March 23, 2018

The Honorable Bill Cassidy, MD
520 Hart Senate Office Building
Washington, DC 20510

Dear Senator Cassidy:

The American Academy of Neurology (AAN), the world’s largest association of neurologists representing more than 34,000 professionals, is strongly committed to improving the care and outcomes of persons with neurologic illness in a cost-effective manner.

One in six people live with a brain or nervous system condition, including Alzheimer’s disease, Parkinson’s disease, stroke, epilepsy, traumatic brain injury, ALS, multiple sclerosis, and headache. The annual cost of treating these disorders in the US is more than $500 billion, and prescription drugs for neurologic conditions are increasingly expensive. Neurologists seek to provide high-value care for their patients at the lowest cost possible, but high drug prices make it challenging to deliver care that is accessible and affordable for patients with complex neurologic conditions. We appreciate the opportunity to comment on price transparency efforts.

What information is currently available to consumers on prices, out-of-pocket costs, and quality?

There is very little information available to consumers, and most of the information that is provided to patients or their physicians lacks standardization and supporting materials that would make it truly meaningful and useful. Consumers deserve clear, concise, and customized communications about the cost of their care. There are currently few resources available for consumers to understand the complexity and nuance of prices and costs of important treatments and medications in a way that allows them to make choices that are best for their needs. Furthermore, physicians lack resources to understand the costs of the medications they prescribe to their patients. Adjustments to list prices, formularies, and insurer policies create an environment where most physicians are unable to make even an educated guess at the actual cost of medications for their patients. Lastly, the information available to consumers varies greatly depending on their insurance status and their individual insurer. There are significant information gaps for consumers based on their insurance status and this disparity perpetuates health inequities.

What information is not currently available, but should be made available to empower consumers, reduce costs, increase quality, and improve the system?

Transparency must be required at all points in the health care system and especially in the prescription drug pricing process. Manufacturers must be accountable for the list prices they set, and they should be required to disclose all information that impacts those prices. This includes greater transparency for manufacturers who benefit from taxpayer-funded research as well as increased simplification and transparency around the processes at the Food and Drug Administration that award priority review.
vouchers, preserve market exclusivity, and limit competition to determine the impact of those incentives on cost. Recent drug approvals for rare neurologic conditions like spinal muscular atrophy (SMA) have brought patients the first-ever medication approved for their disease. However, the list price for this medication is $125,000 per dose. The infants and young children diagnosed with SMA require 3-4 doses of this drug each year for the rest of their lives, requiring families to pay between $375,000 and $750,000 each year. Drugmakers take on significant financial risks to develop critical treatments. However, patients are required to take on even greater personal financial risk to pay for the costs of those treatments and that trade-off is not acceptable.

Industry middlemen like pharmacy benefit managers must also be held to higher accountability and transparency standards. The world of drug rebates and discounts is opaque, and these groups should be required to demonstrate that they offer a true benefit to consumers.

Insurers have many opportunities to improve the quantity and quality of information they provide to consumers. Coverage plan and formulary transparency should be a requirement for all insurers. Consumers cannot be responsible for managing the totality of their health costs, particularly when they are making decisions with such limited information from their insurance providers. Insurers should also work across the industry to develop standardized resources for consumers so they can understand the differences of cost and access across the plans available to them.

Physicians need more resources and support to understand the prices of the drugs they prescribe and incorporate cost in discussions with patients. The lack of information and transparency in the current system makes patient drug costs unknowable for physicians. There are often situations where a physician has several drugs that are relatively equal in efficacy for a patient but have drastically different prices. Frequent changes in drug costs also mean that a medication that was affordable for a patient one month may no longer be affordable the next. Medications for multiple sclerosis (MS) provide examples of the lack of transparency in our current system. The prices for some of these drugs have increased by more than 1,000 percent since coming to market in the late 1990’s, but there have been no changes or improvements to those drugs1. As new options come to market, competitor drugs have increased their prices and patients are left holding the bag. MS patients now face annual costs exceeding $90,000 for the exact same medications they were receiving for one-tenth of the price 20 years ago. High and unpredictable drug costs require consumers to make difficult choices and result in prescription abandonment, rationing, and preventable disease progression. The lack of information drives up costs, increases health care utilization, and prevents patients from getting the care that is best for them. In a system with greater transparency, it is possible that drug prices would be more stable and physicians could more easily consider patient cost in their prescribing decisions.

