COLORADO
Prescription Drug
Affordability Board
Division of Insurance

V2 Draft PDAAC Recommendation Report: Best Practices for Patient Engagement

To: Members of the Prescription Drug Affordability Board (PDAB, “the Board”)

From: Members of the Prescription Drug Affordability Advisory Council (PDAAC, “the Advisory Council”)

Date: *TBD*

Report Purpose and Objective

This draft report has been prepared to provide the Prescription Drug Affordability Board (PDAB, “the Board”) with best practice recommendations for gathering and incorporating patient experience information during the affordability review process.

The objective of this report is to summarize recommendations offered by participants during the **October 14, 2025 PDAAC & Stakeholder workgroup meeting**. The revised proposed approach for the implementation of each recommendation is based on feedback from the participants during the **second workgroup session on December 11, 2025.** The findings presented here reflect the discussions and insights shared by PDAAC members and participating stakeholders throughout the two sessions, and will be shared with the PDAB for consideration as they conduct future affordability reviews. The recommendations are intended to improve transparency, and ensure that patient experience information is considered during different stages of the Board’s affordability review processes.

Background

After completing its first round of affordability reviews in 2024, the PDAB sought to evaluate and refine its processes for gathering patient information and identify additional opportunities to incorporate patient perspectives in its decision-making. The Board directed staff to conduct a time-limited workgroup including the PDAAC and stakeholders to make recommendations for how the Board can improve processes for capturing patient experience information during affordability reviews. Specifically, the workgroup was tasked with identifying best practices regarding:

- Tools for collecting patient experience information (e.g., surveys, meetings, interviews),
- Timeline for collecting patient information,
- Outreach and communication strategies to establish clear channels with collaborators,
- Assessment of information received from stakeholders
- Disclosure of potential conflicts of interest by stakeholders.

Workgroup Recommendations

The initial PDAAC/stakeholder workgroup discussed the Board’s process improvement goals and provided recommendations for each objective listed above. Staff have reviewed the discussion and identified five (5) distinct categories of recommendations:

1. **Utilize PDAAC to Collect Patient Input for Drug Selection**
2. **Establish a PDAB Patient Engagement Toolkit**
3. **Create a Communication Network**
4. **Provide Additional Assessment of Information**
5. **Promote a Process for Voluntary Disclosure of Conflicts of Interest**

Utilize PDAAC to Collect Patient Input for Drug Selection

Issue: Under current statute and rule, patient input is not among the metrics the Board may consider when selecting drugs for affordability review. As a result, opportunities for patients to contribute during the drug identification and selection phases are limited.

Recommendation: Collect and consider patient experience information during the drug selection phase and incorporate summarized findings into the PDAAC’s recommendations to the Board.

Revised Proposed Approach: To offer patients the opportunity to provide input on which drugs pose affordability challenges during the drug selection process, the PDAAC shall gather relevant patient information and feedback. After publication of the eligible drug list, the PDAAC could solicit feedback from patients to help identify drugs for selection. The PDAAC would then incorporate these insights into its recommendations to the Board during the selection phase.

Establish a PDAB Patient Engagement Toolkit

Issue: Patients need a clearer understanding of the Board’s work and guidance on how and when to engage during each phase of affordability review.

Recommendation: Develop a **PDAB Patient Engagement Toolkit** that provides educational resources and opportunities for patient participation. The toolkit will provide an overview of the Board’s processes, outline when and how the Board will seek patient feedback during the affordability review process, and promote knowledge and understanding of the Board’s work. The goal is to increase the amount of patient feedback for the Board to consider as they conduct the affordability review.

Revised Proposed Approach: The toolkit will include materials developed in partnership with patient research partners and patient organizations and will clearly explain the PDAB’s scope of work and authority. Educational materials will accurately describe the prescription drug selection and affordability review process, and upper payment limits. The toolkit will be used by the PDAB, PDAAC, and the Communication Network to assist with outreach and engagement of impacted healthcare consumers.

The toolkit will include:

1. **PDAB 101:** Plain-language educational materials in multiple formats explaining who the Board members are, their role, authority, and the affordability review process.
2. **DOI 101 and Glossary:** Information to help patients understand insurance design and consumer protections, including the role of the Division of Insurance.

3. **Surveys and Engagement Tools:** Use of existing survey instruments with public feedback on survey design. Surveys will be scheduled to avoid major holidays and remain open for sufficient time to encourage participation. Translation into Spanish will be pursued, dependent on staff resources.
4. **Outreach and Promotion:** Consistent outreach materials and toolkits for partners, supported by dedicated staff resources, to ensure equitable and effective dissemination. Collaborate with DOI's communications coordinator to use DOI's existing Facebook, Instagram and other channels to promote surveys, focus groups, and other educational content.
5. **Focus Groups:** The PDAB will continue to host focus groups for discussion related to drug selections. Staff will coordinate with the PDAAC and patient organizations to identify condition-specific focus groups to help capture patient experience.

