



August 13, 2019

**VIA ELECTRONIC SUBMISSION**

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: Section 1557 of the Patient Protection and Affordable Care Act Comment; Docket No. HHS-OCR-2019-0007**

Dear Secretary Azar:

Thank you for the opportunity to submit comments on the Department of Health and Human Services' ("HHS" or the "Department") notice of proposed rulemaking ("NPRM" or "Proposed Rule") on Section 1557 of the Patient Protection Affordable Care Act<sup>1</sup> ("ACA"). Our

---

<sup>1</sup> 42 U.S.C. § 18001 *et seq.*

organizations represent millions of patients and consumers from across the country facing serious, acute, and chronic health conditions. Collectively, we have a deep understanding and a unique perspective on what our communities need to prevent disease, manage health, and cure illness. The undersigned organizations oppose the NPRM and urge the Department to withdraw it, as the Proposed Rule would cause major harm to the health and wellbeing of patients and consumers, including women, LGBTQI+ individuals,<sup>2</sup> individuals with disabilities, and individuals with limited English proficiency.

In this Proposed Rule, the Department proposes to, amongst other things, reduce the number of entities subject to Section 1557's non-discrimination requirements, eliminate protections against discrimination for certain populations, remove the prohibition on discriminatory benefit design, and remove requirements to help individuals, especially those with limited English proficiency (LEP), understand and enforce their rights against discrimination in healthcare. Individually and in the aggregate, the elimination of these important protections and reduction of rights set forth in the NPRM would have severe consequences for the health and well-being of Americans seeking health care services and coverage, especially those with serious, acute, chronic or other pre-existing conditions and those in vulnerable and underserved communities.

We are deeply concerned that the Proposed Rule will reduce the quality of health care services and coverage for Americans, thereby harming individuals, their families, communities, and creating greater costs across the health care system. We therefore urge the Department to withdraw the Proposed Rule and instead focus its efforts on improving our health care system by expanding adequate, affordable and accessible health care coverage for Americans, rather than reducing it.

### **Importance of Section 1557 for Patients with Pre-Existing Conditions**

The ACA has had a transformative impact on all aspects of health care, increasing the scope of benefits, improving access to coverage for millions of Americans, and reducing health care costs for individuals and employers and reducing uncompensated care by more than \$7.4 billion.<sup>3</sup> The ACA also included critical provisions ensuring full and equitable access to essential services without discrimination, including people with pre-existing conditions. .

Prior to the enactment of the ACA, it was legal and indeed customary for health plans to discriminate against individuals who were in the most need of health insurance coverage, including older and sicker Americans and people living with pre-existing conditions. Many individuals were denied coverage due to their pre-existing conditions, were charged higher premiums, were charged more for being older or being a woman, or were left with inadequate benefit packages. As a result, many patients were often forced to delay or forego necessary health care, or risk ending up in medical debt.

---

<sup>2</sup> Refers to individuals who are Lesbian, Gay, Bisexual, Transgender, Queer, or Intersex

<sup>3</sup> U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, New Report Details Impact of the Affordable Care Act (Dec. 13, 2016), <https://www.hhs.gov/about/news/2016/12/13/new-report-details-impact-affordable-care-act.html> [<http://wayback.archive-it.org/3926/20170127135924/https://www.hhs.gov/about/news/2016/12/13/new-report-details-impact-affordable-care-act.html>].

Before the patient protections provided under the ACA, for example, more than half of heart disease patients reported difficulty paying for their care and, of those patients, more than 40 percent said they had delayed care or had not filled prescriptions.<sup>4</sup> Uninsured patients with diabetes were six times as likely to forgo necessary medical care as those with coverage.<sup>5</sup> Uninsured patients were less likely to be screened for cancer and more likely to be diagnosed with later stage disease, which is harder to survive and more costly to treat.<sup>6</sup>

Today, individuals and families with pre-existing conditions rely on critical protections in current law to help them access comprehensive, affordable health coverage that meets their medical needs.