What role should the cash price play in greater price transparency? How should this be defined?

All price determinations, including cash price, must be held to high transparency requirements. The concept of cash price is confusing for patients and calls into question the need for insurers to be involved in the prescription drug process. Greater transparency in the factors that influence a cash price determination are necessary to keep all parties accountable in this process.

What are the pros and cons of different state approaches? What is the best quality and price information to collect for consumers and businesses?

States are recognizing that consumers deserve more information to make high-stakes decisions about their health care. Many of these initiatives also emphasize that most consumers do not plan to be in a situation where they require high-cost therapies or treatments and that they should not be solely responsible for determining the most cost-effective option for their care. The AAN applauds the

---

innovative efforts from states working to improve access and quality of care. However, we are concerned that continued inaction at the federal level will result in an array of positive but disconnected state efforts that create inconsistent access to valuable information on low-cost, high-quality care.

**Who should be responsible for providing pricing information and who should share the information with consumers?**

All stakeholders in the pricing process should be required to disclose information in a way that is publicly available, routinely updated, and easily accessible. Consumers should be able to see how the price of their treatment changes as it moves throughout the health care system and clearly understand the price at their point of access. Manufacturers, pharmacy benefit managers, insurers, and institutions must all provide their information to achieve transparency.

**What role should all-payer claims databases play in increasing price and quality transparency? What barriers currently exist to utilizing these tools?**

All-payer claims databases are important to understand local trends in pricing, utilization, and access. While the information is not comprehensive, the databases provide one of the most robust sources for improving health care quality and reducing cost. There are many valid concerns about the privacy and accuracy of the data within these databases, as well as the burden for insurers and providers to report information across different databases. More standardization and support for all-payer claims databases would improve the quality of the information and the ease of reporting.

**How do we advance greater awareness and usage of quality information paired with appropriate pricing information?**

Quality and pricing information must be integrated into the health care system, and this can be achieved by accelerating the transition from volume to value. The AAN has created the Axon Registry® to support quality initiatives and better serve patients with neurologic disease. Clinical data registries are important tools for capturing quality and pricing information in a way that can ultimately reduce costs and improve care, and they should be supported.

**How do we ensure that in making information available we do not place unnecessary or additional burdens on health care stakeholders?**

Manufacturers, insurers, providers, and pharmacy benefit managers must be accountable for the prices they set. The responsibility of determining health care costs should not fall to consumers. Health care stakeholders have ample resources to implement reporting processes. Reporting mechanisms should be designed in a manner that encourages compliance and supports the integration of transparency into daily operations. The AAN supports the Fair Accountability and Innovative Research (FAIR) Drug Pricing Act, which requires manufacturers of any drug that costs more than $100 per month to report price increases greater than 10 percent annually or 25 percent over a three-year period. This legislation has not yet been passed, but many manufacturers have already worked to keep price increases under the 10 percent threshold from 2017 to 2018. This demonstrates that transparency reporting requirements can be implemented in a meaningful way for stakeholders and consumers.

**What current regulatory barriers exist within the health care system that should be eliminated in order to make it less burdensome and more cost-efficient for stakeholders to provide high-quality care to patients?**

Unnecessary prior authorization contributes to higher administrative fees and poorer health outcomes in the form of prescription abandonment. Regulators and legislators should consider implementation of electronic prior authorization and support continued interoperability of electronic medical records systems. Legislators and relevant regulatory agencies should also consider updating relevant fraud, waste, and abuse laws to be more compatible with the transition to value-based care.
How can our health care system better utilize big data, including information from the Medicare, Medicaid, and other public health programs, to drive better quality outcomes at lower costs?

Data can inform improvements in health care pricing and utilization. It also has the potential to identify areas of resource mismatch and improve the distribution of health care professionals and services, which could improve the efficiency of the entire health care system. Big data is a valuable tool for learning about population health. The health care system must be careful to leverage this information in a way that supports and encourages healthy consumer behavior and not in a way that constructs punitive benchmarks for individuals and groups with high-cost health care needs.

Thank you for considering our concerns on this important topic. Please contact Amber Stock at astock@aan.com if you have questions or request additional information.

Sincerely,

Ralph L. Sacco, MD, MS, FAHA, FAAN
President, American Academy of Neurology