



September 17, 2025

Minnesota Prescription Drug Affordability Board  
Minnesota Department of Commerce  
85 7th Place East, Suite 280  
St Paul, MN 55101

## **Public Comments on Effective Patient Engagement**

Dear Members and Staff of the Minnesota Prescription Drug Affordability Board:

The Ensuring Access through Collaborative Health (EACH) and Patient Inclusion Council (PIC) is a two-part coalition that unites patient organizations and allied groups (EACH), as well as patients and caregivers (PIC), to advocate for drug affordability policies that benefit patients.

We appreciate the Minnesota PDAB's commitment to designing processes that reflect the lived experiences of patients and welcome the opportunity to share our observations from other states, along with data from our patient-led research. Our goal is to encourage the Minnesota PDAB to adopt a patient engagement framework that emphasizes authenticity, inclusivity, and collaboration from the very beginning of its work.

## **Challenges with Patient Engagement in Other States**

Across multiple states, PDABs have faced significant shortcomings in collecting and applying patient data:

- Low response rates: Affordability surveys in states such as Oregon and Colorado suffered from low patient engagement and the data gleaned was insufficient to capture representative experiences.
- Overly simplified questions: Many surveys rely on yes/no or multiple-choice formats asking if a drug is "affordable," without probing for reasons behind that perception.
- Limited transparency: In some cases, patient input was reduced to staff summaries, stripping away context and weakening the value of authentic narratives.

These limitations left boards with inadequate data to identify and address the true drivers of patient hardship. Minnesota has the opportunity to learn from these experiences and create a process that avoids these pitfalls.

## **Lessons Learned from Patients**

To fill this gap, the Patient Inclusion Council worked with research partners and patient advocacy organizations to design the [Patient Experience Survey](#), a 51-question survey incorporating quantitative input on multiple topics (cost data, insurance status, assistance program usage) and qualitative responses (open-ended narratives to capture personal context behind the missing 'why' related to affordability and unaffordability). This dual approach uncovered crucial insights:

- Affordability is subjective and context-driven: 20% of patients paying just \$0–\$10 per month still reported their medication as unaffordable, citing insurance transitions, copay accumulators, or broader medical expenses.
- Affordability and access are intertwined: 100% of patients who stopped taking a drug for “affordability reasons” pointed to insurance barriers such as denials or step therapy, not simply price.
- Assistance and insurance matter most: 71% of specialty drug patients with copay or financial assistance reported affordability, while only 38% without assistance said the same.

These findings demonstrate that drug price alone and even surface-level opinions on affordability are hardly enough to determine the true source of patient hardship. Instead, patient experiences are nuanced and complex, requiring thoughtful outreach and engagement to identify appropriate policy solutions.

### **Implications for PDAB Processes**

We encourage the Minnesota PDAB to create multiple avenues for engaging with patients and capturing their input on drug affordability and access.

The board should employ diverse methods for gathering input from patients and patient organizations, including public meetings, focus groups, comment periods, public testimony, and surveys. These events should be held at varied times and locations to get input on the drugs under review. This will ensure members of the public are given adequate opportunity to attend and provide patients with the opportunity to share their experiences on each drug directly with board members and staff.

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. Patient facing materials should be simple and direct, free from medical terminology, and allow for open-ended responses to ensure patient experiences can be fully conveyed. We urge different surveys for patients, providers, and patient advocacy organizations to ensure that formatting and word choice do not limit input from any of these critical stakeholders.

We recommend that the process for patient engagement be conducted separately from other stakeholders to avoid overwhelm and any potential confusion regarding what is expected from their participation. We also think the board should establish a minimum threshold for patient information submissions on each drug to ensure that they are receiving adequate input from patients.

We also urge the board to ensure that comment periods and survey timelines allow for meaningful participation from patients, caregivers, and patient organizations. We also encourage the board to employ broad efforts to publicize engagement opportunities to ensure patients that will be impacted by board policies are notified and have the opportunity to advocate for their own health. Public awareness and engagement are critical to the legitimacy and success of the affordability review process.



Because of the complex nature of this process and the information being sought, we recommend that patient organizations be recognized as a standalone stakeholder group representing patient voices. There are many proven methods patient organizations have used to collect meaningful, unaltered data from patients (including discussion sessions, surveys, etc.) that we could facilitate, acting as a bridge to enable more voices to be heard. We could combine these efforts with those conducted by the board, in a transparent way that ensures the raw patient data is untouched, thus increasing real-world evidence without any perceived bias of data submission.

## Conclusion

The Minnesota PDAB has the opportunity to build a national model for patient engagement by adopting a collaborative process that begins with patients and ensures their experiences remain central throughout. EACH and PIC stand ready to serve as a partner—sharing our survey data, collaborating on outreach, and helping design engagement methods that yield authentic, actionable insights.

Thank you for your commitment to patients. We look forward to working alongside you to ensure that Minnesota's affordability reviews translate into meaningful improvements in access, affordability, and health outcomes.

Sincerely,

A handwritten signature in blue ink that reads "Tiffany Westrich-Robertson".

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A handwritten signature in blue ink that reads "Vanessa Lathan".

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