



August 13, 2019

Roger Severino  
Director, Office for Civil Rights  
U.S. Department of Health and Human Services  
200 Independence Avenue SW  
Washington, DC

The Honorable Alex M. Azar II  
Secretary  
U.S. Department of Health and Human Services  
200 Independence Avenue SW  
Washington, DC

**RE: Proposed Rule HHS–OCR–2019–0007, Changes to ACA Section 1557**

Dear Mr. Severino and Secretary Azar,

On behalf of the HIV Medicine Association (HIVMA), representing over 5,000 front-line, HIV medical care providers and researchers across the United States, I write to strongly request that you withdraw this proposed rule, which would roll back essential protections for people living with and those at higher risk for HIV as well as populations who already face numerous barriers to accessing quality health care. Finalizing this rule will directly undermine and seriously deter the goals of your department's own Initiative to End the HIV Epidemic in the United States. Ending the HIV epidemic will not happen unless we end it for and with ALL persons with and at higher risk for HIV.

HHS has granted assurances that as part of the commitment to their Ending the HIV Epidemic Initiative all persons with HIV and at higher risk for HIV should have access to HIV treatment and prevention services. However, by eroding protections for populations disproportionately affected by HIV, implementation of this rule would run counter to these assurances

The non-discrimination provisions of the ACA which ensures that people with and at higher risk for HIV including transgender individuals have access to medical care treatment and prevention are critical to achieving the goals of HHS's Ending the HIV Epidemic Initiative. The Initiative's key strategies focused on markedly increasing the number of people living with HIV who are in care, on medication and virally suppressed and the expansion of Pre-Exposure Prophylaxis (PrEP) for people at higher risk for HIV will be greatly compromised if this rule takes effect. Let us respectfully remind you that stigma and discrimination remain two of the biggest obstacles to the success of our national HIV response. Without these non-discrimination protection statutes, persons with and at higher risk for HIV including LGBTQ individuals will be driven further away from not toward medical clinics as health insurers, medical providers and institutions once again are able to vary health benefits in ways that discriminate against them and other vulnerable populations. We have made remarkable progress over the past 30 years combatting these foes, stigma and discrimination. Please do not offer them the opportunity to return.

While Section 1557 of the Affordable Care Act is still the law, this proposed rule attempts to change the administrative implementation in a way that is contrary to the plain language of the law. The proposed changes paradoxically pose significant risks to those the law is intended to protect, including LGBTQ people; people who need reproductive health care, including abortion; women of color; people living

with disabilities and/or chronic conditions; and people whose primary language is not English—all people who already experience significant barriers to accessing health care. The proposed changes will create additional barriers and potentially lead to worse health outcomes, with a disproportionate negative impact on those living with more than one of these medical and socio-economic conditions.

### **Deleting Provisions Specific to Sex Discrimination**

The proposed rule would have a disproportionate discriminatory impact on LGBTQ people -- especially transgender and non-binary people, who already face grave barriers to accessing care, such as higher uninsured rates, refusal of care and harassment by medical care providers. The 2016 final rule implementing Section 1557 clarified that health care providers cannot refuse to treat a patient because of their sexual orientation or gender identity – a fundamental tenant of the Hippocratic oath. The proposed rule illegally purports to allow a health care provider to refuse to treat someone because of their sexual orientation or gender identity. For example, a doctor could refuse to treat a transgender person for a cold or a broken bone, simply because of their gender identity.

According to the Centers for Disease Control and Prevention, “many transgender people face stigma, discrimination, social rejection, and exclusion that prevent them from fully participating in society, including accessing health care, education, employment, and housing, as well as violence and lack of family support.”<sup>i</sup> These factors affect the health and well-being of transgender people, placing them at increased risk for HIV. Twenty-nine percent of transgender individuals were refused medical care by a health care provider on the basis of their perceived or actual gender identity and the same percent experienced unwanted physical contact from a health care provider.<sup>ii</sup> Additionally, the 2015 U.S. Transgender Survey found that 23% of respondents did not see a provider for needed health care because of fears of mistreatment or discrimination.<sup>iii</sup>

