



Mr. Roger Severino
Director, Office for Civil Rights
United States Department of Health and Human Services
200 Independence Ave SW
Washington, DC 20201

**Re: HHS Docket No. HHS–OCR–2019–0007 - Comments in Response to Proposed Rulemaking:
Nondiscrimination in Health and Health Education Programs or Activities**

Dear Mr. Severino:

On behalf of the Hep B United Coalition, we appreciate the opportunity to provide comments on the Notice of Proposed Rulemaking (NPRM) on Section 1557 of the Patient Protection and Affordable Care Act (ACA) (“Health Care Rights Law” or “Section 1557”). The Hep B United Coalition has grave concerns regarding the detrimental impacts the proposed rule will have on individuals who are at most risk of discrimination, especially marginalized communities and individuals with pre-existing health conditions including hepatitis B.

Hep B United is a national coalition of over 40 organizations in 21 states dedicated to reducing the health disparities associated with hepatitis B by increasing awareness, screening, vaccination, and linkage to care for high-risk communities across the United States. An estimated 2.2 million Americans are infected with chronic hepatitis B virus (HBV). Yet, only 25 percent of people are aware of their infection and less than 10 percent of infected individuals are able to access care and receive treatment. Living with chronic HBV can lead to serious health complications, including liver cancer, cirrhosis (scarring of the liver), or liver failure. Significant disparities are associated with hepatitis B. Asian American, Pacific Islander, and African communities are disproportionately affected by the epidemic, with these communities comprising up to 80% of all chronic hepatitis B infections in the U.S.

The proposed rule would exacerbate hepatitis B-related health disparities and reverse progress made to eliminate hepatitis B in the U.S. Among those chronically infected with hepatitis B, an estimated 70 percent are non-U.S. born and face unique barriers in accessing health care services, including language access barriers. Additionally, hepatitis B vaccination coverage among all adults in the U.S. is very low, currently at 25 percent. The proposed rule could lead to increased prevalence of communicable diseases like hepatitis B, including among those who are unvaccinated. The proposed rule would create major barriers to hepatitis B prevention and treatment efforts underway; more importantly, it would severely limit access to health care services for communities at highest risk of hepatitis B infection, including limited English proficient (LEP) communities; lesbian, gay, bisexual and transgender (LGBT) individuals; and people with chronic health conditions such as hepatitis B.

The proposed rule will have a dramatic impact on Asian American and Pacific Islander (AAPI) families. In recent years, three out of every ten individuals obtaining permanent residence status are from Asia and Pacific Island nations, many of whom are LEP.¹ Among an estimated 637,000 LGBT-identified adult documented immigrants in the U.S., approximately 35 percent are AAPI. This rate is expected to be

¹ Department of Homeland Security, Yearbook of Immigration Statistics 2017, <https://www.dhs.gov/immigration-statistics/yearbook/2017>

higher among younger LGBT-identifying AAPIs.² Furthermore, AAPIs have a high private health insurance utilization rate at 67 percent and 66 percent, respectively.^{3,4} When disaggregated into ethnic subgroups, however, AAPI communities have some of the highest rates of being uninsured.⁵ By proposing to decimate existing provisions against discrimination in health care, the proposed rule would effectively allow these American citizens to be denied access to quality health care and critical patient information.

Additionally, the proposed rule will adversely affect Black and African American communities. In 2017, it was estimated that around 119,000 African American individuals obtained permanent residence status, with many being LEP. Among the total population of LGBT-identifying adults, 12 percent are African American.⁶ Consequently, this group would be significantly impacted by the proposed rule change. African Americans also have a high private health insurance utilization rate at 67.2 percent.⁷ However, the uninsured rate for Black/African Americans is 11.1 percent, a relatively high rate. By removing the current provisions preventing health care discrimination, the proposed rule would essentially disproportionately deny access to quality health care and key patient awareness for Black and African American communities.

