

FALL 2023

CANCER POLICY ROUNDTABLE



NATIONAL COALITION
FOR CANCER SURVIVORSHIP

EXECUTIVE SUMMARY

National Coalition for Cancer Survivorship
8455 Colesville Rd, Suite 930
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www.canceradvocacy.org

Fall 2023

CANCER POLICY ROUNDTABLE FALL 2023

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 Cancer Policy Roundtable on Thursday, November 16, 2023, with esteemed speakers from the Johns Hopkins School of Medicine and Bloomberg School of Public Health, Centers for Medicare and Medicaid Services (CMS), KFF, and the Brookings Institution, as well as clinicians, patient advocates, and policy experts. Topics included the survivor's perspective, implementation and innovation for the Inflation Reduction Act, patient-centered research and practice, Medicare Advantage plans, and cancer drug shortages.



Survivor Perspective

Katrece Nolen

Cancer Survivor and Author

Survivor and author Katrece Nolen opened the 2023 Fall Cancer Policy Roundtable by sharing the survivor perspective, recounting her lived experience and lessons learned as a 10-year survivor of inflammatory breast cancer. Katrece discussed the importance of self-advocacy, trust, networking, and connection in overcoming obstacles to care.

Reflecting on her own self-advocacy, Katrece said she had to learn to advocate for herself from the moment she noticed a change in her body and as she tried to see a provider to receive a diagnosis. Katrece recounted the many challenges she

experienced when entering and navigating the health care system, which ultimately led to a cancer diagnosis at just 37 years old. She also stressed the need for change in the health care system and advocated for a better patient experience for cancer patients from the moment they encounter the system.

Katrece discussed the importance of having a support system, consisting of family, friends, or even networks like patient advocacy groups, advocates, or fellow church members. She especially emphasized the importance and power of social media networks, which helped her navigate her own diagnosis. These connections helped her realize that she was not alone, and they ultimately encouraged her to find a specialist in inflammatory breast cancer, which is a rare and aggressive cancer. She said, "Social networking saved my life!"

Importantly, Katrece encouraged cancer survivors to admit when they need help and accept it. She shared her mother's words: "You have to accept help because then you can take that energy and apply it towards your treatment. And, who knows, that ability for others to bless you may help bless somebody else in the future."



Inflation Reduction Act – Implementation and Innovation

Rachel Portman, MS

Policy Advisor, DLA Piper

Mariana Socal, MD, PhD, MS, MPP

Associate Scientist, Johns Hopkins
Bloomberg School of Public Health

Corey Rosenberg

Deputy Director, Division of Drug Price
Negotiations, Centers for Medicare and
Medicaid Services

Shelley Fuld Nasso, MPP (Moderator)

CEO, National Coalition for Cancer
Survivorship



The issue of drug price negotiation is a timely topic for cancer patients, survivors, advocates, and health care professionals. In the first panel of the day, panelists discussed the Inflation Reduction Act (IRA), specifically the implementation of the drug price negotiation provision and potential impacts on innovation. The panel of experts effectively illustrated both the anticipated benefits for patients, as well as the possible implications for pharmaceutical research and development (R&D).

First, Corey Rosenberg provided an update on the implementation of the negotiation process and noted the conclusion of the patient listening sessions on the first 10 drugs selected for negotiation. His team at the Centers for Medicare and Medicaid Services (CMS) is now synthesizing data collected from listening sessions and submitted by manufacturers of the drugs that were selected for negotiation. At the end of this year, CMS will share the methodologies they will use to guide their negotiation with manufacturers. Next August, CMS will announce any prices that have been agreed to, and the prices will go into effect in 2026.

Next, Rachel Portman and Dr. Mariana Socal contributed different perspectives on negotiation and innovation. Drawing from her prior work on Capitol Hill, Ms. Portman provided background into the development and passage of the IRA. She also noted the IRA's impact on innovation and explained that companies are considering the effects of drug price negotiation when making their R&D decisions. She said that over 60% of drug companies have claimed that they would shift their R&D investments out of small molecule drugs as a direct result of the IRA, which could potentially impact cancer patients.