The ACA has been especially important for traditionally underserved communities including individuals and families living in poverty, people of color, women, immigrants, LGBTQI+ individuals, people with disabilities, seniors, and individuals with limited English proficiency. The ACA reduced the number of uninsured to historic lows, including a reduction of 39 percent for the lowest income individuals.<sup>7</sup> These gains are particularly noteworthy for Latinos, African Americans, and Native Americans, and they have had meaningful impacts on health outcomes. For example, one study found that states that expanded Medicaid under the ACA have nearly eliminated racial disparities in timely access to cancer treatment.<sup>8</sup> It is clear that underserved communities, including those we represent, cannot afford to go back to a time when they did not have access to comprehensive, affordable coverage.

The ACA has also been instrumental in covering a wide range of preventive services, ensuring, for example, that individuals have access to life-saving screenings for a range of diseases and conditions and access to effective and affordable contraception and reproductive health care services. In this respect, under the ACA's preventive services coverage, most private health plans in the United States—whether provided by employers, schools, or through the exchanges—must cover preventive care services without any out-of-pocket costs to patients. Similarly, plans are limited in their ability to impose formularies, prior authorization requirements, and other administrative barriers to preventive care services or to benefit designs that may discriminate against persons with specific disease states.

---

<sup>4</sup> *Texas, et al. v. United States, et al.*, Case No. 4:18-cv-167-0, Amici Curiae Brief of the American Cancer Society at 16 (N.D. Tex. June 14, 2018), [https://secure.fightcancer.org/site/DocServer/Texas v. USA - Amici Curiae.pdf;jsessionid=00000000.app337a?docID=25871&NONCE\\_TOKEN=5C7D2B4779B0A5778402EED95B0278B5](https://secure.fightcancer.org/site/DocServer/Texas_v_USA_-_Amici_Curiae.pdf;jsessionid=00000000.app337a?docID=25871&NONCE_TOKEN=5C7D2B4779B0A5778402EED95B0278B5).

<sup>5</sup> Sarah Stark Casagrande and Catherine C. Cowie, *Health Insurance Coverage Among People with and without Diabetes in the U.S. Adult Population*. *Diabetes Care* 35:2243–2249, 2012, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3476921/>.

<sup>6</sup> American Cancer Society. *Insurance Status Linked To Cancer Outcomes*. ScienceDaily, 24 December 2007. [www.sciencedaily.com/releases/2007/12/071220082825.htm](http://www.sciencedaily.com/releases/2007/12/071220082825.htm).

<sup>7</sup> Kelsey Avery, et al., *Affordable Care Act Has Led to Historic, Widespread Increase in Health Insurance Coverage*, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES ASPE ISSUE BRIEF, (Sep. 29, 2016) [https://aspe.hhs.gov/system/files/pdf/207946/ACAHistoricIncrease\\_Coverage.pdf](https://aspe.hhs.gov/system/files/pdf/207946/ACAHistoricIncrease_Coverage.pdf).

<sup>8</sup> Racial Disparities in Access to Timely Cancer Treatment Nearly Eliminated in States With Medicaid Expansion, American Society of Clinical Oncology (June 2, 2019) <https://www.asco.org/about-asco/press-center/news-releases/racial-disparities-access-timely-cancer-treatment-nearly>.

Section 1557 is the essential mechanism of the ACA that ensures that all communities have meaningful access to health care. 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 effective protections for persons to redress discrimination under Section 1557.

Section 1557 specifically prohibits discrimination not only in the specific program or activity receiving Federal financial assistance, but also in all activities of health entities that operate a single covered program. Accordingly, it prohibits hospitals, doctors, and insurers from discriminating against persons seeking health care services or health care coverage.

The Proposed Rule would undo the progress of recent years, erode the scope of those protections and, correspondingly, impair access to critical services by communities who need health care the most. As a direct result, many Americans could be left unable to access important health care services that are essential to preventing the onset of a disease, accurately diagnosing a health condition, or treating a debilitating or life-threatening illness. If the Proposed Rule is implemented as drafted, many Americans and their dependents will be less likely to access preventive, diagnostic, and critical health care, or enforce their rights to obtain such care, all of which is especially detrimental to the health and well-being of those living with serious, acute, or chronic health conditions., including women, LGBTQI+ individuals, people with disabilities, and those with limited English proficiency.