Building on well-established and highly regarded civil rights laws, Section 1557 explicitly recognizes the detrimental effects discrimination has on people. An abundance of research acknowledges its effects, ranging from poor health outcomes to low literacy rates to income inequality among groups that face discrimination.⁸ In effect, discrimination can be attributed to social interactions that occur to protect more powerful and privileged groups at the detriment of other groups. Thus, **by removing and/or altering key nondiscrimination provisions of Section 1557, HHS would grant health care providers, insurance companies, pharmacy benefit managers, and insurers freewill to discriminate, undermining the rights of all Americans.**

The Proposed Rule Narrowly Limits Nondiscrimination Protections for Limited English Proficient Individuals

Under the proposed rule, language access protections set forth in Section 1557 will effectively be stripped from LEP eligible individuals. In the U.S., there are approximately 25.1 million LEP speakers, making up 8% of the total U.S. population. About 77 percent of Asian Americans speak a language other than English at home, and more than one-third, or 35 percent, are LEP.⁹ Moreover, according to 2016 Census

² The Williams Institute, LGBT Adult Immigrants in the United States, 2013, <https://williamsinstitute.law.ucla.edu/research/census-lgbt-demographics-studies/us-lgbt-immigrants-mar-2013/>

³ U.S. Department of Health and Human Services, Office of Minority Health, Minority Population Profiles: Asian Americans, <https://minorityhealth.hhs.gov/omh/browse.aspx?vl=3&vlid=63>

⁴ U.S. Department of Health and Human Services, Office of Minority Health, Minority Population Profiles: Native Hawaiian/Other Pacific Islanders, <https://minorityhealth.hhs.gov/omh/browse.aspx?vl=3&vlid=65>

⁵ Asian American Policy Review, Disparities in Health Insurance Coverage Among Asian Americans, 2013, <https://aapr.hkspublications.org/2013/11/12/disparities-in-health-insurance-coverage-among-asian-americans/>

⁶ The Williams Institute, LGBT Adults in the United States, 2016, <https://williamsinstitute.law.ucla.edu/visualization/lgbt-stats/?topic=LGBT&characteristic=african-american#density>

⁷ U.S. Department of Health and Human Services, Office of Minority Health, Minority Population Profiles: Black/African Americans, <https://minorityhealth.hhs.gov/omh/browse.aspx?vl=3&vlid=61>

⁸ Social Science and Medicine - Population Health, Civil rights as determinants of public health and racial and ethnic health equity: Health care, education, employment, and housing in the United States, 2018, <https://www.sciencedirect.com/science/article/pii/S235282731730191X>

⁹ White House Initiative on Asian Americans and Pacific Islanders, Language Access

population estimates, AAPIs grew by approximately 17 percent, four times as fast as the total population, between 2010 and 2016.¹⁰ Similarly, between 2010 and 2015, the sub-Saharan African immigrant population in the U.S. increased by 29 percent. In 2015, 27 percent of this population reported LEP.¹¹ Limiting language access protections for a growing population in the U.S. not only revokes basic human rights, but it also has serious, adverse health consequences by making critical information only available to English-speaking persons.

In Section 1557, Congress required covered entities to post non-discrimination policies and taglines that describe the ability for individuals to receive free language assistance services in the state's top 15 non-English languages. It also stipulates that covered entities must take reasonable steps to provide meaningful access to "each individual with LEP eligibility to be served or likely to be encountered." If the proposed revision of Section 1557 is finalized, covered entities could provide access to some individuals and refuse others. These protections around language access are required to prevent discrimination based on national origin. Furthermore, providing each LEP individual with meaningful access is important because research shows that ineffective communication between health care providers and LEP patients for the purposes of diagnosis, treatment options, obtaining informed consent, and insurance coverage can result in adverse health consequences or death.¹²

A 2004 study conducted in the Annual Review of Nursing Research underscores that health disparities are magnified for patients who are LEP. Language barriers are associated with more emergency room visits, more lab tests, less follow-up from health care providers, less health literacy among patients, and less overall satisfaction with health services.¹³ Moreover, in a 2014 fact sheet released by the Association of Asian Pacific Community Health Organizations, it is highlighted that Asian Americans have greater difficulty communicating with their doctors, and that LEP AAPIs are less likely to report positive patient-physician interactions than both English proficient AAPIs and all surveyed adults.¹⁴ Having the current protections of Section 1557 empowers patients to recognize when they are being treated unfairly and helps ensure that their needs can and will be heard and respected.

