EACH PIC COALITION

September 23, 2026

Colorado Prescription Drug Affordability Board
Colorado Division of Insurance
1560 Broadway, Suite 850
Denver, CO 80202

RE: Public Comments on the Patient Engagement Toolkit

Dear Members and Staff of the Colorado Prescription Drug Affordability Board:

The Ensuring Access through Collaborative Health (EACH) and Patient Inclusion Council (PIC) is a two-part coalition that unites patient organizations and allied groups (EACH), as well as patients and caregivers (PIC), to advocate for drug affordability policies that benefit patients.

We appreciate the efforts of the Prescription Drug Affordability Advisory Council (PDAAC) to improve patient engagement. Representatives from EACH/PIC and other patient organizations have participated in the Stakeholder Working Group because we believe better engagement can help the PDAB understand the real-world affordability and access challenges patients face and identify policy solutions that address those challenges.

Unfortunately, we have significant concerns with the current draft of the PDAB Education & Patient Engagement Toolkit. Patient organizations that participated in the stakeholder process were not provided an adequate opportunity to review and provide feedback on the current draft before it was advanced for final approval. This is particularly concerning because the toolkit itself envisions an ongoing role for community partners and organizations in connecting patients with the board.

More importantly, the current draft does not provide patients with a complete understanding of the board's work or how its policies may affect them. In particular, it does not adequately distinguish between payer spending and patient out-of-pocket costs when describing Upper Payment Limits (UPLs), nor does it meaningfully address potential unintended consequences for patient access.

As organizations entrusted by patients to provide accurate information and advocate on their behalf, we cannot in good faith distribute or promote educational materials that we believe could leave patients with a misleading understanding of policies that may directly affect their care. We therefore urge the board not to finalize the toolkit in its current form and to provide patient organizations a meaningful opportunity to review and recommend revisions.

The Toolkit Must Clearly Distinguish Payer Costs from Patient Costs

The most significant deficiency in the draft is its explanation of UPLs. The toolkit explains that a UPL is “the maximum amount that can be paid or charged for a prescription drug in Colorado” and describes how the board establishes one after determining that a drug is unaffordable for Colorado consumers. What it does not adequately explain is the critical distinction between what an insurer or other payer pays for a medication and what an individual patient ultimately pays out of pocket.

That distinction is essential for any material intended to educate patients. A UPL may alter what insurers or other entities within the healthcare system pay for a medication, but it does not itself cap a patient's out-of-pocket obligation or guarantee that a patient's costs will decrease. As we have consistently emphasized, system savings and patient savings are not interchangeable.

Without that context, the toolkit risks creating an expectation that does not reflect what the policy actually guarantees. A patient reading that the board has determined their medication "unaffordable" and may then establish a maximum amount that can be "paid or charged" could reasonably conclude that the board is establishing a limit on what they will pay.

At minimum, the toolkit should plainly explain what a UPL regulates, whose payments are directly affected, and that a UPL does not guarantee a reduction in what an individual patient pays.

Patients Should Be Informed About Potential Access Consequences

The toolkit also presents UPLs without adequately informing patients about potential unintended consequences. Patient education should not presume that a UPL will either benefit or harm every patient. It should, however, provide patients with enough information to understand how implementation could affect their coverage or access and what changes they should report to the board.

UPLs can create incentives for insurers to respond through changes in formulary placement, utilization management, coverage, or other benefit design decisions. These changes can result in treatment disruptions or non-medical switching for patients. The omission is especially notable because the toolkit itself tells patients that their experiences with delays, denials, prior authorization, step therapy, switching, and other access problems are relevant information to share with the board. If these experiences are important enough for the board to collect during affordability reviews, patients should also understand that changes in coverage and access are important outcomes to monitor as the board implements its policies.

A credible patient education resource should therefore explain what a UPL is intended to accomplish while also acknowledging what it does not guarantee and the potential access changes patients should be prepared to identify and report.

Meaningful Engagement Requires Meaningful Partnership

These substantive problems also demonstrate why patient organizations must be meaningfully involved in developing patient-facing materials, not simply asked to help distribute them.

Patient organizations have continued to participate in this process because we want patient engagement to succeed. But meaningful collaboration must include the ability to identify substantive concerns and have those concerns addressed before materials are finalized. Asking organizations to help reach patients without giving them a meaningful opportunity to help ensure the information being provided to those patients is accurate is not the partnership envisioned through this process.

We recognize that declining to use the current materials may be characterized as an unwillingness to collaborate. That would misunderstand our concern. Our responsibility to

patients requires us to provide them with complete and accurate information, even when doing so means disagreeing with the board or asking that additional work be done.

We respectfully urge the board to return the toolkit for additional stakeholder review before final approval, provide participating patient organizations a meaningful opportunity to recommend revisions, clearly distinguish payer spending from patient out-of-pocket costs, and provide patients with balanced information about potential access consequences associated with UPL implementation.

We remain committed to helping the board build a credible and effective patient engagement process. Doing so requires educational materials that patients and the organizations they trust can confidently use.

Thank you for your consideration.

Sincerely,

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