



COST CONTAINMENT vs. CARE EQUALITY: How Health Disparities Among Chronic Health Conditions & Rare Diseases are Fueled by Payor-Driven Barriers

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Despite being among the wealthiest and most educated societies, health disparities in the United States are a consistent risk among specific population groups.¹ Black and brown Americans don't enjoy the same access to care as their white counterparts; women experience more years of poor health than men;² age impacts health outcomes,³ as do gender identity,⁴ sexual orientation,⁵ and geographic location.⁶ The humanistic and environmental factors driving health disparities are only made more complex by the fragmented healthcare delivery system, which is known for payors, including public and private health insurers, putting up barriers between patients, their providers, and the treatments and medications they need.

Aside from institutional bias (i.e., racism, agism, and other stigmatizing attitudes toward specific barriers and characteristics), emerging provider deserts where patients live without access to hospitals, primary care physicians, and pharmacies,⁷ as well as the lack of affordable food, housing, and transportation, there is a direct correlation between health insurance coverage and health disparities in this country.⁸ According to the Centers for Disease Control & Prevention (CDC), "Insurance coverage is strongly related to better health outcomes. Substantial disparities in uninsured rates were observed among all the demographic and socioeconomic groups." In 2022, approximately 7.9 percent of the population was uninsured, down by 0.4 percentage points from 2021.⁹ Health insurance coverage in and of itself, however, doesn't necessarily result in equitable access to healthcare services or equitable health outcomes because often it is an insurance policy's benefit and payment parameters that open the door to such disparities.

¹ National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Population Health and Public Health Practice; Committee on Community-Based Solutions to Promote Health Equity in the United States; Baciu A, Negussie Y, Geller A, et al., editors. *Communities in Action: Pathways to Health Equity*. Washington (DC): National Academies Press (US); 2017 Jan 11. 2, *The State of Health Disparities in the United States*. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK425844/>

² AXA; Bogataj, Marie. 2019, Jun 16. Women vs. men: is there a health equality gap? Available from <https://www.axa.com/en/news/women-vs-men-is-there-a-health-equality-gap>

³ U.S. Department of Health and Human Services; Office of Disease Prevention and Health Promotion; 2023, Sep 14. *Social Determinants of Health and Older Adults*. Available from <https://health.gov/our-work/national-health-initiatives/healthy-aging/social-determinants-health-and-older-adults>

⁴ Lee Robertson, Ellesse-Roselee Akre, and Gilbert Gonzales. *Mental Health Disparities at the Intersections of Gender Identity, Race, and Ethnicity*. *LGBT Health*. Dec 2021.526-535. Available from: <http://doi.org/10.1089/lgbt.2020.0429>

⁵ Hafeez H, Zeshan M, Tahir MA, Jahan N, Naveed S. *Health Care Disparities Among Lesbian, Gay, Bisexual, and Transgender Youth: A Literature Review*. *Cureus*. 2017 Apr 20;9(4):e1184. doi: 10.7759/cureus.1184. PMID: 28638747; PMCID: PMC5478215. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5478215/>

⁶ Institute of Medicine (US) Roundtable on Health Disparities. *Challenges and Successes in Reducing Health Disparities: Workshop Summary*. Washington (DC): National Academies Press (US); 2008. 2, *The Impact of Geography on Health Disparities in the United States: Different Perspectives*. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK215365/>

⁷ Horowitz, Brian T; 2022, Jun 2. *What Are Medical Deserts, and How Can Technology Alleviate Them?* *HealthTech*. Available from: <https://healthtechmagazine.net/article/2022/06/what-are-medical-deserts-perfcon#:~:text=Areas%20without%20access%20to%20hospitals%2C%20primary%20care%20physicians%2C,research%20at%20GoodRx%2C%20a%20consumer-focused%20digital%20healthcare%20platform>

⁸ U.S. Department of Health & Human Services; Centers for Disease Control & Prevention; *Morbidity and Mortality Weekly Report*; 2011, Jan 25. *Fact Sheet: Health Disparities in Health Insurance Coverage*. Available from <https://www.cdc.gov/minorityhealth/chdir/2011/factsheets/insurance.pdf#:~:text=Insurance%20coverage%20is%20strongly%20related%20to%20better%20health,with%20a%20higher%20percentage%20of%20males%20being%20uninsured>

