

Insulin Access & Affordability



Diabetes in America

Diabetes impacts [more than 34 million people](#) in the US. This chronic disease is a result of how the body processes [glucose](#). When it goes untreated or is not treated properly it can lead to many other co-morbid diseases and illnesses.

Treatment depends on what type of diabetes you have. The most common form is type 2, where the body doesn't use [insulin](#) properly. Type 1 diabetes, which accounts for 5% - 10% of all cases, is the result of the body not producing any insulin. In the early 1920's, the first pure form of insulin was manufactured as a treatment for patients with diabetes. This scientific breakthrough transformed diabetes from a fatal condition to a manageable disease. Today, between 10% - 20% of people with type 2 diabetes need insulin to control their blood sugar. However, all people with type 1 diabetes require insulin every day to survive – it is a matter of life or death.

Clinical Impact on People with Diabetes

[When insulin therapy is disrupted](#), blood sugar builds up in the bloodstream increasing the risk for many acute and long-term health issues, including [diabetic ketoacidosis](#), which can lead to diabetic coma or even death. Over time, unmanaged diabetes can cause nerve damage, kidney disease, high blood pressure, stroke, skin, and eye complications.

Those who need insulin every day and are confronted with barriers to access (such as lack of affordability) may develop what is referred to as [“insulin insecurity”](#) – the disruption or the threat of disruption in getting access. This can greatly impact the health and well-being for those with type 1 diabetes, causing significant anxiety and distress. In some cases, it means resorting to non-traditional, risky and even desperate measures to access insulin. Research has found that the practice of [insulin rationing](#) (taking smaller doses or skipping a dose altogether) is more common than the health care system wants to admit.

The Problem

Cost. Access. These are the biggest barriers for those in need of insulin. Out-of-pocket costs and outcomes for people with diabetes who rely on insulin vary depending on the type of health insurance they have as well as the type of insulin prescribed. In some cases, a physician might prescribe insulin that is most cost-effective for the patient but not necessarily the best choice for their medical needs or what is available on their formulary. It is well known that patients are more likely to be compliant on a prescription regimen if it is affordable.

Millions of people with diabetes who need this life-saving medication face affordability barriers in the form of rising insulin prices and out-of-pocket costs. For those with insurance, especially in high deductible health plans (HDHP), out-of-pocket costs can come in the form of upfront deductibles, copays, and/or coinsurance. For the uninsured, footing the bill for the entire cost of the drug is often required and out of reach.

