

This Panel Will Decide Whose Medicine to Make Affordable. Its Choice Will Be Tricky.

Do they tackle drugs with extremely high costs taken by a handful of patients, or drugs with merely very high costs taken by a larger group?

June 7, 2023 By Markian Hawryluk and KFF Health News

Catherine Reitzel's multiple sclerosis medication costs nearly \$100,000 a year. Kris Garcia relies on a drug for a blood-clotting disorder that runs \$10,000 for a three-day supply. And Mariana Marquez-Farmer would likely die within days without her monthly \$300 vial of insulin.

At best, a Colorado panel of medical and pharmacy experts seeking to cut the costs of expensive drugs will be able to help only one of them.

Starting this summer, the state's Prescription Drug Affordability Board will choose up to 18 high-cost drugs for review over the next three years to determine if the medications are unaffordable and whether to cap what health plans and consumers pay for them.

But with hundreds of expensive drugs to choose from, the board members face tough decisions about who will get help now and who will have to wait.

Do they tackle drugs with extremely high costs taken by only a handful of patients, or drugs with merely very high costs taken by a larger group? Should they consider only out-of-pocket costs paid by consumers, such as for insulin, whose copays Colorado caps at \$50 a month, or the total cost of the drug to the health system? Will they weigh only drug prices, or will they try to right social wrongs with their choices?

And what does "affordable" even mean?

"That question alone is a lot harder to answer than it might seem at face value," said Jennifer Reck, project director for the National Academy for State Health Policy's Center for State Prescription Drug Pricing. "You immediately get into how utterly complex our drug supply chain is, how opaque it is, how many different prices there are," she said.

Maryland was the first state to establish a drug affordability board in 2019, but funding challenges

and the pandemic have slowed its progress. Colorado passed a bill creating its board in 2021 and has already moved ahead of Maryland in the process. Washington followed in 2022 but is still in its early phases of implementation.

Maine, New Hampshire, Ohio, and Oregon have also established boards, but they lack the power to limit drug payments. And at the federal level, the Inflation Reduction Act of 2022 included a [provision requiring](#) the Health and Human Services secretary to negotiate prices with drug companies for a small number of the most costly medications covered by Medicare.

It's taken years for the Colorado and Maryland board members to create all the rules and regulations to govern their work before getting to the point of looking at specific drugs.

"It's just a long, tortuous government process to get things up and running," said Gerard Anderson, a professor of health policy and management at Johns Hopkins University, and a member of Maryland's board. "You basically have to dot every 'i' and cross every 't' in order not to get sued."

Setting Priorities

On May 12, Colorado released its first list of [hundreds of drugs](#) eligible for review, mostly because they each cost more than \$30,000 for a course of treatment. Next month, they'll release a dashboard ranking those drugs according to the board's priorities. The dashboard can also be used to examine which drugs have the highest price tags, which have had the largest increases in price, and which the state spends the most on. That would allow the board to begin affordability reviews this summer and set payment limits for the first four to eight drugs sometime in 2024. But board members will first have to set their priorities, and those could change from year to year.

"Maybe one year we focus on the impact to the system, and another year we focus on out-of-pocket costs, and one year we focus on a lifesaving drug that has smaller utilization," said Lila Cummings, director of the Colorado board.

Such approaches could pit one group of patients against others looking for cost relief. But Cummings said not all groups are eager to see payment limits.

"Some of them said, 'We want the board to focus on our drugs,' and others said, 'Please leave us alone,'" she said.

That reluctance likely reflects the close ties that some patient groups have with the manufacturers of their medications, including receiving funding from the drugmakers.

"We have seen cases in public hearings — it seems counterintuitive or surprising — where a patient group, instead of being thrilled that they might have access to the drugs at a lower price, instead are arguing against upper payment limits," Reck said. "But in most cases, there's a pretty clear financial connection to drug manufacturers."

Maryland has also received input from patient groups as it finalizes its regulations.

“So far it has not been, ‘Pick me! Pick me! Pick me!’” Anderson said. But that could change once the Maryland board begins its affordability reviews this fall.

The drug that Garcia, 47, of Denver, takes did not make the board’s list. Diagnosed with four bleeding disorders, including von Willebrand disease, he needs the medication Humate-P, made by CSL Behring, to replace one of the clotting factors missing in his blood. This winter, driving home from his job at the airport, Garcia hit a patch of black ice, spun out, and careened into a concrete barrier at 75 mph. He needed the expensive medication every day for the first five days after the accident, and then every other day for a full month.