⁹ United States Census Bureau; 2023, Sep 12. *Health Insurance Coverage in the United States: 2022*. Available from: <https://www.census.gov/content/dam/Census/newsroom/press-kits/2023/iph/20230912-iph-slides-health-insurance.pdf#:~:text=The%20uninsured%20rate%20decreased%20by%200.4%20percentage%20points,in%202022%2C%20the%20uninsured%20rate%20was%207.9%20percent>

The so-called “cost containment tools” utilized by health insurance companies and pharmacy benefit managers (PBMs) are *hurting* patients.¹⁰ Notably, they are driving and exacerbating health disparities. Some of the most common payor-driven barriers encountered by patients include prior authorization (PA), step therapy, copay accumulators, health insurance plan design, and an emerging one: prescription drug affordability boards (PDABs). This article highlights why these cost-containment strategies are problematic for patient access, affordability, and equity.

Prior Authorization (PA) requirements are widely recognized as the Payor’s Boogeyman because they create overly burdensome, layered processes for patients to obtain approval for provider-prescribed care. These processes often result in lengthy delays that increase the likelihood that patients will abandon their care or treatment plans rather than fight the system. Numerous associations representing varied interests within the healthcare sector have correctly labeled PAs as fueling health disparities with disproportionate impacts on poor and minority populations.

The American Medical Association (AMA) has been an [outspoken critic of the practice](#), calling it a “nightmare” for disrupting patient care. Their latest [AMA prior-authorization physician survey](#) found the PA process led to delays in care over ninety percent (90%) of the time, leading Heather McComas, PharmD, Director of the AMA’s administrative simplification initiatives to argue: “Our physicians are saying that prior-authorization care delays actually hurt patients: 80% of physicians reported that prior authorization can lead to patients completely abandoning a prescribed or ordered course of care. Most alarming, one-third of physicians reported that prior authorization has led to a serious adverse event for a patient in their care. And a serious adverse event is something like hospitalization, permanent impairment or even death.”¹¹

Patients who fall within the lower socioeconomic status of our society are less likely to have the education or financial means to remedy the negative impacts caused by the delays in care and treatment. It creates additional hardship on communities of color, rural communities, and immigrant populations where English is probably a second language. The American Academy of Family Physicians (AAFP) made this very argument in a recent [letter](#):

“Evidence indicates that prior authorization requirements may be discriminatory and worsen health disparities, as documented in a study examining access to treatment for HIV pre-exposure prophylaxis and a white paper which examined the disproportionate impact of prior authorization requirements on cardiovascular care for Black and other patients of color. We are concerned that prior authorization requirements can worsen health disparities and create barriers to care for medically underserved patients, patients of color, LGBTQ+ patients, patients in rural areas, and those at risk for poor health outcomes. Federal oversight and action is needed to address the negative impacts prior authorizations are having on patients and physicians.”¹²

¹⁰ American Medical Association; 2023, May 12. How prior authorization disrupts patient care, Part I. Available from: <https://www.ama-assn.org/practice-management/prior-authorization/how-prior-authorization-disrupts-patient-care-part-i#:~:text=Our%20physicians%20are%20saying%20that%20prior%20authorization%20care,that%20prior%20authorization%20leads%20to%20negative%20clinical%20outcomes>

¹¹ Robeznieks, Andis; 2023, May 3. Once just a burden, prior authorization has become a nightmare. American Medical Association. Available from: <https://www.ama-assn.org/practice-management/prior-authorization/once-just-burden-prior-authorization-has-become-nightmare>

¹² American Academy of Family Physicians; (2022, Mar 22). RIN 0955-AA04; Request for Information: Electronic Prior Authorization Standards, Implementation Specifications, and Certification Criteria. Available from: https://www.aafp.org/dam/AAFP/documents/advocacy/health_it/ehr/LT-HHS-ONC-ElectronicPriorAuthorization-032222.pdf

Concerns over disparities in cardiovascular care caused by prior authorization was raised by the Association of Black Cardiologists (ABC), which issued a comprehensive white paper in 2019, [Identifying How Prior Authorization Impacts Treatment of Underserved and Minority Patients](#). The white paper “...hypothesized that lower resource levels at cardiology practices with a majority of patients from underserved and minority populations may pose a unique barrier to responding to PA needs for these patients, further fostering existing treatment disparities.”¹³

ABC found that, when asked, physicians agree 'very much' that PA contributes to delays in care (61%), higher patient confusion (50%), increased medication discontinuation (45%), reduction in medication adherence (32%), and worse outcomes (16%). In terms of time devoted to PA, about half of physicians (47%) note the staff spends five hours or more per week, and a third (32%) say their staff spends seven or more hours a week. This time also includes appeals, since about sixty percent of physicians (61%) submit an appeal if a PA is rejected. The burden on practice staff is considered high or extremely high by a majority of physicians (57%).¹⁴

Not surprisingly, most of ABC's member cardiologists were unable to name a single positive impact of PA for their underserved and minority patients.