Timeline of Insulin Innovations

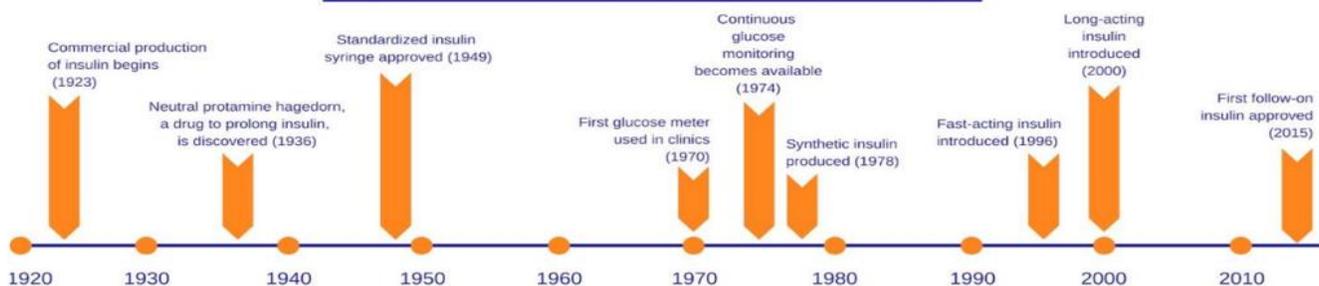


Figure 1: From Congressional Diabetes Caucus Insulin Inquiry 2018

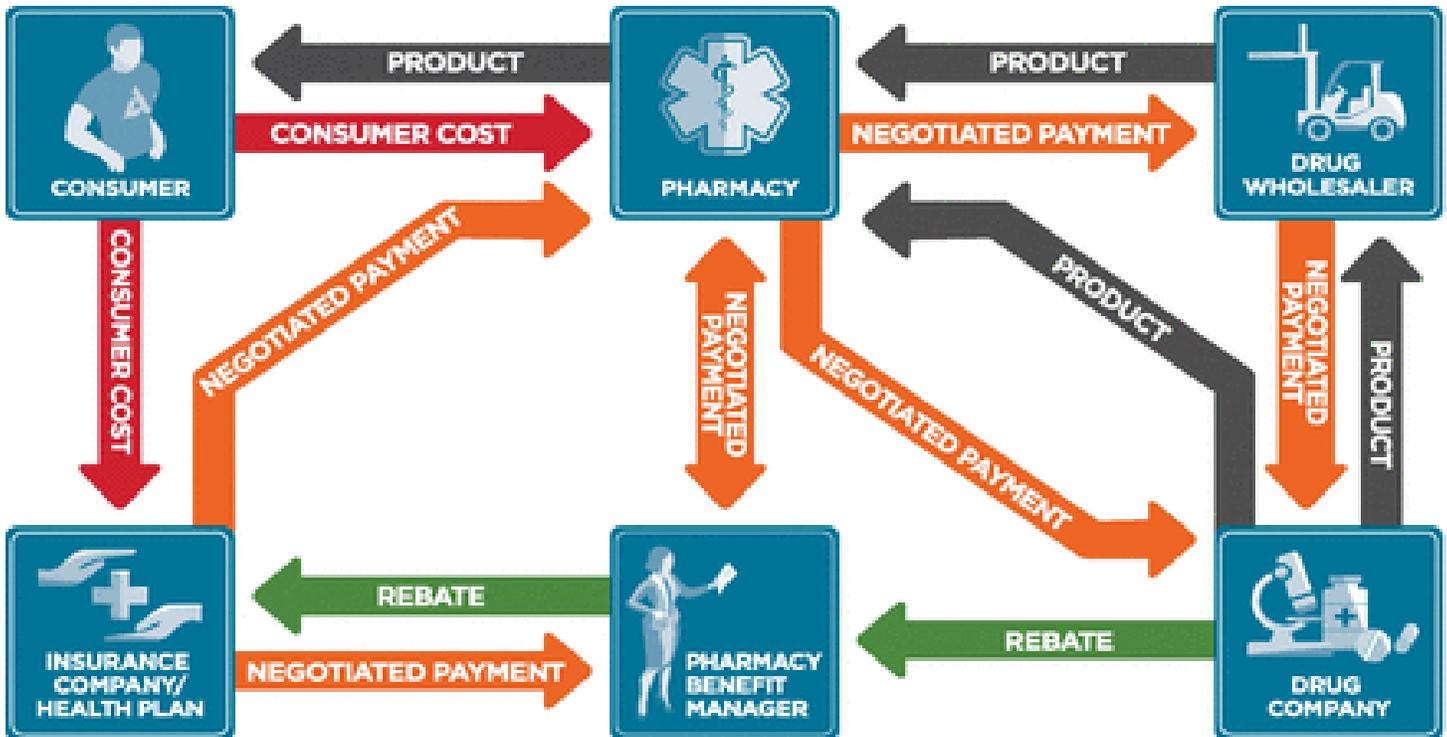


Figure 2: From Diabetes Care 2018 Jun; 41(6): 1299-1311. <https://care.diabetesjournals.org/content/41/6/1299>

Insulin Pricing: The Issues

The average list price of insulin has skyrocketed in recent years, nearly tripling between 2002 and 2013 and doubling between [2012 and 2016](#), making this essential medicine unaffordable for many.

The three multinational drug companies that make insulin for people with diabetes in the US say the price increases are justified – their profits have not increased with inflation, and the cost of research and negotiation with health insurers and pharmacists are high. However, insulin pricing is complex and there is little transparency throughout the supply chain as to the flow of dollars.

