



PATIENTS & PDABS: ENSURING A VOICE IN THE PROCESS

WHY YOUR VOICE IS IMPORTANT

Why Patient Experience Matters?

Patients offer essential, real-world insight into how treatments improve people's health and daily lives, and the financial barriers that impact accessing those treatments.

As PDABs work to identify medications considered “unaffordable,” it's important that boards understand the drivers of unaffordability, which may or may not be directly related to the cost of a prescription drug. For example, recent survey findings show that affordability is personal and context-driven for patients, with insurance coverage serving as a primary determinant of access and costs.

When policies focus solely on drug prices, they may overlook other healthcare system drivers that create financial strain for patients. For example, a prescription drug may be unaffordable because a consumer's prior authorization was denied. Therefore, the drug is considered not covered by their health plan, resulting in the consumer having to pay out of pocket for the medication. Unaffordability can also be related to premium costs and, as well as competing consumer costs (e.g., food, utilities, etc.).

By elevating patient perspectives and ensuring that patient input is treated as a formal data source, boards can assess the holistic picture of the drivers of unaffordability and better identify the reforms necessary to improve costs for consumers.

Opportunities for Patient Input

There are multiple opportunities to share your perspective on prescription drug affordability.



Legislative Process – PDABs are established through states passing legislation that creates them. If your state is considering adopting a PDAB, you can share your experience on your ability to access and afford your medication with your local elected officials, bill sponsors, and legislative leaders. You can also request that your state legislature ensure that any reforms they pass are required to directly improve your prescription drug affordability or health care costs.



PDAB Public Meeting – Most legislation requires PDABs to hold public meetings and hearings as part of their process to select drugs, review drugs, and establish UPLs. These opportunities often allow for written or oral testimony, provided either in person or virtually. Often, individuals can sign up to share testimony before each meeting. Meetings take place either monthly or quarterly depending on the state. By participating, you can share **your** experiences with the board on specific treatments and ask questions **about** how decisions by the board will impact your costs. Your feedback is essential and helps inform how affordability decisions are shaped.

You Provide What Data Cannot

Clinical and economic data don't fully capture patients' experiences of managing a chronic or complex medical condition. Unaffordability can result in skipped doses, delayed treatments, worsening health, and negative impacts on employment and daily life. Sharing your experiences helps boards understand the drivers of inaccessibility and unaffordability and how PDAB approaches will impact those drivers.

Policymakers Need to Hear from Patients

Effective policy depends on a genuine understanding of what patients actually experience in their daily lives. By sharing your experiences and challenges with prescription drug affordability, you help policymakers better understand how access problems affect affordability and develop solutions that address those drivers.



HOW CAN YOU GET INVOLVED?

1. Submit Written Comments to Boards Before Meetings

If your state has already enacted a PDAB, you can engage directly with the board. PDABs accept written comments from a variety of stakeholders, including patients, caregivers, providers and advocates. Sharing your experiences can help boards understand how affordability decisions affect access and health outcomes. Colorado, Maryland, Oregon, and Washington are all moving through drug reviews – these states need to hear from the public and want you to get involved. For details on how to submit written testimony, refer to the chart at the end of this resource.

2. Provide Verbal Testimony During PDAB Meetings

Consumers can speak at public meetings and hearings, offering valuable insight into the challenges created by high drug costs and coverage barriers. Colorado, Maryland, Oregon, and Washington are all moving through drug reviews – these states need to hear from the public and want you to get involved. For details on how to participate, refer to the chart at the end of this resource.

3. Share Testimony Before PDABS Are Passed By Legislatures

Patients can share their stories and experiences with prescription drug affordability to help policymakers evaluate whether PDABs address the root causes of affordability challenges. Patients can do this by reaching out directly to bill sponsors, contacting the chairs or members of legislative committees currently considering PDAB legislation, or partnering with patient advocacy organizations that amplify patient voices and provide guidance on effective outreach.

In 2026 the following states considered adopting PDABs: [Georgia](#), [Hawaii](#), [Illinois](#), [Michigan](#), [Virginia](#), and [West Virginia](#). Additionally, [Florida](#), [Louisiana](#), and [Rhode Island](#) considered legislation that would implement PDAB-like UPLs tied to Medicare's maximum fair price, the negotiated price for specific drugs under the [Medicare Drug Price Negotiation Program](#).

Get Involved with Allied Groups

Patient advocacy groups are always eager to partner with patients. For example, [The Patient Inclusion Council \(PIC\)](#) is a coalition led by patients and caregivers that aims to ensure real-life experiences with medication costs and access shape healthcare and prescription drug affordability policies. Working with patient advocacy organizations can help amplify patient voices and provide guidance on effective outreach.



