



I am essential

August 13, 2019

The Honorable Alex M. Azar II
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SE
Washington, DC 20201

Re: Nondiscrimination in Health and Health Education Programs or Activities
[HHS-OCR-2019-0007] [RIN 0945-AA11]

Dear Secretary Azar:

The XX undersigned members of the **I Am Essential** coalition of patient and community organizations, representing millions of patients and their families, are very concerned that the proposed revisions to the regulations implementing § 1557 of the Affordable Care Act (ACA) will undermine critical patient protections guaranteed by the ACA and may result in lost access to health care, including prescription medications, for people with serious and chronic health care conditions. We respectfully urge you to withdraw this proposed rule.

Section 1557 of the ACA was designed to ensure that health insurance is equally available for all, no matter their health status or health needs. Under § 1557, Americans are protected from discrimination on the basis of race, color, national origin, sex, disability and age by health programs and activities operated or funded by the federal government, including Qualified Health Plans offered through the ACA marketplaces. These landmark protections are critical to fulfilling the requirement of preventing discrimination based on pre-existing health conditions and access to the health care that every American deserves.

Patient Protections in Regulations and Guidance

While the law is the foundation for these protections and still remains in effect, **I Am Essential** and others have been instrumental in ensuring that the implementing regulations and guidance meet beneficiaries' needs. These regulations have brought significant gains in access to comprehensive, affordable, and transparent health care, including prescription drug coverage.

The current regulation implementing § 1557 (42 CFR § 92.207) prohibits plans from taking the following actions on the basis of race, color, national origin, sex, age, or disability:

- Denying, canceling, limiting, or refusing to issue or renew a health insurance policy;
- Denying or limiting coverage of a health insurance claim;
- Imposing additional cost sharing or other limitations or restrictions on coverage; and
- Using discriminatory marketing practices or insurance benefit designs.

The above prohibitions are crucial to ensure equal access to health care for people with chronic health care conditions. **The proposed rule would completely remove these regulatory protections, which will increase the likelihood that insurers will use benefit design to discriminate against people with serious and chronic health care conditions.** Eliminating these explicit protections would offer insurers greater opportunities to craft plans and utilize marketing practices designed to attract healthier enrollees and drive enrollees with serious health care conditions away. Such practices could leave people with serious and chronic health care conditions without the coverage they need to gain access to lifesaving health care and treatment.

Unfortunately, we have observed that some insurance plans continue to limit beneficiary access to critical medications in discriminatory ways. Eliminating regulations prohibiting discriminatory benefit design and marketing may make it harder for individuals to enforce their rights. Even with ACA requirements, state and federal regulators have approved plans with the following discriminatory features:

- Placing all or almost all medications to treat a certain condition on the highest cost tier;
- Not covering all the necessary or treatment guideline recommended medications;
- Charging excessive beneficiary cost-sharing for brand and “specialty” medications, including extremely high coinsurance and deductibles;
- Applying excessive utilization management techniques - such as prior authorization and step therapy requirements - targeting treatments for specific diseases;
- Removing medications from their formularies mid-year, a practice that is particularly harmful to patients on established regimens or whose condition requires a specific treatment.

Such practices, often targeted at specific chronic and serious conditions, not only make it difficult to gain access to necessary medications, but also discourage people living with those conditions from enrolling in these plans. To stop plans from engaging in these practices and ensure beneficiaries have a choice of plans through which they can access the care and treatment they need, § 1557 and its implementing regulations must be maintained and properly enforced.

Covered Entities

The existing regulation implementing § 1557 applies anti-discrimination protections to entities receiving health care-related funds from HHS, and health care programs administered by HHS

or state marketplaces, including health insurance companies. The proposed regulation would significantly restrict the application of § 1557 in two ways:

- 1) differentiating between health care and health insurance, effectively exempting health insurance companies and most plans from anti-discrimination rules; and
- 2) limiting the scope of coverage to entities participating in Title 1 of the Affordable Care Act, as opposed to all health care programs administered by HHS.

By eliminating the current definition of a covered entity, HHS will increase the ability of health insurers to discriminate against patients with serious and chronic health care conditions. We believe that all health care products sold by insurers who receive federal financial assistance should be subject to the ACA's non-discrimination protections, not just those products that receive the financial assistance. This would leave millions of people without the health care protections they need and currently have.

Health insurance is inextricably linked with the provision of health care. Insurers design benefits, define medical management and other utilization criteria, build provider networks, and create payment structures. Thus, through these mechanisms, insurance companies establish the very infrastructure through which patients gain access to lifesaving care. 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.

Eliminating Oversight & Enforcement

Several provisions of the proposed rule would undermine protections against discrimination by making it more difficult for people to learn about their rights and to report a violation. The proposed regulation would remove 45 CFR § 92.7 requiring covered entities to establish a grievance procedure for patients to report discrimination, designate a staff person responsible for coordinating § 1557 responsibilities, and inform people about their right not to be discriminated against. It may also make it more difficult for patients to enforce their rights in court and to receive compensatory damages when warranted. These proposed changes would have the combined effect of reducing anti-discrimination claims, while increasing the likelihood that a patient will be subject to discriminatory action. HHS itself acknowledges that, "an unknown number of persons are likely not aware of their right to file complaints with the Department's Office for Civil Rights and some unknown subset of this population may suffer remediable grievances, but will not complain to OCR absent notices informing them of the process."¹

The proposed rule delegates all enforcement authority to the Director of the Office for Civil Rights, including receiving complaints, investigating complaints, and adjudicating claims. The ACA's anti-discrimination protections are critically important, especially for people with serious, chronic illness and disabilities. The multi-prong enforcement mechanism currently in place includes plan review, certification, and monitoring by state and federal regulators. It also allows

¹ 84 Federal Register 27883

individuals who experience discrimination to file both administrative and judicial complaints. This comprehensive approach to enforcement of § 1557 provides checks and balances and avenues of redress that cannot be achieved if sole enforcement authority lies with the Director of the Office for Civil Rights. Such a change would likely result in complaints of discriminatory behavior going unanswered and unresolved. Without a robust enforcement mechanism, the HHS certification of compliance with § 1557 becomes an empty shell.

Together, these proposed changes to notice and enforcement may substantially gut the impact of § 1557 by making it more difficult for patients to know their rights, report discriminatory actions, and remedy situations where they are not provided equal access to health care under the law.

Conclusion

The ACA has provided health coverage and improved access to care for tens of millions of Americans living with chronic and serious health conditions, many of whom were previously uninsured or underinsured. Additionally, the law established new patient protections for these newly insured individuals and for almost all others in the health care system. This includes a prohibition on preexisting condition exclusions, requiring coverage of essential health benefits, an annual limit on out-of-pocket costs, prohibiting discriminatory benefit design, preventing the utilization of discriminatory marketing practices, and expanding federal civil rights protections and clarifying the application of those laws to health insurance and health care. While those protections still exist in the law, HHS has proposed to remove several existing regulations that will result in greater opportunities for insurers and others to discriminate against people with serious and chronic conditions. Congress passed the ACA to end discriminatory practices by insurers through broadly applicable nondiscrimination protections. We object to any effort to roll back those protections.

We urge you not to renege on the promise of affordable, high-quality care and treatment for everyone, especially those living with chronic and serious health conditions. We respectfully urge you to withdraw this proposed rule.

Sincerely,