

Insulin and Other Prescription Drug Copay Caps: Helpful Solution or Playing Right Into the Hands of the Pharmaceutical Industry?

High Drug Prices Are a Top Concern for America's Families

High drug prices are a top concern for voters across the political spectrum and in all regions of the country. The support from America's voters is not misplaced, as high and rising drug prices leave nearly one in three adults not taking their medicines as prescribed due to the cost. Some patients even report cutting their pills in half or skipping doses in order to afford treatment and other necessities.¹

While prescription drug prices are high to begin with, drug companies actually make most of their revenue by increasing prices on drugs that are already on the market. At the beginning of 2020, drug manufacturers announced price increases that averaged triple the rate of inflation for more than 500 drugs.² Those price increases affect not just patients who take the drugs – they affect all consumers through the resulting premium increases. Prescription drug costs account for more than 23% of health insurance premiums.³

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Drug makers are routinely one of the most powerful interest groups in the United States, spending more than \$165 million in 2019 to lobby Congress and nearly \$20 million in the 2018 elections.⁴ Large drug companies secured more than \$1 trillion in profits from 2011-2019 and are projected to earn more than \$2 trillion in the coming decade.⁵

Public support for lower drug prices is overwhelming. More than 90% of voters consistently report wanting to see the government negotiate lower drug prices at the federal level,⁶ and similar levels of support exist for action at the state level.⁷ For voters, this is a pocketbook issue, and that fact leaves many state lawmakers looking for solutions that affect the out-of-pocket costs for prescription drugs.

Although controlling out-of-pocket costs is very helpful for some patients, this brief explores the weaknesses of implementing standalone out-of-pocket caps at the state level. It also lays out recommendations for addressing prescription drug affordability more broadly.



The Truth About Insulin

Insulin was developed with publicly funded research in 1922 at the University of Toronto. It was then licensed for commercial production for only \$1.⁸

Now, just three companies control the vast majority of the insulin market, and they regularly raise prices in lock step.⁹ Annual costs per patient for insulin nearly doubled from 2012 to 2016.¹⁰

In recent years, more and more Americans have lost their lives while rationing their insulin due to its cost.¹¹

Potential Pitfalls in the Copay Cap Approach for Consumers Who Need Relief

Copay caps are a pro-consumer reform. There is no doubt that for a subset of consumers, a copay cap means important relief from burdensome out-of-pocket costs. In recent years, many state lawmakers passed or introduced legislation to cap prescription drug copays, particularly for insulin and diabetes products.¹² The increased rates of hospitalization and mortality from complications with diabetes in the last decade, brought on by a twofold increase in insulin prices, has spurred a national focus on diabetes in the drug pricing conversation. Patient organizing efforts have also increased the attention and discourse paid to insulin and diabetes treatments.¹³

However, legislators aiming to help solve insulin access in their states inadvertently could be playing right into the hands of the pharmaceutical lobby if they don't also connect copay caps to meaningful

reforms to stop pricing abuses. Moreover, copay cap policies also can leave important segments of their constituents unprotected.

Quieting Consumer Outrage by Shifting Costs to Premiums, Leaving Businesses, Families, And Taxpayers to Pay More and More Over Time

Pharmaceutical costs, like other covered health care costs, are paid through a combination of annual health insurance premiums across an insured population as well as the individual out-of-pocket requirements for each insured person. The number one driver of public outrage around prescription drug costs has been the experience consumers have when they go to their pharmacy and are presented with a sudden and often unexplainable increase in their out-of-pocket costs for drugs. While copay caps are pro-consumer, by themselves, these policies do nothing to take on abusive increases in drug prices, and they prevent consumers from understanding price increases firsthand at the point of sale.

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Thus, by simply enacting a copay cap, legislators are blinding consumers to the increases in their drug prices and, as a result, inappropriately quieting their outrage. Drug companies then have the ability to continue to raise drug prices — or even accelerate increases — without the public's awareness. In fact, state advocates that we work with on drug pricing report that lobbyists for the pharmaceutical industry are arguing that lawmakers that have passed copay laws have no need to address drug pricing further.

