



January 7, 2025

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

RE: Public Comments on the Stakeholder Workgroup Recommendations

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

On behalf of the Ensuring Access through Collaborative Health (EACH) and Patient Inclusion Council (PIC), we are pleased to submit information to the board on the recommendations set forth by the PDAAC Stakeholder Workgroup on patient engagement. We have provided our comment letter that was submitted to the PDAAC below, prior to the final workshop, so that the board can review and consider our feedback in whole.

In addition to the feedback below, we would also like to emphasize and support the recommendation made by the Color of Gastrointestinal Illnesses in their comment letter submitted in conjunction with the last workshop. We also urge the board that if, “data indicates that an Upper Payment Limit will not resolve the affordability challenges facing patients, the PDAB must be open to considering whether an affordability review is a constructive use of its resources.”

We appreciated the opportunity to participate in the workgroup sessions and shape recommendations intended to strengthen patient engagement and transparency. Ultimately, however, the success of any policy changes will depend on how they are implemented and modeled by the board itself. The board sets the tone for how patient organizations and patients are viewed, engaged, and treated throughout the PDAB process.

We urge the board to foster a culture of trust, respect, and consistency. Any policies related to transparency or conflicts of interest must be applied equally and universally. Patient organizations play a critical role in elevating lived experience, and effective engagement depends on the board demonstrating that those perspectives are valued and welcomed.

At every stage, including identifying solutions, affordability should remain centered on patients and the realities they face in accessing and affording their medications. We offer these comments based on both our workgroup participation and our broader experience engaging with PDABs nationwide, in the spirit of supporting a credible, inclusive, and patient-focused process.

Thank you for your consideration. We remain available as a resource as the board continues its work and look forward to seeing the updated draft.

Sincerely,

Sifany Westrich-Robertson



Tiffany Westrich-Robertson
tiffany@aiarthritis.org
Ensuring Access through Collaborative Health (EACH) Coalition Lead

A handwritten signature in black ink that reads "Vanessa Lathan".

Vanessa Lathan
vanessa@aiarthritis.org
Patient Inclusion Council (PIC) Coalition Lead

December 9, 2025

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

RE: Public Comments on the PDAAC Report Best Practices for Patient Engagement

Dear Members of the Colorado Prescription Drug Affordability Advisory Council (PDAAC):

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.

Successful Reforms Center Patient Experiences

Our goal is to ensure that policy interventions, particularly those developed by Prescription Drug Affordability Boards (PDABs), are informed by the realities patients face in affording and accessing their medications.

Patients across the country have reported that the way affordability is currently assessed often does not reflect their lived experience. Common tools tend to ask yes/no questions about whether a single drug is “affordable,” without asking why a patient perceives it that way. This lack of qualitative insight can lead to affordability determinations and policy responses that do not address the underlying drivers of hardship.

We share the council’s commitment to lowering prescription drug costs for Coloradans. Achieving that goal requires a process that starts with and ends with patients. The advisory council and board must focus on patients’ lived experience, their real barriers, and addressing the challenges they report are the cause of affordability issues. We welcome the opportunity to collaborate on designing improved patient engagement processes for future reviews.

Item 1. Enhance the PDAAC's Scope

While we applaud the council for recognizing that patients must be included in the metrics that the board should consider when selecting drugs for affordability review, we caution that providing a summary of patient feedback is not enough. Specifically, the same rigor applied to data collection during drug reviews should also apply at this stage, including clear metrics for evaluating patient responses. Accordingly, the recommendation to “conduct a trend analysis to identify drugs patients recommend for review” should be revised to better determine not only if affordability challenges exist, but what is driving those challenges so that appropriate policy remedies can be sought.

Our [Patient Experience Survey](#) demonstrates why rigor in data collection is essential at this early stage:

- Affordability is often disconnected from drug cost. Patients across all cost ranges—including those paying \$0–\$10—reported unaffordability driven by insurance changes, denials, and broader medical expenses.
- Affordability and access are intertwined. Among patients who said they stopped taking a drug for affordability reasons, 100% cited insurance-related barriers, not price itself.
- Insurance design and financial assistance—not drug type or price—are the strongest predictors of affordability. Seventy-one percent of patients using specialty drugs with financial assistance reported affordability, compared to only 38% without assistance.
- Several respondents cited unaffordability based on opinions about the retail cost of drugs, not their actual out of pocket costs.

