

Congress Should Lower Insulin Costs by Addressing Pricing Abuses in Addition to Capping Co-Pays

Our outrageous insulin cost problem

Medical insulin was developed using publicly funded research in the 1920s,¹ and modern synthetic insulin was developed in the 1980s. Insulin is neither innovative nor expensive to manufacture, and insulin formulations have not dramatically changed. Yet insulin costs have increased rapidly in recent years because of the market power of the small number of manufacturers² that formed an effective cartel and increased prices on a long-established drug.³ Unlike all other advanced countries, the United States has never had the ability to negotiate drug prices federally and as a result, insulin prices have increased 50% or more in five years. There is no justification for these extreme price increases - they are purely the result of price gouging by manufacturers. The United States buys 15% of the world's insulin but accounts for half of the global revenue for insulin manufacturers, with most of these dollars coming from taxpayers and adding to our budget deficit.⁴

Egregious insulin pricing abuses are not only expensive, they are also dangerous for people who need insulin. Of the approximately 7.4 million people in the United States who rely on insulin to manage diabetes,⁵ almost 1 in 10 skip doses or otherwise skimp on insulin because of cost, and one study found that this figure was 1 in 4 for low-income people with diabetes.^{6,7} Individuals who require insulin have been forced to make unconscionable financial decisions between buying this lifesaving drug and purchasing other basic needs, like food. This means some are forced to turn to rationing their insulin due to high costs, sometimes at the risk of their own lives.⁸ The news is riddled with horrifying accounts of preventable deaths of young people who could not afford their insulin.⁹

In the U.S.



1 in 10

people skip or ration
insulin due to cost

About
7.4 million
people rely
on insulin



1 in 4

low-income people skip or
ration insulin due to cost

What Congress has done, and what it should do next

Congress took an important step toward making insulin more accessible when it passed the Inflation Reduction Act, which capped the out-of-pocket cost of insulin at \$35 per month for those who get health care through Medicare. The bill also created for the first time a pathway for the federal government to negotiate fair drug prices, though insulin does not qualify for negotiation under the bill's eligibility criteria. However, Congress has not yet acted on two commonsense goals:

1. **Reducing the price that Medicare pays for insulin.** The current insulin cap means Medicare is paying higher burden without manufacturer price reductions.¹⁰
2. **Capping the out-of-pocket cost of insulin at \$35 per month for people who do not have coverage through Medicare.**

Undoubtedly, a cap for insulin means important relief from burdensome out-of-pocket costs for many families, but such a cap does not address the large-scale issue: Taxpayers are still paying manufacturers too much for this drug.

Additionally, a cap does not help people who rely on insulin and do not have health insurance. Sixty eight percent of people without health insurance pay the full list price for insulin at the counter, compared with 9% of people with private insurance and 3% of Medicaid beneficiaries. Consequently, 38% of people without health coverage report being unable to afford prescription medicines, compared with 10% of people with private insurance.¹¹



How Congress Can
Put a Stop to Drug
Pricing Abuses

COPAY CAPS FOR ALL

The Inflation Reduction Act caps insulin copays at \$35/month but only for those who get health care from Medicare. Extend caps to everyone.

REDUCE PRICE FOR MEDICARE

Medicare pays an exorbitantly high price for insulin and should be given the power to specifically negotiate for lower insulin prices.

ENSURE FAIR DRUG PRICES

Address the list price of insulin so people who don't have Medicare, including those who have no insurance at all, can better afford insulin.

Passing caps on out-of-pocket costs for insulin without addressing manufacturers' arbitrarily high prices will not solve the whole problem. Insulin manufacturers should be held accountable for making reasonable and justifiable price increases, and American families should be able to afford the insulin they need.

Passing out of pocket caps without a return to fair prices obscures the real problem

Congress should act to improve access to insulin for Americans who do not access health care through Medicare. As public pressure mounts for Congress to take action, there is a risk that Congress will cave to monopolistic special interests and simply cap the out-of-pocket cost of insulin without negotiating fair drug prices with insulin manufacturers. If that were to happen, the anti-competitive insulin cartel could continue to gouge U.S. taxpayers by charging prices that are several times higher than what the rest of the world pays, and continue arbitrarily increasing drug prices. Taxpayers, employers, and working people would continue to bear the cost of the outrageous price increases for insulin. We all pay that cost in our private and Medicare insurance premiums now, and we are passing that cost on to the next generation as it adds to our budget deficit.

