preventive therapy drug lists for conditions such as infections, hypertension and diabetes. These drugs are sometimes designated as low or no co-pay and are not subject to deductibles. Policymakers should consider extending the definition of essential health benefits as codified in the Affordable Care Act to include a broader set of treatments like these at a $0 patient co-pay, rather than leaving these choices to individual insurers. CVS Caremark has put together a preventive drug list where members do not need to meet a deductible for preventive prescriptions. Under this plan, diabetes drugs and generics are free and branded drugs are not too expensive. If we considered the drugs on this list to be "essential," it would address 30%-40% of the affordability issues in our data.

Price reform

The prices set by manufacturers for branded drugs must be part of the conversation. With co-insurance structures in Medicare across Part B and Part D, and in many commercial plans, the prices for specialty, oncology and rare disease therapeutics have a direct bearing on what patients are asked to pay. Our analysis found that if the makers of branded drugs lowered their list price by 50% it would improve all affordability issues by 13%. The impact may be modest for such a sharp reduction, but within the context of comprehensive affordability-based reform, pharmaceutical manufacturers will need to think about what constraints they may accept on pricing for the opportunity to both address patient burdens and increase sales volume to patients who will be better equipped to pay for their prescriptions.

Policymakers should also take a close look at how pharmacies establish their "usual and customary" prices and the level of markup those represent over their negotiated prices. If a pharmacy is willing to accept a $5 reimbursement for a prescription from a PBM, it is unreasonable that they charge $100 to a patient who doesn't know to grab a coupon from

GoodRx or a Mark Cuban Cost Plus Drug Company. These discount companies provide an important service today, but their value proposition exists in direct proportion to the level of price-gouging on the part of retailers. Retail pharmacies must find avenues for profit that don't rely on milking their most unsuspecting customers dry. Our analysis found that reducing retail markups on generics have the potential to address 40% of patient affordability issues.

Co-pay reform

Following enactment of the Affordable Care Act, private commercial insurance plans were required to have a maximum annual out-of-pocket cap. However, costs in Medicare remain uncapped. Further, Medicare patients are ineligible for discount cards offered by branded drug manufacturers. Capping Medicare costs for patients, as contemplated by different bills in Congress, and allowing patients to benefit from co-pay discounts offered by drugmakers, will help many Medicare patients better afford their drugs. ZS found that allowing Medicare beneficiaries to use co-pay cards would address 5% of affordability issues. The trend of Medicare Part D plans increasingly placing generic drugs on higher co-pay non-generic tiers should also be evaluated critically.

In the private commercial market, pairing high deductibles with shadowy co-pay accumulators leads to surprising patient bills when manufacturer-offered discounts have been exhausted. These accumulator programs serve no purpose other than to make it more difficult for patients to pay for their medications and they should be banned.

Rebate reform

Branded pharmaceutical manufacturers negotiate substantial rebates off their list prices in many therapeutic areas with health plans and PBMs. According to a study by economic consultancy BRG, manufacturers now receive less than 50 cents net on each gross dollar of their revenue. In the political hot-button insulin category, actuarial firm Milliman has reported that drugmakers collected only 16 cents on the dollar in the first quarter of 2021, with the rest discounted or rebated. The net price for insulin per patient realized by manufacturers is lower today than it was in 2007.

Too often, however, those discounts and rebates don't find their way to the patients who are prescribed the drugs. Instead, they either show up in the profits of intermediaries or as rebates to plan sponsors. While PBMs offer plan sponsors the option to use negotiated rebates to offset patient costs at point of sale, very few plan sponsors choose to do this due to the increased costs for the payer, as CVS acknowledges. Policymakers should take that

decision out of the hands of those sponsors so that patient co-pays reflect the net prices realized by manufacturers. Enacting rebate reforms in Medicare and private insurance could address between 2%-5% of all drug affordability issues, according to our analysis.

Patients deserve comprehensive action on prices

The reasons so many patients struggle to afford their medications are complicated and multifaceted. As a result, addressing the issue will require a comprehensive affordability agenda that would genuinely respond to the many underlying issued that lead to inflated prices. For example, our analysis found that combining two of our recommended reforms—reducing retail markups on generics and enacting a $0 co-pay on preventive drugs—could address two-thirds of all affordability issues.