As noted in Figure 2, numerous stakeholders are involved, including drug manufacturers and wholesalers, health plans, PBMs, pharmacies and employers. **Negotiations and the many transactions between these stakeholders involving prices, fees and rebates ultimately determines the price paid by the person with diabetes at the point of sale.** These factors continue to drive up cost all along the payment system.

Insulin Pricing and the American Diabetes Association (ADA):

In 2017, the American Diabetes Association Board of Directors brought together a [working group](#) to better understand the full scope of the insulin affordability problem and find ways to provide relief for those who lack affordable access. The group identified the following significant issues contributing to this problem:

- Current pricing and drug rebate systems that encourages high list prices
- Lack of transparency throughout the insulin supply chain; it is unclear exactly how the money flows and how much each stakeholder profits
- PBMs which have substantial market power contribute to increased prices
- Impact of people with diabetes who are financially harmed by high list prices and out-of-pocket costs
- Patient's medical care can be adversely affected by formulary decisions
- Burdensome regulatory framework for development and approval of biosimilar insulins for manufacturers
- Prescribing patterns favoring newer, more expensive insulins

[Click here to review](#) the conclusions and recommendations from the working group.

Consumer Actions

As a consumer, there are some key factors for you to consider if you face challenges with insulin access or cost. Some of the actions listed below apply to all consumers while others (as noted) apply to those of you who have coverage through an employer plan.

- Be aware of your plan coverage
 - Understand where your insulin product falls within the plan's formulary
 - Ask your plan about any prior authorizations or step therapy programs that may exist prior to filling or refilling your prescription
 - Understand if any copay cards are available ([a good source here](#))
- Talk to your physician about insulin options
 - Bring your plan information with you to the physician to help in the discussion
 - Be open to exploring other insulin products
- Talk to your employer plan representatives about any insulin access challenges you are having
- At open enrollment each year with your employer, consider options available that may provide better access for your insulin product
- Be aware of changes that are happening at the Federal level as well as in your State.

State Legislative Update

In total, lawmakers in 36 states are trying to tackle the issue of unaffordable insulin prices. [The American Diabetes Association](#) is urging governors in every state to set up a zero-dollar copay for insulin during the pandemic and advance legislation that would cap copays for insulin once the pandemic is over. To date, 10 states have enacted insulin pricing laws since 2019 (CO, IL, ME, NH, NM, NY, UT, VA, WA, WV).

Most of the proposals currently under consideration will likely result in cost shifting versus cost reduction. This strategy means the drug makers do not have to take responsibility for lowering the cost.

[State and federal policymakers and private entities](#) continue to work on a variety of policy changes to address the rising cost of insulin. Some of these include:

- Insurance coverage of insulin as preventive medicine
- Out-of-pocket caps
- Rebate pass-through at point of sale
- Price transparency
- Bulk purchasing
- Free emergency supplies
- State assistance programs

More Info

- [Insulin Access and Affordability Working Group: Conclusions and Recommendations](#) (*Diabetes Care, June 2018*)
- [Insulin: A lifesaving drug too often out of reach](#) (*Congressional Diabetes Caucus, April 2019*)
- [Understanding the Insulin Market](#) (*American Action Forum, March 2020*)
- [Federal and State Actions to Address Insulin Costs](#) (*American Action Forum, April 2020*)
- [States are trying to cap the price of insulin. Pharmaceutical companies are pushing back.](#) (*NBC News, August 15, 2020*)
- [Insulin Cost and Pricing Trends](#) (*American Action Forum, April 2, 2020*)
- [The High Cost of Insulin in the United States: An Urgent Care to Action.](#) (*Mayo Clinic Proceedings, January 1, 2020*)
- [Insulin in America: A Right of a Privilege?](#) (*DiabetesSpectrum, August 29, 2016*)
- [8 Reasons Why Insulin is so Outrageously Expensive](#) (*T1International, January 20, 2019*)
- [Federal and State Actions to Address Insulin Costs](#) (*American Action Forum, April 29, 2020*)