In the end, shifting costs to health insurance plans by implementing a copay cap may result in everyone paying more for their health care, including insured individuals who don't even take drugs, because they are part of an insured group that pays premiums.

Copay Caps Will Help Only a Limited Number of People in your State

State-based copay caps will help limit copays for only a subset of individuals in the state. Nationally, nearly 50% of a state's residents are covered by employer-sponsored health care, while Medicare covers 14%, Medicaid covers 20%, 1% are covered by military health care, and 9% are uninsured. This breakdown is more or less representative throughout the states, with major differences in those states that have expanded Medicaid compared to those that have not.¹⁴ None of these individuals — people with

employer-sponsored insurance, Medicaid, Medicare, military health care, or the uninsured — benefit from state-based copay cap laws. This is because federal regulations pre-empt state law for employer-sponsored plans. People with Medicaid and military plans already have caps on co-insurance.

Copay Caps Do Not Help the Uninsured

With any copay cap, uninsured consumers pay the full price charged for medications. Stories have emerged from all over the United States about the impact of pharmaceutical cost increases on the uninsured. For example, there are stories of young people rationing insulin while uninsured between jobs after they turned 26 and aged off their parents' insurance.¹⁵ These tragic stories, tied with the increases in cases for diabetic ketoacidosis in emergency rooms, point to the very real health consequences that face uninsured Americans with chronic conditions.¹⁶

State Lawmakers Should Think More Boldly About Prescription Drug Affordability

There is no doubt that for a subset of consumers who are purchasing insurance through state-regulated plans on the health care exchange and who face high cost sharing for prescriptions, a copay cap means relief from burdensome out-of-pocket costs. However,

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Policymakers have a number of options to ensure a more comprehensive approach to rein in prescription drug prices. The following policies could be combined with copay cap efforts.

Establish Rate Setting to Ensure Prescription Drug Affordability

In 2019, Maine and Maryland both established prescription drug affordability boards to assess prescription drug costs and affordability at the state, plan, and individual level and review options to bring savings to residents.

These policies are strongest when they:

- » Establish clear price thresholds for review,
- » Set an upper payment limit to guide all transactions made within the state, and
- » Ensure that governing bodies are free of conflicts of interest.

For more information on this approach, see our brief, [Addressing the Prescription Drug Affordability Crisis: A Golden Opportunity for State Lawmakers](#).¹⁷

Fine Drugmakers For Price Gouging

After a prescription drug comes to market, prescription drug manufacturers often increase the price year after year. To limit annual price increases, states can enact legislation that fines drugmakers for price increases that exceed a set threshold. [A Tax on Drug Price Increases Can Offset Costs](#)¹⁸ from The Pew Charitable Trusts provides information about how this could work at the state level. In Illinois, proposed H.B. 28805 (2019) took this approach to curbing excess price increases.

Build a Package of Legislation to Help People Afford Insulin and Diabetes Supplies

Because the price of insulin is so egregiously high, and the case can be made both politically and morally for action to make sure insulin is accessible for all those who need it, lawmakers may be drawn to addressing this particular problem. In that case, lawmakers should not fall into the pharmaceutical companies' trap and simply address insulin copays. Such efforts should be tied to the policies described above that address pricing abuses.

