

T1INTERNATIONAL POLICY BRIEF: INSULIN RATIONING IN THE USA

SUMMARY

Injected insulin is essential for people with type 1 diabetes to survive. The rising costs of insulin and other diabetes supplies is attracting greater scrutiny, especially in the USA. It has been reported that one out of every two people globally in need of insulin cannot access or afford it.¹ In the USA, 35.7% of uninsured adults have not taken their medication as prescribed to reduce their prescription drug costs.² A worrying number of people are rationing insulin, suffering devastating personal and financial consequences. Many young people with type 1 diabetes have died from rationing.³

SCOPE OF USA INSULIN PRICE CRISIS

Insulin is as necessary to a person with diabetes as oxygen is to any human being. Without it, a person with type 1 diabetes will die within days or hours from diabetic ketoacidosis (DKA), which is a lethal buildup of acids in the bloodstream. A person with type 2 diabetes that needs insulin can suffer painful and expensive complications without it, and can also be at risk of death.

KEY FACTS

- Over 7 million Americans rely on injected insulin to stay alive and healthy.⁴
- Insulin was first used to treat a person with diabetes in 1922. The discoverers sold the patent for \$1 each so it could be accessible for all.⁵
- Today, Eli Lilly, Novo Nordisk and Sanofi – the ‘big three’ insulin producers – dominate more than 99% of the world insulin market by value.⁶
- Since the 1990s, the cost of insulin has increased over 1,200%.⁷
- List prices of insulin have been rising at the same rate at the same time for at least the past 10 years.⁸
- Between 2001 and 2015 the price of Humalog insulin increased 585%.⁹
- The cost of production for a vial of most analogue insulins is between \$3.69 and \$6.16.¹⁰
- Spending by patients with type 1 diabetes on insulin nearly doubled from 2012 to 2016, increasing from \$2,900 to \$5,700.¹¹
- List price matters because 8.8% of Americans are uninsured and 47.0% have high deductible plans.¹²
- Average total Medicare Part D spending on insulin products increased by 358% between 2007 and 2016, from \$862 to \$3,949.¹³

"We live in a country where healthcare is considered a privilege instead of a basic human right. People are resorting to extreme measures to make their medications last, and it is costing them their lives. It should be criminal for pharmaceutical companies to price gouge the way that they do. At 24 years old, Jada was supposed to have more time. Until our government takes the action necessary to ensure citizens don't have to make the decisions my sister did, I am going to share her story."

**- Jazmine Baldwin, sister of Jada Louis
who died after rationing her insulin**

COST & RATIONING SURVEY: KEY FINDINGS

T1International conducted an online survey of patients with type 1 diabetes. The survey covered out-of-pocket costs associated with type 1 diabetes, insulin rationing, rationing of blood glucose testing supplies, degree of financial coverage and sources of financial support. The survey was disseminated using social media, the T1International website, and shared via partners around the world. Study data were collected and managed using the REDCap online survey platform. Informed consent was utilized. The survey was completed by a total of 1,478 respondents from 90 countries, with 631 participants from the USA.

- In total 18% of all respondents reported having rationed insulin at least once in the previous year;
- Of USA respondents, 26% reported having rationed insulin in the previous year;
- Among high income countries excluding the USA, only 6% reported rationing in the previous year;
- Rationing of blood glucose testing supplies in the previous year was most common in low and middle income countries (56%), followed by the USA (37%); and
- Government assistance for healthcare costs was much more common in other high-income countries (31%) while the USA only had just over 5% of respondents benefiting from government assistance.

Respondents from the USA reported the highest percentage of insulin rationing of any high income country surveyed. Our findings for the number of people with type 1 diabetes in the United States who had rationed insulin in the past year (26%) aligns with a recent Yale study published in JAMA Internal Medicine.¹⁴ Their findings showed that one in four people with type 1 diabetes in New Haven County, Connecticut rationed insulin due to cost.

SURVEY CONCLUSIONS

T1International's survey is the largest international assessment of out-of-pocket costs, insulin rationing, and blood glucose testing rationing experienced by people with type 1 diabetes to date.

Our findings show:

- Striking differences between the USA and other high-income countries in terms of insulin rationing, blood glucose testing rationing, government assistance (or lack thereof) and overall costs;
- That the United States has by far the highest insulin rationing of any high income country; and
- That the United States also lacks support systems for people with type 1 diabetes who struggle to afford their insulin and other type 1 diabetes costs.

Our survey results provide more evidence to strengthen the efforts by those advocating in the United States for concrete measures to end insulin rationing and associated deaths.

"The only reason Jesy did not have his insulin was because he couldn't afford it. He wasn't lazy. He worked hard, even taking on a second job for some time. Unlike some of the other stories I have heard, Jesy had insurance but the insulin and other supplies were still more than he could afford. My family will continue to fight with others to make insulin more affordable and accessible for all so that no other parent will be forced to go through what we went through."

- Cindy Scherer Boyd, mother of Jesimya Scherer-Radcliff who died at age 21 after rationing insulin

ACTION NEEDED

The public, the media, and politicians are taking notice of the insulin price crisis. Meanwhile, patients have been advocating at the state and federal level, calling for transparency and lower insulin prices. Nevada passed the first insulin price transparency bill in 2017, and other states have succeeded in passing more general transparency legislation.

In response to several protests and continued criticisms, Eli Lilly announced that they would be selling an ‘authorized generic’ at half the current list price. Sanofi has also announced new assistance programs to try to fend off further outcry. These are positive results demonstrating that patient advocacy is working, but the prices are still unaffordable.

A bipartisan Congressional investigation of Eli Lilly, Sanofi, and Novo Nordisk has also been launched. Several Congressional hearings have taken place to explore the high cost of prescription drugs, but no meaningful federal legislation that truly reduces the list price of insulin has been implemented. Furthermore, we are concerned at the huge amount spent on lobbying by the big three insulin manufacturers to push down any legislation that holds them accountable, and thus the lack of culpability they face for continuing the practice of price-gouging patients.

What is needed now to improve the situation for people with type 1 diabetes in the USA is genuine partnership with patient activists to develop workable solutions that impact patients and hold the pharmaceutical industry accountable. The viewpoints of those most impacted, those risking their lives by being forced to ration their essential insulin, must be included in all spaces. List prices for insulin must be lowered – and soon – otherwise more young people will needlessly lose their lives.

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ABOUT T1INTERNATIONAL

T1International is a non-profit run by people with and impacted by type 1 diabetes *for* people with type 1 diabetes. We are passionate about ensuring patient voices are heard and putting an end to the insulin price crisis. We do not accept money from pharmaceutical companies or any other body that might influence our ability to speak out and fight for change.