



October 3, 2022

The Honorable Xavier Becerra  
Department of Health and Human Services  
200 Independence Ave, SW  
Washington, DC 20201

Dear Secretary Becerra,

On behalf of Patients Rising Now, thank you for the opportunity to comment on the Department of Health and Human Services' (HHS) Proposed Rule to reinstate protections from discrimination on the basis of race, sex, age, disability, and other characteristics. Discrimination in care based on a patient's inherent characteristics is unconscionable, especially given the medically necessary and life-saving treatments upon which patients rely. In the context of healthcare, discrimination serves as a barrier to access. These protections will ensure patients can maintain equitable access to care.

Formed in 2015, Patients Rising Now has developed a significant following of over 110,000 patients and caregivers and has guided them on their journeys to advocate for themselves and their loved ones to get the care and treatments they need to live a fulfilling life. As a patient advocacy organization, we support reforms and legislation aimed at advancing patient access to affordable, quality healthcare.

At Patients Rising Now, diversity and efforts to increase diversity sit among the core of our values. As part of our commitment to ensure that all patients have access to treatments and care, Patients Rising maintains a Diversity, Equity, and Inclusion Council. The Council is composed of healthcare stakeholders from a variety of cultural, ethnic, and socioeconomic backgrounds, including youth and patient advocates, health educators, writers, and consultants, as well as case workers and nonprofit leaders – several of whom live with rare and chronic diseases themselves. We support our members in sharing their experiences in facing discrimination to show the need for the proposed rule and ensure these regulations are fully enforced.

Healthcare discrimination takes different forms. Firstly, there's the matter of overt discrimination. This Rule makes efforts to prevent overt discrimination by correcting the past incongruencies of the 2020 Rule. Everyone can agree that overt discrimination is wrong, but not everyone recognizes that discrimination can manifest when certain considerations are not addressed. An equitable delivery of healthcare needs to consider the challenges currently faced by disabled people. For instance, access to public transportation, access to clinics, labs, and



offices, and ongoing social-distancing practices for the immunocompromised. Likewise, healthcare delivery needs to consider the healthcare deserts in rural areas and the disparity between the lived experiences of Black and Indigenous People of Color (BIPOC) compared to the treatment guidelines and standards of care which were built on research that largely excluded BIPOC. Making changes to these, and other such, issues, would make a world of difference for those affected and build on the strong momentum demonstrated with this Proposed Rule.

In addition to discriminating against a patient's inherent characteristics, there's another form of discrimination taking place similarly based on factors out of patients' control: their health. As an organization that advocates for rare and chronic disease patients, Patients Rising Now takes issue with CMS' and the private sector's use of the quality-adjusted life year (QALY) in determining care. Rather than being used to understand which treatment would yield the best outcome for patients, QALY is instead being used as a cost saving tool to steer patients towards older, cheaper treatments and away from newer, more innovative, and often more expensive treatments based on what a cold mathematical calculation determines their life is worth. When perfect health is used as a deciding metric, sick patients will not only be discriminated against but punished. Further, the QALY is inherently prejudiced against chronically ill patients and elderly patients. This Proposed Rule promises to protect against discrimination based on age, but QALY is allowed to continue unchecked. For patients to receive equitable access to care, something must be done.

Again, we thank you for the opportunity to present comments on this critical issue and for HHS' efforts to right past wrongs. Patients Rising Now supports further inspection and correction of healthcare discrimination. On behalf of the patient community, we stand ready to support your efforts to address patient discrimination.

Sincerely,

A handwritten signature in black ink that reads "Rachel Derby". The signature is written in a cursive, flowing style.

Rachel Derby  
Executive Director