There is also evidence that **Step Therapy** and the nonmedical switching of prescription medications are yet another “cost containment” strategy employed by health insurance companies and other payors exacerbate health disparities in the United States. Commonly called “fail-first” policies, step therapy can result in additional visits to the doctor, which disproportionately affects rural communities. Step therapy also means providers have less time to spend with patients, again disproportionately impacting rural communities.

According to a position paper published by the American College of Physicians (ACP), [Mitigating the Negative Impact of Step Therapy Policies and Nonmedical Switching of Prescription Drugs on Patient Safety](#), “Step therapy, nonmedical drug switching, and other cost-curbing formulary designs can also undermine the medical expertise of physicians and fail to adequately account for the individual characteristics and needs of patients, including comorbid conditions, concurrent medications, and demographic factors, all of which can impact a medication's effectiveness and side effects.”¹⁵

As an example, ACP cited patients with rheumatoid arthritis who experienced adverse health events because of step therapy requirements or nonmedical drug switching. Despite being switched to a lower-cost medication, these patients experienced a 126.2% increase in yearly medical payments (\$6,254 to \$14,127).¹⁶ Rheumatoid arthritis disproportionately impacts women and African Americans who have educational attainment levels less than high school and low family incomes, thus offering a clear indication of how these payor-drive cost containment strategies can impact patients living with certain chronic health conditions.

¹³ Association of Black Cardiologists; (Winter 2019). Identifying How Prior Authorization Impacts Treatment of Underserved and Minority Patients. Available from: <http://abcario.org/wp-content/uploads/2019/03/AB-20190227-PA-White-Paper-Survey-Results-final.pdf>

¹⁴ Association of Black Cardiologists; (Winter 2019). Identifying How Prior Authorization Impacts Treatment of Underserved and Minority Patients. Available from: <http://abcario.org/wp-content/uploads/2019/03/AB-20190227-PA-White-Paper-Survey-Results-final.pdf>

¹⁵ American College of Physicians; (2020). Mitigating the Negative Impact of Step Therapy Policies and Nonmedical Switching of Prescription Drugs on Patient Safety. Available from: https://assets.acponline.org/acp_policy/policies/step_therapy_nonmedical_switching_prescription_drugs_policy_2020.pdf

¹⁶ American College of Physicians; (2020). Mitigating the Negative Impact of Step Therapy Policies and Nonmedical Switching of Prescription Drugs on Patient Safety. Available from: https://assets.acponline.org/acp_policy/policies/step_therapy_nonmedical_switching_prescription_drugs_policy_2020.pdf

"Insurance-mandated step therapy exacerbates several factors that contribute to health disparities," says Sarah Buchanan, Co-Chair of the Safe Step Act Ad Hoc Coalition and Senior Federal Government Relations Director at the National Psoriasis Foundation. Many patients and providers don't have the time or resources to pursue step therapy exceptions because the process can be challenging and uncertain. As a result, individuals who find it difficult to access health care—for example, because they live far from a provider with the resources to engage insurers, they don't trust the health system, or they don't speak English well—can lose confidence in their providers and decide not to pursue appropriate care. By the time family members step in, or the patients themselves decide to return for medical care, it is often too late to prevent permanent damage. That is why patient advocacy groups across the country are working to pass step therapy exception laws in states and in Congress. These laws would ensure that health plans offer a reasonable and expedient step therapy exceptions process that is accessible to both the patients and providers. Buchanan further stated:

"By creating a clear exceptions process and carving out circumstances when a patient should be granted an exception, we hope to empower patients and providers to pursue coverage for the right treatment sooner, and ultimately to avoid the severe or irreversible health outcomes that are occurring because of insurance barriers."