It is worth pausing to ask what purpose high patient co-pays for many prescription drugs serves. President Joe Biden has proposed patients pay no more than $35 for a month of insulin. While a welcome move for those with diabetes who need insulin every day, why should so many patients with other diseases be expected to pay more than this? Are those who suffer from, say, Crohn's disease, multiple sclerosis or chronic kidney disease any less worthy of having access to treatments at affordable monthly costs?

In an environment where every stakeholder in the healthcare ecosystem bears some responsibility for the current state of patient affordability, it has been too easy to point fingers at others rather than coming together to formulate solutions on behalf of patients. What if instead, drug manufacturers, insurance plans and pharmacies could come together and align on a set of affordability-centered principles? What if policymakers moved beyond their narrow focus on branded drug list prices and looked at all the sources of affordability challenges? Only with comprehensive action across all the drivers of unaffordable prices will we ensure that whatever their medical need, patients can pay for the treatments their doctors prescribe. They deserve no less.

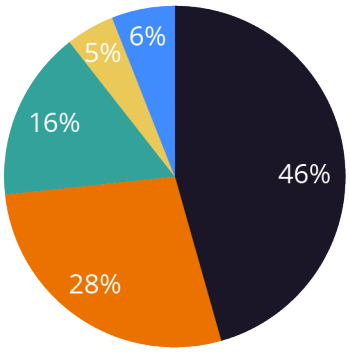
Methodology

We conducted our online, 15-minute survey between September 2-22, 2021. It included 2,977 consumers. To be classified as having an access issue (n=476) or an affordability issue (n=500), respondents had to:

- Be a U.S. adult
- Be able to indicate their insurance status
- Have been prescribed a medication in the past year
- Have the ability to recall medication names and dates
- Have experienced an issue accessing a prescription, such as an insurance denial, or have experienced difficulty affording the prescription medication

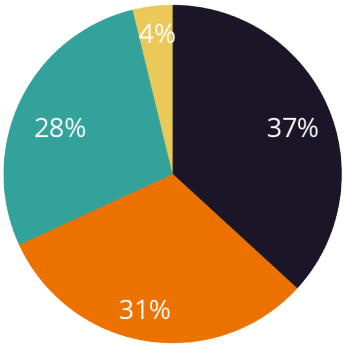
U.S. adults who did not meet the above criteria (n=2,001) only answered questions about their perceptions of affordability and access in the U.S. The demographic break and down of respondents is as follows below:*

Insurance status



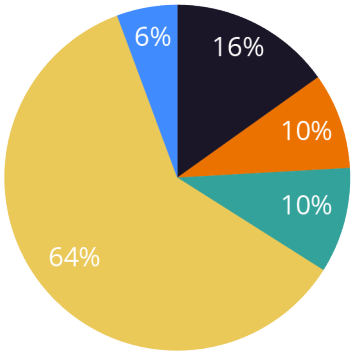
- Commercial insurance
- Medicare
- Medicaid
- Uninsured
- Military, others and unsure

Household income



- <$20,000 - $49,999
- $50,000 - $99,999
- $100,000 - $249,999 or more
- Prefer not to disclose

Ethnicity



- Black
- Asian/Pacific Islander
- Latinx/Hispanic
- White
- Additional categories

Note: Charts will not sum to 100% due to rounding or respondents selecting more than one ethnicity.

About the authors

Howard Deutsch is a principal at ZS and a leader in ZS's strategy and transformation space. He also leads the ZS Research Center. Howard works with life sciences companies on a range of issues, with a focus on complex go-to-market strategies, in-line product growth and market access excellence. Howard has over 15 years of experience working with the life sciences industry, including over 10 years in U.S. value and access. He holds an A.B. in economics from Princeton University.

Megan Sadiua is a manager in ZS's value and access practice. She has experience in navigating the complex web of systems, processes and stakeholders that affects patient access to medicine. In over eight-plus years at ZS, Megan has conducted extensive market research with payers, providers and other healthcare stakeholders in pharma markets across the world. Megan holds a bachelor's degree in intensive psychology with honors from University of California, Santa Cruz.

About ZS

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