



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 findings presented here reflect the discussions and insights shared by PDAAC members and participating stakeholders throughout those sessions, and will be shared with the PDAB to consider as they conduct future affordability reviews.

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 stakeholder workgroup 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, and
- 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. Enhance PDAAC’s Scope
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

1. Enhance PDAAC's Scope

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 input during the drug selection phase, and include summarized patient feedback in PDAAC's recommendation to the Board.

Proposed Approach: To offer patients the opportunity to provide input during the drug selection process PDAAC can gather relevant patient information and feedback. After publication of the eligible drug list, the PDAAC could solicit feedback from patients and conduct a trend analysis to identify drugs that patients recommend or do not recommend for review. PDAAC would then incorporate these insights into its recommendations to the Board during the selection phase.

2. 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.

Proposed Approach: The contents of the toolkit, as well as recommended process improvements for each item, are outlined below:

- **PDAB 101**
 - **Patient education materials** in multiple formats (e.g., written document, slides, recorded webinar) that explain the work of the PDAB. Topics may include:
 - *What is the PDAB?*
 - *What is the Board's authority?*
 - *Overview of the affordability review process.*
 - *What does it mean if my drug has been selected for review?*
 - *What does it mean if the Board finds my drug unaffordable?*
 - *During which part of the Board's work can patients provide input?*
 - *Resources available (e.g., rulemaking guide).*
 - *Health insurance 101 & a glossary of terms.*
 - *Division of Insurance (DOI)'s role in consumer protections.*
- **Surveys**
 - **Survey Content**
 - Continue to collaborate with patient research partners to update surveys.
 - Allow time for public feedback on survey design.
 - Dependent on staff resources, translate surveys into Spanish to increase accessibility and participation.
 - **Survey Promotion & Response:**
 - Leveraging the community partnership network (further detailed below), plan a clear, structured timeline for survey promotion, ensuring promotional and educational materials are distributed at least 30 days ahead of survey release.



- Schedule survey release dates to minimize overlap with holidays.
- Surveys remain open for 30 days to allow for sufficient time for responses.
- **Focus Groups**
 - Work with patient organizations to implement condition specific focus groups.
 - Leverage the Advisory Council to host focus group discussions.
- **Promotion & Outreach**
 - Create promotional materials and a social media toolkit which may include posts, graphics, QR codes, videos, background information, etc.
 - Publish monthly PDAB newsletters to provide updates on the Board's work.
 - Regularly schedule Office Hours where stakeholders can ask PDAB staff questions about processes.
 - Encourage patient organizations and consumer groups to disseminate PDAB's promotional and educational content.
 - 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.

3. Create a Communication Network

Issue: PDAB and staff need to ensure they are engaging with a sufficient number of the relevant community partners at the right time, allowing enough time to educate and recruit stakeholders.

Recommendation: Establish a **Community Partner Network** (e.g., pharmacists, providers, consumer organizations) to assist with outreach and education of impacted consumers and groups about the PDAB.

Proposed Approach: Convene a group of engaged partners to:

- Promote knowledge and education of the Board's work.
- Increase participation and feedback from healthcare consumers, providers.
- Provide quality assurance of the PDAB's stakeholder work.
- Seek out condition-specific groups for input during drug selection.
- Remind patients and providers about surveys during selection and affordability review.

Facilitate communications with Community Partners by developing:

- **Meetings:**
 - Annual meetings to give space for community partners to gather and discuss:
 - 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.
- **Recurring Correspondence:**
 - Maintain ongoing communication to keep the community informed through emails, newsletters, and social media posts.
- **Shared Resources:**
 - Create a shared GoogleDrive containing:
 - educational resources for both patients and providers.
 - QR codes for point-of-sale locations.
 - Program materials.



- A community partner registry.

4. Provide Additional Assessment of Information

Issue: Surveys used for affordability reviews include populations for which a UPL is not applicable and the Board has received feedback that may be confusing/unclear within the affordability review process.

Recommendation: Based on stakeholder feedback, patient and provider surveys should continue to collect information from national residents and all health plan types. However, survey data will be clearly labeled in affordability review reports.

Proposed Approach: Affordability review reports will include:

- A full aggregated summary of all survey responses received, and
- A subset of survey responses excluding:
 - Out-of-state consumers, and
 - Consumers on plans that are not subject to a UPL (Medicare)

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

Issue: The Board requests a consistent and fair approach to managing COI disclosures for all stakeholders who provide feedback or participate in Board's work.

Recommendation: Foster a culture of transparent interactions between the Board and stakeholders by encouraging voluntary disclosure of COIs and providing regular opportunities to share disclosures.

Proposed Approach:

- **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, 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.