

# Health Equity Guidelines for the 119<sup>th</sup> Congress and Trump Administration

## An Open Letter

Dear 119th Congress and the Trump Administration,

We, the undersigned organizations that represent communities of all backgrounds across the country, are committed to improving the health and well-being of underserved populations. Despite the widespread recognition and documentation of health disparities between population groups, many still exist and have even widened over time.<sup>1</sup> These disparities often stem from broader social and economic inequalities and are driving a variety of adverse health outcomes in our communities including higher rates of premature death, infant mortality, and chronic health conditions.

The U.S. healthcare system needs to be significantly reformed to address rising costs, simplify its complex structure, and improve access to quality care. As policymakers, your leadership is crucial to ensuring constructive reforms are implemented and our communities are empowered to overcome pervasive health disparities. We urge your consideration of the following information and guidelines as you and your colleagues advance future healthcare initiatives and policies. The issues that affect diverse communities in America today.

### Confront the Rising Cost of Healthcare

The rising cost of healthcare in the United States translates into higher out-of-pocket costs and a lack of quality healthcare access for underserved populations.<sup>2</sup> To truly lower costs and achieve better outcomes for every patient, all healthcare stakeholders must be held accountable for the rising cost of care. Predatory practices such as surprise and unfair medical bills, exploitation of federal program loopholes, lack of competition in healthcare markets, and rampant profiteering by Pharmacy Benefit Manager (PBM) middlemen in the drug supply chain must end. Increased government oversight and fundamental reforms are necessary to curb existing waste, fraud, and abuse and lower costs for every patient.

### Protect Critical Federal Healthcare Programs

Protecting federal healthcare programs like Medicare and Medicaid is crucial for ensuring the health and well-being of millions of Americans. These programs provide essential coverage to vulnerable populations, including seniors, low-income individuals, and people with disabilities. They help to reduce healthcare costs for families, improve access to preventive care, and provide a safety net for those who might otherwise go without necessary medical treatment. For example, while private insurance remains the primary source of coverage across racial and ethnic groups, programs Medicaid helps fill coverage gaps for underserved patients who are disproportionately impacted by chronic conditions.<sup>3</sup> Widespread cuts to these and other critical government health programs can result in disruptions in services our communities rely on and make the government less efficient and effective.

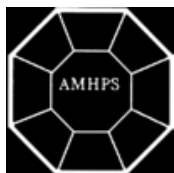


HEALTH EQUITY COLLABORATIVE



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## Promote Patient Empowerment Across the Healthcare Sector

Patient empowerment is a concept in healthcare that emphasizes the active role of patients in their own care. It involves providing patients with the necessary information, resources, and support to make informed decisions about their health and treatment options. Promoting patient empowerment across the healthcare sector is crucial for fostering a more equitable and effective healthcare system. Empowered patients are more likely to be actively engaged in their own care, leading to better health outcomes, increased adherence to treatment plans, and greater satisfaction with their healthcare experience. When patients have access to clear information, understand their treatment options, and feel comfortable communicating with their providers, they can make informed decisions that align with their values and preferences.<sup>4</sup> This not only improves individual health but also contributes to a more responsive and patient-centered healthcare system overall, ultimately leading to higher quality care and better population health.

## Support Breakthrough Medical Technologies and Innovation

Breakthrough medical technology and innovation are crucial for advancing healthcare and improving lives. They drive progress in preventing, diagnosing, and treating diseases, leading to better patient outcomes and increased life expectancy. By supporting research and development in areas like gene editing, artificial intelligence, and personalized medicine, we can unlock new possibilities for fighting cancer, Alzheimer's, and other debilitating conditions. It is equally important to improve access to innovative medicines and therapies that are already available to patients. Treatments like GLP-1s can greatly benefit patients battling chronic conditions such as diabetes and obesity. Investing in and improving access to these advancements not only improves individual well-being but also strengthens our healthcare system and fosters economic growth.<sup>5</sup> Both the public and private sectors must remain committed to pursuing new treatments as more innovation and further medical breakthroughs are needed.

## Improve the Representation of Diverse Populations in Clinical Research and Data Sets

The timely collection, analysis, and distribution of disaggregated data by public health agencies is paramount to addressing the unique health issues faced by underserved communities. Having rich data on diverse communities and strong representation in medical research and clinical trials ensures that the treatments developed meet the various needs of patients. Yet, communities of color are traditionally disproportionately underrepresented within medical research, and data collected on these populations is limited.<sup>6</sup> Disaggregated data broken down by race, ethnicity, primary language, sex (including sexual orientation and gender identity), disability status, age, and other sociodemographic characteristics is critical for understanding health challenges faced by underserved communities. Unfortunately, such data is often incomplete with many instances of chronic undercounting. Also in clinical trials, underrepresentation is even true among diseases and illnesses that disproportionately impact people of color, including diabetes, heart disease, Alzheimer's disease, and cancer.<sup>7</sup> Such gaps endanger potentially significant public health advancements and undermine the value of clinical trials. To address these issues, we must work with trusted messengers to

# Health Equity Guidelines for the 119<sup>th</sup> Congress and Trump Administration



increase awareness and develop educational programs that help to encourage engagement from communities of color. Physicians must also have access to trained medical interpreters to ensure diverse populations receive the highest quality of care in the language that is most comfortable to them.