In addition, we suggest the following policies to help prevent deaths and health risks associated with insulin access:

- » Passing emergency insulin refill legislation would allow patients to get an emergency supply of insulin without a prescription. This legislation makes it possible for patients to get the supplies

they need without having to wait to get in touch with a prescribing physician. A number of states passed this legislation following the death of Ohio resident Kevin Houdeshell in 2014, when he was unable to fill an insulin prescription over the New Year's Day holiday.¹⁹

- » Establishing a state-run insulin assistance program for low-income individuals to receive insulin with a nominal copay. To cover the costs of the assistance program, the proposal, as written in Minnesota House Bill 485, would require a small assessment on pharmaceutical manufacturers.²⁰
- » Requiring transparency from manufacturers and other segments of the pharmaceutical supply chain. Many states have passed legislation on prescription drug pricing transparency and reporting, and each of those laws provides more insight for state lawmakers about what to do next. Nevada is the first state to have done this specifically for diabetes drugs.²¹

Conclusion

The intention behind copay caps is indeed in the right place: to provide consumers with as much protection as possible from high and rising drug prices. However, as a standalone policy, these approaches have the potential to allow drug companies to accelerate their efforts to unfairly and abusively raise drug prices, thereby adding more costs to other parts of the system. A standalone policy on copay caps also leaves a significant proportion of state residents without relief from high drug prices. By combining copay caps with reforms that rein in drug costs, statehouses can provide immediate relief for patients and ensure longer-term solutions to address abusive drug prices.

Endnotes

- ¹ L. L. Gill, “How to Pay Less for Your Meds,” *Consumer Reports*, April 5, 2018, <https://www.consumerreports.org/drug-prices/how-to-pay-less-for-your-meds/>.
- ² Patients for Affordable Drugs, *By the Numbers: New Analysis Finds Over 500 Drug Price Hikes in First Week of January* (Patients for Affordable Drugs, January 8, 2020), <https://www.patientsforaffordabledrugs.org/2020/01/08/500-drug-price-hikes/>.
- ³ America’s Health Insurance Plans, *Where Does Your Health Care Dollar Go?* (America’s Health Insurance Plans, May 22, 2018), www.ahip.org/health-care-dollar/.
- ⁴ Open Secrets, *Pharmaceutical Manufacturing: Lobbying*, 2019, accessed on March 25, 2020, <https://www.opensecrets.org/industries/lobbying.php?ind=H4300>.
- ⁵ S. Dickson and J. Ballreich, *How Much Can Pharma Lose? A Comparison of Returns Between Pharmaceutical and Other Industries* (West Health Policy Center, November 2019), <https://www.westhealth.org/resource/how-much-can-pharma-lose/>.
- ⁶ A. Kudjak, “Poll: Americans Support Government Action to Curb Prescription Drug Prices,” *NPR*, March 1, 2019, <https://www.npr.org/sections/health-shots/2019/03/01/699086303/pollamericans-support-government-action-to- curb-prescription-drugprices>. See also Arnold Ventures, *Poll Reveals Near- Unanimous Call for Aggressive Congressional Action to Lower Prescription Drug Prices* (Arnold Ventures, May 22, 2019), <https://www.arnoldventures.org/stories/poll-shows-publics-frustration-with-congress-over-inaction-on-drug-prices/>.
- ⁷ See Altarum Healthcare Value Hub, *Colorado Residents Worried About High Drug Costs — Support a Range of Government Solutions* (Altarum Healthcare Value Hub, February 2019), <https://www.healthcarevaluehub.org/advocate-resources/publications/colorado-residents-worried-about-high-drug-costssupport-range-government-solutions>; Altarum Healthcare Value Hub, *Virginia Residents Worried About High Drug Costs — Support a Range of Government Solutions* (Altarum Healthcare Value Hub, October 2019), <https://www.healthcarevaluehub.org/advocate-resources/publications/virginia-residents-worried-about-high-drug-costs-support-range-government-solutions>; Altarum Healthcare Value Hub, *Utah Residents Worried About High Drug Costs — Support a Range of Government Solutions* (Altarum Healthcare Value Hub, February 2019), <https://www.healthcarevaluehub.org/advocate-resources/publications/utah-residents-worried-about-high-drug-costssupport-range-government-solutions>.
- ⁸ C. C. Quianzon and I. Cheikh, “History of Insulin,” *J Community Hosp Intern Med Perspect* 2 no. 2 (2012), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3714061/>.
- ⁹ S. J. Tribble, “Several Probes Target Insulin Drug Pricing,” *NBC News*, October 28, 2017, <https://www.nbcnews.com/health/health-news/several-probes-target-insulin-drug-pricing-n815141>.
- ¹⁰ Reuters, “U.S. Insulin Costs per Patient Nearly Doubled from 2012 to 2016, Study Finds: The Increasing Cost of Insulin Has Led Some Patients to Put Their Own Health at Risk,” *NBC News*, January 22, 2019, <https://www.nbcnews.com/health/diabetes/u-s-insulin-costs-patient-nearly-doubled-2012-2016-study-n961296>.
- ¹¹ J. Koepf, “Fighting in Micah’s Memory,” *T1International*, February 15, 2019, <https://www.t1international.com/blog/2019/02/15/fighting-micahs-memory/>.
- ¹² A. Elassar, “After Years of Skyrocketing Costs, Lawmakers Across the U.S. Push for Caps on Life-Saving Insulin Payments,” *CNN*, February 8, 2020, <https://www.cnn.com/2020/02/08/us/states-passing-bills-insulin-insurance-copay-trnd/index.html>.
- ¹³ See, for example, E. Rauhala “As Price of Insulin Soars Americans Caravan to Canada for Lifesaving Medicine,” *Washington Post*, July 31, 2019, https://www.washingtonpost.com/world/the_americas/as-price-of-insulin-soars-americans-caravan-to-canada-for-lifesaving-medicine/2019/06/14/0a272fb6-8217-11e9-9a67-a687ca99fb3d_story.html.
- ¹⁴ Kaiser Family Foundation, *Health Insurance Coverage of the Total Population*, 2018, accessed on March 3, 2020, <https://www.kff.org/other/state-indicator/total-population/?currentTimeframe=0&sortModel=%7B%22collid%22:%22Location%22,%22sort%22:%22asc%22%7D>.
- ¹⁵ See, for example, B. Sable-Smith, “Insulin’s High Costs Leads to Lethal Rationing,” *NPR*, September 1, 2018, <https://www.npr.org/sections/health-shots/2018/09/01/641615877/insulins-high-cost-leads-to-lethal-rationing>.
- ¹⁶ Centers for Disease Control and Prevention, “Trends in Diabetic Ketoacidosis Hospitalizations and In-Hospital Mortality – United States, 2000-2014,” *Morbidity and Mortality Weekly Report* 67 no. 12 (March 30, 2018), 62-365, <https://www.cdc.gov/mmwr/volumes/67/wr/mm6712a3.htm>.

