



# ENSURING ACCESS THROUGH COLLABORATIVE HEALTH

September 22, 2024

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

RE: Comments on Affordability Review Rule and Affordability Review Policy and Procedure Redlines

Dear Chair Mizner, Members of the Colorado Prescription Drug Affordability Board (PDAB), Stakeholder Council (PDAAC), and Board Staff:

We appreciate efforts by the board, staff, and the PDAAC to revisit board policies and procedures around affordability reviews. While we know the outlined changes to board policies aim to improve the process, we are concerned that the procedures around patient engagement still fall short of ensuring patient perspectives are a critical part of the affordability review process. They also lack adequate opportunities for patients to engage directly with the board.

On behalf of our member network and the patients we collectively represent, we urge the board to make significant changes to the policies the board has proposed around patient engagement and also address feedback that patient organizations and advocates have shared throughout the initial round of affordability reviews.

As written, the board policies seem to *allow* for patient engagement but do not *require* specific measures to be a part of the process. We recommend updating the language in the patient engagement section to reflect that the board “shall” engage in the activities outlined, not “may.”

Additionally, we recommend specific requirements or minimum thresholds for public outreach, rather than a laundry list of options board and staff may elect to employ. The board should be required to seek public comment through at least three of the items outlined in the redlined section before an affordability review can proceed.

Similarly, we urge the board to implement minimum requirements for public engagement. The board should be required to hold meetings, focus groups, or other scheduled events at varied times and locations to ensure members of the public are given adequate opportunity to attend. Additionally, focus groups and surveys should have basic parameters for both structure and participant numbers to be considered representative of the viewpoints of the public.

We also believe that comments on affordability reviews should be open to any patient, or caregiver of a patient, who has the condition that is treated by the medication under review. Restricting comments only to those who have been prescribed the treatments precludes comments from patients who have taken the medication in the past, those who were prescribed the medication but were unable to access it due to insurance requirements, and those who might need access to the treatment in the future, all of which are critical viewpoints on the affordability review process.

We urge the board to also allow testimony from patient advocacy organizations about the patient experience on behalf of the patient populations they serve. Many patients hesitate to participate in public sessions due to the intimidating nature of the process and the requirement



## ENSURING ACCESS THROUGH COLLABORATIVE HEALTH

to disclose their personal health status. Patient organizations that understand the life cycle of disease from the lens of prevention, diagnosis, and disease management can offer critical input and perspectives on patient needs.

Additionally, through our coordinating Patient Inclusion Council (PIC), which is a coalition led by patient organizations active on EACH and consists of patient and caregiver members, aims to help equip the non-traditional advocate with skills and confidence training so they feel empowered to get involved. However, if they are still reluctant, patient organizations through PIC are dedicated to providing additional methods to collect their perspectives (i.e., phone recordings, written story submissions, patient facing survey).

As we have outlined during multiple meetings and comments, we believe that the patient survey utilized by the board for the first round of affordability reviews demonstrated fundamental issues in both question design and analysis that lacked opportunity for patients to provide any context regarding “why” a drug was considered affordable or unaffordable . We urge the board to address the inadequacies identified by multiple patient research partners and patient organizations. While the board elected to proceed with the original survey design for the sake of consistency across the first round of affordability reviews, now that the first round of reviews has concluded, it would be irresponsible to continue with a design that is lacking.

We are submitting to the board, as an attachment to this letter, an alternative survey design created by patient research partners and patient organization leaders in our Patient Inclusion Council, which was also reviewed by research professionals for accuracy. We urge the board to consider this survey and design, which aims to accurately capture patient perspectives, including identifying the missing affordability “why”. *As staff may engage party consultants to assist in compiling an/or analyzing the data, we encourage the board to lean on our coalition to assist as an advisor with these efforts - including utilizing our patient research partners to assist designing an improved survey and to help analyze qualitative data for context.*

Finally, we also firmly believe that board members must participate directly in engagement sessions with patients. Staff reports are not sufficient to convey the messages from patients and opinions of the board based on their personal interactions with patients, or based on personal beliefs, is insufficient. As patients are the constituency the board purports to serve, there should be no barriers between the members and the patient populations that will be impacted by their decisions.

We look forward to providing additional context during the Stakeholder Meeting and submitting additional comments prior to the October 18th board meeting. If you have any questions or would like to discuss any points prior to that meeting, we would be pleased to make ourselves and our members available for discussion.

Sincerely,



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