Additionally, the proposed revision would discourage the development of language access plans. These plans help covered entities determine what steps to take to support LEP individuals. In 2003, HHS' Office for Civil Rights LEP Guidance recommended the development of language access plans, and Executive Order 13166 required that all federal agencies develop language access plans. Although Section 1557 does not explicitly require covered entities to develop language access plans, it requires the Office for Civil Rights to consider whether a covered entity has a language access plan when evaluating compliance. Removing this consideration would discourage the use of a planning device that helps entities better comply with the law. Consequently, LEP individuals would be adversely affected and less likely to receive adequate support in navigating their insurance coverage.

<https://sites.ed.gov/aapi/language-access/>

¹⁰ U.S. Census Bureau Census Briefs (2010). The Asian Population: 2010

¹¹ Sub-Saharan African Immigrants in the United States, 2017, https://www.migrationpolicy.org/article/sub-saharan-african-immigrants-united-states#English_Proficiency

¹² Kaiser Family Foundation, HHS's Proposed Changes to Non-Discrimination Regulations Under ACA Section 1557, https://www.kff.org/report-section/hhss-proposed-changes-to-non-discrimination-regulations-under-aca-section-1557-issue-brief/#endnote_link_411029-35

¹³ Annual Review of Nursing Research 22.1 (2004): 59–73, "Language Barriers and Access to Care," http://www.springerpub.com/samples/9780826141347_chapter.pdf

¹⁴ Association of Asian Pacific Community Health Organizations, Limited English Proficiency (LEP) of Asian Americans, Native Hawaiians, and other Pacific Islanders (AA&NHOPIs), 2014 https://www.aapcho.org/wp/wp-content/uploads/2014/08/AANHOPi-LEP-Fact-Sheet_2014_final.pdf

HHS seeks comment on continuing unaddressed civil rights barriers, which are significant when it comes to language access. For example, over the past Open Enrollment periods for the Marketplace, language has presented a significant barrier for AAs and NHPs attempting to enroll in coverage. Once enrolled, many LEP consumers continued to have difficulties understanding their benefits and coverage. For example, AA and NHPI community-based organizations reported cases in which individuals did not know their rights and did not realize they were sent legal notices because notices were not provided in their language. Without enforcement of language assistance services, legal notices and taglines to inform persons of their rights, discrete communities, such as those AAs and NHPs, with large numbers of LEP individuals will be systematically excluded from opportunities to achieve better health and have their civil rights violated. It is this rationale and strong data record that guided the intent behind including the Section 1557 nondiscrimination provision in the ACA and corresponding incorporation of existing civil rights protections.

The Proposed Rule Would Harm People with Serious and Chronic Conditions Through Removing Nondiscrimination Protections in Insurance Coverage

The proposed rule would allow discrimination in health insurance issuance, coverage, cost-sharing, marketing, and benefit design. This is extremely worrisome because prior to the current Section 1557 regulations, healthcare insurers were able to participate in discriminatory benefit design by placing many drugs used to treat a certain condition, such as hepatitis B, on a high price tier or a tier with high cost-sharing without doing so for other drugs. This practice is notoriously known to discourage people with disabilities and chronic conditions from buying a particular health plan, or worse, forgo treatment altogether. These arbitrary restrictions on covered treatment for people living with certain conditions may stem in part from stigma and the belief that the afflicted individuals cannot make a full recovery.

Section 1557 and its 2016 implementing regulations would no longer apply to any federally administered health programs except entities participating in Title 1 of the Affordable Care Act, suggesting that nondiscrimination protections would only be applied to beneficiaries of plans purchased through Medicaid, CHIP, Medicare, or marketplace subsidies. Individuals insured through non-subsidized individual or job-based insurance would lose these protections. Under the proposed rule, if finalized, a person living with a chronic health care condition such as hepatitis B would only be protected from discrimination if he/she is insured through Medicaid, for example, but not if he/she has job-based insurance. Discrimination in any part of the health care system, of which insurers are a critical component, has a reverberating impact throughout the system, and will result in people not getting care they need.

As previously cited, the AAPI population is increasing in the U.S., suggesting that there will be a growing need for healthcare utilization and coverage among these communities. However, according to a study conducted by Health Management Associates, many foreign born patients living in the U.S. who are eligible for public health services choose to forgo health care coverage due to lack of familiarity with the U.S. public health system, fear of consequences related to their immigration status, and a variety of linguistic and cultural barriers.¹⁵ Removing nondiscrimination notices and taglines in different languages will only aggravate these barriers to accessing health.

