+ AMERICAN LUNG ASSOCIATION

Harold P. Wimmer National President and CEO August 13, 2019

The Honorable Alex Azar, Secretary U.S. Department of Health and Human Services 200 Independence Avenue S.W. Washington, D.C. 20201

U.S. Department of Health and Human Services Office for Civil Rights Attention: Section 1557 NPRM, RIN 0945-AA11 Hubert H. Humphrey Building Room 509F 200 Independence Avenue, SW Washington, DC 20201

Re: Non-discrimination in Health and Health Education Activities

Dear Secretary Azar:

Thank you for the opportunity to submit comments on the notice of proposed rulemaking regarding Section 1557 of the Patient Protection and Affordable Care Act (ACA).

The American Lung Association is the oldest voluntary public health association in the United States, currently representing the more than 35 million Americans living with lung diseases including asthma, lung cancer and COPD. The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through research, education and advocacy.

Section 1557 is the essential mechanism of the ACA that ensures that all communities have meaningful access to healthcare. Section 1557 applies the historic civil rights acts of the 1960s and 70s—the Civil Rights Act of 1964, Title VI; Education Amendments of 1972, Title IX; Age Discrimination Act of 1975; and Rehabilitation Act of 1973, Section 504—to health programs and activities that receive Federal financial assistance. Section 1557 prohibits discrimination on the basis of race, color, national origin, sex, age, or disability by any programs or activities that receive Federal financial assistance, such as credits and subsidies (monetary and nonmonetary). Section 1557 also incorporated the enforcement mechanisms available to persons under those laws, providing strong and

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effective protections for persons to redress discrimination under Section 1557.

In the proposed rule, the Department of Health and Human Services (HHS) proposes to, amongst other things, reduce the number of entities subject to Section 1557's non-discrimination requirements; remove the prohibition on discriminatory benefit design; eliminate protections against discrimination for certain populations; and remove requirements to help individuals, especially those with limited English proficiency (LEP), understand and enforce their rights against discrimination in healthcare. These changes would cause significant harm to patients with lung disease, especially women, LGBTQI+¹ individuals, individuals with disabilities and individuals with LEP. The Lung Association urges the Department to withdraw the proposed rule.

Covered Entities

The proposed rule seeks to significantly narrow the scope of entities bound by the non-discrimination rules, contrary to Congressional intent, and increases the likelihood that these now-exempted entities could engage in discriminatory practices that will limit access to care and harm the health of communities currently protected under the final rule regarding Section 1557 issued in 2016.

The proposed rule argues that an entity principally or otherwise engaged in the business of providing health insurance shall not be considered to be principally engaged in the business of providing healthcare. This means the proposed rule would not apply to self-funded health plans under ERISA, the Federal Employees Health Benefits Program or short-term limited-duration insurance (STLDI) plans because those programs do not receive federal financial assistance from HHS, and the entities operating them would not be considered to be principally engaged in the business of providing healthcare. Millions of Americans would be impacted by exemption of these plans from the non-discrimination provisions of Section 1557.

The text of Section 1557 of the ACA is much more expansive, and should be interpreted broadly, consistent with Congressional intent and the 2016 final rule. The legislative text states that that this title will apply to "any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under this title [1] (or amendments)."²

In the 2016 final rule, HHS stated that including issuers of health insurance coverage was appropriate because "[t]his interpretation serves the central purposes of the ACA, and effectuates Congressional intent, by ensuring that entities principally engaged in health services, health insurance coverage, or other health coverage do not discriminate in any of their programs and activities, thereby enhancing access to services and coverage." This rationale holds true today. The proposed rule ignores the fact that health insurance programs are vital to the provision of healthcare in the United States. In controlling how healthcare is paid for, how benefits are designed and which providers are within their networks, health insurance programs have vast influence over access to and the provision of healthcare to Americans.

If exempted from Section 1557, many health plans will resume discriminatory practices that limit access to care for patients, including LGBTQI+ individuals and other patients with lung disease. Taking away these protections means that those who currently receive coverage for certain services would likely experience less protection from discrimination and or lose their coverage entirely. As a direct result, many Americans could be left unable to access important healthcare services that are essential to preventing, diagnosing and treating lung diseases and other health conditions.

The exodus of targeted individuals from health programs and activities receiving federal financial assistance could also negatively impact the institutions and providers who serve in affected communities. Healthcare providers will experience decreased revenue from insurance reimbursements and increased requests for uncompensated care. As a result, citizens and other residents with private, commercial health insurance coverage could see increases in premiums and other healthcare costs as providers attempt to offset their revenue losses. The cost savings analysis from HHS failed to appropriately account for the increased cost to consumers that may result from the proposed rule.

