PATIENT ACCESS & AFFORDABILITY PROJECT

Empowering Patient Perspective.

A program of Patients Rising

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Health Insurance Coverage in America: Current and Future Role of Federal Programs
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Patients Rising is a national nonprofit organization dedicated to advocating for the rights of patients with chronic and life-threatening illnesses. We work at the community, state, and federal levels to activate patients in support of reforms and legislation aimed at advancing patient access to and affordability of healthcare.

The healthcare system in the United States has become complex, expensive, and impersonal. To many Americans, it seems that any healthcare policy debate has become nothing but a food fight between politicians, providers, insurance companies, pharmacy benefit managers, and the biopharmaceutical industry. What should be driving motivation of this debate -- **the patient** -- is being drowned out by special interests on all sides of the issue.

The American healthcare system remains the world's leading market-based system that rewards scientific advancement and medical innovation. But currently, there are too many barriers and entrenched interests working against meaningful change in how healthcare is provided.

Patients Rising, though the ***Patient Access and Affordability Project*** (PAAP), is working to empower patients, encourage advances in medicine, and disrupt the payment landscape to accommodate innovation not only in medicines that save lives, but also finding innovative ways to pay for them.

During the October 20, 2021, Senate Finance Hearing, *Health Insurance Coverage in America: Current and Future Role of Federal Programs*, the areas where each party agrees to disagree are stark, but the places where change for patients is possible exists. It is our aim to work with Congress to advance patient-centered compromises.

According to the CDC, six in ten Americans live with a chronic disease, and four in ten Americans live with two or more chronic diseases. At the same time, between 25-30 million Americans are living with a rare disease, more than 90% of those diseases have no treatment.

These are the Americans that Congress should prioritize when discussing current and future health insurance coverage issues and reforms.

When pre-existing conditions were no longer a barrier to accessing health insurance, this was a monumental moment for many Americans who had been unable to obtain any insurance because of these conditions. But now, those same patients are fighting for reasonable and fair access. They stand there holding a card, that in many instances denies the rightful access to the treatments and services they need. The deductible is too high, the out-of-pocket costs are skyrocketing, and the access to treatment is often limited.

When a patient is left with a relatively useless insurance card, the pre-existing condition coverage becomes nothing more than a talking point. The system has failed, denying those most vulnerable patients meaningful healthcare.

It is true, 90% of Americans agree with negotiating with Medicare. Those same Americans also want ready access to treatments when they need them. There is no model where price controls would result in maintaining world leading innovation and reliable access. For this reason, we hope this Committee will fully support the following health care reforms:

1.) **Capping Out of Pocket Costs in Medicare Part D**: *Cap Medicare Part D below $3,100.* A $2,000 cap in Medicare Part D would be life changing for the patients who find themselves in the catastrophic coverage phase. It is a small percentage of patients, but those who require this type of coverage often face extreme hardship. We have seen caps anywhere between $2,000-$3,100, but all-in-all this is a bipartisan solution that will help the patients who need it the most. This overall cap coupled with a monthly out of pocket cap referred to as smoothing, would go a long way in providing seniors with fixed incomes and high drug costs some much needed relief.

2.) **Insulin**: *All brands of insulin should be available to all patients at a fixed low cost.* Insulin is a life-saving medication to millions of Americans, and no one should be held hostage by the extreme supply chain manipulation of the list price. The pharmaceutical company net price has been decreasing in recent years, despite list prices increases. However, what pharmacy benefit managers are making in kickbacks and fees often pay for the insulin itself several times over. This is an example of a supply chain that is failing patients because of the perverse incentives that exist within it. In this instance -- and possibly EpiPen's as well – the pharmaceutical industry needs to sell a product and the patient needs to buy it from the pharmacy counter. Any entity in the middle purporting to save money for the system or patients has failed abysmally at their job.

3.) **Benefit Design and Healthcare Finance**: *Price negotiations will leave behind the sickest of patients. Therefore, alternative benefit design policies should prioritize doctor-patient relationships.* When it comes to healthcare finance, there is a lot of discussion about price controls and fines to curb pharmaceutical pricing and lower patients out of pocket costs. There is no guarantee that this negotiation will lower out of pocket costs at the pharmacy counter for anyone. Most patients will not even notice. Negotiation is a false promise to the sickest among us that polls well with many Americans who are **not** sick or unhappy with their healthcare nor drug worried about their drug costs.

Members of the Senate Finance Committee should be leading the way on benefit design policy. Health insurance is a card for coverage. Benefit design is a road to providing actual ***care*** for the

patient. In many instances the coverage, (whether it is government provided, employer provided, an off the shelf insurance plan, or something in between) provides insufficient care for those who need it the most. As a nation, we should be addressing these insufficiencies.

Ultimately there are three primary payers: the government, employers, and patients. We recognize and acknowledge when a patient lacks access to coverage that all the burden falls on them. It is for this reason; we must simultaneously address the inequities in coverage. Everyone else in the supply chain is providing a product or service or serving as a middleman for oversight of benefits. Benefit design has become more cumbersome for doctors and patients, leaving many doctors prescribing not what is best for their patients, but what is covered. And sometimes what is best, is not what is covered, and in many instances, it is not even what is the most expensive – but you would never know that from the formulary design.

Benefit decisions are driven by perverse financial incentives in the supply chain, with little regard for the patients themselves. Again, the doctor-patient relationship should be leading the change in benefit design, not the patient-government or the patient-employer relationship.

While medical innovation is unfolding rapidly, our current healthcare finance system is not designed to accommodate it. We must change our healthcare finance system to become more efficient, nimble, and responsive to that innovation.

As America spends twice as much as other industrialized countries on healthcare as a share of our economy. This is due, at least in part, to the perverse incentives created by a dated hodgepodge of federal policy that eliminates efficiency and creates excessive spending throughout the system.

Patients Rising urges the Committee to consider the following solutions:

1.) **Establish a healthcare finance and payment model that rewards improvements in long-term care of patients**.
   - Incentivize innovative insurance and finance models that are designed to reward and encourage major breakthroughs in therapies and cures, while keeping the costs to patients low.
   - Make doctors the primary force behind coverage recommendations, and not flawed frameworks with little regard for the doctor or the patient.
   - Ensure that doctors, nurses, and other healthcare providers can make decisions independently to provide optimal patient care.

2.) **Promote the market-based healthcare model that encourages patient choice and maintains American leadership in life sciences and medical innovation.**

- Audit policies and practices that can create perverse incentives and lead to unnecessary treatments like surgeries or other expensive procedures.
- Establish transparency across the health system to understand the actual drivers of healthcare inflation.
- Encourage entrepreneurial disruption that leads to the health system competing for patients, which would help lower costs and improve the use of health resources.
- Patients, not companies like pharmacy chains, should benefit financially from the data collected on individuals.

Chairman Wyden, Ranking Member Crapo and distinguished members of the Senate Finance Committee, it is our pleasure and privilege to present written testimony on this vital topic on behalf of Patients Rising. We stand ready to serve as a resource and support the work of Congress to protect patients.