For example, studies have demonstrated that 1 in 4 American women went without or delayed care because of costs; and this number increases to half of uninsured women.<sup>9</sup> Almost as many women postponed preventive services (47%) and skipped a recommended medical test or treatment (42%).<sup>10</sup> These difficult economic circumstances have ramifications for children and families as well. In October 2018, March of Dimes found that over 5 million women currently live in a maternity care desert, meaning a county in which access to maternity health care services is limited or absent, either because the services do not exist in that geographic area, or due to other barriers to women receiving care, including access to insurance and other economic factors.<sup>11</sup> About 150,000 babies are born in maternity care deserts every year.<sup>12</sup> The impact is that pregnancy-related death has more than doubled over the past 25 years.<sup>13</sup>

The Proposed Rule will also have negative implications for any patient with pre-existing conditions, a category which can include pregnancy. We believe that no current health status,

---

<sup>9</sup> Usha Ranji, et al., *Overview:2017 Kaiser Women's Health Survey*, (Mar. 13, 2018) <https://www.kff.org/report-section/executive-summary-2017-kaiser-womens-health-survey/>

<sup>10</sup> Id.

<sup>11</sup> Nowhere to Go: Maternity Care Deserts Across the U.S., March of Dimes (Oct. 10, 2018) [https://www.marchofdimes.org/materials/Nowhere\\_to\\_Go\\_Final.pdf](https://www.marchofdimes.org/materials/Nowhere_to_Go_Final.pdf).

<sup>12</sup> Id.

<sup>13</sup> Id.

preexisting condition, or medical history should become a barrier to receiving care today or in the future. By exempting certain insurers from anti-discrimination protections, the proposed rule would allow health plans to once again adopt discriminatory plan designs that could increase the likelihood of excluding applicants who are or may become pregnant, applicants who have ended a pregnancy in the past, or who have any other specific type of pre-existing condition.

Multiple studies have indicated that in comparison to insured individuals, uninsured or underinsured individuals are more likely to have poorer health outcomes. For example, uninsured or underinsured patients suffer greater neurological impairment due to a stroke than their insured counterparts<sup>14</sup>; are more likely to be diagnosed with later stage cancer<sup>15</sup>; to have worse glycemic control when diagnosed with diabetes; to be unable to fully recover following a serious injury; and to have a higher mortality risk due to congestive heart failure.<sup>16</sup>

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. Health care 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 health care costs as providers attempt to offset their revenue losses. The Department's cost-savings analysis failed to appropriately account for the increased cost to consumers that may result from the NPRM.

Beyond deterioration in health outcomes and financial repercussions for patients, their families, and health care providers, the Proposed Rule's policies will catalyze a harmful ripple effect across the economy. Already, chronic conditions such as diabetes, heart disease, obesity, and Alzheimer's Disease cost our economy hundreds of billions of dollars, and altogether 90 percent of our country's health care expenditures are focused on those with chronic and mental health conditions.<sup>17</sup> Without adequate health care, those with chronic conditions may be rendered unable to work, resulting in lost wages, and lost productivity for American employers. The American Heart Association estimates that cardiovascular disease already results in \$237 billion in indirect costs – such as lost earnings and household productivity.<sup>18</sup>

## **Changes to Covered Entities**

---

<sup>14</sup> Thomas Rice, et al., *The Impact of Private and Public Health Insurance on Medication Use for Adults with Chronic Diseases*. 62 Med Care Res Rev 231-249 (Apr. 1, 2005).

<sup>15</sup> Elizabeth Ward et al, *Association of Insurance with Cancer Care Utilization and Outcomes*. CA: A Cancer Journal for Clinicians 58:1 (Jan./Feb. 2008), <http://www.cancer.org/cancer/news/report-links-health-insurance-status-with-cancer-care>.