With respect to the intersection between **Copay Accumulators** and health disparities, a dynamic assessment yields more troubling data. Copay accumulators (also known as "copay maximizers" or "accumulator adjustment schemes") are a policy implemented by a commercial health insurance company or Pharmacy Benefit Manager (PBM) that prevent copay assistance coupons from being utilized toward insurance deductibles or out-of-pocket maximums (OPMs). These policies can be present in both insurance coverage purchased from the health insurance marketplace and in employer-sponsored plans, although employers are able to negotiate with insurance companies or offer at least one option that does not include an accumulator policy.¹⁷

Copay accumulator policies can have devastating financial consequences for patients whose insurance coverage includes them. When copay assistance is not counted toward a patient's deductible and out-of-pocket maximum, they end up spending more money out-of-pocket even though the insurance companies still get paid by both the patient and the drug manufacturer (Figure 1). This is particularly true for patients who are enrolled in High-Deductible Health Plans (HDHPs) for whom "cost-sharing" is already higher.

¹⁷ Aired Alliance. (2020). *Copay accumulator programs: What employers need to know*. Washington, DC. https://aimedalliance.org/wp-content/uploads/2020/07/CopayAccumulators_FactSheet.pdf

Figure 1 - Example of How Copay Accumulator Programs Negatively Impact Patients

- Plan deductible: \$4,600
- Annual out-of-pocket maximum: \$8,550
- Cost-sharing for specialty tier prescription: 50% *after deductible is met*
- Monthly medication cost: \$1,680
- Copay assistance total: \$7,200

Scenario 1: Plan Without a Copay Accumulator Program

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Total	Insurer collects
Copay Assistance	\$1,680	\$1,680	\$1,240	\$840	\$840	\$840	\$80	\$0	\$0	\$0	\$0	\$0	\$7,200	
Remaining Deductible	\$2,920	\$1,240	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$0		\$8,550
Patient Pays	\$0	\$0	\$0	\$0	\$0	\$0	\$760	\$590	\$0	\$0	\$0	\$0	\$1,350	

Scenario 2: Plan With a Copay Accumulator Program

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Total	Insurer collects
Copay Assistance	\$1,680	\$1,680	\$1,680	\$1,680	\$480	\$0	\$0	\$0	\$0	\$0	\$0	\$0	\$7,200	
Remaining Deductible	\$4,600	\$4,600	\$4,600	\$4,600	\$3,400	\$1,720	\$40	\$0	\$0	\$0	\$0	\$0		\$15,160
Patient Pays	\$0	\$0	\$0	\$0	\$1,200	\$1,680	\$1,680	\$40	\$840	\$840	\$840	\$840	\$7,960	

Deductible is met
 Copay assistance limit is met
 Out-of-Pocket maximum is met

Note: Retrieved from The AIDS Institute, 2024¹⁸

To understand how accumulator programs can contribute to disparities in access to care, it's important to first establish who is eligible for, likely to utilize, or already accessing copay assistance programs. Most copay assistance programs offered by both drug manufacturers and private organizations require patients to be:

1. Enrolled in commercial insurance plans.
2. To be uninsured.
3. To have incomes that fall within the maximum income requirements set by each issuer.

¹⁸ The AIDS Institute. (2024). *Unchecked: Copay accumulator adjustment policies in 2024*. Washington, DC. <https://aidsinstitute.net/documents/TAI-2024-Report-2.27.pdf>

A [2022 survey](#) from the American Cancer Society found that 83% of patients who applied to copay assistance programs and were accepted said that the copay assistance coupons enabled them to access the medications they would otherwise be unable to afford. It also found that 27% of assistance recipients reported that those coupons were not counted toward their deductibles or OPMs due to a copay accumulator policy.¹⁹

The utilization rates of copay assistance coupons are largely tied to the types of disease those drugs are designed to treat. Manufacturers, really, only offer assistance programs for medications that treat conditions that are expensive to treat, such as HIV, cancer, and Rheumatoid Arthritis (RA). Black Americans are likelier to develop or be living with each of the conditions, compared to their White peers, and yet, White Americans are likelier to be aware of and utilize copay assistance programs than minority patients.²⁰

Research published in the *Journal of Managed Care & Specialty Pharmacy* found that copay assistance programs have the potential to narrow health outcome disparities in Black and Hispanic patients by increasing medication adherence and decreasing treatment abandonment because of being unable to afford medications. However, increasing awareness and utilization of copay assistance programs will require concerted efforts on behalf of manufacturers, providers, and other people within the healthcare infrastructure.²¹

These data means that, because minority patients are more likely to being living with expensive-to-treat illnesses, and more likely to earn less than their White peers,²² they are more likely to both need copay assistance and, if they are commercially insured, likely to be negatively impacted by copay accumulator programs.

