



Testimony Submitted to the Record
Insulin Access and Affordability: The Rising Cost of Treatment
United States Senate Special Committee on Aging
By the Endocrine Society

On behalf of our more than 18,000 physician and scientist members, the Endocrine Society appreciates the opportunity to provide testimony on the issue of insulin affordability and its impact on the millions of Americans who rely on this therapy to survive. Our members treat people with diabetes and work to advance research in the field. As such, we see the impact of rising insulin costs on our patients: Our members have shared that they regularly spend a lot of time during discussing what medications patients can afford instead of focusing on their patients' health. Many doctors are uncomfortable discussing costs with patients; many patients are embarrassed to admit they cannot afford medication, and some do not acknowledge they are not taking their full dosages in order to extend the length of their prescriptions. Our Society believes something must be done to help our patients and we thank the Senate Special Committee on Aging for its thoughtfulness in identifying opportunities to address this growing problem.

Of the more than 30 million Americans with diabetes, approximately 7 million use insulin to manage their disease. Diabetes is most expensive chronic disease in America, costing more than \$327 billion annually, including \$15 billion for insulin. Medical costs for patients with diabetes are twice as high as for patients without the disease. In fact, one in three Medicare dollars is spent treating diabetes and the—often unnecessary—complications and hospitalizations that can result from not taking insulin and other medications as prescribed.

Over the past 15 years, the cost of insulin has nearly tripled further exacerbating already high costs for patients, and the healthcare system more broadly. Given the influx of high deductible



insurance plans that offer lower premiums but force patients to pay full cost for medications until meeting their deductible, rising insulin cost has had a direct impact on out-of-pocket expenses for many Americans. Those who are uninsured or in the Medicare Part D donut hole face similar challenges. The lack of affordable insulin has resulted in patients skipping doses, rationing their medication, taking on more debt, or having to make other difficult tradeoffs to afford their insulin.

These challenges are particularly problematic for the one in four seniors who have diabetes. These individuals are more likely to be taking insulin than other demographics and may also be struggling to afford their medications due to fixed incomes and other costs incurred from comorbidities. Unfortunately, these decisions are not a choice; access to affordable insulin can be a matter of life and death.

Identifying ways to reduce out-of-pocket costs for patients on insulin is critical given the significant scope of the problem and its impact on millions of Americans. We are encouraged that entities in the drug supply chain are beginning to take steps to address this issue. For example, Novo Nordisk is pledging to limit annual percentage price increases to single digits and is partnering with CVS Caremark to offer Novolin R, Novolin N, and Novolin 70/30 for \$25 per 10ml vial. Eli Lilly is offering insulin at a steep discount for patients in high deductible plans and exploring benefit design changes to mitigate out-of-pocket costs. Many companies offer drug savings cards and patient assistance programs (PAPs). And United Healthcare is starting to pass rebates onto patients at the point of sale.

However, we believe there are additional opportunities to build on this progress including broadening the eligibility criteria for PAPs, allowing insulin offered at discounted rates to count toward deductibles, and understanding whether drug savings cards may be having the unintended consequence of driving patients toward higher cost medications. We believe that increasing transparency, improving access to patient assistance programs, integrating cost information into electronic health records, and reducing cost-sharing would help mitigate out-



of-pocket costs. While we recognize that tackling this problem is challenging due to its complexity, we believe there are several steps the Committee can take to begin improving insulin access and affordability.

Increasing Transparency

We believe the first step toward understanding what is driving the cost of insulin is increasing transparency across the drug supply chain. Unfortunately, understanding the complexity of the supply chain, who is profiting, and to what extent, is an extraordinarily difficult but necessary measure for meaningful changes to take place. The insulin supply chain is comprised of manufacturers, pharmacy benefit managers (PBMs), health plans, drug wholesalers, and pharmacies that are mutually dependent on negotiations with each other to maximize profitability. While the list price of insulin (the price manufacturers set and that uninsured patients may have to pay at the pharmacy) has risen precipitously, the net price (the price manufacturers receive for insulin from PBMs and other large customers) has grown at a steady, albeit much slower rate based on data we have received from the manufacturers.

