

Action Steps for Patients

Patients looking to contribute to the conversation about drug affordability and Upper Payment Limits (UPLs) can start here.

This info, along with our (coming soon!) **Social Media Sample Posts, PDAB Letter Template, PDAB Policy Resources, and Submitted State Comments and Coalition Letters**, offers a straightforward way to help inform your thoughts and concerns, share your experiences, and actively participate in shaping policies that directly impact patient care and access. We will be posting all of these documents and items to this Resource Center soon.

Stakeholder Engagement: Engaging a wide range of stakeholders—including patients, healthcare providers, insurers, and policymakers—is crucial for Prescription Drug Affordability Boards (PDABs) and the legislators who approved them to fully grasp the comprehensive effects and address how Upper Payment Limits (UPLs) can potentially disrupt the interconnectedness of programs for vulnerable communities. The importance of person-first voices cannot be overstated. Understanding that unintended access implication for patients can outweigh the benefits of healthcare cost management strategies is essential.

Patient Access and Impact: Concerns about how cost containment measures affect patient access to medications—particularly for chronic, severe, rare, and orphan conditions, are common. There's a focus on ensuring that policies do not inadvertently reduce the quality of care or unnecessarily limit access to essential health medications or treatments.

Remember, your story has the power to inspire change and make a real difference in shaping policies that can improve the lives of countless others facing similar challenges.

Providing Testimony: Sharing your experiences and providing testimony in forums can be a powerful way to contribute, but it often means disclosing or talking about your health status—and that's a step that can be daunting, given the real potential for stigma or discrimination.

In fact, across many states, town halls need to be more attended and populated. The times they're held and

equally valid can limit participation, as can the personal agency of some very vulnerable groups.

For those considering participation, it's essential to weigh the impact of your voice against the personal considerations of privacy and the challenges of public disclosure. Encouraging the submission of written testimonies might provide a more accessible and comfortable avenue for all individuals to contribute meaningfully to the dialogue.

Data and Evidence-Based Decision Making: Reliable data—both qualitative and quantitative, encompassing real-world insights and person-first perspectives—is critical to inform policy decisions. This includes gathering data on drug pricing, healthcare utilization, patient outcomes, and the economic impacts of proposed measures, as well as evaluating how programs could serve as patient assistance or alternative funding sources for out-of-pocket costs. To fill gaps in their understanding, states often seek input from a wide range of sources, including patient surveys and healthcare industry analysis.

Policy Implementation and Review: States exploring Upper Payment Limits (UPLs) or those that currently give their Prescription Drug Affordability Boards (PDABs) the authority to set a UPL, along with other cost containment measures, typically undergo a process of policy development, implementation, and ongoing review. This process includes assessing the effectiveness of policies in achieving their goals, such as reducing healthcare costs without compromising patient care and making adjustments as necessary based on feedback and observed outcomes.

Learning from Other States: States like Minnesota may look to the experiences of others, such as Colorado, Oregon, and Maryland, to learn from their approaches, challenges, and successes. This can help tailor policies to address their healthcare systems' and patient populations' specific needs and circumstances.