

FALL 2024

# CANCER POLICY ROUNDTABLE



NATIONAL COALITION  
FOR CANCER SURVIVORSHIP

## EXECUTIVE SUMMARY

National Coalition for Cancer Survivorship  
8455 Colesville Rd, Suite 930  
Silver Spring, MD 20910  
[www.canceradvocacy.org](http://www.canceradvocacy.org)

Fall 2024

## CANCER POLICY ROUNDTABLE FALL 2024

Since 1986, NCCS has been a trusted source in the cancer community and a leading voice in the field of cancer survivorship. For more than 20 years, NCCS has hosted twice-yearly Cancer Policy Roundtable (CPR) meetings, convening diverse stakeholders to discuss pressing cancer policy issues.

NCCS convened another successful CPR on November 13, 2024, hosting a compelling series of panels and guest speakers, discussing the critical issues in quality cancer survivorship care.



## Keynote Presentation

### “Further, Faster: Working Together to End Cancer As We Know It.”

---



### **KIMRYN RATHMELL, MD, PHD**

Director  
National Cancer Institute

“We're very lucky in cancer to have very broad bipartisan support. That has always been true. I've met with members of Congress on all sides and have never met someone who wasn't fully supportive... When I talk to folks, especially on appropriations, they really want to fund the work that we do. And to me, the most important part is to help them see where there's real value added — how it is that we help extend lives, save lives, but also create a good workforce and stimulate the economy.”

Fall 2024 Cancer Policy Roundtable attendees were inspired by NCI Director Dr. Kimryn Rathmell's keynote presentation “Further, Faster: Working Together to End Cancer As We Know it.” She shared an optimistic but realistic assessment of cancer research progress, emphasizing the importance of clinical trial access. She noted a statistic from [NCCS's 2024 State of Survivorship Survey](#) that 74% of people who don't participate in clinical trials never were asked, highlighting a clear opportunity for improvement.

She outlined NCI's commitment to modernizing clinical trials and shared an example of the Pragmatica-Lung Study to illustrate how NCI aims to streamline clinical trials and make them more accessible. Dr. Rathmell noted that simpler, more efficient trial designs can still generate valuable scientific insights while enrolling patients more quickly. She highlighted several key areas for increased NCI investment, including early onset cancers, financial toxicity, and cancer vaccine development.

---

## NCCS State of Survivorship Results

---



### **Shelley Fuld Nasso, MPP**

Chief Executive Officer

National Coalition for Cancer Survivorship

NCCS CEO Shelley Fuld Nasso summarized the findings of our [2024 State of Survivorship Survey](#), particularly the results related to young adult cancer survivors, as well as data on post-treatment survivorship. Over the years, NCCS surveys have consistently highlighted the substantial physical, financial, and emotional burdens faced by young adults. In 2024, NCCS partnered with Stupid Cancer to oversample this population. Some key data points:

- While just over a third (35%) of respondents felt they needed to advocate for themselves to get the best care, certain groups were much more likely to need to advocate for themselves: Black patients (59%), younger patients (56%) and Hispanic patients (48%). These groups are also less likely to rely solely on their doctors' recommendation.
- Two-thirds of people who are five years or less from treatment are receiving post-treatment care. Among those more than five years out, only one-third are receiving post-treatment care. The primary reason cited for not receiving post-treatment care was that their physician deemed it unnecessary.
- There has been a significant decline in primary care physician management of post-treatment care, which decreased from 40% to 30% to just under 20% over the past three years. Meanwhile, the percentage seeing their oncologist has increased and only 38% said they would be willing to have a primary care physician manage their post-treatment care.
- Only 29% of patients sought a second opinion, though this was higher for younger patients (47%), Hispanic patients (43%), LBGQTQ+ patients (42%), and people living with Stage IV cancer (41%). The main reason patients didn't seek a second opinion was that they trusted their health care team.

The full survey results are available at [www.canceradvocacy.org/survey](http://www.canceradvocacy.org/survey).

