

## BACKGROUND

- The Inflation Reduction Act (IRA) created the Medicare Drug Price Negotiation Program (MDPNP), which allows the federal government to negotiate prices for select high-cost prescription drugs.
- To fully value clinical benefit, it is imperative for the Centers for Medicare & Medicaid Services (CMS) to gather as much input as possible from patients and caregivers, including their experiences, insights, preferences, perspectives, and outcomes.
- CMS established formal feedback channels, which Cancer Support Community (CSC) actively used to ensure patient/caregiver voices were represented.

## QUESTION ADDRESSED

**?** How can **patient and caregiver experience** be meaningfully incorporated into engagement opportunities offered by CMS to inform patient-centered drug pricing and coverage policy?

## METHODS

- CMS released initial guidance for the MDPNP in March 2023, followed by revised guidance in June 2023 that broadened opportunities for stakeholder input. In response, CSC convened its 2023 IRA Summit to help support and elevate patient-centered perspectives in the implementation of the program.
- CSC developed consensus-based principles, amplified in partnership with nearly 70 patient advocacy organizations that signed a joint letter urging CMS to ensure patients and caregivers have a meaningful and prominent voice in policy development and implementation, with the goal of aligning stakeholders on the definition of clinical benefit as the MDPNP is implemented. <https://bit.ly/CMSPatientEngagement>
- Identified CMS MDPNP engagement opportunities, including **Initial Price Applicability Year (IPAY) "Patient and Caregiver Considerations" requests for comment** and **patient listening session testimony**.
- Synthesized input into formal comments and testimony drawing on:
  - CSC's Cancer Experience Registry (CER) data, reflecting patient and caregiver experiences across sociodemographic and clinical factors, and how these may change over time;
  - Additional CSC psychosocial research (qualitative and quantitative) to gain deeper insights into patient/caregiver experiences across relevant cancer types;
  - Patient, Caregiver, & Patient Navigator input
  - Oncologist input and medical review; and
  - Published evidence, including National Comprehensive Cancer Network (NCCN) guidelines.

## CONTACT

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## LESSONS LEARNED



**Translating research into actionable, policy relevant messaging on patient caregiver perspectives of clinical benefit requires more time and coordination than anticipated**



**Aligning Cancer Experience Registry data, patient, caregiver, and navigator input, and medical review across specific drugs, cancer types, and CMS timelines is resource intensive**



**Bridging scientific evidence and lived experience requires careful framing to maintain credibility while elevating patient voice**



**Early preparation is critical; compressed timelines limit depth of patient engagement**



**CMS timelines are so tight, that patient advocates must start working on their testimony before they know whether they will be chosen to speak at a Roundtable**

### PATIENT-CENTERED ENGAGEMENT PRINCIPLES

- ❖ Engage patient advocacy organizations, patients and caregivers throughout the process
- ❖ Define clinical benefit around data that matters most to patients
- ❖ Develop critical infrastructure
- ❖ Refer patients to navigators
- ❖ Develop a monitoring and evaluation platform
- ❖ Collect and report specifically on access challenges facing patients
- ❖ Collect and incorporate meaningful data and real-world evidence
- ❖ Prioritize outreach to patients, people with disabilities, and people living in rural communities
- ❖ Consider the groups and populations that have not already engaged

"At 54, I felt like I was done with my manhood... I've been fighting this ever since, just taking it one day at a time. Now at 64, my wife tells me she'd rather have no intimacy than no Warren."

– a patient's experience shared to CMS in our prostate cancer roundtable testimony

## CONCLUSIONS

- Patient-centered engagement with CMS is feasible and impactful but requires substantial infrastructure and coordination, posing challenges for individual patients, caregivers, and smaller advocacy groups.
- Robust, diverse patient and caregiver perspectives are critical to informing clinical value.

## NEXT STEPS

Adjusting the MDPNP engagement process timeline is necessary to allow more time for collection of patient/caregiver input and their direct participation in IPAY and listening sessions for meaningful engagement.

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