

August 5, 2022

The Honorable Charles Schumer Leader United States Senate Washington, DC 20510

The Honorable Nancy Pelosi Speaker U.S. House of Representatives Washington, DC 20515 The Honorable Mitch McConnell Republican Leader United States Senate Washington, DC 20510

The Honorable Kevin McCarthy Republican Leader U.S. House of Representatives Washington, DC 20515

Dear Senator Schumer, Senator McConnell, Speaker Pelosi, and Leader McCarthy:

On behalf of the National Health Council (NHC), I am writing to urge Congress to improve health care access, equity, and innovation to help patients, now and in the future, as reconciliation legislation is considered in the Senate and House. This letter provides feedback on certain elements of the Inflation Reduction Act (IRA). Given the size and scope of the legislation and its disparate impacts on different patient communities, the NHC is not endorsing or opposing the entirety of the bill.

The IRA includes provisions such as the Part D out-of-pocket cap and enhanced Affordable Care Act subsidies. It omits other previously considered improvements and creates concern from some in the patient community regarding potential effects on access to future treatments.

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 health care. Made up of more than 145 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.

The NHC's strategic priorities focus on advancing reforms to optimize patient health, prioritize health equity, assure patient-centricity, and support patient group impact. Our priorities on health care cost reduction are shaped by three guiding <u>principles</u>:

- Promote High-Value Health Care
- Stimulate Research and Competition
- Curb Costs Responsibly

Provisions We Support

The IRA advances important provisions the NHC supports, including:

 Extension of the enhanced Affordable Care Act (ACA) subsidies for people purchasing coverage through the Marketplace is a crucial patient benefit and a sound investment. Enhanced subsidies have contributed to the current near record-low number of uninsured individuals. Barring action at this time and starting next year, some 13 million people would likely experience an unwanted and, for many, unaffordable, rise in premiums. While a three-year extension is imperative, we urge Congress to extend them longer if possible.

- The \$2,000 Medicare Part D out-of-pocket cost cap included in the Senate reconciliation legislation and the creation of a pathway for beneficiaries to spread out the payments that count toward the cap over several months will help seniors and people with disabilities to budget and afford their medications. This will notably help by bringing critical fiscal relief to a subset of the population with the most expensive health needs, often people with chronic diseases and disabilities.
- The expanded access to premium and co-pay assistance under the low-income subsidy program (LIS) under Medicare Part D will help more low-income seniors afford their prescriptions; and
- Vaccines will be free for older adults under Medicare to help protect them and the community.

Finally, we are pleased to see the IRA *does not* include provisions of the House-passed Build Back Better Act that would reduce the value of the Orphan Drug Tax Credit, thereby reducing investment in rare disease research. We urge Congress to resist including this provision in the final package.

Recommendations for Further Improvement

Since the beginning of the reconciliation process, the NHC has advocated for key priorities on behalf of the patient community. We are disappointed that many of these provisions were not included in the Senate's legislation. Prioritizing deficit reduction over patient-centered health reform, realignment of resources and investments, and multi-stakeholder engagement is a significant missed opportunity. We continue to encourage you to work to achieve these goals:

- Continue incentives for states to expand Medicaid and create a federal alternative for people in the gap in states that do not expand Medicaid eligibility. Failure to address the Medicaid coverage gap will continue to harm all individuals who are affected, which are predominantly people from marginalized populations.
- Expand access to home and community-based services (HCBS) in Medicaid, for example, by enhancing the Federal matching funds available to states to provide HCBS services, as proposed in the Better Care Better Jobs Act (S. 2210) and by rebalancing home and community-based services under Medicaid by making permanent the Money Follows the Person Demonstration Program, as proposed in H.R. 1880.
- Drive as much of the drug savings as possible to expand coverage and lower out-ofpocket costs for patients at the point of care, such as policies to cap copays for insulins and other medications for chronic diseases and disabilities.

The NHC believes that a far greater share of savings generated by reconciliation should be reinvested in patients rather than returned to the Treasury for deficit reduction. Such investments would begin to close harmful gaps in our health care system for people with chronic conditions and disabilities and other marginalized populations – especially with the burden of the pandemic still a reality and equity priorities yet fulfilled.

Ultimately, the NHC would recommend a more holistic approach to address access and affordability. Employers, insurers, clinicians, hospitals, biopharmaceutical companies, and other health ecosystem components collectively contribute to the nation's health and well-being. All parties need to be engaged in – and held accountable for – developing solutions in policy and

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practice to achieve a more accessible, equitable, efficient, affordable, transparent, and sustainable patient-centric health care system.

Potential Consequences

The NHC, as a multi-stakeholder organization, represents a broad range of perspectives. Even within the patient community, there are varying views and priorities on many issues such as medical innovation, access, and affordability. Many patient organizations within our membership are concerned with the potential for unintended consequences resulting from this overhaul of our health care system.

- While we are strong proponents of the proposed redesign of the Part D benefit, we are concerned that a potential unintended consequence may be insurers responding to the increased financial liability by exposing Medicare beneficiaries to increased utilization management, prior authorization, formulary restrictions, or other benefit reductions. Congress and the Administration must monitor such impacts during implementation and consider additional guardrails.
- The bill as drafted does not define a role for patients and patient organizations to provide input into the negotiation process. Patient engagement is essential in determining value, access, and cost of medicines and medical products. And it is imperative that during any negotiation process, the HHS Secretary must refrain from the use of methodologies that discriminate against populations such as people with disabilities and older adults.
- We recognize concerns raised by the biopharmaceutical sector, including the investment community, that this bill will reduce investment in future drug development, potentially resulting in fewer drugs coming to market. The Congressional Budget Office has also found this to be a likely result. For many patient organizations that represent people with serious conditions with limited or no treatment options, this is of particular concern. Ninety percent of rare diseases have no treatment. Millions of patients attribute their health and quality of life to the innovative treatments available today, and millions more await break-through and additional medicines.

We look forward to working with you to advance these policy recommendations and next steps to achieve shared goals for reform. 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,

Ron Inlaz. Rutta

Randall L. Rutta Chief Executive Officer