



February 14, 2025

Oregon Prescription Drug Affordability Board
Department of Consumer and Business Services
350 Winter Street NE
Salem, OR 97309-0405

RE: Public Comments on Drug Selection Criteria and Cost Reviews

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

We thank you for this opportunity for patients to provide comments on the Drug Selection Criteria and Cost Review process. Patient Inclusion Council (PIC) members are all patients and caregivers, some who have extensive professional experience as Patient Research Partners (PRPs). These members reviewed the patient-facing portion of the survey draft and have provided recommendations to enhance patient-facing data collection efforts.

About the Patient Inclusion Council (PIC). We aim to empower patients and caregivers to shape healthcare policy through peer-led education, perspective sharing, and activities to ensure patient-reported needs are incorporated into drug affordability solutions. The PIC is the only patient and caregiver coalition created to advocate for drug affordability policies that benefit patients. All patients and caregivers are welcome to participate, and are invited to speak their truth related to drug affordability without involving personal opinions regarding PDABs, pharmaceutical companies, or insurers/payers.

In addition to utilizing creative and inclusive methods to capture all voices, members with experience as Patient Research Partners (PRPs) are also invited to participate in data collection question design, coding, and analysis related to PIC-created surveys and in regards to reviewing PDAB initiated surveys.

The PIC operates both independently and in collaboration with the Ensuring Access through Collaborative Health (EACH) side of this two-part coalition.

General Revision Suggestions

We appreciate the time and dedication spent by the OR PDAB to develop this initial draft of questions that aim to collect meaningful data from those who have experience taking the drugs under review. The following are patient-reported recommendations that address who should be completing the survey and language improvements.

- **Clarification regarding who should take this survey.** We are uncertain why “the general public” is included in a section intended for data regarding personal experience with prescription drug use: “*Questions for patients, caregivers, advocacy groups, and general public.*” What value would the board gain from hearing experiences (or opinions) about prescription drug costs from anyone other than those who have utilized the drug? If the purpose is to also collect information from people who may have been prescribed



the drug but were unable to obtain access, then this should be stated in place of “and general public.”

- **Drug usage (timing).** Will your data collection be limited to patients currently on the drug or will it include patients who have been on the drug in the past? If the latter, what is the time restriction for gathering data from those no longer on the drug? Due to a variety of contextual influencers (such as inflation related to drug costs, benefit design, COVID era, and a time when access to medications was tied to pre-existing conditions), understanding when the patient used the drug, or if they are currently using the drug, would be beneficial for analysis.
- **Confidentiality clarification.** “Answers are not confidential and if received by this date, will be included in the board materials prepared for the affordability review and posted on the website.”
 - **Suggestion:** Given providing personal information (i.e., name, contact information) is optional, clarify publicly available information does not include personal information and by providing personal information this is done only to reach out for clarification in answers.
- **Link/References to (OAR-925-200-0020 2.k.A.i.II).** We are assuming these links are added as a guide for reviewers to view the statute requirements and will only be included in the header/opening information of the survey once published. It is not needed, and is intimidating, to add it to every question.

Question Specific Revisions and Suggestions

We hope the following recommended changes will ensure robust patient-reported data is collected.

- **2. Dosage, *strength*, and frequency.** Provide definitions/examples, in particular for strength to avoid answers such as, “I take the strongest dose.” Additionally, we are not certain the difference between dosage and strength.
 - **Suggestion:** Please provide more details, including Dosage (example: 150 mg), Frequency (example: once a day). Clarify what data intended to collect from “strength”.
- **3. Medical condition or disease.** [Our coalition launched a pilot survey in 2024, which is being relaunched in February 2025.](#) Due to numerous responses that included a multitude of diagnoses for this question, we have updated our question and suggest this revision in your survey design as well.
 - **Suggestion: *ADDITIONAL Question - Co-existing conditions or multiple diagnoses.*** Given most people are diagnosed with more than one condition, and this often impacts which prescription drug they should or should not take, we suggest collecting this information, too.
- **4. What is the expected outcome of the treatment of the disease?** Our patient reviewers requested more guidance on how to answer this question. Patient outcomes and expectations are varied based on many factors, such as disease duration, disease

progression, existing damage, potential for remission or not, etc. As worded, we anticipate the board could capture answers such as, “To achieve remission.” We suggest clarifying endpoints (what the board hopes to gain from this question), then rewording it to do so. Once we are clear of the boards goals for this question, we are happy to provide more revisions.

- **5. Are there therapeutic alternatives* (for example, a *different therapeutic agent*) for this drug?** If the goal of this question is to understand if the patient has ever taken any other similar drug to treat this condition, or if there are other options, this should be worded to reflect this (do not use “therapeutic alternatives”, as most patients will tell you there is no therapeutic alternative to the drug that works for them and, in turn, you will not gather the data you hope to from this wording.) Also, using a “different therapeutic agent” is too high level and should be reworded altogether.

