PATIENTS RISING

Sharing Your Lived Experiences

for CMS Roundtables

Terry Wilcox

Co-Founder and Chief Mission Officer

Patients know better than anyone what works and what doesn't, what they can live with and what they can't. When pricing decisions are made without listening to patients, we end up with policies that look good on paper but fail in practice. CMS has opened the door for patient input. We need to walk through it.

Your Experience as Evidence

Cost is not the same as value. A medication's price tag doesn't capture its value to the patient who can work again, care for their family, or avoid a hospital stay. Only patients can explain what access means, and what losing it would cost.

CMS needs to hear that patients aren't just line items in a budget. Your quality of life, your independence, your ability to function—none of that shows up in a cost-effectiveness calculation. But it matters.

Your Voice Can Protect Access to the Treatments That Work

When the government negotiates drug prices, those decisions don't just affect Medicare budgets—they affect whether patients can access the medications keeping them alive, stable, and functional.

That's why the Medicare Drug Price Negotiation Program includes formal opportunities for you to share your real-world experience directly with the Centers for Medicare & Medicaid Services, aka, the CMS. Without patient voices, pricing decisions are made using only cost models and clinical data—which can't capture what it means to finally find a treatment that works, or what happens when that access disappears.

Sharing Your Diagnosis

When you introduce your diagnosis, you are also introducing the people who live inside it with you, including caregivers, partners and family members. Keep this under 30 seconds.

- State your condition plainly and briefly.
- Mention how long you have been living with it.
- If relevant, name your role in your family, for example parent, spouse, caregiver to someone else.
- Acknowledge that your diagnosis affects more than just you.

Example framing, not a script:

"I was diagnosed with ___ ___ years ago. I manage this condition daily, and my care also involves my family and caregivers who help me stay on treatment and functioning."

Your Life

The most effective stories focus on how you build your routines, maintain your quality of life and overcome the obstacles associated with your care.

- Think about what a normal day requires because of your diagnosis.
- Explain the limits, routines and advance planning that shape your day and may not be visible to others.
- Talk about how energy levels, pain, mobility or cognitive load affect your ability to work, travel, rest or participate in daily activities.
- Note how your schedule is often built around treatment, symptoms or recovery time rather than convenience.
- If applicable, explain how caregivers are part of this daily structure, including reliance on another person for transportation, reminders, monitoring or care coordination.

If CMS remembers one thing from my story, I want it to be:

____

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Your Medication

As you talk about what it means to you, and your quality of life, when you have access to your medication, you're creating a personal narrative that humanizes your experience.

- Describe what your medication allows you to do that would otherwise be difficult or impossible.
- Explain how treatment supports stability, predictability or independence in your daily routine.
- Describe how symptom control, prevention of flare-ups or reduced side effects change how you plan your days or weeks.
- Note whether effective treatment reduces emergencies, additional appointments or disruptions.
- If applicable, explain how stable treatment also reduces the workload on caregivers or family members.

If CMS remembers one thing from my story, I want it to be:

Your Medication + Life

Consistent access to medication is what allows routines to hold. Describing periods when treatment was delayed, interrupted or unavailable helps clarify what breaks when that stability is lost.

- Describe what daily life looked like before you had access to this medication or during periods of delay, switching or interruption.
- Focus on instability, including disrupted routines, increased symptoms or loss of predictability.
- Explain how gaps in access affected your ability to work, manage responsibilities or maintain consistency in care.
- Note whether those periods increased reliance on caregivers, additional medical visits or crisis management.

When access is delayed, restricted, or uncertain, it affects me by:

____

Examples (physical, emotional, financial, practical):

____

Written Comments

Written comments are also a powerful way to participate. You don't need medical records, scientific citations, or legal language. CMS is looking for something only you can provide: your real-world experience.

Share your story. Explain your condition or diagnosis (general terms are fine). Describe how you arrived at your current treatment—what you tried first, what worked, what didn't. Talk about what this medication allows you to do. Work. Care for family. Function independently.

If access has been disrupted—through delays, insurance denials, or forced switches—describe what happened and how it affected your health. If losing access to this medication would mean going backward, say so. Be specific. Concrete examples carry more weight than general statements.

Reassurance

Feeling nervous in a policy discussion is normal, especially when talking about personal health experiences in a professional setting. Keep in mind that CMS is listening for insight into how policy decisions play out in real life, and there is no expectation that you speak perfectly, cover every topic or represent anyone beyond your own experience.

If you feel nervous:

- Remember that you are the subject-matter expert on your own care.
- Pause before answering; taking a moment to think is appropriate.
- Stay grounded in what you know directly, your daily routines, your treatment experience and how access affects your life and family.

If I feel nervous, I can stay grounded by:

____

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Your experience is valid. Your voice belongs here.

Closing Thoughts

As you wrap up, it helps to return to the big picture. You do not need to summarize everything you shared or make a recommendation. A brief closing thought can reinforce why your experience matters and what stability in care allows you and your family to do.

Good closing thoughts often:

- Emphasize the importance of consistency and predictability in care
- Reflect on how access supports daily functioning and quality of life
- Acknowledge that policy decisions have ripple effects beyond the patient

If it feels natural, you can end by naming what works when the system works well, or what becomes difficult when access is disrupted. One or two sentences is enough.

Your closing does not need to persuade. It simply helps decision-makers leave the conversation with a clear understanding of what is at stake in real life.

If given the opportunity, I would like to end by saying:

PATIENTS RISING

Together in Community. Stronger in Impact.

SCAN HERE

The Patients Rising Circle Community connects you to events, workshops and opportunities that amplify your voice in policy.