



## Cost-Sharing Roundtable:

### The Patient Assistance Safety Net: How Many Need Help? How Many Are Helped?

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

# Executive Summary

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Kaiser Family Foundation's Barbara Jordan Conference Center

1330 G Street, NW, Washington, D.C. 20005

**N**ow in its third year, the 2018 Cost-Sharing Roundtable, *The Patient Assistance Safety Net: How Many Need Help? How Many are Helped?*, hosted by the Patient Access Network (PAN) Foundation and *The American Journal of Managed Care*® (AJMC®), was attended by a diverse group of participants and stakeholders with an interest in the challenges that result from high out-of-pocket (OOP) medication costs. The Roundtable was successful in continuing its role in providing a forum for presenters and panelists from health policy organizations, patient advocacy and provider organizations, health systems, charitable foundations, specialty pharmacies and the pharmaceutical industry to engage in thoughtful discussion about the financial hardships being faced by patients, and how these burdens can be mitigated. With a focus on Medicare beneficiaries and safety net organizations, the 2018 Cost-Sharing Roundtable also facilitated important conversations on illness-related financial toxicity and potential strategies to address this challenging and complex problem. This Executive Summary provides an overview of the daylong conference, which was held in Washington, D.C., on February 23, 2018.

Roundtable participants explored many aspects of financial hardship, with a sharp focus on the increasing impact of the financial toxicity that results from OOP costs for medical treatment. A major component of financial toxicity—OOP prescription drug costs—was discussed widely, as was the steep rise in the cost of specialty medications and the parallel increase in patients’ obligations to share in these costs. High-deductible health plans, specialty drug tiers, and other cost-sharing mechanisms were covered in the meeting. Various aspects of financial hardship were explored (e.g., psychological response and coping behaviors), as were the many impacts of these hardships (e.g. bankruptcy, medication nonadherence, poor health outcomes). Gaps in the existing literature on financial hardship were defined, and there was a call for additional research to fill these gaps and provide a solid evidence base to assess the effects of financial hardship on health outcomes in different patient populations.

As in past years, Roundtable discussions touched often on how increasing OOP costs limit access to treatment for Medicare beneficiaries. Issues such as the relationship between cost and access, problems with understanding and navigating the Medicare system, factors that inhibit beneficiaries from changing drug plans, and how patient assistance organizations are attempting to help were discussed, and system-level and short-term solutions were explored.

The 2018 Roundtable allocated significant time to exploring healthcare providers’ perspectives on the impact that their patients’ OOP medication costs have on clinical practice and patient outcomes. The importance of providing patients with financial navigation services was discussed at length, suggestions for optimizing this process were offered, and a case study showing results of a financial navigation system was presented. The question of whether financial considerations have an impact on clinical decision-making was also explored, as was the impact of cost on patients’ adherence to treatment and clinical outcomes. In general, providers expressed great concern about the ability of low-income patients

to access needed medications. Providers agreed that although the emergence of financial navigation would likely increase patients' understanding of their OOP expenses and that this support could connect patients with some needed resources, they also supported identification and implementation of longer-term solutions to the challenges that are created by high OOP medication costs.

Policy considerations that might mitigate patients' financial hardship were a frequent topic of discussion at the Roundtable, and several recommendations were made concerning how these hardships could be addressed. Implementation of value-based insurance design (VBID) was mentioned several times throughout the Roundtable, and participants generally agreed that incorporating financial incentives to use treatments that work could be a valuable tool for improving outcomes and reducing costs, with the added benefit of reducing financial hardship. The importance of safety net organizations, including charitable patient assistance organizations such as the PAN Foundation, was discussed, including how these organizations coordinate with each other to facilitate patient access to financial assistance for OOP prescription medication costs. The ability of another component of the safety net—federally qualified health centers (FQHCs)—to facilitate access to medications for underinsured patients was explored in depth. The role that these organizations play in facilitating access to treatment was the topic of this year's winning PAN Challenge paper.

