

## Healthcare Equity Guidelines for the 116th Congress

**Dear Members of the 116th Congress,**

We, the undersigned organizations, who represent diverse communities across the country are very concerned with the current healthcare policy debate. It is our shared belief that the state of healthcare for underserved communities truly reflects the health and wellness of a diverse nation. Unfortunately, our communities have been excluded and underrepresented in the policymaking process by Congress and the Trump Administration. This lack of inclusion reflects the reality of our healthcare system that diverse communities are less likely to receive quality care and more likely to face poorer health outcomes.

Bridging the health equity gap must be prioritized at the highest level. The utilization of a holistic and intersectional approach which promotes social justice is essential to eliminating health disparities for diverse populations. This includes addressing the social determinants of health by creating environments that promote good health for all. As Members of Congress, we urge your consideration of the following information and guidelines as you and your colleagues pursue future healthcare initiatives. The priorities we outline below enjoy broad support and are directly responsive to the issues that affect diverse communities in America today.

- **Reduction of Health Disparities:** Social determinants of health - race, ethnicity, sex, sexual identity, socioeconomic status - are factors that influence an individual's health. Health disparities based on these factors are a pervasive problem in the United States that result in higher mortality rates, chronic conditions, and infectious diseases. It is estimated that Latinos and African Americans experience 30 to 40 percent poorer health outcomes than Caucasians<sup>i</sup>. For all cancers combined, the death rate is 25 percent higher for African Americans than for Caucasians.<sup>ii</sup> Furthermore, nearly 49 percent of African American women have cardiovascular disease, while Latino women are likely to develop heart disease 10 years earlier than non-Latinos.<sup>iii</sup> Asian Americans face health disparities in cancer and chronic diseases, such as heart disease, hypertension, and diabetes.<sup>iv</sup> Acknowledging these staggering disparities and empowering greater participation in the stakeholder process through civic engagement and education is the first step towards achieving health equity.
- **Holding Healthcare Industry Actors Accountable:** The rising cost of healthcare in the U.S. translates into higher insurance costs, under-resourced hospitals, and lack of quality health access for marginalized communities. Lack of price transparency has allowed chief executives and stockholders to get incredibly rich while a staggering one in five insured Americans report having problems paying their medical bills.<sup>v</sup> Every sector of the healthcare industry needs to be held accountable for predatory practices such as surprise and unfair medical bills, exploitation of federal program loopholes at the expense of patients, and rampant profiteering by middlemen in the drug supply chain. Increased government oversight and fundamental reforms are necessary to curbing this waste, fraud, and abuse and ensure savings are passed directly to patients.

- **Confronting the Coverage Gap:** Despite historic gains by the Obama Administration through the Affordable Care Act to help over 20 million people gain insurance coverage, more needs to be done to level the disparities in coverage for diverse communities. African Americans and Latino communities have significantly higher uninsured rates than non-Hispanic Whites. Currently, ethnic minorities make up 42 percent of the nonelderly U.S. population, but account for over half of the total nonelderly uninsured population.<sup>vi</sup> 6.6 percent of Asian Americans were uninsured, as compared to 5.9 percent non-Hispanic white Americans.<sup>vii</sup> Sky-high deductibles, premiums, and ineffective cost-sharing schemes are used by the insurance companies to price people of color out of healthcare while reaping in billions in profits. We must seek to better inform our communities of the real cost of insurance plans through easily accessible out-of-pocket cost information in their primary language about coverage prior to enrollment.
- **Improving Access to Addiction Care and Safe Medicines:** Throughout our communities, we have witnessed a growing number of overdoses and deaths due to the opioid epidemic and the use of fentanyl-laced counterfeit medicines.<sup>viii</sup> Disturbingly, more than half of all opioid overdose deaths last year were from fentanyl manufactured overseas.<sup>ix</sup> Just months ago, the DEA seized over 73,000 counterfeit pills containing fentanyl in Arizona. Reform initiatives should include greater access to addiction care services in underserved communities and increased education efforts about the dangers of counterfeit prescription drugs. Furthermore, strong domestic government safeguards and regulatory policies are critical to fortifying our nation's domestic drug supply from the dangers of foreign-borne counterfeit drugs.
- **Promoting a Diverse Healthcare Workforce:** Research shows that African Americans and Latinos are much less likely to trust physicians and hospitals; thus, are significantly less likely to seek treatment.<sup>x</sup> This distrust is rooted in a longstanding history of discrimination and exploitation of people of color by the U.S. medical establishment. Increasing the diversity of America's healthcare workforce is essential to gaining diverse communities' trust and ensuring all segments of our society receive quality care. A culturally competent and diverse workforce leads to improved access to high-quality care for all Americans. Pro-diversity policies, which ensure diverse populations have access to pursue medical school or related healthcare professions are essential to providing care for the changing demographics of our nation. People of color make up nearly one-third of the population yet only account for 14 percent of our nation's primary doctors.<sup>xi</sup> It's time to recognize this disparity is a problem and prioritize diversifying our healthcare workforce.
- **Addressing Underrepresentation of Diverse Communities in Clinical Trials:** Clinical trials are critical to developing safe and effective treatments and therapies to prevent and treat diseases. It is important to ensure that the participants in trials are selected according to scientifically justified criteria. We encourage stakeholders to take steps, where appropriate and scientifically justified, to recruit participants from diverse communities.

