

Prescription Drug Affordability Advisory Council & Stakeholder Workgroup Meeting

October 14, 2025

October 14 PDAAC & Stakeholder Workgroup Agenda

The purpose of this meeting is to develop initial recommendations for actionable, feasible, and transparent practices for improving patient engagement during the Prescription Drug Affordability Board's (PDAB) affordability review process.

PDAAC Business

12:00 - 12:10 pm

- *Call to Order, Roll Call, Minutes Approval*
- *PDAAC Update*
- *PDAB Member Report Out*

Stakeholder Workgroup Session 1

12:10 - 3:00 pm

- *Workgroup Introduction*
 - *Workgroup participants will introduce themselves using a Google form.*
- *Workgroup background, purpose, and goals*
- *Overview of workgroup objectives and scope*
- *Workgroup discussion on best practices and recommendations*
- *Next steps*

The Council may meet in Executive Session to receive legal advice, pursuant to section 24-6-402(3)(a)(II), C.R.S.

If you are in need of an accommodation to access PDAAC meetings or materials, please notify staff at dora_ins_pdab@state.co.us.

Board members of the Prescription Drug Affordability Board may attend the October 14, 2025, Prescription Drug Affordability Advisory Council Meeting and may participate in the meeting.



PDAAC Business

Call to Order

Roll Call

April 24 Meeting Minutes Approval

PDAAC Update

PDAAC Business

PDAB Member Report Out

Stakeholder Workgroup Session 1

Stakeholder Workgroup

Meeting Facilitation & Rules of Engagement

Introductions

- Please introduce yourself by filling out the linked form in the chat.

Meeting Facilitation

- Today's meeting will be facilitated by Dr. Kimberley Jackson, PDAAC chair, and Dr. Amy Gutierrez, PDAB member.
- Workgroup sessions will be recorded and published on the PDAB website.
- All comments from workgroup will be shared with the Board.

All participants are encouraged to share recommendations based on their own experience and expertise.

- To allow space for all participants to engage, please virtually raise your hand and you will be called on in order.
- Use the chat to add to the conversation.

Norms

- Share the air - please be mindful of your speaking time and allow space for others to share.
- Listen to understand.
- Address issues, not people. This meeting is intended to be solutions-focused.
- Please try to stay on topic - Staff will use a parking lot to capture off-topic ideas.
- If staff needs to move to another topic in the interest of time, there is still opportunity to provide written feedback after the meeting.

Stakeholder Workgroup

Background, Purpose, & Goals

Before beginning the second round of affordability reviews, the Board asked staff to organize a stakeholder workgroup to provide suggestions for developing a framework for capturing patient data in a holistic, standardized manner.

The Board must consider input from specified stakeholders during affordability review:

- Patients and caregivers affected by the condition or disease that is treated by the prescription drug under review by the Board, and
- Individuals who possess scientific or medical training with respect to a condition or disease treated by the prescription drug under review by the Board.

Stakeholders expressed challenges with the following themes regarding stakeholder engagement during the first round of affordability reviews:

- **Trust** - Build trust and rapport with PDAB stakeholders and adopt a culture of process improvement.
- **Clarity** - Establish clarity for patients regarding what input the Board is seeking and how feedback will be used.
- **Analysis** - Ensure that patient feedback is considered and patients feel their input is heard by the Board.

PDAB members and staff are committed to improving processes to address the feedback we have received.

Stakeholder Workgroup

Meeting Goals

Meeting 1

- **Goal:** Develop initial recommendations for actionable, feasible, and transparent practices that meet workgroup objectives.
- Staff will prepare a draft report that includes workgroup recommendations and publish before the second meeting. Public comment is welcome on the draft report and will be shared with the stakeholder workgroup for further discussion.

Meeting 2 - December 11 from 9am-12pm (tentative)

- **Goal:** Review the draft report, identify if all objectives are met, and suggest any final changes. Identify any voices that are not captured in the Board's current work and help formulate recommendations on how to include them.
- Individuals who wish to provide feedback, but are unable to attend the meetings, may submit written comments to the workgroup.