<sup>16</sup> J. Michael McWilliams, et al., *Health of Previously Uninsured Adults After Acquiring Medicare Coverage*. JAMA. 2007; 298:2886 –2894.

<sup>17</sup> *Health and Economic Costs of Chronic Diseases*, Center for Disease Control and Prevention, <https://www.cdc.gov/chronicdisease/about/costs/index.htm> (last reviewed Feb. 11, 2019)

<sup>18</sup> Cardiovascular Disease: A Costly Burden for America – Projections through 2035, American Heart Association, <https://www.heart.org/-/media/files/get-involved/advocacy/burden-report-consumer-report.pdf?la=en&hash=0A2A75E9FE82F7BEAE6A6A0FDB64E3FCE2BD8669> (2017).

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 harm the health and well-being of communities that are currently protected under the 2016 rule.

The Proposed Rule draws a distinction between “health insurance” and “health care,”<sup>19</sup> unlike the 2016 Final Rule which applied to “all of the operations of an entity principally engaged in providing or administering health services or health insurance coverage.”<sup>20</sup> Office of Civil Rights (OCR) justifies this change in interpretation by citing the Civil Rights Restoration Act of 1987 (CRRRA): “The CRRRA... defined “program or activity”...to cover all the operations of entities only when they are ‘principally engaged in the business of providing education, *health care*, housing, social services, or parks and recreation.”<sup>21</sup> (emphasis added).

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 health care.<sup>22</sup> 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 health care. 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).”<sup>23</sup>

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.”<sup>24</sup> This rationale holds true today. The proposed rule ignores the fact that health insurance programs are vital to the provision of health care in the United States. In controlling how health care 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 health care to Americans.

Indeed, HHS even cites a definition of “health insurance coverage at 42 U.S.C. 300gg-91 that includes “benefits consisting of *medical care (provided directly, through insurance or*

---

<sup>19</sup> 45 C.F.R. §92.3 (2018)

<sup>20</sup> 45 C.F.R. §92 (2016)

<sup>21</sup> 45 C.F.R. §92.3 (2018)

<sup>22</sup> 45 C.F.R. §92.3 (2018)

<sup>23</sup> 42 U.S. Code § 18116.

<sup>24</sup> 45 C.F.R. § 92

*reimbursement, or otherwise and including items and services paid for as medical care*) under any hospital or medical service policy or certificate, hospital or medical service plan contract, or health maintenance organization contract offered by a health insurance issuer.” (emphasis added) This very definition makes it clear that the provision of health insurance coverage is inextricably linked to the provision of health care itself.

Further, Section 1557 applies to “any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or *contracts of insurance...*” (emphasis added) which strongly suggests that Congress intended for the law to apply to entities receiving a contract of insurance from the Federal government, such as a Federal Employees Health Benefits Program plan. Excluding health insurance programs from the scope of Section 1557 would fundamentally frustrate the objective of Congress, which was to avoid discrimination in the provision of health care, including denial of benefits. This change will permit unlawful discrimination against specific communities, including LGBTQI+ individuals, women, and people with pre-existing conditions, in direct conflict with existing constitutional and statutory protections.

### **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 (e.g. placing all HIV drugs on the highest formulary tier<sup>25</sup>).

By definition, these predatory practices and discriminatory designs make health insurance widely inaccessible to our patient populations. We are deeply concerned that these practices will resume if the Proposed Rule’s policies are finalized.

#### *Impact on LGBTQI+ Individuals and Patients with Chronic or Pre-Existing Conditions*

Some health plans, if exempted from Section 1557, will resume discriminatory practices that will negatively impact health and well-being for many different patient populations, including LGBTQI+ individuals and those with chronic, acute, or pre-existing conditions. Taking away these protections means that those who currently receive coverage for certain services would likely experience less protection from discrimination and could experience loss of coverage due to updated plan policies (as discussed above, OCR itself admits that many covered entities would

---

<sup>25</sup> Jane Perkins and Wayne Turner, *NHeLP and The AIDS Institute Complaint to HHS Re HIV/AIDS Discrimination by FL*, <https://healthlaw.org/resource/nhelp-and-the-aids-institute-complaint-to-hhs-re-hiv-aids-discrimination-by-fl/>.

revert back to former policies, many of which contained provisions that discriminate against individuals).