According to the FDA, African Americans represent 12 percent of the population but only 5 percent of clinical trial participants. Latinos represent 16 percent of the population but only 1 percent of clinical trial participants.<sup>xii</sup> The critical first step is to identify and address potential barriers to enrollment (e.g., limited access to clinical trial sites), retention, and a positive patient experience. Having strong representation from diverse communities may help ensure that the treatments developed meet various, unique needs. Steps should be taken in the public and private sector to ensure outreach to historically under-represented communities for participation in trials is culturally appropriate and sensitive, including increasing clinical trial awareness and educational programs.

- **Supporting Breakthrough Medical Technologies and Innovation:** Medical innovation has undeniably led to the treatment of many previously untreatable diseases such as HIV/AIDS over the last thirty years. However, more needs to be done to combat life-threatening diseases, which currently plague diverse communities at higher rates. Therefore, we encourage the research and development of medical treatments to improve health outcomes and combat diseases that predominately affect diverse communities disproportionately such as sickle cell disease. For example, recent scientific and clinical advancements in gene therapy offer new hopes for patients suffering from sickle cell, diagnosed with cancer, Hepatitis B, cystic fibrosis, and Parkinson’s disease. We urge lawmakers and private industry actors to remain committed in their pursuit for new treatments as more innovation and further medical breakthroughs are needed.
- **Revolutionizing Value-Based Care:** When it comes to healthcare, one size does not fit all. It is critical that lawmakers and industry stakeholders provide meaningful tools and personalized services to meet the needs of diverse populations. Putting our patients and communities first depends on steering the healthcare industry towards consumer-focused and consumer-driven solutions. This can include utilizing value-based contracts to improve patient access and reduce out-of-pocket costs but should not utilize discriminatory assessments from outside entities, or from other countries, that put arbitrary numbers on patient lives.

---

<sup>i</sup> <https://www.forbes.com/sites/robertpearl/2015/03/05/healthcare-black-latino-poor/>

<sup>ii</sup> <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=16>

<sup>iii</sup> <https://newjersey.heart.org/2018/04/03/health-crisis-remains-heart-minorities/>

<sup>iv</sup> <https://www.nimhd.nih.gov/news-events/features/training-workforce-dev/center-asian-health.html>

<sup>v</sup> <https://www.kff.org/health-costs/press-release/new-kaisernew-york-times-survey-finds-one-in-five-working-age-americans-with-health-insurance-report-problems-paying-medical-bills/>

<sup>vi</sup> <https://www.kff.org/uninsured/fact-sheet/key-facts-about-the-uninsured-population/>

<sup>vii</sup> <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=63>

<sup>viii</sup> <https://www.usatoday.com/story/news/health/2019/03/22/fentanyl-drug-overdose-deaths-africanamericans-hispanics/3243635002/>

<sup>ix</sup> <https://www.cdc.gov/media/releases/2018/p0329-drug-overdose-deaths.html>

<sup>x</sup> <https://www.sciencedirect.com/science/article/abs/pii/S0049089X15001325?via%3Dihub>

<sup>xi</sup> <https://www.deseret.com/2019/3/20/20668770/guest-opinion-the-u-s-health-care-system-needs-more-diversity>

<sup>xii</sup> <https://www.fda.gov/media/84982/download>

*Sincerely,*

**Dr. Charles Steele**  
President/CEO  
Southern Christian  
Leadership Conference

**Brady Buckner**  
Co-Founder and Director  
Partnership for Innovation  
and Empowerment

**Rosa Mendoza**  
President and CEO  
ALLvanza

**Ronald Blackburn-  
Moreno**  
President and CEO  
ASPIRA Association

**Tammy Boyd**  
Chief Policy Officer  
Black Women's Health  
Imperative

**Charles Brooks**  
President  
Faithworks

**Hector Vargas**  
Executive Director  
GLMA: Health  
Professionals Advancing  
LGBTQ Equality

**Gustavo Paredes**  
Treasurer  
The Hispanic Institute

**Alejandro Roark**  
Executive Director  
Hispanic Technology &  
Telecommunications  
Partnership

**Tracy Harvey**  
Co-Founder  
Leading Ladies of  
Richmond

**Amy Hinojosa**  
President and CEO  
MANA, A National Latina  
Organization

**Hilary Shelton**  
Washington Bureau  
Director  
NAACP

**Leon Townsend**  
Director  
National Association of  
Neighborhoods

**Brian Hujdich**  
Executive Director  
National Coalition of LGBT  
Health

**Burton Eller**  
Legislative Director  
National Grange

**Justin G. Nelson**  
Co-Founder & President  
National LGBT Chamber of  
Commerce

**Martin Hamlette**  
Executive Director  
National Medical  
Association

**Justin Vélez-Hagan**  
National Executive Director  
National Puerto Rican  
Chamber of Commerce

**Julian Martinez**  
Director  
SER: Jobs for Progress  
National

**Dr. Juan Andrade Jr.**  
President & Co-Founder  
U.S. Hispanic Leadership  
Institute

**Candace Waterman**  
President & CEO  
Women Impacting Public  
Policy

---

*Thank You*