



NATIONAL HEALTH COUNCIL

November 8, 2023

The Honorable Chuck Schumer
Majority Leader
United States Senate
322 Hart Senate Office Building
Washington, DC 20510

The Honorable Mike Johnson
Speaker
U.S House of Representatives
568 Cannon House Office Building
Washington, DC 20515

The Honorable Mitch McConnell
Minority Leader
United States Senate
317 Russell Senate Office Building
Washington, DC 20510

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
2433 Rayburn House Office Building
Washington, DC 20515

Dear Majority Leader Schumer, Speaker Johnson, Minority Leader McConnell, and Minority Leader Jeffries:

On behalf of the National Health Council (NHC), I am writing to ask that you enact legislation on transparency and affordability by the end of the year and to include provisions of importance to the patient community. We recognize the factors impacting access and affordability are numerous and immense. While there has been great progress throughout 2023 by both House and Senate committees on improvements to health care transparency and affordability, there are certain provisions that are of the highest priority to the patient community, and we urge you to include them in upcoming legislation.

Created by and for patient organizations more than 100 years ago, the NHC brings diverse organizations together to forge consensus and drive patient-centered health policy. We promote increased access to affordable, high-value, sustainable, equitable health care. Made up of more than 160 national health-related organizations and businesses, the NHC's core membership includes the nation's leading patient organizations. Other members include health-related associations and nonprofit organizations including the provider, research, and family caregiver communities; and businesses representing biopharmaceutical, device, diagnostic, generic drug, and payer organizations.

System-Wide Public Transparency

The health care system is complex and opaque, and the NHC has long advocated for transparency across the health care system from every sector that impacts patients' lives. This includes hospitals, health care providers, insurers, pharmacy benefit managers (PBMs), and medical product manufacturers. For example, there has been much discussion about the role of Pharmacy Benefit Managers (PBMs), whose contracts with other firms in the drug supply chain are kept secret. The same can be

said for other contracting arrangements throughout the health care system. One study published in January 2023 found variable transparency levels for commercial prices across hospitals. In one example, the authors found that “only 29% to 56% of academic hospitals disclosed commercial prices for 5 common urologic procedures” in March 2022¹. Without understanding whether decisions account for patient perspectives, whether and how they are grounded in clinical evidence, and how incentives drive decisions, we far too often lack the data needed to educate our patient populations.

This lack of transparency not only leads to difficulty in seeking appropriate and timely care, but it also leads to difficulty in making needed policy changes. If patient advocacy organizations had better data about the incentives and decision-making in the health care system, we would be able to better analyze legislative and regulatory proposals and advocate for needed change. This would, in turn, help policymakers better understand the impact of changes on the lives of the American public.

Finally, transparency requirements should also include government entities. For example, we would like to see the Centers for Medicare and Medicaid Services expand reporting on drug costs and spending, including price concessions and rebates, to help inform cost-containment strategies and drive informed action by health care stakeholders.

Request: The NHC asks Congress to examine transparency across the health care system and work with patients and advocates to approach legislative proposals to increase transparency holistically.

Utilization Management

The NHC knows that utilization management (UM) protocols should be grounded in sound clinical decision-making. For example, some prior authorization protocols are intended to limit drug-to-drug interactions or to prevent overprescribing of potentially addictive medication. However, the development of prior authorization and other UM protocols is typically done without much or any patient input, and the rationale for such decisions is not always public or accessible to patients. This often results in utilization management serving as one of the most persistent barriers to care that patients face. A survey of the NHC membership identified addressing concerns about the overuse of utilization management as their top policy concern for the coming year. The NHC has developed a [set of principles and priorities](#) for utilization management, and these guide our advocacy. We urge Congress to use these as a guide as well.

The bipartisan Safe Step Act (S. 632/H.R. 2630) would ensure that employer health plans offer an expedient and medically reasonable step therapy exceptions process. Step therapy is a complex form of prior authorization that requires patients to try and fail on certain treatments before the plan covers other treatments, including those initially selected by the patient and their provider. When medically inappropriate, step therapy is particularly egregious, as it can delay needed care for months and lead to negative

¹ 1 Xuefeng Jiang, John, Ranjani, K., “Price Transparency in Hospitals – Current Research and Future Directions” JAMA Network Open

health outcomes for patients. The Safe Step Act was included as an amendment to the [Pharmacy Benefit Reform Act](#) approved by the Senate's Health, Education, Labor, and Pensions (HELP) Committee in May.

Request: The NHC urges passage of the Safe Step Act.

Another issue that patients face in utilization management is long delays in processing prior authorization requests. While prior authorization can be a helpful tool for reducing overutilization of inappropriate care, it can also be an overly burdensome process leading to dangerous delays in treatment, diverting clinician time away from patient care, and general inefficiency. For individuals with chronic diseases and disabilities, onerous prior authorization can create significant barriers to timely, appropriate care and negatively impact patient health outcomes.

The Improving Seniors' Timely Access to Care Act would make it easier for seniors to get the care they need and improve health outcomes. The bill would establish an electronic prior authorization process within Medicare Advantage, require "real-time decisions" for items and services that are routinely approved, develop data on the use of prior authorization in Medicare Advantage, and align prior authorization with clinical guidelines or other valid sources. The legislation was included in the Health Care Price Transparency Act of 2023 (H.R. 4822) passed by the House Ways and Means Committee this summer.

Request: The NHC urges passage of the Improving Seniors' Timely Access to Care Act.

Copay Accumulators

Another issue that patients often face is that when they receive assistance in meeting their copays for their medication, which can often be astronomical, that amount can be excluded from counting towards a patient's deductible or out-of-pocket maximum. This means that they will have to continue paying more out-of-pocket to meet their deductible, even if the total amount paid is much more than they would have paid without assistance. This mechanism punishes those that are most vulnerable and need assistance meeting high copay amounts for needed medication. The NHC believes that it should not matter what the source of meeting a copay is. If a patient is responsible for it and it is paid, it should count towards their yearly deductible.

The bipartisan Help Ensure Lower Patient (HELP) Copays Act (S. 1375/H.R. 830) would require that the value of copay assistance count towards a patient's cost-sharing requirements. This important legislation would protect patients from loopholes that financially penalize the most vulnerable.

Request: The NHC urges passage of the HELP Copays Act.

Improving Affordability

As Congress addresses issues driving increases in drug costs and creates solutions to lower those costs, it is critical that policies ensure all savings and rebates be passed through to patients, so that individual patients realize appropriate savings and not just the health care system writ large. While patients may benefit from lower premiums that result from rebates, for those with chronic conditions, these savings are often much smaller than the higher costs they pay due to coinsurance being tied to list prices instead of negotiated rates.

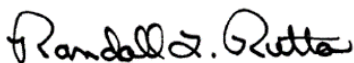
The NHC supports the concept of patients sharing in the savings realized by rebates, whether it be through rebate passthrough or policies that tie cost sharing to negotiated rates.

Request: Congress should enact legislation that directly reduces out-of-pocket expenses by ensuring negotiated savings are shared with patients.

Conclusion

Please do not hesitate to contact Eric Gascho, Senior Vice President of Policy and Government Affairs, if you or your staff would like to discuss these issues in greater detail. He is reachable via e-mail at egascho@nhcouncil.org.

Sincerely,



Randall L. Rutta
Chief Executive Officer