Our organizations believe that health care for all patients and consumers should be as expansive and inclusive as possible. Ensuring that everyone living in the United States has access to health insurance is not only beneficial for our sickest and most vulnerable people, but also for overall cost reduction across the health care system and our national economy. Policies that would remove such coverage would certainly result in more individuals facing mounting unpaid medical bills, long-term impacts on their financial well-being, and lifelong health implications. Today, 79 million Americans face medical bill problems or medical debt.<sup>26</sup> The Federal government must focus on expanding coverage to as many people as possible; not making it easier for plans to discriminate and take coverage away. All people, regardless of health status, gender identity or sexual orientation, should be able to gain health insurance without undue barriers.

If finalized, the proposed rule will once again allow insurance companies to use benefit design and coverage decision-making to limit and exclude treatment for patients and discriminate against them, leaving patients who are denied services with no recourse. 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 use provider networks to exclude particular providers based on the scope of their practice including health services for transgender individuals, such as transition-related surgeries or therapies. Denial of insurance coverage could result in LGBTQI+ individuals losing access to crucial health care services like cancer screenings, treatments for cardiovascular disease, and tobacco cessation programs. This rule would impose a disparate impact on any group the federal government and States decide not to protect.<sup>27</sup>

#### *Impact on Individuals with Disabilities*

Exempting health plans from Section 1557 will remove protections for people with disabilities and permit entities that are no longer covered by Section 1557 to discriminate against people with disabilities, including many people living with serious and chronic conditions. Undermining adequate coverage of people with disabilities is counter to the Department's express intention "to continue its robust enforcement of civil rights laws prohibiting discrimination on the basis of...disability." As discussed above in Section 2, policies that allow for increased discrimination against individuals with disabilities will result in more individuals receiving inadequate health care coverage who will be unable to meet their medical or financial needs.

In addition, the Department has requested comment on the proposed 45 CFR Sections 92.102 through 92.105, pursuant to which the Department has retained the requirements imposed by

---

<sup>26</sup> *Survey: 79 Million Americans Have Problems with Medical Bills or Debt*, The Commonwealth Fund, <https://www.commonwealthfund.org/publications/newsletter-article/survey-79-million-americans-have-problems-medical-bills-or-debt>.

<sup>27</sup> See Section III.B.A.3.

Section 1557 through Section 504 with respect to disability.<sup>28</sup> The Department should retain these provisions as they allow individuals with disabilities greater access to health care. The benefits to the health and wellbeing of the individuals with disabilities who rely on the protections and accommodations set forth Sections 92.102 through 92.105, and the alleviation of further costs and complications across the health care system and our national economy that would result from reduced access to care for people with disabilities, outweighs burdens of covered entities complying with these requirements.

## **Discrimination**

The Final Rule defines “on the basis of sex” to “include[], but is not limited to, discrimination on the basis of pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related medical conditions, sex stereotyping, and gender identity.”<sup>29</sup> In the Proposed Rule, HHS would remove this definition from the regulatory text, returning to a more restrictive definition based on biological sex.<sup>30</sup>

### *Impact on Patients in the LGBTQI+ Community*

OCR states that eliminating this definition will increase clarity in the market. This is a problematic argument in two ways. First, in order to increase clarity, OCR and other agencies in HHS regularly add expansive or complex new definitions.<sup>31</sup> Removal of definitions, or specifics within those definitions, only serves to create more ambiguity, and increase regulatory burdens on covered entities as they will have to subsequently navigate this change and ambiguity. Second, as OCR itself points out in its Regulatory Impact Analysis, 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. Therefore, any reduced costs would likely only result from less “grievances related to sex discrimination complaints as they relate to gender identity under Title IX, because such claims would not be cognizable under the proposed rule.”