If Congress passes a cap on out-of-pocket costs for insulin without negotiating manufacturer prices for insulin, many individuals and families would be blind to future price increases. As a result, many Americans might not be aware enough to voice their outrage at the high and rising cost of lifesaving insulin. Instead, they would unknowingly pay for the cost of these pricing abuses through health insurance premiums and future tax burdens.

Conclusion

Addressing the rising costs of insulin is essential, and Congress has already taken important first steps toward helping families afford the lifesaving and life-sustaining drug. Now American families deserve Congress' full commitment to taking a comprehensive approach to fixing this problem. Passing caps on out-of-pocket costs for insulin without addressing manufacturers' arbitrarily high prices will not solve the whole problem. Insulin manufacturers should be held accountable for making reasonable and justifiable price increases, and American families should be able to afford the insulin they need.

Endnotes

- ¹ Celeste C. Quianzon and Issam Cheikh, “History of Insulin,” *Journal of Community Hospital Internal Medicine Perspectives* 2, no. 2 (2012), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3714061/>.
- ² *Insulin: Examining the Factors Driving the Rising Cost of a Century Old Drug* (Washington, DC: U.S. Senate Finance Committee), [https://www.finance.senate.gov/imo/media/doc/Grassley-Wyden%20Insulin%20Report%20\(FINAL%20\).pdf](https://www.finance.senate.gov/imo/media/doc/Grassley-Wyden%20Insulin%20Report%20(FINAL%20).pdf).
- ³ Maxim Jacobs, “How the Insulin Cartel Keeps Its Grip,” *The American Conservative*, May 12, 2021, <https://www.theamericanconservative.com/how-the-insulin-cartel-keeps-its-grip/>.
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- ⁵ Ismaeel Yunusa, “Fewer Diabetes Patients Are Picking Up Their Insulin Prescriptions – Another Way the Pandemic Has Delayed Health Care for Many,” *The Conversation*, November 12, 2021, <https://theconversation.com/fewer-diabetes-patients-are-picking-up-their-insulin-prescriptions-another-way-the-pandemic-has-delayed-health-care-for-many-171364>.
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- ⁸ Tiffany Stanley, “Life, Death and Insulin,” *The Washington Post*, January 7, 2019, https://www.washingtonpost.com/news/magazine/wp/2019/01/07/feature/insulin-is-a-lifesaving-drug-but-it-has-become-intolerably-expensive-and-the-consequences-can-be-tragic/?utm_term=.7d6e15666caa&itid=lk_inline_manual_18.
- ⁹ Aris Folley, “Minnesota Mom Says 26-Year-Old Son Died Because He Couldn’t Afford the Cost of Insulin,” *The Hill*, January 4, 2019, <https://thehill.com/blogs/blog-briefing-room/news/423874-minnesota-mom-says-26-year-old-son-died-because-he-couldnt/>; Doug Irving, “The Astronomical Price of Insulin Hurts American Families,” *RAND Review*, January 6, 2021, <https://www.rand.org/blog/rand-review/2021/01/the-astronomical-price-of-insulin-hurts-american-families.html>.
- ¹⁰ Zain Rizvi, “Prices for Leading Insulins Will Likely Not Be Negotiated Under New Drug Pricing Package,” *Public Citizen*, July 26, 2022, <https://www.citizen.org/article/prices-for-leading-insulins-will-likely-not-be-negotiated-under-new-drug-pricing-package/>.
- ¹¹ Sherry A. Glied and Benjamin Zhu, “Not So Sweet: Insulin Affordability Over Time,” *The Commonwealth Fund*, September 25, 2020, <https://www.commonwealthfund.org/publications/issue-briefs/2020/sep/not-so-sweet-insulin-affordability-over-time>.



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