¹⁵ Health Management Associates, Public and Private Insurance Coverage for Chronic Hepatitis B Patients: Health Reform Will Facilitate Early Investments Providing Long-Term Benefits, June 2012
https://nvhr.org/sites/default/files/HBV%20and%20Uninsured%20%20Full%20Report%20-%20June%2018%20%202012_0.pdf

The Proposed Rule Would Allow Discrimination on the Basis of Sex

The proposed rule will negatively impact the health outcomes of many gender nonconforming individuals. Gender nonconforming is “a broad term referring to people who do not behave in a way that conforms to the traditional expectations of their gender, or whose gender expression does not fit neatly into a category.”¹⁶ Explicitly, the proposed rule would remove and undermine all major nondiscrimination protections for especially vulnerable individuals.

People who are high risk for HIV, including gay and bisexual men, are also at risk for hepatitis B and C.¹⁷ Nationally, men who have sex with men (MSM) are at heightened risk for hepatitis—nearly 20% of new hepatitis B cases are among MSM.^{18,19} This means that Asian MSM and African MSM are doubly threatened by this disease.²⁰ This is especially pertinent to the communities we serve because liver complications associated with hepatitis B or C infections are the most common non-AIDS-related cause of death for people living with HIV.²¹ HIV and hepatitis coinfection can be complicated to manage and may require ongoing specialty care and treatment.

The proposed rule would reinforce the stigmatization of gender and sexual nonconforming individuals by allowing physicians to discriminate based on personal preferences. Everyone should be able to access the health care they need without fear of being turned away, shamed, or treated unfairly.

Conclusion

Although the NPRM would have a direct impact on certain groups, including LGBTQ+ folk, LEP, and women, it would uphold discrimination in virtually all facets of health care, negatively affecting all U.S. health and healthcare stakeholders. HHS must remain committed to its mission to “enhance and protect the health and well-being of all Americans,” not just a select group.

For these reasons, Hep B United urges HHS to uphold Section 1557 and immediately withdraw the proposed revisions. We appreciate the opportunity to provide comments on this matter. Please contact Kate Moraras, Director of Hep B United, at kate.moraras@hepb.org for further information.

Sincerely,

Hep B United
Hepatitis B Foundation (Co-Chair of Hep B United)
Association of Asian Pacific Community Health Organizations (Co-Chair of Hep B United)

¹⁶ Glossary of Terms, Human Rights Campaign, <https://www.hrc.org/resources/glossary-of-terms>

¹⁷ HIV and Asians Fact Sheet, Centers for Disease Control and Prevention, May 2019
<https://www.cdc.gov/hiv/pdf/group/raciaethnic/asians/cdc-hiv-asians.pdf>

¹⁸ HIV and Gay and Bisexual Men, Centers for Disease Control and Prevention, September 2018
<https://www.cdc.gov/hiv/pdf/group/msm/cdc-hiv-msm.pdf>

¹⁹ Hepatitis B and men who have sex with men (MSM), American Liver Foundation, 2018
<https://www.liverfoundation.org/wp-content/uploads/2018/03/Hepatitis-B-At-A-Glance-Men-Who-Have-Sex-with-Men-MSM.pdf>

²⁰ HIV and Gay and Bisexual Men, Centers for Disease Control and Prevention, September 2018
<https://www.cdc.gov/hiv/pdf/group/msm/cdc-hiv-msm.pdf>

²¹ Recommendations for *Morbidity and Mortality Weekly Report (MMWR)*, 57(RR08), 1-20. Retrieved from: Identification and Public Health Management of Persons with Chronic Hepatitis B Infection.
<https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5708a1.htm>

Asian American Community Services
Asian Health Coalition
Asian Pacific Community in Action
Charles B. Wang Community Health Center
Center for Pan Asian Community Services
Hawaii Health & Harm Reduction Center
Hep B United Philadelphia
Hep Free Hawaii
Hepatitis Education Project
Immunization Action Coalition
Liver Health Connection
National Task Force on Hepatitis B Focus on Asian and Pacific Islander Americans