Final Work Product

- A report to the Board outlining recommendations for best practices and process improvements for the PDAB's future affordability reviews.
- Staff will present the workgroup's report to the Board at a future PDAB meeting and will work with the Board to identify applicable next steps for implementation.

Overview of Workgroup Objectives & Meeting Format

Objectives include identifying best practices for the following:

- **Tools** for collecting patient experience information (e.g., surveys, meetings, etc.)
- **Timeline** for collecting patient information
- **Outreach and communication** for establishing clear communication channels with collaborators
- **Assessing information** received from stakeholders
- **Conflicts of interest** disclosure from stakeholders

The following information is included with each objective:

-  **Round 1 Affordability Review Outcomes:** An overview of what the Board did during the first round of affordability reviews.
-  **Stakeholder Suggestions:** Improvements suggested by stakeholders.
-  **Research:** An overview of initial research about each objective, including methods used by other organizations, such as: CMS, HCPF, CDPHE, PhRMA, NASHP, other state PDABs, etc.
-  **Recommendations for Round 2:** Guiding discussion topics for the workgroup.

Objective 1: Tools to Collect Patient Experience Information

Affordability Review Outcomes & Stakeholder Suggestions



Affordability Review Outcomes

Surveys

- The Board distributed two surveys for each drug under review. Surveys were not drug-specific and intended to capture the health and financial impacts of a prescription drug on patients.
- 375 patient and caregivers | 72 from Colorado
- 25 individuals with scientific or medical training

Focus Groups

- 46 patient and caregivers
- 31 individuals with scientific or medical training



Stakeholder Suggestions

- Improve survey questions about utilization management practices to get to “why” patients report unaffordability issues.
- Include patient advocacy groups in the development of survey questions.
- Improve patient engagement throughout the affordability review process.

Objective 1: Tools to Collect Patient Experience Information

Research



Research

Surveys

- Patients need to have the opportunity to explain how insurance, health status, and financial strain impact affordability.
- Additional patient insights should be collected from direct conversations through roundtables, listening sessions, or moderated discussions.
- Survey questions should be well-aligned with the research objective(s) and specific to the targeted concept for the research question with minimal redundancies across questions.
- Oregon PDAB's patient and caregiver survey is available in both English and Spanish. The survey also asks if the patient filling out the form is an Oregon resident.

Focus Groups & Small Group Meetings

- Conduct separate focus groups for different types of participants to ensure everyone's openness and comfortability in sharing their perspectives without the influence of hierarchical dynamics.
- Consider accessibility features during a virtual setting (e.g., closed captioning).
- Introductions should help participants and facilitators develop rapport and mutual trust.
- Exclude tangential questions and focus on questions directly related to the objectives.
- The moderator of a focus group can explore issues at the individual level, as well as encourage discussions among participants at the group level, eliciting a range of experiences.

One-on-One Interviews

- Offer opportunities to explore topics in-depth at an individual level using probing questions.
- Can also be used to address sensitive topics and explore diseases or conditions with many different symptoms that vary from patient to patient.

Objective 1: Tools to Collect Patient Experience Information

Workgroup Recommendations for Round 2



Workgroup members are encouraged to discuss:

- Other tools the Board should consider when collecting patient experience information during affordability reviews.
- Tips for improving survey design (examples are encouraged).
- Tips for improving survey response rate.
- Strategies to promote and publicize surveys to target populations.

Objective 2: Timeline for Collecting Patient Information

Affordability Review Outcomes & Stakeholder Suggestions



Affordability Review Outcomes

Selection

- The Board selected five drugs for review on August 4, 2023.

Voluntarily Submitted Information

- Manufacturers, carriers, PBMs, and other entities have 60 days from the last day of selection (October 3, 2023) to provide voluntarily submitted information to the Board.