Several important themes emerged from the 2018 Roundtable discussion, as follows:

### **Continued Importance and Vulnerability of the Safety Net**

- » As costs of treatment continue to rise, the safety net is becoming increasingly important
- » Patient assistance organizations cannot keep up with the rising demand for help with OOP costs, leaving some patients with nowhere to turn
- » The current safety net is a patchwork of resources, many of which are dwindling, or in jeopardy

### **Relevance of the Emerging Study of Financial Hardship**

- » Financial hardship continues to be a detrimental side effect of illness that may have a devastating impact on patient outcomes
- » Examination of the types and categories of financial hardship helps identify risk factors and possible intervention strategies
- » The importance of research on the impact of financial hardship is expected to increase in the future in parallel with decrements in the safety net and continued increases in prescription drug costs

## The Immediate Impact of Policy Changes on Medication Access

- » Certain emerging policies, such as high-deductible health plans and co-pay accumulator adjustor programs by health insurers, increase OOP costs for patients
- » Policies that might have an immediate impact on reducing OOP costs include implementing caps on OOP expenditures; addressing high drug prices; and updating the Medicare payment structure, including closing the donut hole
- » Uncertainties in the current policy landscape leave large numbers of vulnerable patients without a clear-cut path to ensuring ongoing access to needed treatments

## Continued Challenges for the Medicare Population

- » High OOP costs persist, including high coinsurance obligations, and costs are concentrated at the beginning of the year for many Medicare beneficiaries
- » The complexity of Medicare's benefit structure—especially for Part D drug plans—makes it hard for beneficiaries to choose the plan that best fits their needs, and it inhibits beneficiaries from changing plans to meet their needs
- » Scrutiny of patient assistance programs have made it challenging for organizations to assist a growing number of Medicare beneficiaries with their OOP costs for prescription medications

## The Burden of OOP Health Costs Extends Far Beyond Medications

- » Nonmedical OOP costs and logistics, such as transportation and childcare, greatly contribute to financial hardship and have a large impact on adherence to treatment
- » High OOP costs have an impact on housing and food security (ability to pay rent or buy food)
- » Even when treatment is complete, the lingering effects of OOP healthcare costs have a far-reaching impact on patients' lives

## The Growing Importance of Financial Navigation

- » Providing patients with financial navigation services is becoming increasingly important as OOP costs rise and resources provided by the safety net become more scarce
- » Financial navigation should begin early to manage patients' expectations and minimize financial toxicity as much as possible
- » Trained financial navigators can be effective in finding resources to help patients pay for their care, which helps both patients and hospitals

## Providers Face Increasing Challenges

- » Financial hurdles associated with paying for OOP costs for medications often result in treatment delays
- » Financial considerations may be a factor in choice of treatment plan
- » High cost of treatment results in patients not adhering to their treatment plan, which affects the disease course and worsens clinical outcomes

## Potential Policy Solutions

- » Several changes could be made to modernize Medicare to better meet the needs of patients:
  - Changing the Part D benefit structure to even out OOP expenses during the calendar year, eliminate the donut hole, and placing a hard cap on OOP costs
  - Eliminating the asset test for Medicare extra help programs
  - Improving patient education about plan choices
- » Trained financial navigation professionals should be used to help patients and their families with financial issues
- » Providing patients with the benefit of drug rebates at the point of sale
- » Placing zero co-pays on generic medications
- » Implementing value-based insurance design (VBID); limit co-pay amounts for high-value medications
- » Providing transparency in the prescription drug supply chain
- » Building in flexibility to allow people to change plans mid-year

One Roundtable participant predicted what health organizations will continue to face in trying to help economically vulnerable patients access medications by saying, “we’re going to struggle for a while.” This is an accurate, but troubling summary of PAN’s 2018 Roundtable discussions. Ongoing confusion about Medicare coverage, continued threats to an already-fragile safety net, and growing evidence of the extent and impact of financial hardship all suggest that challenges associated with securing access to needed treatments will remain a persistent problem into the foreseeable future. Although PAN and other stakeholders will continue to respond to these challenges to the greatest extent possible, Roundtable participants agreed that only sustainable, policy-driven solutions will be able to address these problems over the long term.