Transgender people represent an historically and currently neglected and discriminated against population who have borne a significantly disproportionate burden of HIV infections. A recent meta-analysis estimates that 14% of transgender women in America are living with HIV, and that 44% of Black transgender women and 26% of Latina transgender women are living with HIV.<sup>iv</sup> Even among clients in HRSA’s Ryan White HIV/AIDS Program, which has a national viral suppression rate of 86%, only 80% of transgender patients have achieved viral suppression, and among those with temporary and unstable housing, the viral suppression rate drops to 73% and 65%, respectively.<sup>v</sup>

In order for the HHS Initiative to be successful, it will need to seek out, engage and anchor these persons in long-term, consistently welcoming and high-quality healthcare, not drive them away with discriminatory rules.

Access to affordable, high-quality health care coverage is enough of a challenge for many transgender people, especially those who live in states that have not expanded Medicaid where rates of new HIV cases are the highest. Health care settings, hospitals, and all clinical visits should be seen as welcoming, safe havens for patients, especially those accessing HIV care, which regrettably remains a stigmatized endeavor, particularly in regions and jurisdictions being targeted through the Ending the HIV Epidemic Initiative. HHS’s Initiative to End HIV as an Epidemic will not happen unless we end the HIV epidemic for transgender people. Allowing medical providers, insurers, and institutions to again systematically refuse care to transgender people is discriminatory, runs counter to the Hippocratic Oath and is bad public health policy.

## Narrowing the Scope by Limiting Covered Entities and Removing Key Regulatory Protections

Finally, OCR's new interpretation of Section 1557 would eliminate prohibitions of discriminatory benefit design, drawing a capricious line between providing health care and health insurance coverage, and would arbitrarily redefine the types of federal programs that must enforce nondiscrimination protections by not applying nondiscrimination regulations across the board to all programs administered by HHS. Patients with chronic medical conditions, including HIV, require life-long, consistent access to medical care, and prior to the Affordable Care Act, people with pre-existing conditions were discriminated against – either summarily by being denied health coverage by insurers or implicitly through higher premiums and prohibitively expensive tiering of specific and necessary prescription drugs. Allowing insurance companies to return to pre-2010 tactics would dramatically and negatively affect patients' ability to access life-saving care and would completely cancel out the progress we have made over the last three decades to bring people living with HIV into quality care.

Again, we urge you to consider the direct and destructive implications of these changes on the entire health care system, and specifically on people living with HIV and those seeking to prevent HIV infection through PrEP and other effective biomedical interventions. The health of our patients and our ability to improve public health depend on these protections. Please rescind this proposed rule. Please contact George Fistonich at [gfistonich@hivma.org](mailto:gfistonich@hivma.org) with questions regarding our comments.

Sincerely,



W. David Hardy, MD  
Chair, HIVMA Board of Directors

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<sup>i</sup> CDC. HIV and Transgender People. <https://www.cdc.gov/hiv/group/gender/transgender/index.html>.

<sup>ii</sup> Shabab Ahmed Mirza & Caitlin Rooney, *Discrimination Prevents LGBTQ People from Accessing Health Care*, Ctr. for American Progress, (Jan. 18, 2018),

<https://www.americanprogress.org/issues/lgbt/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care/>.

<sup>iii</sup> National Center for Transgender Equality, *The Report of the 2015 U.S. Transgender Survey 5* (2016), <https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf>.

<sup>iv</sup> Becasen JS, Denard CL, Mullins MM, Higa DH, Sipe TA. 2019. Estimating the Prevalence of HIV and Sexual Behaviors Among the US Transgender Population: A Systematic Review and Meta-Analysis, 2006–2017. *American Journal of Public Health*, 109, e1\_e8, <https://doi.org/10.2105/AJPH.2018.304727>.

<sup>v</sup> HRSA. January 2019. HRSA's Ryan White HIV/AIDS Program: Transgender Clients, 2017. <https://hab.hrsa.gov/sites/default/files/hab/data/datareports/2017-rsr-transgender.pptx>.