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(HEAL) Group

Industry Advisory Group (IAG)

National ADAP Working Group (NAWG)

July 9, 2025

Colorado Prescription Drug Affordability Board
Colorado Division of Insurance
1560 Broadway, Suite 850
Denver, CO 80202

RE: Ongoing UPL Development

Dear Honorable Members of the Colorado Prescription Drug Affordability Board,

The Community Access National Network (CANN) is a 501(c)(3) national nonprofit organization focusing on public policy issues relating to HIV/AIDS and viral hepatitis. CANN's mission is to define, promote, and improve access to healthcare services and support for people living with HIV/AIDS and/or viral hepatitis through advocacy, education, and networking.

While CANN is primarily focused on policy matters affecting access to care for people living with and affected by HIV, we stand in firm support of all people living with chronic and rare diseases and recognize the very reality of those living with multiple health conditions and the necessity of timely, personalized care for every one of those health conditions. State Prescription Drug Affordability Boards are of profound importance to our community.

Concern with Staff Collaborating Across States; Contractor Conflict of Interest

We are deeply concerned with the Colorado PDAB staff expressly stating a "collaboration" with staff serving other states' PDABs. CANN wishes to be clear: the Colorado PDAB and its staff have an obligation to serve Coloradans, not import the staff perspective of other states or the policy or political motivations of private actors. If the Colorado Board is interested in the posture of the Oregon Board, when there is a conflict in report from public participants and staff, it is incumbent upon the Colorado Board to solicit information from the Oregon board Chair, not relay messages of conflicting content through staff.

Additionally, we would sincerely encourage the Board to examine the background of entities such as PORTAL and ICER in the same manner as advocacy groups and other organizations, with their motivations and funding being scrutinized.

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The Connecticut legislature released a [report examining questions surrounding PORTAL](#) (also attached), the Harvard Program on Regulations, Therapeutics, and Law. The report indicates that its relationships include a wide range of associations, including direct involvement with organizations such as Arnold Ventures, NASHP, and RePo4EU.

Directly, NASHP's PDAB project and model legislation discloses project funding from Arnold Ventures. NASHP testified in favor of similarly structured legislation initiating this Board in the Colorado legislature. PORTAL, now contracted as the data analysts for this Board, is also funded by Arnold Ventures, as is ICER, and certain groups purporting to be representative of patients.

It is incumbent upon both the Board and staff of the Colorado PDAB to serve the interests of Coloradans, not import the pre-determined outcomes and motives (political or otherwise) of outside interests. The funding source, which both initiates the legislation and seeks a contract to serve the Board, presents an exceptional conflict of interest. The Board is responsible for reviewing the ethical implications and conclusions of such contracts. Put directly, if specific funding is pushing both for specific legislation and funding the consultant entity being contracted to advise the Board established by the legislature, is the Board truly "independent" rather than a governmental arm of a private actor? If the answer is "no" then the Board is obligated to halt all associations with entities funded by that private actor and seek immediate review of any materials, conclusions, and decisions guided by those entities funded by that outside actor and report those findings as appropriate to either the legislature, the Attorney General, the Governor, and the public writ large.

Clarification of CANN's Allusion to Oregon Report

During the May 23, 2025 meeting, staff expressed concerns with how CANN commented on and relayed the posture of the Oregon independent consulting analysis report regarding Upper Payment Limits. CANN has referred to this report on multiple occasions. The reasoning for this particular allusion was in reference to the paucity of information provided in Colorado's cost-benefit analysis prepared by staff. Many questions were left unanswered in the cost-benefit analysis, with the explanation that because a UPL had not yet been set, it was not possible to give a more specific analysis of the potential effects of a UPL. CANN referred to the Oregon report because although no UPL has been set since Oregon doesn't currently have the authority to set one, their independent consulting firm was still able to provide a more detailed and informed analysis than Colorado's cost-benefit analysis with quantifiable data of a UPL's potential effects to stakeholders, including numerical data, such as the Medicaid program.

