



August 12, 2019

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

Re: Nondiscrimination in Health and Health Education Programs and Activities (Section 1557 NPRM), RIN 0945-AA11

Dear Mr. Severino,

Treatment Action Group (TAG) thanks the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) for the opportunity to comment 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”). TAG is an independent, activist and community-based research and policy think tank fighting for better treatment, prevention, a vaccine, and a cure for HIV, tuberculosis (TB), and hepatitis C virus.

Section 1557 prohibits discrimination on the basis of race, color, national origin, sex, age, and disability. As an organization that is committed to upholding the civil rights of all persons, we strongly oppose the NPRM provisions which seek to eliminate and limit protections for individuals with limited English proficiency, LGBTQ+ persons, persons with disabilities and chronic conditions, and persons needing reproductive health services. Section 1557 addresses not only protections for each protected class covered, but the intersection of those protections. As such, an attack on the civil rights of one group in the NPRM is an attack on the civil rights of all.

As an organization that is deeply involved in movements to improve science, medicine and access to health care, TAG is committed to the ethical treatment of patients, research participants, and all those who place their trust in a physician’s care. The changes in the NPRM would be catastrophic for the protections needed as part of such ethical treatment. In order to give informed consent, one of the cornerstones of ethically administering a medical procedure, a patient must be able to understand the risks and benefits of the care they are provided. Without language access protections, such as those ensured under Section 1557, a patient with limited English proficiency cannot provide informed consent and their provider cannot abide by their ethical obligations.

This is of particular concern in the case of infectious diseases such as the ones on which TAG focuses. If patients are not able to adequately understand their instructions for treatment, they risk inappropriately using their medications, which can result in drug resistance. Drug resistant infections are often more complicated and up to thousands of times more expensive to treat. Similarly, people with limited understanding of their conditions will be less empowered to take the preventive steps needed to prevent transmission of their infection, especially so for TB, an airborne infection. Furthermore, people vulnerable to these infections need to understand their risk and how to prevent infection, which requires at a minimum information given in a language

they can understand. Removing Section 1557 language access protections is dangerously short-sighted and would not only harm individuals with limited English proficiency but will have a broader public health impact.

If finalized, this proposed rule would also severely threaten LGBTQ+ patients' access to all forms of health care, create confusion among patients and providers about their rights and obligations, and promote discrimination. The proposed rule would encourage hospitals to deny care to LGBTQ+ people, and enable insurance companies to deny transgender people coverage for essential health care services that they cover for non-transgender people. By proposing to eliminate protections against discrimination based on transgender status and sex stereotyping, HHS is contradicting over 20 years of federal case law and clear Supreme Court precedent.

By rolling back the aforementioned protections, the OCR would also subject people living with HIV (PLHIV) to tremendous risk of being denied testing and care, as such services are often administered as part of reproductive health care. LGBTQ+ persons are also disproportionately impacted by HIV, and are therefore more likely to be denied the care necessary to diagnose and treat HIV. This would directly contradict the administration's plan to End the HIV Epidemic in the US by 2030, and would set us back by years in that fight. We have already seen what widespread neglect of PLHIV looks like, as we experienced devastatingly high death rates in the early years of the epidemic before our current standards of treatment were available. Should the proposed rule go into effect and eliminate protections and access to care for LGBTQ+ people and people seeking reproductive health services, we risk jeopardizing many of the gains we have made.

The central goal of the Affordable Care Act (ACA) has been to eliminate discrimination in health care that has routinely and historically denied millions access to lifesaving care, particularly for the most vulnerable in our nation which include individuals with limited English proficiency, LGBTQ+ persons, persons with disabilities and chronic conditions, and persons needing reproductive health services. Section 1557 is the policy provision that carries out this mandate, and affords these needed protections by offering a pathway for legal remedies against unlawful, unjust, and unethical discrimination in health care. In sum, we have no doubt that the proposed rule would place millions of Americans' lives at risk and undo years of effort to ensure equitable access to nondiscriminatory health care for the most vulnerable in the U.S.

Thank you for the opportunity to submit public comments on the proposed rulemaking, and we hope you commit to keeping in place the existing protections under Section 1557. Please do not hesitate to contact Erica Lessem, TAG's Deputy Executive Director for Programs, at erica.lessem@treatmentactiongroup.org for further information.

Signed,
Treatment Action Group (TAG)