As a result, a widening gap has begun to emerge between the net price and list price with little understanding of who is benefiting from the disparity as this does not lead to lower costs for patients. This is, at least in part, driven by increasing discounts and rebates that are used as an incentive to have a certain brand of insulin included in the lowest cost tier of a particular formulary. Typically, only one brand of insulin is included in this tier, leading to competitive environment in which manufacturers try to outbid the other companies without lowballing the price too much.

While price competition is desirable, these negotiations are entirely confidential, making it difficult for anyone to know how much each entity in the supply chain is profiting and what portion of the discounts or rebates are actually being passed along to patients. We believe that increasing transparency across the entire supply chain could help determine potential solutions, as each entity plays a different role in determining the cost of insulin. We urge the Committee



to engage with all stakeholder groups across the supply chain to discuss the cause of rising insulin costs and what can be done to remedy the problem.

Improving Access to Patient Assistance Programs

Another option for reducing out-of-pocket costs for patients most in need is to make Patient Assistance Programs (PAPs) more accessible. PAPs are offered by all drug manufacturers to help patients afford their medication. While each of the insulin manufacturers has a PAP, the eligibility requirements are largely restrictive and the application forms are often difficult to complete. Patients who have some level of insurance coverage typically do not qualify, nor do patients who are on Medicare or Medicaid. Our endocrinologist members have described that the application process requires significant staff time, considerable documentation (sometimes including personal financial information), and must be completed annually. They have also shared how difficult it is for their patients to obtain information about PAPs and their application.

The Society believes that expanding the eligibility requirements (loosening income restrictions, expanding PAPs to include Medicare and Medicaid, etc.) for accessing these programs would be helpful as well as making the application process less onerous. We have discussed with the manufacturers the feasibility of a common application, similar to the common college application process, that could be used for each program and saved for future use. While expanding access to PAPs does not address the underlying issue of rising insulin costs, it may be a short-term solution for certain patients while other options are explored.

Reducing Patient Cost-Sharing

We also encourage Congress to explore policies that would reduce patient cost-sharing for insulin and ensure that patients receive rebates at point of sale. This includes evaluating the feasibility of exempting insulin from coinsurance in high-deductible plans and whether insulin could be added to preventive drug lists without increasing premiums. Uninsured patients are disproportionately exposed directly to the high cost of insulin. Those who are insured are also



affected while in the deductible phase or when their brand of insulin has a nonpreferred formulary status that leads to higher cost-sharing. One policy option to address this is to cover insulin in the same manner as other preventive drugs regardless of the patient's benefit design. We hope Congress will consider this and other policies if they can reduce cost sharing without increasing premiums, which will only drive more people into high deductible plans and further exacerbate this problem.

Improving Treatment Decisions

Improving treatment decisions at point of care could also be helpful in reducing the financial and administrative burden on patients and physicians. While such improvements do not directly address the high cost of insulin, they would allow for more informed discussions about treatment options and may reduce some degree of financial burden on patients. Patients who may not be able to afford their insulin may be able to use a cheaper form of the drug (e.g. human insulin) or another treatment approach. However, it is not always possible for physicians to know what particular insulin is covered on a patient's formulary and what the out-of-pocket costs will actually be when the patient picks up the prescription. Integrating cost and formulary information into electronic health records would enable physicians and patients to have a conversation about affordable treatment alternatives. Providing such information would allow the patient and physician to pick the most appropriate and affordable therapy, increase compliance with the therapy, and reduce unnecessary stress on patients and healthcare providers.

In addition, over the last 20 years, physicians have received training on many of the newer, more expensive insulins, but lack the knowledge of how to use human insulin, which is much less expensive. While human insulin may lack some of the advantages of the newer insulins (and would not be appropriate for every patient), it could be lifesaving for patients who are rationing or going into debt to cover the cost of their medications. Congress should explore options for integrating cost and formulary information into EHRs, as well as opportunities to



provide physician education on lower cost solutions for patients who cannot afford their insulin.

The Endocrine Society thanks the Committee for its interest in addressing insulin affordability. It is our hope that with policy changes, patients will have greater access to this lifesaving therapy without its current financial burden. Should you have any questions, please contact Robert Lash, MD, Chief Professional and Clinical Affairs Officer at rlash@endocrine.org.

Thank you.