November 9, 2015

The Honorable Sylvia Mathews Burwell
Secretary of Health and Human Services
200 Independence Avenue SW
Washington, D.C.  20201

Re:  Comments on Office of Civil Rights, ACA Non-discrimination Proposed Rule

Dear Madame Secretary:

We, the undersigned xx patient and community organizations representing millions of patients and their families, remain dedicated to the successful implementation of the Affordable Care Act (ACA). With the close of the second open enrollment period, an estimated 17.6 million Americans have gained health coverage under the ACA and the number of uninsured in the country has dramatically decreased. While there are numerous provisions in the ACA that protect patient rights, one key provision is Sec. 1557, which prohibits discrimination in the health care system on the basis of race, color, national origin, sex, age, or disability.

We are pleased that the long awaited proposed regulation to implement Sec. 1557 has now been issued. While the proposal does an adequate job of defining discriminatory practices by insurance plans for some individuals, it does not define discriminatory practices in plan benefit design as it relates to all beneficiaries, particularly those with serious and chronic health conditions who rely on prescription medications and other healthcare services.

While §92.207(b) mentions in very general terms that plans shall not “deny or limit coverage of a claim, or impose additional cost sharing or other limitations or restrictions, on the basis of an enrollee’s or prospective enrollee’s race, color, national origin, sex, age, or disability; [and] (2) Employ marketing practices or benefit designs that discriminate on the basis of race, color, national origin, sex, age, or disability in a health-related insurance plan or policy, or other health-related coverage,” it is not very specific. Therefore, we strongly urge HHS to better define what discriminatory plan practices are in the final rule.

Beneficiaries have witnessed discriminatory benefit design by some insurers, particularly in the coverage of prescription medications, which many beneficiaries living with chronic and serious health conditions rely on to remain healthy and alive. Some marketplace plans are placing all or
almost all medications to treat a certain condition on the highest cost tier. In the preamble of the *Notice of Benefit and Payment Parameters for 2016* and in the 2016 *Letter to Issuers*, HHS has gone on record and stated that these practices could be discriminatory. In the *Letter to Issuers*, the Centers for Medicare & Medicaid Services cautions issuers from discouraging enrollment of individuals with chronic health needs and provided examples of discriminatory plan designs. One example identified was “if an issuer places most or all drugs that treat a specific condition on the highest cost tiers, that plan design might effectively discriminate against, or discourages enrollment by, individuals who have those chronic conditions.”

In order to protect beneficiaries and to provide clarity to state and federal regulators, now and in the future, HHS must provide a clear definition of what constitutes discrimination. Therefore, we urge HHS to include in regulatory language the practice of placing all or nearly all medications to treat a certain condition on the highest tier to be discriminatory.

In addition, beneficiaries have experienced other design benefits that amount to discrimination of people with chronic conditions, including not covering certain medications or not following treatment guidelines, imposing excessive medication management tools such as unreasonable prior authorizations and/or step therapy, charging patients high cost sharing, and having narrow provider networks.

Therefore, in the final rule, we recommend that employing these types of practices also be clearly defined as discrimination. Standards and parameters for benefit and plan design should be detailed in the final rule, along with acceptable practices. Unfortunately, the proposed rule is completely silent in this area and regulators, beneficiaries, and insurers are not provided with any clarity on what constitutes discrimination.

Additionally, we believe that HHS needs to clarify that the definition of who is protected under Sect. 1557 is not only limited to beneficiaries who are “disabled” under the definition in the Americans with Disabilities Act (ADA), but to all beneficiaries with chronic health conditions or serious illness. Using the definition under the ADA will include only some individuals or health conditions and overlooks many beneficiaries who may be exposed to discrimination in their health care coverage. These individuals should also enjoy the same patient protections.

Finally, any law or regulation is useless if it is not enforced. We urge HHS and the Office of Civil Rights to properly enforce the law now, and act on any discrimination complaints that have been filed in order to ensure beneficiary rights are protected.

We greatly appreciate all you and the rest of the Department are doing to improve the health of all Americans and look forward to another successful open enrollment period. We thank you for your continued dedication to improving implementation of the ACA so that it meets the needs of patients throughout the country.

Sincerely,

[list in formation]
The AIDS Institute
Arthritis Foundation
Easter Seals
Epilepsy Foundation
Leukemia & Lymphoma Society
Lupus Foundation of America
National Alliance on Mental Illness
National Kidney Foundation