---

## Survivor Perspective



**Stephanie Gayhart, MHI, RN**

AYA Cancer Survivor  
Chief Learning Officer  
Presently

**Shelley Fuld Nasso, MPP**

Chief Executive Officer  
National Coalition for Cancer Survivorship



"We're finding that that [peer support] really helps with patient activation. It empowers them. It makes them want to go out and do more, which is what we need, because we've created this dependency on the health care system, and we want patients to do more for themselves, but we haven't figured out how to do it. And I think the answer is empowering them."

Cancer survivor, nurse, and wellness coach Stephanie Gayhart shared her powerful story as a young adult survivor, diagnosed with oral cancer at age 37. Her experience illustrated the cascading effects of cancer on family life, career, and long-term wellbeing. She talked about her Initial misdiagnosis and delayed diagnosis due to age bias. Gayhart recalled preparing her six-year-old son for her treatment. "Before my surgery, I taught him sign language because I didn't know if I was ever going to be able to talk again. And the one I taught him was, 'I love you'."

Gayhart discussed the high need for mental health support for cancer survivors. She described her work developing trauma-informed peer support groups through Presently, where she creates curriculum and trains cancer survivors to be peer support facilitators. She explained that in their pilot program with Kaiser in San Francisco, participants reported that, despite support from family, friends, and physicians, they found the most value in connecting with others who had shared similar cancer experiences. She emphasized that peer support is valuable not only because participants receive support, but because giving support to others helps with patient activation and empowerment.

## Health Policy Outlook for 2025

### **Emily Mace, JD**

Former U.S. House Staff Member

### **Debra Curtis**

McDermott+ Consulting

### **Lydia Isaac, PhD, MSc**

National Urban League

### **Rodney Whitlock, PhD**

McDermott+ Consulting

### **Shelley Fuld Nasso, MPP (Moderator)**

National Coalition for Cancer Survivorship



The discussion provided nuanced insight into health care priorities under the new administration. As Debbie Curtis noted, "Health care is not the number one Trump agenda...but health care impacts every single person." Rodney Whitlock emphasized that while dramatic changes to health care policy may be unlikely, stakeholders must remain vigilant: "The clown car show of 2017, I'm going to generously give them the opportunity to show that, in fact, they might have learned something."

The panelists assessed the fate of the Affordable Care Act (ACA), with a consensus that unlike 2017, a full repeal attempt is unlikely. However, they anticipate potential changes through insurance deregulation, modifications to tax credits, and state-level flexibility in Medicaid, reforms to Medicare Advantage, and rural health care access. Other policy changes will depend on personnel tapped to lead the various health agencies.

The panel emphasized that advocacy strategy will need to evolve. Emily Mace, a former Republican House staff member, emphasized the importance of sharing patients' stories and talking with members of Congress in the district and before legislation is proposed. "When you tell the stories and when you come in and have an honest conversation and come to them from a place of respect and wanting to collaborate with them, you can almost always do that," she said.

Lydia Isaac of the National Urban League provided an optimistic charge to the audience, emphasizing that "whoever you voted for, it actually doesn't matter right now. The people who are elected are working for the people of the United States, and we have to hold them accountable."

# The Cancer Drug Acquisition, Coverage, and Payment System: Does it Support Quality Cancer Care and Protect Affordable Patient Access to Quality Care?

---

**AARON MITCHELL, MD, MPH**  
Oncologist, Health Services Researcher  
Memorial Sloan Kettering Cancer Center

In his analysis of cancer drug payment systems, Dr. Aaron Mitchell, an oncologist and health services researcher from Memorial Sloan Kettering, explained how the current "buy and bill" system directly links physician compensation to drug prices, creating potential conflicts of interest. His memorable quote captured the ethical tension: "It feels like we've somehow crossed a threshold from doctors making money for taking care of patients, which I don't think anyone is supposed to, and at some point crossed over to what feels like viscerally, doctors making money off of patients."



His research revealed that commercial insurers typically pay about triple the Medicare rates for drugs, leading to significant profit margins for providers. While research suggests this compensation model might influence whether treatment is initiated, Mitchell found surprisingly that it does not appear to affect which specific drugs physicians choose when treating patients.

He recommended reforming the system to separate physician compensation from drug costs, while ensuring sustainable practice models, emphasizing that such changes must be carefully implemented to maintain access to care. The evidence suggests that realigning financial incentives could be achieved without compromising quality of care, though careful monitoring would be essential to ensure patient access is preserved.