Health Insurance Plan Design is also a significant driver of disparate health outcomes, particularly amongst lower-income and minority patients because it impacts the ability to access and afford either public or commercial health insurance. But, beyond just its accessibility and affordability lies another factor that is often overlooked: health insurance plan and benefits design.

When a patient selects health insurance coverage through an employer, the health insurance marketplace, or some other source, they are often provided with a variety of options or plans that ostensibly allow them to select the plan that best suits their needs. But several questions should be considered:

1. Will this plan cover my current provider or providers local to me?
2. Will this plan cover the medications I currently use?
3. Will my insurance be accepted at the pharmacy of my choosing?
4. Will I be able to afford the premiums, deductible, co-insurance, copays, and out-of-pocket maximums?

¹⁹ American Cancer Society. (2022, May). *Survivor views – copay assistance: May 2022 survey findings summary*. Washington, DC: American Cancer Society: Cancer Action Network. https://www.fightcancer.org/sites/default/files/national_documents/survivorviews-copayassist_0.pdf

²⁰ Institute for Patient Access. (2022, December). *Health disparities & medication access*. https://instituteforpatientaccess.org/wp-content/uploads/2022/12/IFPA_HealthDisparitiesReport_Dec-2022.pdf

²¹ Wong, W. B., Donahue, A., Thiesen, J., & Yeaw, J. (2023, January 24). Copay assistance use and prescription abandonment across race, ethnicity, or household income levels for select rheumatoid arthritis and oral oncolytic medicines. *Journal of Managed Care & Specialty Pharmacy*, 29(3), 229-334. <https://doi.org/10.18553/jmcp.2023.22288>

²² Office of Federal Contract Compliance Programs. (n.d.). *Earnings disparities by race and ethnicity*. Washington, DC: United States Department of Labor: Office of Federal Contract Compliance Programs: About Us: Data and Results: Earnings Disparities. <https://www.dol.gov/agencies/ofccp/about/data/earnings/race-and-ethnicity>

The answers to these questions may not always result in a patient finding an insurance plan that suits their needs. This is where the concept of “health insurance plan and benefits design” comes into play.

Plan design includes (*but is not limited to*):

- What services are covered;
- Which providers and hospitals are included, and;
- Out-of-pocket costs²³

In order for health insurers to remain profitable, they design plans using a system of constraints and incentives applied to both healthcare providers and patients. The first level applies those constraints and incentives to providers, such as by requiring them to submit prior authorization requests before treating patients with high-dollar procedures and medications. The second level is applied to patients in the form of cost-sharing (i.e., deductibles, copays, co-insurance, and out-of-pocket maximums).²⁴

Another aspect of plan design that supports this profitability model involves selecting in-network providers and hospitals. In order for an insurance plan to be useable for patients, they need to be able to access in-network providers that are relatively local to them. For those who live in rural, geographically isolated, or underserved parts of the country, this can mean that, while services are technically covered, the healthcare providers and services required to treat chronic illnesses, such as cancers, non-infectious diseases, and infectious diseases may be out of reach for many poor or minority patients.

The reality is that virtually *every* cost, regardless of how nominal payors may consider them to be, can serve as a barrier to accessing care and treatment. Insurance companies and other payors often fail to consider the reality that even a \$5.00 copay may result in a patient deciding between buying medications and paying rent or utility bills...and patients will usually choose the latter over medication.²⁵ Moreover, they often don't consider the costs of transportation to or from providers to access even basic healthcare services when determining cost-sharing levels for services.

These plan design issues often contribute to and exacerbate existing health disparities in lower-income and minority communities. For example, both the lack of insurance and the inability to afford the cost-sharing associated with seeking services and treatment can increase rates of late-stage breast and cervical cancer detection and decrease survivability. In Alabama's Black Belt—17 counties in which Black Americans make up at least 50% of the population that lack access to social and medical services, whose economies depend primarily upon agriculture, and have per capita incomes around \$13,000 per year—only 4 had at least one obstetrician-gynecologist as of 2018.²⁶ This means that Black people living in those counties are less likely to be able to get to, access, or afford screening services on a regular basis that might identify cancers earlier in their progression and increase survivability among Black people. When examining data from 2009-2018, Black

²³ Baicker, K. (2021). Rethinking health insurance design. *JAMA Health Forum*, 2(5), e211440. <https://doi.org/10.1001/jamahealthforum.2021.1440>