Create a Communication Network

Issue: PDAB and staff need to engage a broad and representative group of partners early enough to support meaningful education, outreach, and participation.

Recommendation: Establish a **Community Partner Network** (e.g., pharmacists, providers, consumer organizations) to support outreach and education to impacted patients, caregivers, providers, and advocacy organizations.

Revised Proposed Approach: PDAB and PDAAC will develop a transparent process for identifying and engaging community partners, including (but not limited to) patient advocacy organizations, consumer groups, providers, pharmacists, wholesalers and other pharmaceutical supply chain entities. The network will leverage the PDAB Patient Engagement Toolkit to support education on the Board's work, promote opportunities for patient input, and help identify condition-specific stakeholders during drug selection and affordability reviews.

To support accessibility and transparency, staff will evaluate improvements to communication infrastructure. This would include transitioning from ad hoc document-sharing systems to a centralized, navigable public-facing website that houses educational materials, engagement opportunities, and partner resources.

In addition, the PDAAC will **facilitate** communications with Community Partners by developing:

- **Recurring Correspondence:**
  - Maintain ongoing communication to keep the community informed through emails, newsletters, and social media posts.
  - Create a community partner registry for entities to maintain up-to-date information with the PDAB.
- **Meetings:**
  - Annual meetings to give space for community partners to:
    - Identify community partners who should be engaged.
    - Discuss strategies for outreach to healthcare consumers and other affected stakeholders.
    - Promoting PDAB's educational materials and patient feedback surveys.
    - Maintaining an active stakeholder registry to support ongoing engagement.
  - Ad hoc meetings will be conducted throughout drug selection and affordability review phases so partners can identify key stakeholders for specific drugs.

Provide Additional Assessment of Information

Issue: Survey data used during affordability reviews included populations and plan types for which a UPL may not apply, and summary-level reporting may be confusing/unclear within the affordability review process.

Recommendation: Continue collecting broad patient input while clearly segmenting and contextualizing data in affordability review reports.

Revised Proposed Approach: Affordability review reports will include both aggregated summaries of all responses, and clearly labeled subsets to identify out-of-state respondents and Medicare beneficiaries. Redacted patient narratives will continue to be published as part of the affordability reports, with appropriate privacy protections, to preserve context that may be lost in summary statistics. Similar segmentation approaches will be applied to claims data, where feasible, to avoid skewed findings.

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

Issue: The Board seeks a consistent, fair, and transparent approach to disclosures of conflicts of interest from all participants in PDAB and PDAAC processes.

Recommendation: Encourage voluntary disclosure through a standardized “Conflict/Duality of Interest” framework that emphasizes transparency rather than exclusion.

Revised Proposed Approach: The PDAB will consistently request disclosures from all participants while reframing the process to reduce stigma and provide context regarding how funding supports programs and services. Disclosure standards will be applied consistently across all stakeholders, including patient organizations, and entities funded by foundations with cost-containment missions. Optional explanatory fields will allow submitters to describe how funding is used.

- **Establish a Shared Purpose for Disclosures:**
    - Replace “Conflict of Interest” with “Statement of Interest” or “Duality of Interest” to reduce stigma and increase comfort with disclosure.
    - Emphasize that we all have dualities of interest and our goal is to create transparency for all who participate in PDAB.
    - When the Board asks for a "Statement of Interest or Duality of Interest”, the intent is to ask for transparency and better understand everyone involved in helping with this work, not to dismiss feedback. All input is welcome and contextualized, not dismissed.
- **Process for Voluntary Disclosure:**
    - Stakeholders will be asked to disclose COIs during public comment and public testimony portions of Board meetings.
    - Staff will create a stakeholder COI form that may be used for those who would like to provide the disclosure electronically.
        - The PDAB requests that stakeholders complete the COI form, but stakeholders are not required to complete the form in order to provide comment/testimony.

Conclusion

Stakeholders are a vital part of efforts to improve drug affordability in Colorado. Being successful in this endeavour depends on grounding affordability reviews in data that captures authentic patient experiences, and provides transparent decision-making and inclusive engagement processes. By incorporating these recommendations from the PDAAC and the stakeholder workgroup, the PDAB can enhance the affordability review process by creating additional opportunities for patient experience feedback, engaging the right community partners at the right time, and educating stakeholders on the PDABs work.