# READOUT: Cancer Support Community (CSC) | 2025 Utilization Management Summit (June 10, 2025 | 10:00 a.m. – 2:00 p.m. ET)

On June 10, 2025, the Cancer Support Community (CSC) gathered patient and caregiver advocates, healthcare providers, policy experts, healthcare innovators, and thought leaders for the ***2025 Utilization Management Summit*** to discuss pressing healthcare issues of the moment and explore collaborative solutions that center patients, support providers, and strengthen our healthcare system – shaping the future of utilization management policy and practice.

The summit was part of the 7th year of CSC's Forum on Utilization Management, which was created to foster thoughtful dialogue to inform and engage a broad range of healthcare stakeholders in the creation and implementation of utilization management (UM) strategies that incorporate the patient and caregiver perspective and incentivize cost-efficiency through improved patient care and outcomes.

## Key Themes of the Event

Throughout the discussion, several themes emerged surrounding the need to broaden the engagement and education of patients, caregivers, survivors, payers, employers, policymakers, and other stakeholders. These efforts aim to increase access to care, protect patients from the potential negative impacts of UM practices, and ensure that the complexities of treatment and patient care are better understood and utilized in coverage and value decisions. To effectively protect patient access to care against the inappropriate use of utilization management practices, patient advocacy communities must work to:

- **Center the patient voice in value-based care models**. Human-centered, comprehensive care that is informed by patient priorities and integrates physical, emotional, and social support is critical to improving the patient experience and building trust within the healthcare system.
- **Prioritize whole person care to improve outcomes and community health**. Employers have an important role in supporting comprehensive care and workplace protections for people with chronic conditions to promote a healthy, productive workforce.
- **Increase transparency around the use and impact of Pharmacy Benefit Managers (PBMs) and utilization management practices.** Transparency and patient education are vital to protecting individuals from high out-of-pocket costs and access challenges.
- **Reduce financial barriers through structural and patient-centered reforms.** Policy solutions that eliminate profit-driven incentives in drug access and ensure the enforcement of existing patient protections are key to improving affordability and health outcomes.

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## Key Takeaways: Panel Discussions

### *PANEL 1: "Centering the Patient Voice: Defining Experience in a Changing Healthcare Landscape"*

*Speakers: Sally Werner (Moderator, CSC), Kyle Amey (Cancer Policy Advocate), Stephanie Broadnax Broussard (Thyme Care), Brandy Farrar (American Institutes for Research), Lisa Fitzpatrick (Grapevine Health)*

- **Healthcare policy must be informed by human-centered research and patient priorities.** Human-centered research that captures patients' lived experiences, goals, and barriers can help identify policy levers that improve patient care and outcomes.
- **Comprehensive patient care must be the standard, not the exception.** When choosing a treatment pathway and measuring health outcomes, it is imperative to address a patient's emotional and mental well-being, in addition to their disease. We must reframe access to social determinants of health assessments, distress screenings, psychosocial emotional support services, and referral and follow-up care as the standard of care, not as supplemental services.
- **Healthcare literacy and accessible patient education and communication build trust.** Practices must be put in place to increase patient education, as a lack of understanding leads to distrust, which then causes a lack of engagement in clinical trials, preventative care services, clinical care, and more.
- **Interdisciplinary models of care can impact utilization and improve health outcomes.** Delivering effective, value-based care means providing access to a full care team – primary care, specialists, patient navigators, social workers, community health workers, and more – who communicate and collaborate to break down barriers to increase treatment adherence, improving health outcomes.

### *PANEL 2: "Supporting the Whole Patient: Employer-Based Strategies for Oncology and Other Chronic Conditions"*

*Speakers: Kimberly Beer (Moderator, NHC), Melissa Bartlett (The ERISA Industry Committee), Millicent Gorham (Alliance for Women's Health and Prevention), Andrea Hans (NCCS), William Sarraille (University of Maryland Francis King Carey School of Law)*

- **Cancer care must go beyond treatment to include survivorship care, care coordination, workplace support, and more.** With over 18 million cancer survivors in the U.S., employer-sponsored plans must address long-term survivorship needs, including late-stage effect management, caregiving, mental health services, and workplace accommodations to support a resilient and productive workforce.
- **Obesity should be treated as a chronic disease in employer-based plans.** Coverage of comprehensive obesity care – including treatment, surgery, nutrition, mental health

support, and more – has the potential to increase productivity, and employee retention, and employee satisfaction.