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Dr. Socal provided an overview of the existing drug pricing process in the US, highlighting how the process differs from other countries. She noted that when drugs have been in the market for more than three years, the prices in the US continue to rise, while prices in other countries fall. She described the benefits of the IRA for Medicare beneficiaries, noting the reduced prices of negotiated drugs, the out-of-pocket cap on drugs, greater transparency about the drugs that are negotiated, and increased access because of the requirement for negotiated drugs to be covered on all formularies. When addressing potential impacts to R&D, Dr. Socal acknowledged that it is hard to quantify the number of drugs that are not developed and we may see fewer drugs developed, but the drugs

not developed will likely be ones that had less potential benefit for patients. She said we need to incentivize more selective, targeted, and curative treatments.



Patient-Centered Research and Practice: The PROTEUS Consortium

Claire Snyder, PhD

Professor, Johns Hopkins School of Medicine
Principal Investigator, The PROTEUS Consortium

Dr. Claire Snyder, a pioneer in patient-centered outcomes research, delivered the keynote address titled "Patient-Centered Research and Practice: The PROTEUS Consortium." The presentation detailed her work leading the PROTEUS Consortium to help ensure that patient-reported outcomes (PROs) are incorporated in clinical trials and clinical practice. Dr. Snyder has been at the forefront of engaging with the advocacy community to ensure that her research is meaningful and relevant to cancer patients and survivors. Dr. Snyder's innovative knowledge translation efforts are helping to ensure that rigorous research can be applied in practice and that patient data can inform clinical decision-making by creating user-friendly tools and resources.

During her presentation, Dr. Snyder emphasized what drives her work, stating, "This is why I get up in the morning and this is why I do my work, because I think it's really critically important that how patients feel drives their care." She explained that PROTEUS first focused on the use of PROs in clinical trials and later expanded its focus to the use of PROs in clinical practice. The program's objective is to ensure that patients, clinicians, and other decision makers have the information from the patient perspective to make the best decisions they can about treatment options.

Dr. Snyder also presented evidence of the benefits of using PROs in clinical practice. She explained that research has consistently shown that collecting PROs in a clinical setting can facilitate patient-clinician communication.



Medicare Advantage: Access and Quality for Cancer Care

Ezekiel J. Emanuel, MD, PhD

Vice Provost for Global Initiatives
Co-Director of the Healthcare Transformation Institute
University of Pennsylvania Perelman School of Medicine

Tricia Neuman, ScD

Senior Vice President, Executive Director for Program
on Medicare Policy, KFF

John Shevock, FACHE, FACMPE

Executive Director, Bayhealth Cancer Institute

Natalie Stevenson

Cancer Survivor, NCCS CPAT Member, and
NCCS Elevate Ambassador, Cancer Community Clubhouse

Shelley Fuld Nasso, MPP (Moderator)

CEO, National Coalition for Cancer Survivorship



The second panel discussion of the day examined the Medicare Advantage program and how it could be improved to better serve cancer survivors. The panel opened with the patient perspective, sharing a recorded video from Natalie Stevenson – a metastatic breast cancer survivor, NCCS CPAT member, and NCCS Elevate Ambassador – who qualified for disability and has a Medicare Advantage plan. She illustrated the benefits and challenges she has experienced as a Medicare Advantage beneficiary, including the lower costs of her plan but also the access issues she has encountered because of network restrictions and the inability to see a provider specializing in her type of cancer. While her latest test results showed no evidence of disease, she fears that a recurrence would require her to move to receive the specialized care she needs.

Next, the panelists described the landscape of Medicare Advantage plans, which enroll just over half of Medicare beneficiaries, and their impact on cancer care quality and access. Dr. Tricia Neuman gave an overview of Medicare Advantage trends in beneficiary usage, highlighting that a larger share of people from communities of color are enrolled in Medicare Advantage plans compared to less than half of white beneficiaries. She also pointed out that the Congressional Budget Office has estimated that 60% of the population will be enrolled in a Medicare Advantage plan by 2030, a projection she believes may be underestimated.

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Panelists examined trade-offs of Medicare Advantage plans, as well as potential concerns for patients. They highlighted tactics that plans use to draw people in, including offering extra benefits like dental coverage and gym memberships, inundating individuals with numerous plan options, and bombarding potential beneficiaries with aggressive and sometimes deceptive marketing. While these plans provide benefits like out-of-pocket caps on drugs, the use of prior authorizations is higher in Medicare Advantage plans, which can delay care for patients. John Shevock offered insight into the burden that prior authorization can have on providers as well. The process increases the workload and stress for providers, which is compounded by existing staff shortages in health care and the current drug shortages affecting patients.