---

## Medicare Drug Price Negotiation Update



**Lara Strawbridge, MPH**

Centers for Medicare & Medicaid Services

**Elizabeth Carpenter**

PhRMA

**Shawn Maree Bishop, MPP**

Akin Gump Strauss Hauer & Feld LLP

**Gary Puckrein, PhD**

National Minority Quality Forum

**Shelley Fuld Nasso, MPP (Moderator)**

National Coalition for Cancer Survivorship

This panel provided a look at the implementation and implications of Medicare drug price negotiations that were enacted as part of the Inflation Reduction Act (IRA). Lara Strawbridge of the Centers for Medicare and Medicaid Services (CMS) detailed the results of the first round of negotiations, which achieved a 22% reduction in costs for negotiated drugs, projecting \$6 billion in savings, including an estimated \$1.5 billion in beneficiary savings by 2026. She also described process improvements for the second round of negotiation set for 2025, including restructured patient engagement through smaller, private roundtables; enhanced data collection methods, and streamlined negotiation timeframes. She emphasized stakeholder engagement: "Our door is always open. We know that we haven't got it all right yet and we are going to evolve."

Elizabeth Carpenter from PhRMA raised several industry concerns, including potential impacts on small molecule drug development, market stability, and post-approval research. She noted: "50% of what we're spending is going to somebody who didn't make the medicine...we should also ask questions about that other 50%, where is that going?"



Shawn Bishop, a former U.S. Senate staff member drawing from her experience helping craft the legislation, provided valuable context on statutory requirements and timeframes, as well as areas where CMS has flexibility in implementation: "The statute allows for that a lot of leeway there. CMS does not have leeway to not consider a certain factor, but how it considers it, that's up to CMS."

The panel debated the potential impact on rare disease treatments and community oncology practices. A key point of discussion was the "technical fix" proposed by community oncologists to maintain physician compensation levels while reducing drug prices. The panel acknowledged the complexity of balancing cost reduction with maintaining access and innovation.

Gary Puckrein of the National Minority Quality Forum provided a perspective on health equity and systemic reform: "By 2050, when we should have cancer reduced to a common disease that we can control... how do we pay for that? IRA isn't going to do that." He emphasized the need to focus on outcomes rather than just cost savings.

### **Key Themes from this Cancer Policy Roundtable**

One theme emerged consistently: the critical role of patient voices in policy development. The discussions highlighted how policy changes, whether in drug pricing or care delivery, must be evaluated through the lens of patient access and outcomes.

The meeting demonstrated both the complexity of cancer care policy and the shared commitment to improving outcomes for cancer survivors. While political and systemic challenges remain, the discussions pointed toward opportunities for progress through collaborative effort and patient-centered policy development.

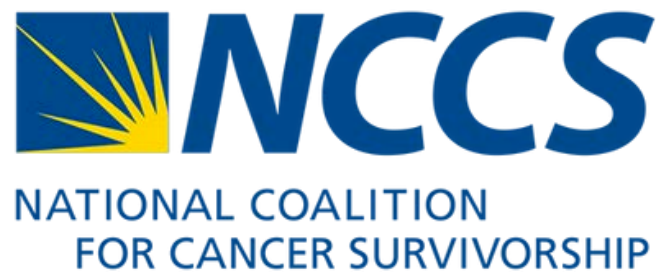
Both panel discussions emphasized the importance of proactive engagement with policymakers and the need to carefully monitor implementation impacts on patient access and outcomes. The conversations highlighted the tension between achieving cost savings and maintaining a robust health care delivery system that serves all patients effectively.

Behind every policy discussion are real patients facing life-changing decisions. As Gary Puckrein powerfully stated: "We need to collaborate to save each other's lives. That's our social contract."

**The next Cancer Policy Roundtable is scheduled for March 27, 2025.**

---

[www.canceradvocacy.org](http://www.canceradvocacy.org)



National Coalition for Cancer Survivorship  
8455 Colesville Rd, Suite 930  
Silver Spring, MD 20910

877-NCCS-YES  
[Info@CancerAdvocacy.org](mailto:Info@CancerAdvocacy.org)

---