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

---

<sup>28</sup> [Footnote to the Article or Reg] ((a) 92.102 requires that communications with individuals with disabilities must include provision of appropriate auxiliary aids and services, bars requiring that individuals with disabilities bring their own interpreters, sets minimum standards for video remote interpreting and telephone relay services, exempts covered entities from actions that result in a fundamental alteration in the nature of a service, program, or activity or in undue financial and administrative burdens, and requires appropriate timeliness, respect for privacy concerns, and independence of the individual with a disability; (b) 92.103 requires that new construction or alteration of buildings or facilities subject to Section 1557 must comply with the 2010 ADA Standards for Accessible Design; (c) 92.104 requires covered entities to ensure that their health programs or activities provided through information and communication technology are accessible to individuals with disabilities; and (d) requires covered entities to make reasonable modifications to policies, practices, or procedures when necessary, to avoid discrimination on the basis of disability).

<sup>29</sup> 81 Fed. Reg. at 31,467/3.

<sup>30</sup> 84 Fed. Reg. at 27,852.

<sup>31</sup> See, e.g. Protecting Statutory Conscience Rights in Health Care; Delegations of Authority, available at: <https://www.federalregister.gov/documents/2019/05/21/2019-09667/protecting-statutory-conscience-rights-in-health-care-delegations-of-authority>

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 health care such as smoking cessation programs, chronic condition management, mental health benefits, and hormone therapies and related surgeries 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 or cardiovascular disease.<sup>32</sup> Researchers have found that these issues may be caused or exacerbated by LGBTQI+ individuals' anxiety about how they will be treated by primary care doctors and other health care stakeholders.<sup>33</sup> These patients already experience disrespectful treatment in health care settings due to providers' lack of awareness or implicit biases. According to one survey, more than half of LGB patients, 70 percent of transgender and gender-nonconforming people have had the experience of being denied care, facing harsh or abusive language or actions, or being blamed for their health care status.<sup>34</sup> 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.<sup>35</sup> Similarly, lesbian and bisexual women may have higher risk of heart disease due to the stress and trauma they face.<sup>36</sup>

All of these disparities are aggravated by a lack of access to health care 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.

### *Discrimination Based on the Definition of Sex*

A purported need for consistency with other definitions is likewise no compelling rationale to allow discrimination. To the contrary, context is important, and any presumption that the phrase "on the basis of sex," and in particular, the term "sex," must mean the same thing regardless of context "readily yields whenever there is such variation in the connection in which the words are used as reasonably to warrant the conclusion that they were employed in different parts of the act with different intent."<sup>37</sup> To be sure, just as "age," as a word, "has several commonly understood

---

<sup>32</sup> *More Attention Should be Paid to Heart Health of Lesbian, Gay and Bisexual Adults, Study Suggests*, American Heart Association News, <https://www.heart.org/en/news/2018/10/18/more-attention-should-be-paid-to-heart-health-of-lesbian-gay-and-bisexual-adults-study-suggests> (Mar. 20, 2018).

<sup>33</sup> *Id.*

<sup>34</sup> *When Health Care Isn't Caring: Lambda Legal's Survey of Discrimination Against LGBT People and People with HIV*, Lambda Legal, [https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report\\_when-health-care-isnt-caring.pdf](https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf) (2010).

<sup>35</sup> *Lesbian, Gay, Bisexual, and Transgender Persons and Tobacco Use*, Centers for Disease Control and Prevention, <https://www.cdc.gov/tobacco/disparities/lgbt/index.htm>

<sup>36</sup> Hattie Gladwell, *Lesbian and Bisexual Women are at Higher Risk of Heart Disease, Study Finds*, <https://metro.co.uk/2018/11/06/lesbian-and-bisexual-women-are-at-higher-risk-of-heart-disease-study-finds-8109602/> (Nov. 6, 2018).