²⁴ Prager, E. (2023, November 03). *Smarter health insurance plan design*. Rochester, NY: University of Rochester: Simon Business School: Simon Blog: Dean's Corner. <https://simon.rochester.edu/blog/deans-corner/smarter-health-insurance-plan-design>

²⁵ Schilling, B. (n.d.). *Hitting the copay sweet spot*. New York, NY: The Commonwealth Fund: Areas of Focus: Improving Health Care Quality. <https://www.commonwealthfund.org/publications/newsletter-article/hitting-copay-sweet-spot>

²⁶ Brady, K. C., Stephens, C. P., Sudan, S. K., Singh, A. P., Dasgupta, S., & Singh, S. (2022, December). Breast and cervical cancer disparities in Alabama: Current scenario, ongoing efforts to reduce the disparity gaps, and what more we could be doing. *Cancer Health Disparities*, 6, e1-e10. <https://pubmed.ncbi.nlm.nih.gov/36777282>

women were more likely to be diagnosed with and die from both breast and cervical cancer than their White peers.³⁵ While this disparity cannot entirely be blamed upon plan design, insurers *can* subsidize preventive and routine screenings to reduce some of the costs associated with seeking these services.

Another way that insurers could mitigate some of these costs is to provide either reimbursement for and subsidize (in whole or in part) transportation to and from healthcare providers in these types of areas. This is something that often exists in public insurance coverage but is infrequently found in commercial coverage. This generally involves patients submitting receipts for fuel and mileage for reimbursement or scheduling subsidized transportation services to and from certain types of services through a 3rd-Party company that is contracted by their state's Medicaid agency to help patients access care.

A new and yet alarmingly troubling trend at the state level are the emergence of so-called **Prescription Drug Affordability Boards**, or PDABs. "Affordability" is a nuanced term with these little understood government-sanctioned price control entities.

A National Minority Quality Forum's [webinar](#) focused its attention on the escalating prevalence of state prescription drug affordability boards and their intersection with efforts to embed health equity as a tenant of the American health system. The reality is that PDABs can enable or hinder equitable access to efficacious therapies.²⁷

According to Jen Laws, President & CEO of the Community Access National Network (CANN)—a transgender man living with HIV in the American South—PDABs, on the surface, are supposed to make prescription drugs more affordable, but the application in how these entities move forward doesn't necessarily address the issues of access, especially for marginalized communities. The rate-setting mechanism utilized by PDABs hasn't demonstrated an ability to translate into better access, better health equity on marginalized community access to care, or even better network availability around access to care.

In a recent blog post, CANN argued:

"It's no secret that the high cost of healthcare is a significant concern for most Americans. The total national health expenditure in 2021 increased by 2.7% from the previous year to [4.3 trillion dollars](#) which was 18.3% of the gross domestic product. The federal government held the majority of the spending burden at 34%, with individual households a close second at [27%](#). A cornerstone component of medical treatment is the access to prescription drugs. In 2019 in the U.S., the government and private insurers spent [twice](#) as much on prescription drugs as in other comparatively wealthy countries. Despite catchy phrases that poll well, and "simple" solutions by politicians that promise to fix the problem—such as Prescription Drug Advisory Boards (also known as Drug Pricing Advisory Boards)—it is mindful to remember one thing: if it sounds good to be true, then it probably isn't true."²⁸

²⁷ National Minority Quality Forum; (2024, February 2). State Prescription Drug Affordability Boards & Health Equity. Retrieved online at https://www.youtube.com/watch?v=ZC_XSrWP9eE

²⁸ Simons, Ranier; (2023, July 10). Prescription Drug Advisory Boards: What They Are and Why They Matter to Patients. Community Access National Network. Retrieved online at <https://www.hiv-hcv-watch.com/blog/pdab-2023-1>

In Colorado, CANN has sounded the alarm on how that state's price control board could further fuel health disparities among marginalized populations living with cancer, HIV, and Hepatitis C (HCV). According to the Centers for Disease Control & Prevention, there are 24,280 Coloradans living with cancer, 13,442 Coloradans living with HIV, and 1,840 Coloradans living with HCV.²⁹

Why are these figures relevant to health disparities?