- **Employers must support young adults with cancer and other chronic diseases through access, education, and workplace protections.** With an increasing incidence of cancer in young adults, employers must invest in providing access to preventative services, flexible accommodations, and benefit transparency. Education about available resources is critical to reducing the fear of discrimination that comes with disclosing a disease diagnosis and improving benefit utilization.
- **Greater transparency is needed in the 340B Drug Pricing Program and in PBM practices.** Employers and patients often face higher drug costs despite the promise of discounts under the 340B program due to a lack of transparency in rebates and contract pharmacy arrangements.

***PANEL 3: "The Cost of Access: Copay Assistance Programs, Policy Shifts, and the Future of Treatment Affordability"***

*Speakers: Rich Brennan (Moderator, The ALS Association), Anna Schwamlein Howard (ACS CAN), Charles Husser (Arthritis Foundation), Kaliesha Johnson (Medstar Washington Hospital Center), Allyn Moushey (ASCO)*

- **Increased transparency and clearer communication requirements are urgently needed to protect patients from copay accumulator assistance programs (CAAPs).** Patients often do not realize they are enrolled in a plan that uses CAAPs until they face high out-of-pocket costs or delayed treatment.
- **Patient education and navigation services are critical to reduce patient burden.** Navigating complex benefit structures and cost-sharing rules requires clear education through pharmacies and other patient-facing health care staff. Access to patient navigation can empower patients to make informed decisions and advocate for themselves.
- **State-level copay accumulator legislation is laying the groundwork for urgently needed federal reform.** With over half of U.S. states expected to pass legislation by the end of the year, state laws serve as important policy models and data sources to support federal action like the *HELP Copays Act*.
- **Patient stories are powerful tools for policy change.** Sharing real-life experiences and impacts helps policymakers understand the need to address complex issues like CAAPs, step therapy, prior authorization, and other UM practices.

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## *PANEL 4: "Pharmacy Benefit Management Reform: Untangling Access, Affordability, and Patient Impact"*

*Speakers: Conor Sheehey (Moderator, Leavitt Partners), Leslie Ritter (National Multiple Sclerosis Society), Carl Schmid (HIV+Hepatitis Policy Institute), Polly Webster (United States Senate Committee on Finance), David Weissman (National Community Pharmacists Association), Jess Wysocky (National Association of Manufacturers)*

- **Transparency is essential to drive reform and accountability.** There is an urgent need for greater transparency around PBM practices and their relationships with payers, sponsors, and third-party administrators. This visibility is key to developing effective, patient-centered solutions.
- **PBMs create misaligned incentives that undermine patient-provider decision-making.** Rather than supporting shared decision-making between patients and providers, PBMs often promote the use of higher-cost medications due to rebate-driven incentives. Utilization management tools like step therapy can increase costs and delay care, leading to poorer outcomes. Reform efforts related to delinking PBMs from rebate structures are critical to increasing patient access and reducing costs to the patient and the system overall.
- **Patient protections exist but are not being enforced.** Protections against harmful practices like excessive use of prior authorization and high-tier formulary placement are in place, but a lack of enforcement allows PBMs to continue limiting access. Direct regulation of PBMs and shifting fiduciary responsibility from insurers to PBMs could help correct these imbalances and increase access.
- **Employers need more transparency to support a healthy workforce and control costs.** Employers, particularly in manufacturing, where there is a strong need for workers, are committed to providing healthcare but lack insight into PBM practices and pricing structures. Policies requiring PBM transparency, delinking PBMs, and full rebate pass-through would empower employers to reinvest savings back into employee health, strengthening the healthcare ecosystem and supporting a healthier, more productive workforce.
- **PBM practices may undermine the intent of the IRA's Medicare drug price negotiations.** As the IRA's Medicare Drug Price Negotiation Program's pricing reforms are implemented, PBM practices may continue to favor highly rebated drugs over lower-cost alternatives, limiting patient access to drugs with a lower negotiated price.
- **Community pharmacies are essential access points, especially in rural areas.** Unlike many PBM-owned or chain pharmacies, community pharmacies often work directly with patients, serving as the first line of care and often providing direct support to help patients navigate affordability and access challenges. Policies should recognize and support community pharmacies as critical partners in ensuring access to medication.