To the Honorable Members of the House Health Committee,

Thank you for the opportunity to provide this written testimony for today’s hearing on prescription drug prices. My organization, the Institute for Clinical and Economic Review, or ICER, is a nonpartisan, nonprofit research organization that does not lobby for any particular piece of legislation, but instead strives to ensure that consequential decisions around drug pricing, patient access, and legislation are informed by an independent analysis of the evidence. Today, I am happy to provide you with our perspective on the problem, how ICER is addressing the problem, and a number of solutions states can take to tackle this growing issue.

How does drug pricing work now?

Right now, a drug’s price is picked by the manufacturer of the prescription drug. Drug makers have offered a number of explanations for how they pick a price – value to patients, value to society, what the market will bear, size of the potential market, the prices of other drugs for the same condition, and even a “moral requirement” to charge as much as possible. But what I do not need to tell any member of this committee, because I know you are hearing it from your constituents, is that patients are hurting because there is no connection between the price and how much clinical benefit they will receive from the drug. In fact, in November, a Kaiser Family Foundation poll found that 79% of respondents thought “the cost of prescription drugs was unreasonable.”

Drug makers also have no regulatory or statutory constraint on raising prices. Some companies raise prices multiple times a year, often at rates well above inflation, seemingly because they can. In our first annual analysis of Unsupported Price Increases, ICER found that price increases for just seven drugs in 2017 and 2018 cost Americans $4.8 billion.

It is also important to note the role that rebates play in drug pricing for a number of drug classes, especially when there are many drugs available to treat the same condition. In those cases, payers and pharmacy benefit managers extract large discounts in the form of rebates from drug makers in exchange for a preferred status on the payer’s formulary. On the face of it, this would seem like a benefit to patients – we are getting drugs at lower prices. Unfortunately, some patients are still required to pay the full price for the drug (until they meet their deductible) or a co-insurance for the drug based on list price, not the post-rebate price. I’m happy to report that more and more payers are offering point of sale rebates, so patients pay their co-insurance on net price, but this continues to be an important part of the drug pricing landscape that impacts patients directly. And we as society have little transparency
into how the rebate savings are shared with various members of the drug purchasing chain – employers, health plans, and patients.

You may have heard the two sides of this issue, pharma and the pharmacy benefit managers, pointing fingers at each other. And there are behaviors on both sides that are ripe for legislative intervention. But at the end of the day, patients want to be able to afford the drugs they need; employers want to be able to provide health insurance to their employees; and drug makers want to make a fair profit to invest in the next round of amazing innovation. At ICER, we believe this is all possible – when you have fair prices, patients deserve fair access, and drug makers have incentives for future innovation.

How does ICER determine a fair price?

Simply, ICER uses the evidence on clinical benefit for patients to calculate a fair price for drugs. A drug value assessment report from ICER is a systematic review of a drug’s comparative clinical effectiveness versus other drug treatment options, combined with an analysis of the drug’s long-term cost-effectiveness versus those other options. We prepare our reports using transparent methods through a public, eight-month process, with patients and their families at the center of that process, to provide a fair benchmark with which to evaluate drug prices set by manufacturers. Importantly, our work aims to signal what a fair price is for a new drug – not to signal whether a drug should be available to patients at all.

So, what is cost-effectiveness? Cost-effectiveness analysis measures all of the health gains, and side effects, offered by two or more different treatments, compared to all of the new costs, cost savings, offered by the therapies. Simply point, cost-effectiveness measures the improvements in length of life and quality of life, often through a measure called the quality-adjusted life year, and then scales the price to the benefits demonstrated by the drug using a consistent and well-established approach linked to the overall wealth of our society. When ICER conducts cost-effectiveness, we are able to judge the fairness of an estimated net price which can help signal to policymakers therapies in need of more attention.

It is possible to have a health system where the prices of drugs are aligned with value, and we’re seeing promising examples of just that. One of ICER’s reports focused on a new drug called dupilumab for patients with severe eczema. The manufacturers of that drug, Regeneron and Sanofi, worked with us during our review because they wanted to price their drug at the ICER price – to ensure that patients would get access to the new, innovative medicine. And they did. Their launch price, after discounts, was at the highest value end of ICER’s range, and payers responded to this responsible pricing behavior by allowing patients broad access to the drug. This grand bargain is a critical component of fixing the drug pricing problem.