“It’s not like I can just sit there and say no to this medication, because my bleeds get so bad,” he said.

According to Perry Jowsey, executive director of the National Hemophilia Foundation’s Colorado chapter, about 300 to 400 individuals are being treated for von Willebrand disease in Colorado. That’s far fewer than the roughly 10,000 Coloradans with MS or the 74,000 who manage their diabetes with insulin.

“In my shoes, I would target what would help the most people,” Garcia said. “You have to find a balance, especially starting out. You’re not going to be able to help everyone.”

The Colorado and Maryland boards will rely on data from state databases that show how much various public and private health plans pay for drugs. That data, however, doesn’t capture what uninsured patients pay, and it doesn’t give any insight into how much manufacturers pay for research and development.

“The goal is not to stifle innovation,” Anderson said. “But we can’t get any public data, so we have to ask the pharmaceutical industry, and they’re not required to give us the data.”

The boards want to ensure that patients like Reitzel still have access to new and better therapies. Reitzel, 38, of Highlands Ranch, was diagnosed with multiple sclerosis in 2008 and has switched medications several times seeking one whose side effects she could tolerate. “They’re all terrible in their own special way,” she said.

In 2021, she began taking a relatively new drug from Biogen and Alkermes called Vumerity, which was included on Colorado’s list of eligible drugs. But the cost of a three-month supply was nearly \$24,000, including a copay of more than \$7,000. Biogen provides up to \$20,000 in annual copay assistance through a debit card she can use at the pharmacy. But now her health plan no longer credits those payments toward her deductible. It makes it almost impossible for her to meet the \$25,000 out-of-pocket maximum under her plan.

“Primarily for this reason, I am no longer taking any medication,” Reitzel said, “and have to only hope my disease does not progress.”

Colorado legislators passed a bill to require health plans to count copay assistance programs toward patients' deductibles for drugs with no generic equivalents, but that provision does not take effect until 2025.

Insulin as an Outlier?

Just a couple of years ago, insulin may have been a higher priority for drug affordability boards, but now it's not so clear. Both Colorado and Maryland have established insulin copay caps that provide pocketbook relief, at least for patients with coverage. And manufacturers are making their own [moves to lower insulin prices](#). That could prompt the boards to bypass insulin and concentrate their limited resources on other high-cost drugs.

Copay caps do not lower the actual cost of insulin but instead spread it among members of the health plan through higher premiums. The Colorado copay caps don't help new state residents and initially did not help those without insurance, either. Both of those hurdles would have applied to Marquez-Farmer when she moved from California to Colorado Springs a couple of years ago.

"I got married to my husband during COVID because I didn't have insurance," she said. "I loved him, and it all worked out, but a big reason for me to marry him was because I would not be able to afford insulin."

Marquez-Farmer, 34, said that while insulin may not be the most expensive drug on the market, many Coloradans, particularly those from marginalized communities who have higher rates of diabetes, struggle to afford it.

"I'm not saying the other medicines are not important, because obviously they are," she said. "The reality is there's more people who are being affected by not being able to afford their insulin and a lot of people who are dying because of them rationing insulin."

Andrew York, executive director of the Maryland board, said the payment limits should be viewed as a last resort, a tool that can be used when other cost-control measures haven't worked.

"The goal is for folks to never be able to say that they can't afford their insulin. And I think we may get there soon enough just because of how much is happening in that space," he said. "So if that's the case, then maybe boards don't need to use the upper payment limit tool."

At least one form of insulin was included on Colorado's list of drugs eligible for review, but not the most commonly taken brand-name insulins. That precludes the Colorado board from addressing insulin costs more broadly.

The pharmaceutical industry has pushed back against the concept of payment limits, warning that drugmakers could pull out of states that set payment limits.

"The boards are acutely aware of this discussion point. The interest and the purpose of these boards is to increase access to the drugs, not decrease it," York said. "But there's kind of this game theory element of: How will manufacturers react?"

Reck discounted the notion that a payment limit would prompt a manufacturer to abandon a profitable market.

“Unfortunately, it’s kind of a scary message and it can be impactful on patients,” she said.

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