Local data for all cancer sites (meaning all types of cancer in sites throughout the body) indicate that cancer rates are highest amongst people aged 50 and older, with rates in the thousands (per 100,000 residents) once Coloradans turn 65. The most reliable predictor of cancer diagnoses is age. As the body ages, cells become damaged and degrade both through normal aging and through external factors, such as exposure to certain chemicals, including those in cigarettes, the excessive consumption of alcohol, or too much ultraviolet radiation from the sun. In addition to age-related rates, American Indians and Alaska Natives in Colorado have a rate of 1,349.4 (per 100k)—a significantly higher rate than members of other races.³⁰ This aligns with national risk evaluations. According to the Roswell Park Comprehensive Cancer Center, based in Buffalo, NY, Native Americans, despite regional and tribal differences, have overall higher-than-average rates of most cancers and have the lowest cancer survival rates in the United States. This may be attributed to several disparities faced by Native Americans and Alaska Natives, including:³¹

1. Native Americans communities tend to have higher rates of poverty and lower levels of education and educational attainment than other communities.
2. Native Americans also have the highest rates of cigarette smoking in the U.S., are 10 times more likely to die of alcohol-related reasons, and twice as likely to die from a drug overdose than other U.S. residents.
3. Native Americans are more likely to suffer from obesity than other races, with obesity rates varying widely by tribe and geographic location.
4. The diets of Alaska Natives tend to include foods that are high in salty, preserved fish and low in fresh fruits and vegetables.
5. Native American and Alaska Native communities are disproportionately impacted by environmental pollutants caused by the agricultural, drilling, and mining industries.

Compounding these environmental risks is the fact that healthcare services, along with other necessities, including electricity, phone service, sewage and water treatment, and internet access, are harder to access in indigenous communities. What healthcare services do exist are chronically underfunded, under-resourced, and understaffed.

²⁹ Community Access National Network; (2023, November 20). Prescription Drug Advisory Boards: Where They Are and How to Influence Them. Retrieved online at https://www.tiicann.org/pdf-docs/2023_CANN_PDAB_Project_Infographic_3_11-20-23.pdf

³⁰ Colorado Department of Public Health & Environment; (2024). Colorado Health Information Dataset (CoHID), Cancer Cases, Counts. Retrieved online at https://cohealthviz.dphe.state.co.us/t/HealthInformaticsPublic/views/COHIDCancerIncidenceRates/CancerIncidences?iframeSizedToWindow=true&%3Aembed=y&%3AshowAppBanner=false&%3Adisplay_count=no&%3AshowVizHome=no

³¹ Haring, Rodney C.; (2018, April 30). Native American Cancer Risks. Roswell Park. Retrieved online at <https://www.roswellpark.org/cancertalk/201804/native-american-cancer-risks>



With respect to HIV, Black residents of Colorado are disproportionately impacted, with a diagnosis rate of 34.2 (per 100k) compared to just 5.5 in White Coloradans, and a prevalence rate of 1,029.0, compared to 215.6 in Whites. Indigenous and Hispanic persons are also disproportionately impacted, with infection rates of 18.5 and 12.8, respectively, and prevalence rates of 267.8 and 332.9, respectively.³² Again, these disparities are doubly felt because accessing and affording medications to treat HIV is likely to be difficult for these communities due to higher levels of poverty and lower levels of education and educational attainment. Hispanic populations also face additional race-related stigma, with many members of the community fearing interactions with public health officials from fear of being accused of being in the country illegally.

Finally, Viral Hepatitis (including Acute and Chronic Hepatitis B and Hepatitis C) statistics are less clear. With acute cases of both HBV and HCV, the state of Colorado's county and state departments of health have never fully recovered or staff their departments to address hepatitis-related case investigations. As a result, the last year for reliable data is 2019. The diagnoses of chronic HBV and HCV, however, are much easier to determine, as they are reported directly from physicians and do not require confirmatory testing, making 2021 the most reliable year for information. Men and persons aged 20-39 are disproportionately impacted by Acute HCV, with men accounting for 68.6% of new diagnoses and persons aged 20-39 accounting for 60.8% of diagnoses. Women are more likely to be diagnosed with Acute HBV, representing 52.2% of cases, and most cases are diagnosed in persons aged 20-59, with persons aged 20-39 accounting for 43.5% and those aged 40-59 accounting for 47.8% of new Acute HBV diagnoses. White Coloradans account for much of both acute HCV and HBV diagnoses. As it relates to chronic HCV and HBV, Men are disproportionately impacted by both diseases, accounting for 69.5% of Chronic HCV and 55.6% of Chronic HBV cases. Again, persons aged 20-59 account for most chronic diagnoses, with persons aged 20-39 accounting for 44.7% of chronic HCV and 40.6% of chronic HBV diagnoses, and persons aged 40-59 accounting for 31.2% of Chronic HCV and 39.3% of Chronic HBV diagnoses. No racial demographic data are available for Chronic HCV, and many new diagnoses for Chronic HBV are in patients whose race was reported as "Unknown," indicating that reporting on race is incomplete.³³

CANN isn't alone in its concern over the unintended consequences of PDABs, in general, but also specifically on driving health disparities. The Global Coalition on Aging (GCA) contends that such price controls will have an adverse impact on patient outcomes through the lens of an aging population.