Absent responsible pricing behavior from manufacturers, there are other examples of widespread use of these price benchmarks to ensure fair pricing for patients. Private insurers and pharmacy benefit managers have started using our price benchmarks in their coverage processes as a guide to fair pricing and fair access. The US Department of Veterans Affairs is making greater use of our work in price negotiations with drug makers, leading to better access for veterans.

Now, using evidence and data to determine a fair price is not without controversy. Many actors in the system would like to see the status quo remain – unfettered pricing power by drug makers. To protect
this monopoly, many in the pharmaceutical lobby are using fear and misinformation to scare patients into thinking cost-effectiveness is about denying access, and even worse, about discriminating against older Americans and those with disabilities. This is categorically false. Measuring the benefit patients receive using cost-effectiveness is never used to say that patients that start out healthier should get medicine before patients that are older, sicker, or have disabilities. That would be unethical. As mentioned above, the main measure of clinical effectiveness used in cost-effectiveness, called the quality-adjusted life year, or QALY, helps society know the fair prices for all the patients that took a drug—regardless of age, other conditions, or any disabilities those patients have. It would be unethical to try and decide a fair price for the drugs for just people without disabilities, or just for young people. ICER never uses cost-effectiveness to identify subpopulations for which a treatment would be less cost-effective due to severity of illness, age, or pre-existing disability. Our work does not discriminate against anyone. We are willing to stand by that statement by working with states, federal policymakers, and others to enact safeguard language that would prevent our work from ever being used to do so. The language states: When using cost-effectiveness analyses, policymakers cannot use information that uses the cost-per-quality adjusted life year or similar measure to identify subpopulations for which a treatment would be less cost-effective due to severity of illness, age, or pre-existing disability.

What can states do about this?

There are a number of ways that states can use independent drug price benchmarks to improve the value of prescription drug spending. ICER’s reports are increasingly being used by state Medicaid programs. In 2017, the State of New York passed a law allowing Medicaid to demand supplemental rebates from pharmaceutical companies for expensive drugs. In the first two years, New York’s Medicaid program negotiated with drug makers for rebates on dozens of drugs, saving the state $85 million.

In the first year, when a lone manufacturer, Vertex, refused to offer a discount to New York taxpayers for its drug Orkambi, state Medicaid officials launched a transparent process for determining a fair price. The Drug Utilization Review Board of New York used ICER data about use and effectiveness to determine a fair price. The board called for a supplemental rebate equal to a 75% discount off the list price. Although negotiations between the Medicaid program and Vertex continue, the principle is established: Independent drug value assessment can guide an explicit pricing mechanism for drugs, especially those lacking competition.

In addition to its use by Medicaid departments, many employers are considering moving to a value-based formulary where ICER’s work can inform a pay up to approach. The general principle is that ICER’s value-based prices could set the ceiling reimbursement a payer would agree to for drugs, while giving access to all drugs through the formulary. This approach ensures that all pharmaceutical spending is based on value, and not based on volume or rebates, and ensures broad access for patients.

And finally, independent drug value reports provide the fair benchmark by which to gauge the reasonableness of prices that drug manufacturers set and often increase unilaterally, with limited or no justification. Specifically, our annual Unsupported Price Increase report can help state policymakers know if a price increase is justified by new evidence of clinical benefit for patients. We have heard from many states that are experimenting with price transparency that having an independent assessment of a fair price, or a price increase, helps identify drugs needing more attention by the state. As policymakers experiment with transparency initiatives, bulk purchasing programs, and prescription drug affordability
boards, independent drug value reports can help determine how effective those initiatives have been in bringing drug prices more in line with the benefit they deliver to patients.

States must find their own ways to address the effects of increasing drug costs for patients, private insurance markets, and state budgets. While the federal government may remain in deadlock over this for years to come, states have the flexibility to align drug prices fairly with the benefits they provide. By continuing to produce independent reports that put evidence at the center of the equation, we hope ICER can support multiple and even coordinated efforts to find solutions.

At the end of the day, we must remember that patients and families are the ones losing when we allow prices out of line with value. Patients like Ray. Ray recently saw a drug approved for his rare disease – available for $450,000 year. Even with insurance, he was facing an unmanageable expense. And Ray knew that his small employer would face difficult tradeoffs around wages, expansion, and premium increase if he were to take the drug. So, he was deciding whether to take the drug or enter palliative care, to preserve some financial resources for his family after he was gone. This is not a decision any of us would every want to have to make – and yet faces families in this country every day. We can do better. We can have amazing innovation that improves the lives of patients like Ray, without bankrupting families, employers, and states.