These findings illustrate that focusing narrowly on the price of an individual drug will not address the core issues patients face. Expanded engagement early in the process can also help identify correctable barriers, such as utilization management practices, accumulator policies, or lack of access to assistance programs, long before policy decisions are made.

Additionally, we recommend that all raw patient input collected by the council or board be made public in its full, unedited form (with appropriate privacy protections). As we have observed in other states, summarized or filtered data often lacks the nuance needed to understand patient experiences and can unintentionally distort the meaning of patient testimony.

Item 2. Establish a PDAB Patient Engagement Toolkit

We appreciate that several of the recommendations outlined in this section reflect the same best practices we have consistently advanced nationwide. We stand ready to collaborate with the council and the board to help shape patient-facing resources and ensure they are accessible, accurate, and aligned with how patients communicate and share their experiences.

However, for this collaboration to be effective, it must be accompanied by a good-faith commitment from board members to respect the contributions of patient organizations. In past Colorado PDAB processes, some patient organizations have experienced skepticism or dismissal of their perspectives. A successful engagement toolkit requires not only strong materials, but also a culture that values and trusts patient-centered expertise.



Furthermore, even the strongest toolkit will fall short without a practical, well-funded outreach strategy. Without dedicated resources for public education, advertising, and community outreach, patient engagement efforts will not break through the crowded landscape of information competing for public attention. Meaningful engagement requires proactive and adequately resourced communication.

Regarding patient-facing surveys and focus groups, we appreciate the council's willingness to collaborate with patient research partners (PRPs) on data collection efforts. As a reminder, a PRP is a patient who has experience working with research teams and whose expertise should be considered equal to other professionals; they are not advisors. The Patient Inclusion Council (PIC) is positioned to help the council identify individuals with this level of experience.

Item 3. Create a Communication Network

Expanding engagement channels is an important goal, but the process for selecting outreach partners must be broad, transparent, and inclusive. Ensuring that no group is marginalized, particularly groups raising concerns about current PDAB processes, is essential for a credible and inclusive engagement network.

Item 4. Provide Additional Assessment Information

We again urge the council to move beyond summaries and instead provide full transparency by publishing all survey responses and input materials, with appropriate redactions for privacy. As our Patient Experience Survey illustrates, open-ended narratives are often where the real insight resides.

Summaries that lack context behind affordability challenges or identify underlying access barriers tend to flatten nuance, making it difficult to understand the real drivers. Transparency is a foundational requirement for trust, both among patient communities and within the broader stakeholder ecosystem.

Item 5. Promote a Process for Voluntary Disclosure of Conflicts of Interest (COI)

We appreciate the council's acknowledgment that the board has on more than one occasion demonstrated an attitude of dismissal and distrust towards patient organizations. We broadly agree with the underlying belief of the duality of interest approach - that all stakeholders have merit and deserve to share their views.

However, we strongly caution that implementing new disclosure requirements will only be effective if the board first demonstrates a commitment to treating all organizations, even those with "dual interests", with respect and without presumption of bias.

A voluntary disclosure framework can help build trust, but only if it is applied universally and is paired with meaningful cultural change within the board. Further, we urge that all COI statements should be open ended to allow submitters to provide context regarding the acceptance and use of any and all donor funding.



Without such change, additional disclosures risk being misused to marginalize stakeholder voices rather than enhance transparency. We urge the council to recognize that creating a culture of trust is not the responsibility of stakeholders alone, the board must lead by example.

Conclusion

Thank you for your ongoing work to improve drug affordability. We look forward to the opportunity to work alongside you to ensure that affordability reviews translate into meaningful improvements in patient access, equity, and health outcomes.

Sincerely,

A handwritten signature in cursive script that reads "Tiffany Westrich-Robertson".

Tiffany Westrich-Robertson
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Ensuring Access through Collaborative Health (EACH) Coalition Lead

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