## Build a Representative Healthcare Workforce

Creating a healthcare workforce that looks like America is essential to gaining patient trust and ensuring all segments of our society receive quality care. Efforts within medical education include targeted recruitment and outreach programs aimed at attracting students from underrepresented backgrounds, holistic admissions processes that consider a broader range of qualifications, and the creation of more comprehensive learning environments that support the success of all students. Many institutions are also developing pipeline programs that partner with undergraduate institutions and community organizations to prepare students from all backgrounds for careers in medicine.<sup>8</sup> Such initiatives are essential for building a future healthcare workforce that reflects a multi-faceted population and is better equipped to address the complex health needs of all communities.

## Modernize Value-Based Treatment and Clinical Care

When it comes to healthcare, one size does not fit all. Lawmakers and industry stakeholders must provide meaningful tools and personalized services to meet the needs of underserved populations. Putting our patients and communities first depends on steering the healthcare industry towards consumer-focused and consumer-driven solutions, including the utilization of value-based contracts to improve patient access and reduce out-of-pocket costs. However, discriminatory assessments from outside entities, or other countries, that put arbitrary numbers on patient lives should not be used. Our infrastructure for providing home and community-based services (HCBS) can also be improved to better meet the needs of disadvantaged communities. Currently, too many low-income older adults and people with disabilities are forced into institutional settings to receive the care they need, particularly women, communities of color, and individuals with cognitive disorders.<sup>9</sup> Conventional metrics to measure value to patients, such as the Quality-Adjusted Life Year (QALY) metric, should also be revisited to ensure these tools are not contributing to increased health disparities.<sup>10</sup>

Sincerely,

**Health Equity Collaborative**

**African American Diabetes Association**

**ALLvanza**

**American Association of People with Disabilities**

**American Muslim Health Professionals**

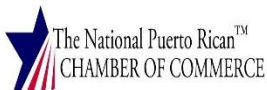
**ASPIRA Associations, Inc.**

**Association of Black Cardiologists (ABC)**

**Association of Minority Health Professions Schools**

**Autism Society of America**

**Black, Gifted, & Whole Foundation**



**Organization for Latino Health Advocacy**



## Health Equity Guidelines for the 119<sup>th</sup> Congress and Trump Administration



**Black Women's Health Imperative (BWHI)**

**Center for Black Equity**

**Choose Healthy Life (CHL)**

**Consumer Action**

**Debbie's Dream Foundation**

**Financial Services Innovation Coalition (FSIC)**

**GLMA: Health Professionals Advancing LGBTQ+ Equality**

**HealthHIV**

**Latino Commission on AIDS**

**LatinoJustice PRLDEF**

**League of United Latin American (LULAC)**

**MANA, A National Latina Organization**

**National Alliance for Caregiving (NAC)**

**National Association of Hispanic Federal Executives (NAHFE)**

**National Black Nurses Association (NBNA)**

**National Coalition for LGBTQ Health**

**National Consumers League (NCL)**

**National Down Syndrome Society (NDSS)**

**National Grange**

**National Hispanic Health Foundation (NHHF)**

**National Medical Association (NMA)**

**National Puerto Rican Chamber of Commerce (NPRCC)**

**Organization for Latino Health Advocacy (OLHA)**

**Partnership for Innovation and Empowerment (PIE)**

**SER National**

**Southern Christian Leadership Global Policy Initiative**

**South Asian Public Health Association (SAPHA)**

**The Balm in Gilead, Inc.**

**The Hispanic Institute**

**The Latino Coalition**

**Women Impacting Public Policy (WIPP)**

**United Spinal Association**

**United States Hispanic Chamber of Commerce (USHCC)**



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<sup>1</sup> <https://www.kff.org/racial-equity-and-health-policy/issue-brief/disparities-in-health-and-health-care-5-key-question-and-answers/>

<sup>2</sup> <https://www.kff.org/health-costs/issue-brief/americans-challenges-with-health-care-costs/>

<sup>3</sup> <https://www.kff.org/medicaid/issue-brief/how-many-uninsured-are-in-the-coverage-gap-and-how-many-could-be-eligible-if-all-states-adopted-the-medicare-expansion/>

<sup>4</sup> <https://pmc.ncbi.nlm.nih.gov/articles/PMC9411825/>

<sup>5</sup> <https://www.sciencedirect.com/science/article/abs/pii/S0040162524002464>

<sup>6</sup> <https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-and-ethnic-disparities-in-access-to-medical-advancements-and-technologies/>

<sup>7</sup> <https://www.sciencedirect.com/science/article/pii/S0146280618301889>

<sup>8</sup> <https://pmc.ncbi.nlm.nih.gov/articles/PMC6984344/>

<sup>9</sup> <https://www.americanprogress.org/article/how-dehumanizing-administrative-burdens-harm-disabled-people/>

<sup>10</sup> <https://www.sciencedirect.com/science/article/pii/S109830152402789X>