

PATIENT IMPACT REPORT: PHARMACY BENEFIT MANAGERS

What are Pharmacy Benefit Managers (PBMs)?

PBMs are the middlemen who work for insurance companies to determine what drugs are and aren't covered on an insurance formulary. They are a player in the supply chain *between* the manufacturers who make the drug and the patients who need them.

What does that mean?

The actual price of pharmaceutical medications is not what patients pay. Everyone in the supply chain has their hand out, and PBMs pocket one of the largest pieces of the cost of the medicine.

Let's use insulin as an example. From 2014 to 2018, the net price received by insulin manufacturers decreased by 31%, but at the same time, the share earned by [PBMs increased by 155%](#).

Aren't there coupons and rebates to help me afford my medicine?

PBMs negotiate prescription drug prices with manufacturers on behalf of health insurance companies, earning billions of dollars in annual "rebates," which they pocket and do not pass the savings to the patient.

If the rebate process worked as it's intended to – and the way patients are led to believe – patients would see a lower cost for their medicine at the pharmacy counter.

Worse, despite the rebates, patients pay a co-insurance on the list price, which is the original price of the drug before the rebate. Patients don't actually get the coupon or rebate.

Murky business practices

Contracts between the health insurers/PBMs and their network pharmacies often include a "gag clause" which prevents pharmacists from telling the patient about additional purchase options, including that their medication could cost less if they pay the out-of-pocket price instead of going through their insurance. Patients end up paying more in copayments than what it costs their health insurance/PBM.

Consolidation in the health care industry has also resulted in [PBMs steering patients away from unaffiliated and neighborhood pharmacies toward PBM-affiliated or PBM-owned specialty/mail-order/retail pharmacies](#), often without the patient's consent. When patients in underserved areas are forced to switch pharmacies, it worsens health disparities due to transportation issues.

How are these practices even legal?

Well, it's dishonest and there is no transparency in where our money goes when we stand at the pharmacy counter. It is an unfair practice that adds expensive and ineffective layers of bureaucracy within the health care system and unnecessary costs to patients and their families.

Bottom Line: Murky business practices of PBMs create barriers to medication for patients, exacerbate health inequities, and lead to worse outcomes.

Some of the Things You May Hear from PBMs:

TALKING POINT: *“PBMs negotiate with drug companies to lower prescription drug costs, reducing patient drug costs by nearly \$1,000 each year.”*

FACT CHECK:

PBMs demand high rebates from manufacturers to get drugs and therapies listed on insurance formularies. [A study found](#) that for every \$1 increase in rebates, the list price rose by \$1.17, illustrating the relationship between rebates and list price.

TALKING POINT: *“PBMs work with pharmacies to deliver prescription drugs to patients safely and seamlessly.”*

FACT CHECK:

PBMs are actually a colossal cause of unaffordable prescription drugs, [as their profits on these “negotiations” have grown higher and higher](#). A report called “Understanding the Evolving Business Models and Revenue of Pharmacy Benefits Managers,” released by consumer protection groups, showed [PBMs' gross profit increased 12% from 2017 to 2019, from \\$25 billion to \\$28 billion](#).

Because of the monopoly held by PBMs ([the three largest PBMs control 79% of the market](#)), they can decide which pharmacies patients can use. For rural patients who live far away from big chains, it puts their covered medication out of reach.

TALKING POINT: *“PBMs help patients stay on their prescription drugs to live healthier lives.”*

FACT CHECK:

PBM practices like prior authorization, step therapy, and non-medical switching wreak havoc on patient health. These practices interfere with the doctor-patient relationship and often force patients into alternative drugs on a formulary [instead of the treatment prescribed by their provider](#). A patient should take the drug recommended to them by their doctor.

The negative health impacts are real. [One study of rheumatoid arthritis \(RA\) patients](#) found those forcibly switched to a different medication experienced [42 percent more ER visits](#) and 12% more outpatient visits within the first six months.

Actual Patient Testimonials

Jody Quinn

MA-09



Jody was diagnosed with psoriatic disease, mild psoriasis and moderate to severe psoriatic arthritis in 2003.

“I have also suffered irreversible joint damage due to a poorly executed prior authorization process that took months for approval. I also have been subjected to using ineffective treatments due to the unreasonable step therapy process. These delays in proper treatment due to step therapy and inefficient approval process have caused me severe joint damage, weight gain due to extended use of steroids, loss of quality of life and loss of income due to my inability to work full-time.”

Beth Joyner Waldron

NC-04



A rare blood clotting disorder, a thrombophilia, puts Beth at risk of clot recurrence. She will be on lifelong anticoagulation, but the medication she was stable on for eight years was switched with another medication by the PBM.

“I received a letter in the mail from my insurance pharmacy benefits manager (PBM) that the medication I had been taking for the past eight years would no longer be covered. It said I should ask my doctor about writing a new prescription for a different listed medication.

That was it. The letter provided no phone number to call if I had questions. It did not mention an appeals process.

After contacting my PBM, I learned I could ask my doctor to file an exemption request. However, my PBM's approval criteria required I first take and fail the new medication or have other clinical indication, which was not defined. If the exemption was approved it would be at a higher copay tier, making it subject to coinsurance and deductible. **In practical terms, only after a documented adverse event on the new medication could I go back to the medication I had been stable on for eight years and my costs would rise by \$2,400 a year.”**

Todd

NC-12

Todd lives with arthritis and was non-medically switched off a stable medication.