<sup>37</sup> *Gen. Dynamics Land Sys., Inc. v. Cline*, 540 U.S. 581, 595 (2004) (quoting *Atl. Cleaners & Dyers, Inc. v. United States*, 286 U.S. 427, 433 (1932)) (ruling that "age" means "old age" when coupled with the term "discrimination").

meanings among which a speaker can alternate in the course of an ordinary conversation, without being confused,”<sup>38</sup> so too does the word “sex.” OCR cites other instances of HHS agencies separating the term “sex” from “gender identity” or “sexual orientation,” including NIH to treat sex as a biological variable, and the Office of the National Coordinator for Health IT (ONC)’s decision to require separate standards and coding requirements for “sex,” “gender identity” and “sexual orientation.” These examples are relevant in their own contexts, but not within the context of Section 1557.

The NIH primarily deals with medical research, and therefore may need to conceptualize sex and gender identity differently. Medical and scientific conceptualizations of sex and gender are complex, subject to many nuanced variables, and continuously evolving.<sup>39</sup> A binary paradigm for two biological sexes is quickly becoming outdated, as science shows us that there may be a much wider spectrum of biological sex differences than simply “male” and “female.”<sup>40</sup> Similarly, ONC’s regulatory task is to determine technical standards for vocabulary and coding in electronic health records, so within that context, more granular separation may make sense, as health IT standards are typically designed for machine-readability and effective interoperability between systems.

Section 1557, on the other hand, is focused on discrimination in health care. The rule’s legal definition of sex should be aimed at protecting the most patients from discrimination in access to health care services. Given the medical and scientific flux noted above, we urge OCR to retain the current, more expansive definition of sex to address critical health disparities in the LGBTQI+ community. In the context of a statutory provision expressly incorporating protections against discrimination in a range of statutes, giving the term its broadest possible meaning is more important than any claimed consistency rationale.

Finally, HHS claims that removing the definition of “on the basis of sex” would “significantly restore the ability of States to establish policies in this area, based on their weighing the competing interests at stake.”<sup>41</sup> However, the Federal government sets an important minimum standard for civil rights in this country, particularly on issues of discrimination. HHS nowhere explains what “competing interests on questions related to gender dysphoria” could possibly exist, or what “questions” could lead to such competing interests, much less counsel in favor of allowing discriminating against individuals seeking care. What this rule really would do is to allow States to decide that some groups are not deserving of civil rights protections. HHS’s rationale that States are “heavily reliant on the continued receipt of Federal funds subject to Title IX requirements,”<sup>42</sup> and therefore they cannot be expected to extend civil rights protections, could be used to justify rolling back all progress since States first accepted federal funds. In the

---

<sup>38</sup> *Id.* at 596.

<sup>39</sup> Arnold De Loof, *Only Two Sex Forms But Multiple Gender Variants: How to Explain?* Communicative & Integrative Biology, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5824932/> (2018).

<sup>40</sup> Claire Ainsworth, *Sex Redefined*, *Nature* 518, 288-291, <https://www.nature.com/news/sex-redefined-1.16943#/spectrum> (Feb 19, 2015).

<sup>41</sup> 84 Fed. Reg. at 27,857.

<sup>42</sup> *Id.*

case of “on the basis of sex,” States cannot reasonably argue that they could not have been “cognizant” of the consequences of their participation.

### *Impact on Access to Emergency Care*

The Emergency Medical Treatment and Active Labor Act (“EMTALA”) requires all hospitals—including those that are private, public, and religiously affiliated—that receive Medicare funds to provide appropriate medical screening to any patient who presents to an emergency room and, if the patient is suffering from a medical emergency, to either stabilize the condition or transfer the patient to another facility that is more equipped to handle the condition.<sup>43</sup> Repealing the Final Rule’s definition of “on the basis of sex” could encourage workers to violate EMTALA by refusing to provide care to, for example, transgendered individuals. While we anticipate, based on its response to comments in the preamble to the “Protecting Statutory Conscience Rights in Health Care; Delegations of Authority” Final Rule<sup>44</sup> issued in May 2019, HHS will claim that EMTALA and religious exemption will be applied “harmoniously,”<sup>45</sup> their inevitable conflict will lead to violations of this guarantee for emergency care.