Surveys

- Surveys were published on September 12, 2023 (a little less than 6 weeks after selection) and open until October 12, 2023. The Board voted to re-open the surveys for another month for four out of the five selected drugs.

Office Hours

- Staff held weekly one-hour meetings in August and September, 2023, where stakeholders could ask any questions about the affordability review process and how to provide input to the Board.

Focus Groups & Stakeholder Meetings

- Staff facilitated two focus group meetings per selected drug, and held small group meetings as requested.

First Affordability Review

- The first affordability review, which was for Trikafta, was completed on December 8, 2023.



Stakeholder Suggestions

- More time is needed to complete the surveys and participate in group meetings.
- A wider dissemination of surveys would help with reaching more respondents.

Objective 2: Timeline for Collecting Patient Information

Research & Workgroup Recommendations



Research

Research

- The ideal timeframe to gather patient input is three to four weeks, as it allows staff to establish and coordinate relationships with patient advocacy groups, in addition to recruiting and engaging participants.
- This three to four week timeline also depends on the resources required to support patient engagement activities.
- Transparency with stakeholders regarding timeline is important because it facilitates reaching an agreement on timescales that suit everyone involved.
- Provide a clear and thorough visual of the timeline for collecting information so stakeholders are able to participate at the right time.



Workgroup members are encouraged to discuss:

- Strategies the Board can use to keep stakeholders informed and engaged during affordability reviews.
- The best time to distribute surveys and facilitate meetings to maximize stakeholder awareness and participation.
- The amount of time needed to collect information.

Objective 3: Outreach & Communication

Affordability Review Outcomes & Stakeholder Suggestions



Affordability Review Outcomes

Outreach and Recruiting

- Stakeholders were recruited primarily through the PDAB listserv and outreach via the PDAB website.
- Staff discussed recruitment with patient advocacy organizations.
- Staff offered to meet directly with interested organizations and established collaborative communication channels.

Communication

- Office Hours: Staff held weekly one-hour open meetings in August and September 2023 to answer stakeholder questions about the affordability review process.
- Office hours were not a public comment forum, but an informal space for stakeholders to ask for clarification on the Board's work and provide insight into participation opportunities.
- Staff authored a stakeholder engagement guide and updated it regularly based on stakeholder suggestions.



Stakeholder Suggestions

- Better explain the process of the Board's work.
- Better explain the purpose of stakeholder input.
- What will the Board do with the stakeholder input?
- How will it guide the Board's decision making?

Objective 3: Outreach & Communication

Research & Workgroup Recommendations



Research

- Comprehensive recruitment plans describe who and how stakeholders will be recruited, and what recruitment materials they will use.
- One-on-one outreach is a key strategy for recruiting patient stakeholders.
- Identify trusted community partners to assist with recruitment.
- Patients need readable, comprehensible, and consistent materials disseminated in order to stimulate their interest.
- Information should be provided in payment terms utilizing visual aid as often as possible.



Workgroup members are encouraged to discuss:

- Workgroup members are encouraged to discuss how the Board can:
- Reach a wider population of Coloradans, particularly priority populations and uninsured Coloradans.
- Leverage its current stakeholder network to identify other relevant and impacted stakeholders.
- Educate patients/providers about the Board's work.
- Explain to patients what they will do with their input.

Objective 4: Assessment

Affordability Review Outcomes & Stakeholder Suggestions



Affordability Review Outcomes

- Board staff performed a thematic analysis of the qualitative data from the surveys and meetings.
- Appendix H on page 117 of the Affordability Review Summary Report for Enbrel details the assessment and results of the surveys and meetings.
- The Board included all surveys received in the results, which included responses from individuals in other states and patients covered by plans that will not be subject to an upper payment limit (Medicare).



Stakeholder Suggestions

- If the Board accepts out-of-state input, should it be weighted differently than information from CO residents? How so?
- Patient and caregiver input should not be considered as speaking for all Coloradans.