Given previous staff, Lila Cummings', December 2024 staff hours response of "We won't be doing that", when a member of the public informally requested a comparable cost-benefit analysis, and the sheer absence of any sufficiently comparable analysis as Oregon's, a reasonable conclusion this Board should be concerned with is staff never intended to provide a meaningful cost-benefit analysis. If this Board wishes to maintain the public trust, it must consider not only the obvious data failings outlined in this meeting's agenda, but also the actual statements and chronological order of facts as they've occurred.

We are in support of the General Assembly Recommendations

We support the recommendation of allowing consumers to identify prescription drugs for consideration for affordability review since it directly empowers patients to express what they deem as affordability challenges. This is tangentially related to another of the Board's recommendations which is reducing the threshold for identified brand name drugs to below the current 30,000/yr threshold. List prices do not directly translate into affordability. Targeting high-cost drug prices results in a prejudicial selection of therapies that affect many vulnerable populations without many options for treatment, who often are not having issues with affordability for their medications. Lowering the threshold coupled with allowing consumers to report what they deem as unaffordable seems to be a more patient-centered course of operations to benefit Coloradans. We are also in support of suggesting the legislature address the pros and cons of adding a consumer advocate/representative to the board. Since the board expressed concerns about the expertise and abilities of such a member, it would be helpful to include the Board's suggestions in that recommendation.

Methodology still unclear

A vast amount of information is being requested from various stakeholders through data submission guides as well as data sourced by staff. Because there is not currently a working interpretation of what the Board would consider to be a successful outcome of a UPL, what kind of savings would be worth the fiscal expenditure of implementation once implementation is defined, and other questions, it is unclear how the Board will use the data collected to determine what an effective UPL would be. It also remains unclear how a UPL would directly benefit patients at the pharmacy counter. This is especially true in light of, as mentioned during the last meeting, that patient out-of-pocket expenses have increased over time, possibly as a result of shifting benefit plans.

We Encourage the Board to Ensure Its Goals Stay at the Forefront

The Board has been tasked with the noble and arduous task of effectuating positive change to improve affordability for Coloradans. This requires the utilization of staff, including the solicitation of information from various subject matter experts, a range of consulting services, and multiple categories of data sources and interpretations. Moreover, in the national PDAB landscape, states are looking to one another to find ways to best assist their constituents.

We encourage the Board to be mindful of ensuring its desires are explicitly acted upon and that its endeavors are not inadvertently steered by influences not clearly beneficial to Coloradans. Various state PDABs have their own challenges they are working through, including fleshing out how the extraordinarily complex drug supply chain, payer mechanics, and entities providing care to patients all interact. What the PDAB is tasked with is new, very necessary, but cautiously speculative in the effects decisions may impart.

It is essential to ensure that every consideration is based on meaningful data and analysis and approached with an open mind to the nuances involved. There is independent data that explains the very real possibility of cost-control decisions resulting in increased costs to patients. Consistently evolving data includes direct commentary from payers. When advocacy groups and individual patients raise various concerns, those concerns are valid.

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The pharmaceutical industry is not a monolithic big bad wolf. [High-cost interventions are still valuable](#) because of their significant benefits, just as some lower-cost interventions are not as valuable or effective. Analysis indicating how improper affordability actions can affect Medicaid and other programs is real.

The best interests of Colorado citizens regarding affordability are at the forefront of concern. While affordability concerns are universal, the needs of Coloradans are specific. The inquiries you desire and the discourse you generate should remain under your guidance and not be inadvertently improperly informed.

We thank you for all of your ongoing hard work and thoughtful deliberations.

Respectfully submitted,



Ranier Simons
Director of State Policy, PDABs
Community Access National Network (CANN)

On behalf of
Jen Laws
President & CEO
Community Access National Network

Program on Regulations, Therapeutics, and Law (PORTAL)

By: James Orlando, Chief Attorney
July 29, 2024 | 2024-R-0123

Issue

This report answers several questions about the Harvard Program on Regulations, Therapeutics, and Law (PORTAL). We contacted PORTAL for information on several of these questions, as noted below.

Who/what is the Harvard Program on Regulations, Therapeutics, and Law (PORTAL)?

