PAN Foundation

Cost-Sharing Roundtable:
Improving Patient Access to Critical Therapies

Hosted by the PAN Foundation in collaboration with
The American Journal of Managed Care

Executive Summary

February 26, 2016 • 8:30am – 3:00pm

Kaiser Family Foundation's Barbara Jordan Conference Center

1330 G Street, NW, Washington, DC 20005

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Hosted by the Patient Access Network (PAN) Foundation and *The American Journal of Managed Care (AJMC)*, the Cost-Sharing Roundtable facilitated ongoing discussions about the growing burden of out-of-pocket (OOP) medical expenses in the United States. Invited speakers included representatives from advocacy organizations, academia, as well as the pharmaceutical and insurance industries. The meeting examined many challenges that are imposed on patients and families by increased cost sharing, and it explored potential solutions to these challenges. The daylong conference was held in Washington, DC on February 26, 2016.

Some Roundtable presentations featured data from national surveys, polls and targeted analyses of CMS data, while others offered lessons learned from state-level policy development efforts focused on cost-sharing. Advocacy organizations shared information about support programs developed to help their constituents cope with cost-sharing, and a panel discussion offered insights on cost-sharing. Despite the diversity of speakers, data sources and topics, a number of common themes emerged from the Roundtable, and these are explored in detail in PAN's Cost-Sharing Roundtable Proceedings Report. This Executive Summary provides an overview of these themes.

What do we know about cost sharing?

- The Affordable Care Act has shifted concerns away from problems associated with people who are *uninsured* to addressing the many challenges of people who are *underinsured*.
- Americans—even those with health insurance—are worried about how to pay for needed healthcare treatments and services.
- Cost-sharing is a major driver of Americans' concerns about being able to afford healthcare and pay their medical bills.
- Americans respond to cost-sharing burdens in many ways, including skipping doses of needed medications, delaying needed medical care or opting out of care entirely. Americans also cut expenses for food, heat and other necessities in order to pay their OOP medical expenses.
- The overwhelming financial burdens related to OOP medical costs are a major cause of personal bankruptcy in the United States.
- Many Americans have trouble understanding their health insurance benefits, including the link between their coverage and OOP expenses.
- Patients' efforts to negotiate payment plans for needed health services, to shop for competitive pricing for their treatment and other efforts to mitigate the impact of cost-sharing are rarely successful.
- Cost-sharing is implemented in a "one size fits all" manner it does not incorporate the concept of "value," and in many cases, it causes the greatest hardship for the most vulnerable populations.

» Among Medicare beneficiaries, the Part D prescription drug benefit has not kept up with the rapid advances in drug development and the accompanying costs associated with new products. Among other pressures, the rising cost of new therapies has contributed to increased cost-sharing, particularly for patients with chronic and rare diseases.

What does the newest research of the PAN Challenge show?

» Among Medicare beneficiaries with chronic myeloid leukemia, those with high OOP costs had significantly lower fill rates and significantly longer time to initiation of life-saving therapy compared to their counterparts with minimal OOP costs due to receipt of low-income subsidies.

» Redesign of health benefits at Covered California with respect to specialty drugs for the 2016 enrollment year—an effort led by advocacy organizations representing patients with HIV, multiple sclerosis, epilepsy, hepatitis C and other chronic conditions—demonstrated that patients can be shielded from the heaviest cost-sharing burdens while keeping premiums affordable for the entire enrolled population, but that sustainable access to care requires reductions in the underlying cost of new clinical technologies.

What do advocacy organizations say about cost-sharing and what are they doing to help?

» It is challenging for patients and families to understand the financial implications of the many strategies that health plans employ to implement cost sharing. These strategies include deductibles, co-payments, coinsurance, penalties for out-of-network care, step therapy and placement of certain drugs on specialty tiers.

» Accumulation of even modest OOP expenses can initiate a cascade of events that results in financial ruin for vulnerable populations, even when patients have health insurance coverage.

» The financial impact of cost sharing is often compounded by lost income due to illness, and this contributes to a downward spiral from which patients often can't escape.

» Effective treatment can be disrupted when patients transition to Medicare because certain medications are placed on specialty tiers and become out of reach due to high OOP costs.

» Advocacy organizations have seen a dramatic shift from problems associated with lack of insurance to those involving underinsurance, and they have developed a variety of programs to support patients with overwhelming OOP expenses.

» Advocacy organizations support their constituents by helping them to navigate the complex health insurance landscape, optimize the insurance they have, find more appropriate plans, and by connecting patients with external sources of support to cover OOP expenses.

- Patient advocacy groups collaborate with pharmaceutical companies, health insurance plans, and medical organizations to identify sustainable solutions to meet the needs of their constituents.
- Many advocacy organizations agree that problems with OOP costs can't be addressed with existing resources and programs.

What potential solutions to enhance access to critical therapies were offered at the Roundtable?

- Reducing specialty-tier drug costs by increasing lower-tier drug costs.
- Implementing strategies to more evenly distribute costs, and insulating Medicare Part D beneficiaries from high and variable cost sharing for specialty drugs.
- Enhancing efforts aimed at benefit redesign, including separation of deductibles for drugs and other medical expenses.
- Ensuring that at least one specialty drug in each therapeutic class is on a non-specialty tier.
- Limiting monthly OOP costs to a defined maximum.
- Implementing "reverse deductibles."
- Increasing prepaid care.
- Eliminating waste in the system.
- Enhancing the focus on value-based insurance design through an increased role for cost sharing that is based on clinical value and clinical nuance.

What is the bottom line?

- Roundtable participants acknowledged the importance of advocacy organizations and charitable assistance programs like PAN in supporting the needs of growing numbers of economically vulnerable patients with overwhelming OOP costs.
- There was widespread agreement that these organizations and supports will not provide a viable, long-term solution to the cost-sharing problem.
- To effectively address this complex issue, current efforts need to be supplemented by innovative, policy-based solutions that address cost sharing on a broader scale.

For more information about the PAN Challenge and Cost-Sharing Roundtable, contact Amy Niles, Vice President of External Affairs, at aniles@panfoundation.org.

About the PAN Foundation

The PAN Foundation is an independent, national 501 (c)(3) organization dedicated to helping federally and commercially insured people living with life-threatening, chronic, and rare diseases with the out-of-pocket (OOP) costs for their prescribed medications. Partnering with generous donors, healthcare providers and pharmacies, PAN provides the underinsured population access to the healthcare treatments they need to best manage their conditions and focus on improving their quality of life. Since its founding in 2004, PAN has provided more than 500,000 underinsured patients with more than $1 billion in financial assistance, through more than 50 disease-specific programs.

About The American Journal of Managed Care

The American Journal of Managed Care (AJMC) is an independent, peer-reviewed forum for the dissemination of original research related to financing and delivering healthcare. *AJMC*'s mission is to publish research relevant to clinical decision makers and policymakers as they work to promote the efficient delivery of high-quality care. *AJMC* addresses a broad range of issues relevant to clinical decision making in a cost-constrained environment and examines the impact of clinical, management, and policy interventions and programs on healthcare and economic outcomes. *AJMC* circulates to nearly 49,000 clinical decision makers in managed care, including physicians, hospital directors, and medical/pharmacy/formulary directors at managed care organizations.

The *AJMC* family of publications also includes *The American Journal of Accountable Care, Evidence-Based Oncology, and Evidence-Based Diabetes Management*. In addition to the print platform, *AJMC* also hosts live meetings and conducts panel discussions that bring together payers, pharmacy benefit managers, providers, patients, and healthcare policy experts, to ensure a continuing dialogue among key stakeholders.