Objective 4: Assessment

Research & Workgroup Recommendations



Research

- Using surveys to collect qualitative data may not allow for structured and in-depth exploration of a given topic but offers a feasible way to collect information from a broad range of individuals.
- For in-depth exploration, focus groups and interviews are the preferred methods, as they can effectively explore collective perspectives on a topic.
- It is critical to thoroughly describe the data collection method used and justify its use in relation to its ability to support the research aims.
- Include members of the target population (for example, patients or clinicians) and subject matter experts in the design of interview questions, focus group guide or survey.
- Develop code lists and perform thematic analysis of the surveys and focus groups.
- Substantiate reported themes with the data collected by using verbatim extracts or text excerpts. Triangulate findings with other data sources as well.
- Transcribe and code interviews and focus groups to be able to conduct synthesis and abstraction to group the codes.
- Qualitative data or research should be assessed in an adaptive and refinement manner based on lessons learned from earlier steps in the process.
- The assessment process for evidence from identified patient experience outcomes will likely need to rely largely on expert opinions of participants and stakeholders.



Workgroup members are encouraged to discuss:

- If the Board should prioritize input from Coloradans. What could this look like?
- If the Board should limit input from patients covered by plans that will not be subject to a UPL.
- Tips for analyzing stakeholder input.

Objective 5: Conflicts of Interest (COI) Disclosure

Affordability Review Outcomes & Stakeholder Suggestions



Affordability Review Outcomes

- The Board did not have a COI disclosure policy for stakeholders during the first round of affordability reviews.



Stakeholder Suggestions

- Individuals with scientific and medical training should provide disclosures about funding, industry involvement, and other relevant activities across any part of the supply chain that could be considered a conflict of interest.
- How can a COI disclosure policy be established for stakeholders?

Objective 5: Conflicts of Interest (COI) Disclosure

Research & Workgroup Recommendations



Research

- Outline precisely what the organization views to be a conflict of interest: financial, non-financial, institutional.
- Transparency allows stakeholders to evaluate decisions critically and ensures that professionals act in the best interest of their organization or the public.
- Develop a robust COI disclosure policy to maintain ethical standards and transparency.
- Clearly define the purpose of the COI, why it exists, and who it applies to. Outline when and how conflicts are to be disclosed.
- A diverse committee free from significant conflict of interest is important and must be taken into consideration.
- Linked below are examples for conflict of interest disclosure languages to utilize.



Workgroup members are encouraged to discuss:

- When and how should COIs be disclosed (e.g., focus group meetings, written comments, public comment sessions, etc.).
- Disclosure format (e.g. verbal, written, both).
- What the disclosure should include (e.g., name of the prescription drugs, manufacturing company, any financial benefit/funding from the prescription drug or its manufacturer).

Workgroup Next Steps

Between Meetings 1 & 2: October 14 - December 10, 2025

- Staff, along with the PDAAC chair, will draft a recommendations report based on the discussion from the first workgroup meeting.
- Staff will publish the draft report on the PDAB website and through the listserv at least two weeks prior to the second workgroup meeting.
- Stakeholders may provide written feedback on the draft report and are asked to submit comments at least two business days prior to the second workgroup meeting.

Meeting 2: December 11, 2025 (tentative)

- Workgroup members will receive a copy of the draft report and an overview of comments and suggestions received from written feedback.
- The workgroup will discuss the report and include any final changes before members of the PDAAC vote on the report.

After Meeting 2

- After the PDAAC votes to approve the report, it will be shared with Board members at a future meeting.

Upcoming Meetings

PDAB Meeting: November 14 at 10 am MT

PDAAC/Stakeholder Workgroup Meeting: December 11 at 9 am MT
(tentative)

For meeting minutes, agendas, and general information about PDAB and PDAAC, visit <https://doi.colorado.gov/insurance-products/health-insurance/prescription-drug-affordability-review-board>

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Break

The meeting will resume after a 10-minute break.