PORTAL is a research core within the Division of Pharmacoepidemiology and Pharmacoeconomics at Harvard Medical School and Brigham & Women's Hospital. According to its [website](#), PORTAL:

bring[s] together concerned researchers, analysts, and trainees from the fields of medicine, law, epidemiology, and health policy to critically evaluate emerging issues on the regulation, use, and reimbursement of therapeutics (prescription drugs and medical devices). We are interested in how laws and regulations influence the development, utilization, and affordability of therapeutics, as well as the ethical questions that current and proposed policies raise for patients, physicians, policymakers, and payors. Particular areas of focus include drug and device regulation, intellectual property, cost-effectiveness, and comparative effectiveness.

Among other things, the website states that the goals of PORTAL's research "include its publication in major medical, legal, and health policy journals; dissemination through the lay media and

international, national, regional, and local professional meetings; and interaction with key decision-makers in the public and private sectors to ensure translation into actionable health care policy.”

Currently, PORTAL [includes](#) four core faculty members (all from Harvard Medical School) and a research team consisting of several research fellows, research assistants, and students in a range of disciplines. Their website also lists affiliated faculty and researchers from various other institutions.

Who and where does their funding come from? Is any of that funding from health insurers or pharmacy benefit managers?

According to its website, PORTAL’s funding sources include the following private entities:

- [Arnold Ventures](#): a philanthropy organization focused on evidence-based policy solutions
- [CeBIL – Centre for Advanced Studies in Biomedical Innovation Law, Novo Nordisk Foundation](#): a research initiative, based at the University of Copenhagen, focused on “legal challenges and rapid developments in the health and life science area,” funded in part by the [Novo Nordisk Foundation](#), an independent Danish enterprise foundation focused on medical research and affiliated with the pharmaceutical company, Novo Nordisk
- [The Commonwealth Fund](#): a private foundation that supports independent research on health care issues, with a focus on improved equity in health care access
- [Elevance Health](#): a health insurance company, formerly known as Anthem, Inc.
- [Gary and Mary West Foundation](#): a private foundation focused on addressing the needs of vulnerable seniors
- [The Greenwall Foundation](#): a private foundation with a mission “to expand bioethics knowledge to improve clinical, biomedical, and public health decision-making, policy, and practice”
- [National Academy for State Health Policy \(NASHP\)](#): a nonpartisan organization focusing on “developing and advancing state health policy innovations and solutions”
- [Kaiser Permanente Institute for Health Policy](#): an organization with a mission “to shape policy and practice with evidence and experience from the nation’s largest private integrated health care delivery and financing organization,” and affiliated with Kaiser Permanente, an insurer
- [RePo4EU](#) (an organization developing an online platform for precision drug repurposing)

The website also states that PORTAL receives funding from the [Massachusetts Health Policy Commission](#) and the U.S. Food and Drug Administration.

How many states does PORTAL work with?

According to PORTAL, “[w]e currently have a grant from NASHP to advise a cohort of seven states on implementing prescription drug affordability boards (PDABs) – Colorado, Maine, Maryland, Minnesota, New Hampshire, Oregon, and Washington. You can see some of the output [here](#). We have also been consultants for the Massachusetts Health Policy Commission.”

How many states does PORTAL have a contract with and what is the contract amount?

PORTAL reports that “[s]eparate from the NASHP grant (see above) we have contracts with Colorado, Oregon, and Washington to support the more technical operations of their PDABs.”

What is PORTAL’s relationship to NASHP, the Institute for Clinical and Economic Review (ICER), and the Arnold Foundation?

PORTAL reports that “[o]ur government and foundation funders include the FDA, NIA, Arnold Ventures, Commonwealth Fund, and the Greenwall Foundation, among others. We have no formal relationship with the Institute for Clinical and Economic Review (ICER).”

Does PORTAL have any patient representation or input?

PORTAL reports that “[w]e do not have patient representatives working within PORTAL, but we often connect with patient groups and understanding the patient impact of high drug costs is a key research area.”

Does PORTAL have any direct drug industry expertise or is it only academic?

PORTAL reports that it “is an academic group at Brigham and Women’s Hospital and Harvard Medical School, and no one in PORTAL accepts any personal financial support from pharmaceutical or medical device companies.”

Does PORTAL have any contracts with Connecticut’s Office of Health Strategy (OHS) or have they presented to OHS?

We contacted OHS for this information and their representative was unfamiliar with PORTAL. It appears that PORTAL has no affiliation with OHS.

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