State PDABs and Opportunities for Patient Engagement

STATE	HOW TO GET INVOLVED
Colorado	Learn more about the Colorado PDAB. Register to attend upcoming meetings. Register to receive PDAB updates via email. To provide verbal testimony, sign up during each virtual meeting. Comments will be limited to 2 minutes per person. Email written comments to dora_ins_pdab@state.co.us up to 48 hours before each meeting.
Maryland	Learn more about the Maryland PDAB. Register for upcoming meetings. To submit general written comments, email comments.pdab@maryland.gov at least two business days before the meeting: with (1) your name; (2) contact information; (2) any organizational affiliation, and (4) the agenda item you wish to address. Review the Board's announcements to learn about specific requests for testimony. To provide verbal testimony, email comments.pdab@maryland.gov by the deadline specified before the meeting and include (1) your name, (2) your address, and (3) the agenda item you wish to address. Learn more about public comment opportunities. Register to receive PDAB updates via email.
Maine	Learn more about the Maine PDAB. Register to attend upcoming meetings. No formal process for submitting written or oral testimony. Contact the Maine Office of Affordable Health Care, which provides staffing support to the Board.
Oregon	Learn more about the Oregon PDAB. Register to attend upcoming meetings. Register to receive PDAB updates via email. To provide verbal testimony, complete and submit the public comment form at least 24 hours before a meeting. To provide general written comments, complete and submit the public comment form at least 48 hours before a meeting. Additional instructions for participation.
Minnesota	Learn more about the Minnesota PDAB. Submit written testimony via online portal. There are no specific deadlines or time requirements for submission.
New Jersey	Learn more about the New Jersey Drug Affordability Unit. Register for upcoming meetings. No formal process for submitting written or oral testimony. To contact the Affordability Unit, email DAU@dca.njoag.gov.
Washington	Learn more about the Washington PDAB. Register for upcoming meetings. To submit general written comments, email a one-page maximum testimony to HCA_WA_PDAB@hca.wa.gov. To provide verbal testimony on any topic listed on the agenda, email HCA_WA_PDAB@hca.wa.gov the Monday before the meeting date with: (1) your name; (2) the organization you represent, and (3) the topic name on the agenda. Comments are limited to 3 minutes per person. To receive PDAB updates via email, register here.

General Timeline of Engagement Opportunities

The following table outlines the public participation opportunities available during each stage of the PDAB's work. Please note that this chart serves as a general estimate and may not reflect the specific practices of all boards.

TIMELINE	MAJOR ACTIVITIES	PUBLIC PARTICIPATION OPPORTUNITIES
Year 1 Board Formation & Organizational Development	• PDAB legislation enacted • Board members appointed and confirmed • Initial board meetings held • Staff hired and Advisory Council established (if applicable) • Board develops workplan and implementation strategy	• Legislative hearings prior to enactment ◦ Written and verbal opportunities • Open board meetings • Public comment during board meetings
Year 1–2 Rulemaking & Program Development	• Board adopts implementing regulations • Develops affordability review methodologies • Establishes policies, procedures, and data collection processes • Creates guidance documents and operational framework	• Public comment at board meetings ◦ Written public comment ◦ Verbal public comment • Formal rulemaking hearings ◦ Written and verbal opportunities • Stakeholder meetings and listening sessions
Year 2 Drug Identification & Selection	• Identify drugs eligible for review • Publish methodologies and selection criteria • Release dashboards or other data tools • Select first drugs for affordability review	• Public comment at board meetings ◦ Written and verbal opportunities • Stakeholder meetings and listening sessions
Year 2–3 Affordability Reviews	• Conduct affordability reviews • Analyze clinical, utilization, pricing, and access information • Receive manufacturer and payer submissions • Develop affordability review reports	• Public comment at board meetings ◦ Written and verbal opportunities • May offer specific stakeholder listening sessions • May request patient and caregiver testimony • May issue public surveys • May offer office hours and educational sessions
Year 3 Affordability Determinations	• Board votes on whether reviewed drugs are unaffordable • Determines whether unaffordable drugs are eligible for UPL consideration	• Public comment at board meetings ◦ Written and verbal opportunities • Public testimony before board votes ◦ Written and verbal opportunities • May offer specific stakeholder listening session • May request patient and caregiver testimony • May issue public surveys • May offer office hours and educational sessions

TIMELINE	MAJOR ACTIVITIES	PUBLIC PARTICIPATION OPPORTUNITIES
Year 3–4 UPL Rulemaking	• Develop UPL methodology • Draft drug-specific UPL regulations • Adopt final UPL rules	• Public comment at board meetings ◦ Written and verbal opportunities • Rulemaking hearings ◦ Written and verbal opportunities • May request patient and caregiver testimony • May issue public surveys • May offer office hours and educational sessions
Year 4 Program Refinement	• Implement adopted UPLs (if applicable) • Update rules and policies based on experience • Refine methodologies and stakeholder engagement practices	• Public comment at board meetings ◦ Written and verbal opportunities • Potential rulemaking hearings ◦ Written and verbal opportunities • May request patient and caregiver testimony • May issue public surveys • May offer office hours and educational sessions
Year 5 + Additional Review Cycles	• Restart cycle: Conduct additional affordability reviews before potential UPL adoption	• Public comment at board meetings ◦ Written and verbal opportunities

To learn more about specific PDABs, visit <https://aimedalliance.org/prescription-drug-affordability-boards/>.

This resource is part of Aimerd Alliance's Consumer Education Series on PDABs. If you want to learn more, check out our resources on Upper Payment Limits and Getting Involved.



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REFERENCES

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