This is the same issue in Q9 - What are the benefits of using this prescription drug compared to therapeutic alternatives (for example, a different therapeutic agent)? and Q10 - What are the disadvantages of using this prescription drug therapeutic alternatives (for example, a different) therapeutic agent)?

Your definition of therapeutic alternative: *Therapeutic alternative means, a drug product that contains *a different therapeutic agent* than the drug in question, *but is FDA-approved, recognized as off-label use for the same indication, or has been recommended as consistent with standard medical practice by medical professional association guidelines to have similar therapeutic effects, safety profile, and expected outcome when administered to patients in a therapeutically equivalent dose.*

This definition is exceptionally high level and would be very confusing for a patient. Rewording this at a 5th grade level is recommended.

- **6. What is the patient treatment preference?** We do not understand what the board is trying to obtain with this question. Is the board looking for the patient to say, “This is the drug I prefer?” or “I prefer to be on a different drug but I’m on this one, because” or is this about method of application (i.e., infusion versus injection versus pill)? It would be difficult to answer the follow up questions (7. Why is it the preferred treatment? 8. If the patient is not using the preferred treatment, why not?) until this is clarified.
- **11. How much did you pay out of pocket for this drug?** First, is the board asking for out of pocket costs *for the month?* For *the year?*

Second, as worded, it would be difficult to capture **important contextual factors, such as any differences in out of pocket costs based on different times of the year and causes related to times of elevated costs** (i.e., insurance companies not applying copay assistance programs in a timely manner, switching jobs mid-year, etc.)

Additionally, how long a person was taking this drug influenced the response to this question. For example, some people who have been taking the drug for 8 years have cycled through different types of insurance. Once on commercial insurance and

paying \$10 out of pocket, are now on Medicare and have higher out of pocket costs. In the survey we have designed for patients, we had to go back and analyze all the open-ended responses to understand the complexity of this question and have incorporated these changes into our most recent survey. Keep in mind, we also asked how long they have been taking the drug and if they stopped taking it, how long ago. This may be another consideration for addition to your data collection to ensure robust analysis.

- **Suggestion: (Based on our wording from our survey)** - Thinking of the impact of (drug name) what was the most recent monthly out of pocket cost that you paid for this drug? We also suggest considering adding clarity (month or year) and the addition of questions to determine if they are currently on the drug or when they stopped the drug.
- **12. If you used a patient assistance program, how much did it cover?** The wording on this question suggests the board is asking the patient to come up with a percentage (“It covered 100%” or “It covered about 80%”).
- **14. Is the drug covered by your insurance?** A patient may not actually know how to answer this question, as many scenarios are possible.
 - One example: “My doctor prescribed it and the insurance company said they won’t cover it,” when they likely mean that the insurance company applied step therapy and maybe they could gain access (and afford it), but at this time the insurance company technically does not cover the drug.
 - Another example: “My insurance covers this drug, but I can’t afford it because I just can’t keep up with my deductible and pay \$500 a month for it, no one could!” What they could be trying to explain is that their insurance company covers the drug but they have an accumulator program, so the patient cannot meet their deductible and so their insurance to cover the drug does not kick in. After 6 months, the copay assistance runs out and they are left with the full bill.
 - **Suggestion:** Be prepared for a lot of qualitative analysis for this one! And enlist the help of PRPs from the PIC to assist to ensure responses include intended context. The board may also utilize our services to facilitate continued conversations with respondents (peer-to-peer) to gain clarity for the board.

Demographics

Please **circle** which applies to you:

Private health insurance _____

Medicare

Medicaid

- Is the board asking for patients to print out the survey, circle the type of insurance, and mail it back in?
- Patients will need a definition of what is meant by private insurance. As worded, many will likely respond with the insurer’s name (i.e., Cigna)



PATIENT INCLUSION COUNCIL

- We strongly encourage the board to clarify when collecting Medicare information that the PDAB cannot address Medicare. While it is good practice to identify affordability issues for all Oregonians, it is ethically responsible to educate patients who are responding - and who think the PDAB may help them - that Medicare is out of their jurisdiction and information collected will be forwarded to CMS.

Thank you again for the opportunity for patients to weigh in on survey questions that will be used to ensure robust data is collected from those utilizing the prescription drugs under review. We respectfully urge the board to consider the suggestions provided by patients, as outlined in this letter. We offer the PIC as a resource to board members seeking to connect more with patients, not only during recruitment for data collection, but also as advisors for question design and analysis.

Sincerely,



Tiffany Westrich-Robertson
Person living with Axial Spondyloarthritis
Patient Inclusion Council (PIC)