Guidelines to Ensure Prescription Drug Affordability Boards Protect Rare Disease Patients

Abstract

Lawmakers say that making medications more affordable to patients is a top priority. Yet some policy approaches overlook what matters most to patients and providers—and even make it more difficult for patients to access the treatment they need. One such approach is prescription drug affordability boards.

Prescription Drug Affordability Boards (PDABs) are state-level organizations that explore ways to lower prescription drug spending. 11 states have created a PDAB thus far, while 16 additional states are considering legislation to enact one.

PDAB members include health insurance representatives and health care economists who have been appointed by the governor or other state officials. Decisions made by these boards typically apply to state and Medicaid health plans but can apply to commercial plans as well.

However, it is important to recognize the impact these boards' policy recommendations may have on patient access, specifically for those with rare diseases.

Given their focus on government spending, prescription drug affordability boards often take an overly narrow view of health care value. Board members drive discussion focused on cost to the state rather than cost to the patient, meaning patient and provider priorities and input get left out.

Some PDABs seek to utilize discriminatory metrics such as the QALY (quality-adjusted life year) and EVLYG (equal value life years gained) that often undervalue the impact of certain treatments. Others seek to set upper payment limits for medications, that may increase patient costs and decrease patient options.

With an already limited number of available FDA-approved treatments for rare diseases, protecting patient access to treatment is critical. With this in mind, AfPA has developed principles that should remain at the forefront of conversation as state lawmakers approach discussions of affordability.

RECOMMENDATION:
Incorporate meaningful input from patients, providers and other stakeholders of the rare disease community.

OUTCOME:
Policymakers would benefit from the unique perspective of patients and providers who may feel a disproportionate impact of these policies.

RECOMMENDATION:
Exclude the direct and indirect use of discriminatory metrics, including the quality-adjusted life year and equal value of life years gained.

OUTCOME:
Excluding discriminatory metrics will support a more patient-centered focus.

RECOMMENDATION:
Exclude treatments with rare disease indications from potential reviews.

OUTCOME:
Excluding treatments with rare disease indications will not only protect current patient access, but also help ensure that future rare disease patients receive timely, appropriate access to innovative options.

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