Access to emergency care is critical for the patients our organizations represent. All people must be able to receive lifesaving care for a breathing problem, a heart attack, hyperglycemia, complications from a cancer treatment or any other critical health problem that requires immediate care. When people do experience severe symptoms, they should not try to self-diagnose their condition or worry that they might be refused care. Delays in care could have harmful impacts on the short- and long-term health of individuals with serious, acute and chronic diseases.

### *Exemptions and Patient Access to Care*

The Proposed Rule would incorporate the broadest possible set of religious- and moral-based exceptions for health care discrimination, which in turn will allow health programs and activities receiving federal financial assistance to restrict health care 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.<sup>46</sup> For example, contraceptive care is a vital service, as integral to a person’s health as preventive medicine. Indeed, nearly 60-percent of women who use contraception use it to help

---

<sup>43</sup> See 42 U.S.C. §1395d(e)(3)(A); 42 U.S.C. §1395dd(b).

<sup>44</sup> 84 FR 23170.

<sup>45</sup> 84 Fed. Reg. 23,170, 23,188 (May 21, 2018).

<sup>46</sup> 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).

treat several medical conditions other than pregnancy prevention, including bleeding disorders such as von Willebrand disease.<sup>47</sup>

It is imperative to our organizations that health care coverage must be adequate, covering the services and treatments patients need. The intent of Section 1557 is to protect the patient from discrimination, not the provider. Section 1557 must make it easier, not more difficult, for Americans to live their lives, to work and live where they want, without worrying about what services may or may not be covered. The Proposed Rule would turn 1557 on its head, reducing adequate health care options for those seeking care and privileging provider values over patient interests. Allowing health programs to limit health care coverage on the alleged basis of religious- or moral-based exceptions will result in inadequate, even discriminatory, coverage to the communities our organizations represent.

### **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 with serious and chronic health conditions may be unaware of their rights under Section 1557 and therefore unable to file complaints and get the care they need.

These and other changes in the NPRM will make it especially hard for individuals with limited English proficiency (LEP) to enforce their rights under Section 1557. The proposed revisions to Section 1557 of the ACA seek to repeal certain provisions that provide individuals with limited English proficiency (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 health care, 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.<sup>48</sup> 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,

---

<sup>47</sup> Rachel K. Jones, *Beyond Birth Control: The Overlooked Benefits of Oral Contraceptive Pills*. <http://www.guttmacher.org/pubs/Beyond-Birth-Control.pdf> (2011).

<sup>48</sup> 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>.

and were more likely to be readmitted to the hospital within 30 days.<sup>49</sup> The existing protections ensure LEP persons understand their rights and help limit the barriers they have to accessing quality health care. 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 health care 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 health care quality and outcomes improve for LEP patients and families when professional interpreters are used or language-concordant providers are available.<sup>50</sup> Although professional interpretation can present logistical and financial challenges for health care providers, many LEP patients do not have access to quality health care 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.<sup>51</sup> Providing such services is particularly essential in the health care 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 health care and services as it undermines their ability to understand and utilize health programs and activities receiving federal financial assistance. This could affect the marketplace as a whole as it could lead to an increase in use of emergency rooms and emergent care as a method of

---

<sup>49</sup> 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.

<sup>50</sup> 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.

<sup>51</sup> 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](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.

primary health care, and an increase in uncompensated care in which a treatment or service is not paid for by an insurer or patient.

## **Conclusion**

Given the substantial negative impact on the populations we serve, we urge the Department to immediately withdraw this proposed rule and dedicate its efforts to advancing policies that strengthen—rather than undermine—the ability of Americans to support the health and well-being of themselves and their families. If you would like to discuss these comments further, please contact Amy Friedrich-Karnik at WomenHeart at [afriedrich@womenheart.org](mailto:afriedrich@womenheart.org).

Sincerely,

WomenHeart: The National Coalition for Women with Heart Disease

ALS Association

Epilepsy Foundation

National Alliance on Mental Illness (NAMI)

Apha-1 Foundation

National Psoriasis Foundation

Mended Hearts

Chronic Disease Coalition

National Organization for Rare Disorders

National Health Council

American Kidney Fund

Adult Congenital Heart Association

Leukemia & Lymphoma Society

Family Voices