

Washington, DC

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The failed promise of the US's Inflation Reduction Act for patients with diabetes

Laura Marston describes how recent legislation missed an opportunity to tackle exorbitant insulin prices in the United States

Laura Marston attorney and patient with type 1 diabetes

Five years ago, I wrote an article for *The BMJ*¹ describing the struggles I've experienced in trying to afford insulin as a type 1 diabetic in the United States. Since my diagnosis in 1996, my unchanged Humalog insulin has increased in list price from \$21 a vial (£17.80; €21.07) to \$275 or more a vial.²

Like most people with type 1 diabetes, I need three or more vials a month to survive. Even with health insurance, I've given up seemingly everything to afford this essential medicine: I've sold all of my belongings, including my car; moved away from my family; cashed out my retirement account; borrowed money from my retired parents; and even given up my dog, Nicky, because I could no longer afford to keep both of us alive and healthy.

With US headlines proclaiming earlier this year that "House passes bill to cap insulin prices" and "House passes insulin price cap as Senate looks for path forward," it may have seemed as though US Congress was finally poised to consider legislation that would protect the seven million Americans who, like me, rely on exogenous insulin to survive.⁵

As part of the Inflation Reduction Act of 2022, the Democrats originally proposed a \$35 a month insulin co-pay cap that applied only to certain Americans with private insurance and those on Medicare. Ultimately, the co-pay cap passed earlier this month, but only for Medicare beneficiaries and not for people with private insurance.

A human right

Neither of the US's two political parties proposed legislation to help people without insurance afford insulin, even though those who are uninsured pay the most and, as a result, are more likely to be among the one in four Americans who depend on insulin and must ration it to survive. By focusing solely on insulin co-pays for people who are already insured, the act did nothing to tackle the ever increasing price of insulin for those who are uninsured or how much companies can charge for insulin. Consequently, the price of insulin can still reach \$300 or more a vial.

If I can't afford insurance or if I lose my job and the insurance provided by my employer, there's still no safety net to cushion me from the soaring costs of this lifesaving medicine. I know first hand how easy it is, in the US, to be one of the roughly 31 million people currently without health insurance. I know what it's like to pay astronomical prices for the insulin I need to survive. No one should be in that position. If life is a human right, so is insulin.

US Congress must pass a law to limit the price insulin makers can charge for a vial of insulin. Capping the price per vial to no more than it sells for in other countries would benefit all Americans with diabetes, while still allowing insulin makers to maintain huge profit margins on insulin—which costs less than \$5 to produce. Price capped insulin would also save taxpayers billions in annual Medicare expenditures on insulin. Most importantly, price caps would end the status quo where around a million Americans spend over 40% of their post-subsistence income on insulin.

Americans overwhelmingly support a price cap on insulin. Congress must listen to patients with diabetes, and it must cap insulin prices for all. As I wrote in 2017, "For grassroots patients like me... this is quite literally a fight for our lives. We will not be silenced, we will continue to disrupt the status quo pharma has enjoyed for decades at the expense of our health and finances, and we will not stop until [insulin is] affordable and easily accessible to all those who need [it] for survival."

We will continue our fight to achieve affordable insulin for all who need it in the US.

Competing interests: I have read and understood BMJ policy on declaration of interests and declare the following interests: none.

Provenance and peer review: commissioned; not externally peer reviewed.

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