In a recent letter to the Colorado PDAB, GCA wrote:

“Many diseases that once burdened aging populations have evolved into manageable chronic conditions due to modern, safer, and more effective treatments, allowing many aging patients to live longer, healthier lives. However, while there have been significant strides to discover new treatments in recent decades, there remains a vast unmet patient need for new solutions to complex, age-related health challenges, including Alzheimer’s disease, HIV, heart disease, cancer, bone health, and more.”³⁴

³² Centers for Disease Control & Prevention; (2024, February 9). Social Determinant of Health Data. U.S. Department of Health & Human Services (HHS). Retrieved online at <https://www.cdc.gov/nchhstp/atlas/index.htm>

³³ Colorado Department of Public Health & Environment; (March 2023). Viral Hepatitis Surveillance in Colorado - 2021 Annual Report. Retrieved online at https://drive.google.com/file/d/1FnoK1zBcwOoVtlyxe5C_k-HxmeOt8GK/view

³⁴ Global Coalition on Aging; (2023, September 12). Colorado PDAB Must Be Accountable in Drug Affordability Reviews & Ensure Patient Access. Retrieved online at https://www.linkedin.com/posts/global-coalition-on-aging_gcoa-letter-of-concer-to-colorado-pdab-activity-7107343258887806976-LwZl/



The potential impact on patients with chronic health conditions and rare diseases by these government-sanctioned boards is cause for alarm. According to Linda Goler Blount, President & CEO of the Black Women’s Health Imperative, African Americans, and Latinos die disproportionately from rare diseases. In fact, during a [speech](#) at The National Press Club, Blount highlighted that “Blacks have higher death rates than whites for 12 of the 15 leading causes of death in the United States, and almost are rare diseases,” that “Black women also have 42% higher breast cancer mortality rates,” and “Latinos have higher death rates than whites for diabetes, hypertension, liver cirrhosis and homicide.”³⁵

The [Rare Access Action Project](#) (RAAP) has echoed some of these very same concerns. Michael Eging, who leads RAAP, contends:

“PDABs will continue to increase health disparities as rare patients are increasingly treated under a center of excellence model. These patients often travel out of state for their care, see specialists at centers of excellence, and are prescribed, and even receive their therapies (whether through infusion or prescription outpatient) from sources located outside their state. Creating upper payment limits will put those delivery systems at risk; and patients will find a growing patchwork of access as those providers cut back on services and fulfillment of prescription therapies. Already some institutions require patients to “brown bag” or supply the therapy rather than the center of excellence take the risk for payment. Rare patients in Medicaid will find this particularly acute as they will be the most vulnerable to limitations on access without recourse. And of those patients, children from low-income minority families will be impacted by the reductions in access.”³⁶

There are varied social and health indicators related to the growing trend of health disparities and inequities in the United States. These disparities can be examined by race and ethnicity, gender, sexual orientation and gender identity, disability status, and geographic location. Of equal importance is a better understanding of the drivers behind these health disparities and inequities, including the access to care and payment reimbursement policies pushed by health insurance companies, pharmacy benefits managers, and other payors. There is clear evidence to suggest these policies are a key driver behind the inequities that exist by gender, geography, socioeconomic status, race and ethnicity, and other areas.

PlusInc works to improve *health disparities* among marginalized communities in the United States. Learn more at <https://www.plusinc.org>.

³⁵ Clark, Sydney; (2021, September 21). African Americans underrepresented in research and clinical trials; Historical discrimination, malpractice and lingering mistrust block the path to significant diversity in rare disease research. *National Press Foundation*. Retrieved online at <https://nationalpress.org/topic/diversity-elusive-in-rare-disease-research/>

³⁶ National Organization for Rare Disorders (NORD) [Internet]. NORD (National Organization for Rare Disorders). [cited 2017 Apr 19]. <https://rarediseases.org/>