DC Health Benefit Exchange Authority

September 30, 2022

U.S. Department of Health and Human Services
Office for Civil Rights
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue, S.W.
Washington, D.C. 20201

RE: Proposed Rule, Nondiscrimination in Health Programs and Activities, RIN 0945-AA17

To Whom It May Concern:

The District of Columbia Health Benefit Exchange Authority (HBX) appreciates your consideration of our comments.

By way of background, HBX is a private-public partnership established by the District of Columbia (District) to develop and operate the District's on-line health insurance marketplace, DC Health Link (DCHealthLink.com). We cover approximately 100,000 people -- District residents and people who work for District small businesses. DC Health Link fosters competition and transparency in the private health insurance market, enabling individuals and small businesses to compare health insurance prices and benefits and to purchase affordable, quality health insurance. Since we opened for business, we have cut the uninsured rate by half and now more than 96% of District residents have health coverage.

HBX strongly supports the proposal to reinstate civil right protections, including the prohibition of discrimination based on gender identity and sexual orientation. HBX has commented in the past about the importance of all protections under section 1557.[1] The need for these protections is greater today with attempts around the country to deprive people of their civil rights.[2]

Research shows that the transgender community has been subject to discrimination in health insurance benefits – coverage being denied that is not denied to others. We believe that the Federal regulations to protect every person's civil rights and to prohibit insurance practices that

[1] D.C. Health Benefit Exchange Authority, Comment Letter on Proposed Rule, Nondiscrimination in Health and Health Education Programs or Activities, Docket ID HHS-OCR-2019-0007, RIN 0945-AA11. August 13, 2019, available at: https://hbx.dc.gov/sites/default/files/dc/sites/hbx/publication/attachments/DC_HBX_Comment_OCR_0945-AA11.pdf; D.C. Health Benefit Exchange Authority, Comment Letter on Proposed Rule, Nondiscrimination in Health Programs and Activities – RIN 0945-AA02, November 9, 2015, available at: https://hbx.dc.gov/sites/default/files/dc/sites/hbx/publication/attachments/DC_HBX_Comment_OCR_%200945-AA02.pdf.

[2] *See e.g.* Sandy West, Targeted by Politicians, Trans Youth Struggle with Growing Fear and Mental Health Concerns, Kaiser Health News. February 23, 2022, available at: https://khn.org/news/article/transgender-youth-mental-health-targeted-by-politicians/. Kelsey Butler & Andre Tartar, Transgender Health Care Becomes Target for Wide GOP-Led Rollback, Bloomberg News, September 20, 2022, available at: https://news.bloomberglaw.com/health-law-and-business/transgender-health-care-becomes-target-for-wide-gop-led-rollback;

create barriers to accessing medical care were necessary when first issued in 2016 and remain essential today. The District of Columbia has protections in place to prevent health insurance carriers from discriminating on the basis of sexual orientation, as well as on the basis of gender identity and expression. We strongly supported these federal protections when proposed in 2015 and opposed their removal by the prior administration in 2019.

Although federal protections lapsed, District residents continued to have civil rights protections under our local laws and regulations. The District of Columbia led in addressing discrimination based on gender identity and expression. Working with HBX, the District of Columbia Department of Insurance, Securities and Banking (DISB) issued guidance to clarify that health insurance carriers are prohibited from discriminating on the basis of gender identity or expression and specified that "exclusionary clauses that discriminate on the basis of 'gender identity or expression' are *prima facie* prohibited."[3] DISB also clarified that "attempts by companies to limit or deny medically necessary treatments for gender dysphoria, including gender affirming procedures, [is] discriminatory."[4]

HBX continues to support federal protections. We believe that these protections are necessary nationwide and especially important to protect people who live in states that lack similar civil rights protections.

Use of Clinical Algorithms in Decision Making (§ 92.210)

HHS is clarifying that nondiscrimination protections under §1557 apply to clinical algorithms defined broadly to include clinical decision making. HBX strongly supports the proposed approach to both apply nondiscrimination protections to clinical algorithms and to define clinical algorithms broadly to include clinical decision-making standards and guidelines as well as software used in clinical decision making and management, and machine learning, e.g., artificial intelligence. Although our comments below focus on race-based discrimination, we support HHS's effort to address all discrimination.

Events over the last several years continue to expose the systems of inequity and racism in which we all live and work, including in healthcare, and have forced our country to take a more honest look at ourselves, our values, and our commitment to justice. COVID-19 threw a spotlight on the long history of racism and mistreatment of people of color in the health care system in the United States.