Discriminatory Benefit Design

The proposed rule eliminates the prohibition against discrimination in insurance practice and design at 92.207. Currently banned discriminatory practices include denying, canceling, limiting, or refusing to issue insurance; denying or limiting coverage of a claim; imposing additional cost-sharing or other limitations or restrictions on coverage; and using discriminatory marketing practices or insurance benefit designs. Some of these practices overtly discriminate against particular groups (e.g. charging women higher premiums than men). Others are "backdoor" tactics used by health plans to lower their own costs by limiting enrollment of people with expensive chronic and pre-existing conditions. For example, insurers could put therapies or medications specific to transgender or women's health in the highest cost-sharing tier, while not doing so for other conditions. Insurers could also use provider networks to exclude particular providers based on the scope of their practice to discourage enrollment from patients who need access to the services they provide.

These changes could result in patients, especially LGBTQI+ individuals, losing access to crucial healthcare services. For LGBTQI+ individuals with lung disease, this could include access to services like cancer screenings, treatments for asthma and COPD and tobacco cessation programs. The Lung Association is deeply concerned that discriminatory practices will resume and that patients with lung disease will lose access to care if the proposed rule is finalized.

Discrimination on the Basis of Sex

The proposed rule removes the definition of "on the basis of sex" used in the 2016 final rule, returning to a more restrictive definition based on biological sex.⁴

As a result of this change, many covered entities are likely to revert back to their original nondiscrimination policies that do not include added protections based on gender identity or sexual orientation. Health plans in particular have historically designed their coverage and benefits structures in ways that discriminate against women and the LGBTQI+ community. Without Section 1557 in its current form and the inclusion of protections based on gender identity, we anticipate that many of these discriminatory plan designs would return to the market, for example, limiting the ability of transgender individuals to access important healthcare such as smoking cessation programs, chronic condition management and other services that are readily available to non-transgender people.

Further, there is growing evidence that the LGBTQI+ community is already more at risk for certain conditions that require preventive or chronic care management, such as tobacco use. LGBTQI+ individuals may also have additional risk factors for smoking, including the daily stress and anxiety related to discrimination that they face on a regular basis. All of these disparities are aggravated by a lack of access to healthcare services. The proposed rule would make it easier for covered entities to discriminate against these communities, denying them access to critical preventive care and ongoing treatment, and making it less likely that LGBTQI+ individuals will be aware of educational materials and resources to improve their health.

The proposed rule would also incorporate the broadest possible set of religious- and moral-based exceptions for healthcare discrimination, which in turn will allow health programs and activities receiving federal financial assistance to restrict healthcare services available to individuals based upon the purported values of the health care provider. Patients being refused care based on religious or moral beliefs of covered health programs and activities may suffer devastating health consequences. Section 1557 must make it easier, not more difficult, for Americans to access the care they need whenever and wherever the need it, without worrying about what services may or may not be covered.

Notice and Tagline Requirements

The 2016 final rule also requires covered entities to provide notice of nondiscrimination policies in significant communications, in physical locations where the entity interacts with the public, and on the home page of their website. The notice of nondiscrimination must include information about the characteristics protected from discrimination under Section 1557, the availability of and how to access auxiliary aids and services, the availability of and how to access language assistance services, contact information for the designated employee coordinating the entity's Section 1557 responsibilities, the entity's grievance procedures, and complaint procedures for OCR. The proposed rule improperly attempts to eliminate these provisions entirely.

Without these requirements, patients may be unaware of their rights under Section 1557 and therefore unable to file complaints. Again, this will limit access to needed care for lung disease patients.

These and other changes in the proposed rule will make it especially hard for individuals with limited English proficiency (LEP) to enforce their rights under Section 1557. The proposed revisions seek to repeal certain provisions that provide individuals with LEP with necessary language services. In underserved communities, laws such as Section 1557 can make all the difference in ensuring that persons receive the care they need and are entitled to. The proposed revisions would open the door to national origin discrimination in healthcare, and the existing protections of Section 1557 should remain in place.

Ensuring language access touches the lives of millions of Americans—25 million of whom are LEP.8 Research has shown that language barriers negatively impact the quality of care and ability of a person to access care and maintain coverage. For example, LEP patients have been found to experience longer hospital stays when professional interpretation services are not used, and were more likely to be readmitted to the hospital within 30 days.9 The existing protections ensure LEP persons understand their rights and help limit the barriers they have to accessing quality healthcare. The revisions to Section 1557, on the other hand, would raise language barriers. While HHS seeks to justify the revision on the ground that it might save money, this justification does not outweigh the pernicious impact the rule change will have on individuals with LEP. And further, the proposed change does not account for the increased costs the healthcare system will ultimately bear when LEP individuals are placed at higher risk when their access to medical care is inevitably reduced and their understanding impaired.

By contrast, research has proven that healthcare quality and outcomes improve for LEP patients and families when professional interpreters are used or language-concordant providers are available. Although professional interpretation can present logistical and financial challenges for healthcare providers, many LEP patients do not have access to quality healthcare without such services. And given that such institutions are receiving federal funding, they must comply with the federal requirement not to discriminate based on individuals with a different national origin. Part of this obligation is to provide individuals with LEP adequate translation services. Providing such services is particularly essential in the healthcare sphere, given that LEP patients might otherwise avoid or postpone seeking the medical care they require out of fear of discrimination or mistreatment due to their national origin or the language they speak.