The panelists also discussed proposed reforms to Medicare Advantage that would improve quality for cancer survivors. Dr. Zeke Emanuel proposed simplification and standardization across Medicare Advantage plans, including out-of-pocket expenses and deductibles, which he explained was done with Medigap plans. He also proposed removing deductibles and copays for cancer patients, for whom he said health care services are necessary rather than discretionary. Dr. Emanuel said, “We should not be discouraging people from taking their medications. We should not be discouraging people from getting the tumor markers or the scans or the exam they need... It should not be on the patient to decide this. It should be on the doctor.”



Dr. Neuman stressed the need for transparency and access to Medicare Advantage plan data with metrics on network scope and denials by type of service so that patients can effectively compare plans and make informed decisions. She also emphasized the importance of making reforms to traditional Medicare to sustain the program and make it a viable and competitive option for patients.

Drug Shortages

Kalah Auchincloss, JD, MPH

Executive Vice President, Regulatory Compliance
& Deputy General Counsel, Greenleaf Health

Chad Ramsey, MPA

Vice President, Policy

Ovarian Cancer Research Alliance

Ryan Spencer, MD, MS, FACOG

Associate Professor, University of Wisconsin
School of Medicine and Public Health

Marta E. Wosińska, PhD

Senior Fellow, Schaeffer Initiative on Health
Policy, The Brookings Institution

Shelley Fuld Nasso, MPP (Moderator)

CEO, National Coalition for Cancer Survivorship



In the final panel of the day, panelists engaged in a lively discussion about the impact of ongoing chemotherapy drug shortages on cancer patients and providers. They raised concerns about the lack of movement on this issue and discussed potential policy solutions to address the complex problems of market incentives and manufacturing quality.

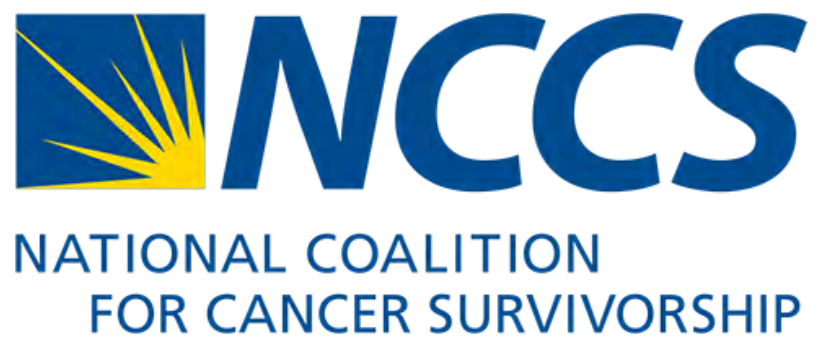
A recent survey conducted by the American Cancer Society Cancer Action Network found that 10% of cancer patients have experienced a drug shortage, but for certain populations of patients, larger proportions are affected by shortages. Many ovarian cancer patients, for instance, have been affected by drug shortages because the drugs on which they rely have been in long-term short supply. Chad Ramsey opened the panel by describing the experience of ovarian cancer patients that his organization represents and their efforts to help patients access the therapies they desperately need. Dr. Ryan Spencer, who has experienced the dramatic effects of drug shortages as a gynecologic oncologist, explained how the shortages have impacted patients as well as physicians as they make decisions about their patients' treatment. According to a survey of the Society of Gynecologic Oncology's member organizations, 98% of providers have had to talk to patients about chemotherapy shortages at least once, while 66% said that it was a daily occurrence. Both Ramsey and Dr. Spencer stressed that the current shortages have delayed treatment for patients or seriously limited their options.

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Reflecting on the current work on this issue and potential solutions, Dr. Marta Wosińska and Kalah Auchincloss acknowledged that the US Food and Drug Administration's (FDA) power to address drug shortages is somewhat limited and stressed the importance of addressing the root causes of the issue, which they said are systemic. Ms. Auchincloss explained some of the root causes, as well as tools the FDA can utilize when responding to drug shortages. Dr. Wosińska stressed that drug shortages have been an ongoing problem, stating, "our memory might be short, but there were definitely cancer shortages about a decade ago," and called on the advocacy community to keep the window open on this issue. She also discussed her recent proposal to involve CMS in providing payments to hospitals to prioritize reliability of manufacturing when purchasing drugs. She also proposes a pay-for-performance program where hospitals are rated according to what they do before a shortage.



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