To help address health disparities and institutional racism, the HBX Executive Board established a Social Justice and Health Disparities Working Group. The Working Group included diverse stakeholders committed to social justice and health equity, including all of the issuers offering coverage on DC Health Link, patient advocates, health equity experts, brokers, and providers including doctors and hospitals. The Working Group provided recommendations on how HBX

[3] District of Columbia Department of Insurance Securities and Banking, Bulletin 13- IB-01-30/15 Revised (February 27, 2014), available at: https://disb.dc.gov/sites/default/files/dc/sites/disb/publication/attachments/Bulletin-ProhibitionDiscriminationBasedonGenderIdentityorExpressionv022714.pdf
[4] *Id*.

and our health plan partners can work to reduce health disparities in the District.[5]

In our initial research and implementation work with our health plans, we identified how health care clinical decision-making tools perpetuate health disparities among communities of color. People of color are less likely to be eligible for intensive care management or receive timely diagnoses or appropriate care for heart failure, kidney disease, certain cancers, osteoporosis, and many other conditions. Examples of clinical decision-making tools perpetuating health disparities:

- A clinical decision-making tool called GFR estimates how well kidneys function. The tool's "race adjustment" automatically added points to the score for Black patients, making it look like their kidneys functioned better. The artificially inflated score delayed kidney treatment and prevented some patients from receiving life-saving transplants. Importantly, the National Kidney Foundation revised its guidelines to prohibit the use of race in estimating GFR.[6] And DC Health Link insurers all agreed to prohibit the use of race in estimating GFR by their network providers.

- During the COVID crisis, we all learned that pulse oximeters can measure oxygen saturation, a critical indicator of the severity of COVID disease. What we learned only recently is that pulse oximeters are calibrated based on white skin, resulting in less accurate results for those with darker pigments. The FDA recently initiated a review. However, doctors and other medical providers continue to use pulse oximeters. When the oximeter does not accurately reflect low blood oxygen level in Black and Brown patients, those patients are likely getting delayed or no medical treatment.[7]

- Vaginal Birth after Cesarean Risk Calculator deemed Black women high risk and classified them as candidates for C-section delivery if they had a prior C-section, while White women would be given a choice of C-section or vaginal birth. C-sections are not only more expensive but have a much higher medical risk of severe complications and death. The good news is that this standard was revised recently to eliminate this race adjustment.[8]

Many clinical standards developed by national medical and clinical organizations use race in treatment guidelines. While it may be highly warranted to use race to achieve health equity,

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[5] DC Health Benefit Exchange Authority, Executive Board Resolution, "To adopt the consensus recommendations of the Social Justice and Health Disparities Working Group to advance equity and reduce health disparities in health insurance coverage for communities of color," July 14, 2021, available at: https://hbx.dc.gov/sites/default/files/dc/sites/hbx/publication/attachments/Resolution%20on%20Social%20Justice%20%20Health%20Disparities%20Working%20Group%20Recommendations.pdf%20FINAL.pdf; Recommendations of the Social Justice & Health Disparities Working Group to the District of Columbia Health Benefit Exchange Authority, 12 July 2021, available at: https://hbx.dc.gov/sites/default/files/dc/sites/hbx/event_content/attachments/HBX%20Social%20Justice%20and%20Health%20Disparities%20Working%20Group%20Final%20Report_0.pdf

[6] National Kidney Foundation. "Laboratory Implementation of the NKF-ASN Task Force Reassessing the Inclusion of Race in Diagnosing Kidney Diseases", available at: https://www.kidney.org/content/laboratory-implementation-nkf-asn-task-force-reassessing-inclusion-race-diagnosing-kidney.

[7] Simar Bijaj, Racial bias is built into the design of pulse oximeters, Washington Post, July 20, 2022, available at https://www.washingtonpost.com/made-by-history/2022/07/27/racial-bias-is-built-into-design-pulse-oximeters/.

[8] Katie Palmer, Changing the Equation: Researchers Remove Race from a Calculator for Childbirth, STAT, June 3, 2021, available at https://www.statnews.com/2021/06/03/vbac-calculator-birth-cesarean/

many guidelines using race unfortunately perpetuate health disparities. Many standards have not been reevaluated for bias and have not been revised. As you note in the preamble, in a New England Journal of Medicine Article in 2020, researchers identified 13 clinical tools that use race-adjustment, exacerbating health disparities and inequities.[9] While clinical standards were changed for a few (e.g. eGFR and C-Section Risk), many other clinical tools continue to use race adjustment to the detriment of Black people and other communities of color.