The proposed rule could have a chilling effect on individuals with LEP accessing affordable healthcare and services as it undermines their ability to understand and utilize health programs and activities receiving federal financial assistance. This could affect the healthcare system as a whole as it could lead to an increase in use of emergency rooms and emergent care as a method of primary healthcare and an increase in uncompensated care in which a treatment or service is not paid for by an insurer or patient.

Conclusion

The Lung Association believes that the proposed rule would cause significant harm to patients, including individuals with lung disease, and urges HHS to withdraw it. Thank you for the opportunity to provide comments.

Sincerely, Deboral P Brown

Deborah Brown Chief Mission Officer

- ⁷ For documented instances where religious health care providers denied care to patients on the basis of religious beliefs, *see* Compl. 2, *ACLU of Mich. v. Trinity Health Corp.*, 2016 U.S. Dist. LEXIS 30690 (E.D. Mich. Mar. 10, 2016); Freedman et al., *When There's a Heartbeat: Miscarriage Management in Catholic-Owned Hospitals*, 98 Am. J. Public Health 1774 (2008), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2636458/; National Women's Law Center, *Refusals to Provide Health Care Threaten the Health and Lives of Patients Nationwide*, https://nwlc.org/resources/refusals-to-provide-health-care-threaten-the-health-and-lives-of-patients-nationwide/ (last visited Oct. 20, 2017).
- ⁸ Migration Policy Institute (MPI) tabulations from the U.S. Census Bureau's 1990 and 2000 Decennial Censuses and 2010 and 2013 American Community Surveys (ACS), https://www.migrationpolicy.org/article/limited-english-proficient-population-united-states.
- ⁹ Glenn Flores, et al., Errors of Medical Interpretation and their Potential Clinical Consequences: A Comparison of Professional Versus Ad Hoc Versus No Interpreters. Ann Emerg Med. 2012 Nov; 60(5):545-53. See also Leah S. Karliner, Review Do Professional Interpreters Improve Clinical Care for Patients with Limited English Proficiency? A Systematic Review of the Literature. Health Serv Res. 2007 Apr; 42(2):727-54.
- ¹⁰ Errors of medical interpretation and their potential clinical consequences: a comparison of professional versus ad hoc versus no interpreters. *Flores G, Abreu M, Barone CP, Bachur R, Lin H Ann Emerg Med. 2012 Nov;* 60(5):545-53. See also Review Do professional interpreters improve clinical care for patients with limited English proficiency? A systematic review of the literature. *Karliner LS, Jacobs EA, Chen AH, Mutha S Health Serv Res. 2007 Apr; 42(2):727-54*.
- ¹¹ See, e.g., U.S. Dep't of Health and Human Services Office for Civil Rights, Settlement Agreement with AL Dep't of Human Resources (Oct. 25, 2017) ("OCR's investigation found that the father's LEP was a significant factor in ADHR's failure to provide timely language assistance and other services essential for reunification. Additionally, OCR's investigation found that ADHR consistently failed to take reasonable steps to ensure meaningful access to its programs by Latino persons with LEP. Thus, OCR determined that ADHR administered its programs in a manner that had the effect of delaying or denying access to its programs and services on the basis of national origin in violation of Title VI."), available at: https://www.hhs.gov/sites/default/files/alabama-child-welfare-agreement.pdf; U.S. Dep't of Health and Human Services Office for Civil Rights, Resolution Agreement with MI Dep't of Human Services Division of Family & Children's Services, Transaction Numbers 09-099895/10-109106 (Apr. 15, 2014) ("The compliance review was initiated in response to information received from the U.S. Department of Justice that indicated MDHS-DFCS may be discriminating against persons based on their national origin (Hispanic) in violation of Title VI of the Civil Rights Act of 1964 (Title VI) in the operation of its programs by failing to ensure that limited English proficient (LEP) persons have meaningful access to its programs and services." As a result, MDHS-DFCS agreed to expand language services to resolve the complaints.), available at

https://www.hhs.gov/sites/default/files/ocr/civilrights/activities/agreements/miss_dhs_vra.pdf; see also, 42 U.S.C. § 2000d; 45 C.F.R. Part 80.

¹ Refers to individuals who are Lesbian, Gay, Bisexual, Transgender, Queer, or Intersex

² 42 U.S. Code § 18116.

³ 45 C.F.R. § 92

⁴ 84 Fed. Reg. at 27,852.

⁵ Lesbian, Gay, Bisexual, and Transgender Persons and Tobacco Use, https://www.cdc.gov/tobacco/disparities/lgbt/index.htm

⁶ Lesbian, Gay, Bisexual, and Transgender Persons and Tobacco Use, https://www.cdc.gov/tobacco/disparities/lgbt/index.htm