“Express Scripts says that my company who is self insured determines insurance coverage, but of course my company charges Express Scripts with developing the formulary and abides by the formulary that is set up. They are each pointing at each other as the driver for this decision. I am stable on Cosentyx and **it is unconscionable that from year to year a pharmacy would take away your ability to stay on a medication that has been working for you** by having me risk switching from medication to medication in an attempt to play one medication vendor off of another for profit, while I may suffer finding (or not finding) another medication that maintains my quality of life.”

Charlene

KS-03

Charlene has battled arthritis and chronic pain. Instead of getting immediate access to a new medication recommended by her doctor, her insurance forced her to try numerous other medications on the formulary before it approved the recommended medication.

“I felt like my care was dictated by what insurance wanted based on a cookie cutter formulary for certain types of arthritis, not my unusual one, and not what my doctor and I thought was right for me. I am not standard. A lot of people are not standard. With all the waiting and jumping through these loops, my physical health was severely impacted dealing with the long term side effects like osteoporosis, increasing pain, and needing a cane/wheelchair to get around in my 30s.”

Nicole

NY-20



Nicole was misdiagnosed with multiple sclerosis, only to discover three years later that she actually had a rare autoimmune disease called Neuromyelitis Optica Spectrum Disorder.

“Because of the incidence of misdiagnosis, many patients have been treated with MS [Multiple Sclerosis] medications. Some of these medications exacerbate NMOSD [Neuromyelitis Optica Spectrum Disorder] and can cause further disability. In an appeal to my insurance company in the two last years, **eight out of nine medical examiners did not know what NMOSD was and had to be told about the potential risks of further disability because of delayed treatment.**”

Nisha Trivedi

CA-14



Nisha lives with epidermolysis bullosa, a rare genetic disorder that leads to fragile skin.

Listen to Nisha's story [here](#).

(At 32:08) “The [insurance] company also refuses to cover a compounded ointment I use in my mouth to prevent and treat oral lesions. **In their denial, they suggested a lower-cost therapy instead. One that my physician already knew would not be effective.**”

Diane Talbert

MD-05

Diane, who lives with psoriasis, psoriatic arthritis, and fibromyalgia, has experienced delays due to step therapy.

Listen to Diane's story [here](#).

(At 32:38) “As I've gotten older, my joints have gotten worse along with fibromyalgia. I also have severe psoriasis. My condition became worse about seven months ago when I couldn't get the medication that I needed because the insurance company refused to pay. **This was a process called step therapy. I had to try a medication that was cheaper and I knew wouldn't work and then step up to a more expensive medication. In less than six months I was 80% covered in psoriasis and had to have help to walk.**”

Elisa Comer

TN-01



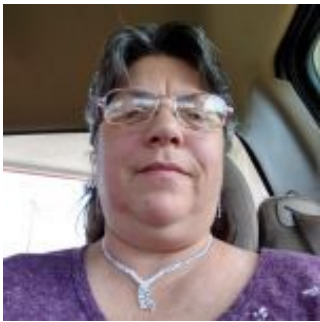
Elisa has been diagnosed with rheumatoid arthritis, Sjogren's, and myasthenia gravis. With a background in health care administration, she has a unique perspective on the role of PBMs.

Listen to Elisa's story [here](#).

(At 34:19) "Since 2017, perhaps nothing has affected my chronic illness journey quite like pharmacy benefit manager "gotchas." Those terrible, impossible to manage and plan for surprises that PBMs are allowed to put upon the patients they're supposed to serve. Some years ago I coined the term "insurance injury." An "insurance injury" is any occurrence where my care or the care of my family is negatively affected due to sketchy insurance and PBM behaviors. **Things like intentional delays from prior authorization policies or PBMs making money grabs on patient assist funds that are intended to help me and my family. Wouldn't it be helpful if we could track this information and truly learn the scope of the problem upon patients?"**

Vickie Wilkerson

LA-04



Vickie lives with psoriasis and psoriatic arthritis and has gone through step therapy, a PBM tactic to lower costs for payers.

Read Vickie's story [here](#).

"Having had Psoriasis for 17 years and Psoriatic Arthritis for seven years I have had to deal with step therapy and not having price transparency. **Step therapy is a complete waste of time in that it forces you to take drugs that do not work. In my case it impacted a year of my life in that I had to take a drug for six months that did nothing to help.** Then I had to wait another six months to get put on something else that did work. It was what my doctor wanted me on to begin with."

Jade Nealious

SC-02



Jade lives with lupus and rheumatoid arthritis. Throughout her healthcare journey Jade has encountered PBM barriers to care like step therapy.

Read Jade's story [here](#).

“At times, I found myself crying in frustration because of issues like prior authorization and step therapy. When I was first diagnosed with my lupus, I had to undergo the step therapy process as my physician attempted to find the medication that worked for me. Luckily, my physician not only advocated for me for a medication that was not FDA approved for lupus patients. I resubmitted my appeal three times before actually receiving full approval... **Unfortunately, during the entire process, my physician kept trying a number of medications to keep me alive. I suffered from multiple flares and was forced to home-school for a period of time because of the frequent hospital visits during the process.** But my parents and my physician did not give up. This was while I was in high school.”

Patient stories from across the nation can be found on PatientsRisingStories.org

Patients Rising Now advocates for access, affordability, and transparency in health care on behalf of the 133 million Americans living with chronic conditions. We believe that we should know where our money is going when we stand at the pharmacy counter. We believe that patients should have the right to control their own health care decisions.