Your proposed standards when finalized will reduce such disparities in health care:

- Entities responsible for setting clinical standards will be incentivized to review their standards for bias. Currently, some but not all medical bodies have voluntarily initiated reviews for bias. Consequently, absent legislative action, your proposed standards will be an important tool to address bias in guidelines.

- Doctors and other medical professionals will be incentivized to be more mindful of bias. Many doctors strive to avoid bias in the health care they provide. Despite such efforts, studies show significant bias. A recent article in Health Affairs examined medical records looking at physician descriptions of patient behavior. Researchers found that, compared with White patients, Black patients had 2.54 times the odds of having at least one negative descriptor in their history and physical notes.[10] Other studies also document bias. For example, studies[11] show that many 3rd year medical students and medical residents believe incorrectly that Black skin is thicker than White skin and that Black people have a stronger immune system than White people. Doctors' bias impacts how they diagnose and treat their patients.[12] An example of bias and treatment outcome from one of our health plans: a Black patient who went to the emergency room and was treated for drug overdose by the ER treating physician who erroneously assumed a drug overdose instead of a severe episode of sickle cell.

Your standards will incentivize doctors and other health care professionals to examine their own bias and to address them.

Improving national clinical standards and how doctors treat their patients is difficult to do at a local level. Although initially in our work with our health plans we assumed that some bias can be rooted out with updated network provider contracts that require for example bias training or

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[9] Vyas, D., Eisenstein, L., and Jones, D. Hidden in Plain Sight – Reconsidering the Use of Race Correction in Clinical Algorithms, New England Journal of Medicine, August 2020, available at: https://www.nejm.org/doi/full/10.1056/NEJMms2004740.

10 Sun, M., Oliwa, T., Peek, M. and Tung, E., Negative Patient Descriptors: Documenting Racial Bias in the Electronic Health Record, Health Affairs, January 19, 2022, available at: https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01423.$

[11] Janice A. Sabin, How we fail black patients in pain, AAMC News, January 6, 2020, available at: https://www.aamc.org/news-insights/how-we-fail-black-patients-pain; Hoffman K. *et. al*, Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites, Proceedings of the National Academy of Sciences (PNAS), March 1, 2016, available at: https://www.pnas.org/doi/pdf/10.1073/pnas.1516047113.

[12] D.C. Health Benefit Exchange Authority, "Ensuring Equitable Treatment for Patients of Color," Presentation to the Social Justice and Health Disparities Working Group, February 25, 2021, available at: https://hbx.dc.gov/sites/default/files/dc/sites/hbx/event_content/attachments/Focus%20Area%203%20DCHBX%20Social%20Justice%20and%20Health%20Disparities%20Working%20Group.pdf

network providers to not use race adjusted eGFR, we've learned that this approach does not address non-network providers, that provider contracting is a slow process, and that it is difficult to challenge validity of national clinical standards. To address embedded bias, your proposed nation-wide discrimination standard is necessary and we strongly support it.

Proposed Enforcement

While we strongly support your proposed new protections, we are concerned that your proposed case-by-case fact specific enforcement approach may not work because it relies on a consumer or a patient complaining to you. Your proposed approach places the burden on patients to report potential bias or discrimination in medical care. For example, if a patient suffered complications from an avoidable C-Section, you assume that the patient would know that a C-Section could have been avoided. This is not a reasonable assumption for patients who are not medically trained. Furthermore, a guideline that allows for a race adjustment would deter even a medically trained patient from reporting a bias. In addition to relying on patients to complain to you, we encourage you to proactively review medical providers' treatment of patients of color for patterns to help detect bias.

Conclusion

HBX strongly supports the proposals to reinstate civil rights standards and processes, as originally implemented by HHS in 2015. We applaud this return to strong protections against discrimination for people who historically have experienced significant barriers to accessing medical care, including the LGBTQI+ community, women who need reproductive health care (including abortion), women of color, people living with disabilities and/or chronic conditions, and people whose primary language is not English. We strongly support and encourage you to finalize the new proposed nondiscrimination in clinical algorithms rule. The new nondiscrimination protection will help address institutionalized racism and bias in medical care.

Thank you for considering our comments.

Sincerely,

Mila Kofman
Executive Director
DC Health Benefit Exchange Authority