



September 9, 2024

**The Honorable Charles Schumer**

The Office of the Senate Majority Leader  
S-221 Capitol Building  
Washington, DC 20510

**The Honorable Mike Johnson**

The Office of the House Speaker  
H-232 Capitol Building  
Washington, DC 20515

**The Honorable Mitchell McConnell**

The Office of the Senate Minority Leader  
2-230 Capitol Building  
Washington, DC 20515

**The Honorable Hakeem Jeffries**

The Office of the House Minority Leader  
H-204 Capitol Building  
Washington, DC 20515

**RE: Prioritize Patient Engagement in Health Care Policymaking**

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

We, the undersigned organizations, represent a diverse community of individuals including patients, survivors, and caregivers impacted by cancer and other complex conditions such as HIV, AIDS, arthritis, lupus, and other chronic conditions. We appreciate your commitment to finding legislative solutions aimed at assisting individuals who struggle to access and afford lifesaving and life-enhancing medications and care. However, we remain concerned about policies that may have unintended consequences on treatment access for patients without incorporating patient perspectives, such as the Medicare Drug Price Negotiation Program (MDPNP) within the Inflation Reduction Act (IRA).

Last year, Cancer Support Community (CSC) – in close collaboration with diverse patient advocacy, caregiver, and health care innovator communities – established recommended principles for patient-centered engagement to support the future of health care policymaking. While originally intended for the Centers for Medicare & Medicaid Services (CMS) to consider as they implement the MDPNP, the principles are broadly applicable to laws and policies considered by Congress that impact patients and their care providers.

**We urge you to prioritize a patient-centered approach when considering and advancing health care legislation to ensure patient, survivor, and caregiver perspectives are incorporated in conversations about policies that stand to impact them most.**

***Consider the Impact of the IRA on Patients***

Patients living with cancer, chronic conditions, and other complicated diagnoses are often required to plan and manage their care while continuing with daily responsibilities. Patients are left to become experts at addressing both expected and unintended consequences, such as side effects or the unavailability of a prescribed drug, that arise as a result of their diagnosis and treatment. Although patients may be warned of these unintended consequences by their provider, that does not lessen the impact of such events on their physical, mental, and emotional health.



Engaging with patients, survivors, caregivers, and advocacy organizations that represent them is the only way for policymakers and regulators to understand the true impacts of the MDPNP – or any other policy – on the patient experience and inform policy solutions to mitigate adverse, down-stream effects.

Policies such as the MDPNP must be adaptable and not standardized because each patient has unique needs. A one-size-fits-all approach to implementing policies will not benefit patients and may take away the choice and empowerment that patients often seek in choosing their care.

We recognize and support that the original intent of the IRA was to increase access to medicines for Medicare beneficiaries, and there are indeed some policies within the law that will undoubtedly achieve this goal. However, like any legislation, we must continue to evaluate how patients will be impacted by these policies and provide accessible and intentional opportunities for feedback, especially as we prepare for the second round of Medicare drug price negotiations.

Patient input from a broad group of populations and communities is critical to achieving policies that incorporate and reflect their needs, perspective, and goals as it relates to treatment outcomes – and it all starts with meaningful and ongoing patient engagement.

Thank you for your leadership on these issues and others that impact the patient and caregiver communities we serve. If you have any questions, or if there is any way that we can be helpful to you, please contact Daneen Sekoni at [dsekoni@cancersupportcommunity.org](mailto:dsekoni@cancersupportcommunity.org).

Sincerely,

Cancer Support Community (CSC)  
Cancer Support Community Arizona  
Cancer Support Community Central Ohio  
Cancer Support Community Greater Cincinnati-Northern Kentucky  
Cancer Support Community Indiana  
Cancer Support Community Iowa & Northwest Illinois  
Cancer Support Community of the Greater Lehigh Valley  
Cancer Support Community San Francisco Bay Area  
Cancer Support Community Washington, D.C  
Gilda's Club Chicago  
Gilda's Club Kansas City  
Gilda's Club Kentuckiana  
Gilda's Club South Florida

ADAP Advocacy Association  
AiArthritis  
Aimed Alliance  
Allergy & Asthma Network  
Alliance for Aging Research  
Association of Cancer Care Centers (ACCC)  
CancerCare  
Caregiver Action Network (CAN)



Center for Medicine in the Public Interest (CMPI)  
Chronic Care Policy Alliance (CCPA)  
Community Access National Network (CANN)  
FORCE: Facing Our Risk of Cancer Empowered  
Global Coalition on Aging (GCOA) Alliance for Health Innovation  
Global Healthy Living Foundation (GHLF)  
Immune Deficiency Foundation (IDF)  
Let's Kick ASS Palm Springs (AIDS Survivor Syndrome)  
LUNGeVity Foundation  
Lupus and Allied Diseases Association, Inc. (LADA)  
Mosaic Life Care  
National Alliance for Caregiving (NAC)  
National Hispanic Medical Association (NHMA)  
Nevada Chronic Care Collaborative (NCCC)  
PlusInc  
Rare Disease Diversity Coalition (RDDC)  
RetireSafe  
StopAfib.org  
Susan G. Komen  
The Headache & Migraine Policy Forum

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### Cancer Support Community Principles for Patient-Centered Engagement

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- **Engage patient advocacy organizations, patients, and caregivers** in structured, meaningful ways throughout MDPNP process.
- **Define clinical benefit** to prioritize evaluations around endpoints, patient reported outcomes, patient experience data including impact on quality of life, and preferences that matter most to patients living with cancer and other complex conditions. This includes both qualitative and quantitative measures such as clinical endpoints, patient preference data/models, patient reported outcomes, and social impacts.
- **Develop critical infrastructure** necessary to educate the patient community and facilitate meaningful feedback that prioritizes patient definitions of value, including feedback on the evidence being considered by CMS and whether it reflects patient experiences and preferred outcomes.
- **Diversify outreach to patients and people with disabilities** to ensure that the MDPNP supports all patient populations and does not threaten healthcare access.
- **Refer to patient navigators** to provide information to patients about the impact of these policies and to receive feedback from patients, with an explicit goal to identify any changes in utilization management practices as a result of IRA implementation.

- **Develop a monitoring and evaluation platform** and reporting framework surrounding the MDPNP and its impacts on patients to support continuous improvement in ongoing implementation and expansion.
- **Collect and report specifically on access challenges** facing patients as a result of the IRA to allow for continuous improvement of the MDPNP process and lessen these unintended consequences of this process on patients.
- **Collect and incorporate meaningful data and real-world evidence** that amplifies patient values and input within the MDPNP implementation process, including patient reported outcomes, patient experience data, impact to quality of life, and models that capture the dynamic and varied preferences of patients.
- **Consider the groups and populations that have not already engaged** in defining patient-focused clinical benefit and impact of the MDPNP process and determine how best to activate those individuals to avoid exacerbating existing health equity challenges.

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