¹⁷ J. Mendoza and F. Isasi, *Addressing the Prescription Drug Affordability Crisis: A Golden Opportunity for State Lawmakers* (Families USA, February 19, 2020), <https://familiesusa.org/resources/addressing-the-prescription-drug-affordability-crisis-a-golden-opportunity-for-state-lawmakers-2/>.

¹⁸ The Pew Charitable Trusts, *A Tax on Drug Price Increases Can Offset Costs* (Pew Charitable Trusts, July 2, 2018), <https://www.pewtrusts.org/en/research-and-analysis/fact-sheets/2018/07/a-tax-on-drug-price-increases-can-offset-costs>.

¹⁹ “Kevin’s Law Fact Sheet,” *T1International*, 2018, https://www.t1international.com/media/assets/file/Kevins_Law_Fact_Sheet.pdf.

²⁰ H.F. 485, 91st Legis. Minn. (2019-2020), https://www.revisor.mn.gov/bills/text.php?number=HF485&type=bill&version=1&session=1s91&session_year=2019&session_number=0.

²¹ L. Ramsey, “Nevada Just Passed One of the Strictest Drug Pricing Transparency Laws in the Country,” *Business Insider*, June 15, 2017, <https://www.businessinsider.com/nevada-passes-insulin-drug-pricing-transparency-bill-2017-6>.

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