

**IN THE UNITED STATES DISTRICT COURT
FOR THE SOUTHERN DISTRICT OF MISSISSIPPI
SOUTHERN DIVISION**

STATE OF MISSISSIPPI; STATE OF
ALABAMA; STATE OF ARKANSAS;
COMMONWEALTH OF KENTUCKY;
STATE OF LOUISIANA; STATE OF
MISSOURI; and STATE OF MONTANA,
Plaintiffs,

v.

XAVIER BECERRA, in his official
capacity as Secretary of Health and
Human Services; THE UNITED
STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES;
CHIQUITA BROOKS-LASURE, in her
official capacity as Administrator of the
Centers for Medicare and Medicaid
Services; THE CENTERS FOR
MEDICARE AND MEDICAID
SERVICES; THE UNITED STATES
OF AMERICA,
Defendants.

No. 1:22-cv-113-HSO-RPM

**MEMORANDUM OF LAW IN SUPPORT OF PROPOSED DEFENDANT
INTERVENORS' MOTION TO INTERVENE**

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The NAACP State Conferences from eight states and the Greensboro Health Disparities Collaborative (collectively “Proposed Intervenor”) move to intervene as defendants under Federal Rule of Civil Procedure 24(a)(2). Proposed Intervenor timely seek to intervene and hold legally protected interests that may be impaired by the disposition of this case. The NAACP State Conferences’ members are the intended beneficiaries of the rule that the States of Alabama, Arkansas, Louisiana Mississippi, Missouri, Montana, and the Commonwealth of Kentucky (collectively “State Plaintiffs”) hope to strike down. Moreover, the NAACP State Conferences *and* the Collaborative have an interest in preserving research and program funding that may be diverted if this Court condemns a rule designed to combat discrimination as discrimination itself. Plaintiffs’ suit threatens these interests, and Proposed Intervenor are uniquely capable of bringing the implications of Plaintiffs’ theory into full view. Alternatively, Proposed Intervenor request permission to intervene under Federal Rule of Civil Procedure 24(b). Again, Proposed Intervenor’s motion is timely. And their defense shares issues of fact and law with that of Defendants Xavier Becerra, the United States Department of Health and Human Services (“HHS”), Chiquita Brooks-LaSure, the Centers for Medicare and Medicaid Services (“CMS”), and the United States of America (“Agency Defendants”).

BACKGROUND

I. Health Disparities and Discrimination in Health Care

Black people in America “tend to receive less and lower quality health care than whites, resulting in higher mortality rates.” The Sullivan Comm’n on Diversity in the Healthcare Workforce, *Missing Persons: Minorities in the Health Professions* i (2004).¹ Although the federal government has made efforts to combat these racial biases, those efforts have fallen short.

¹Available at <https://campaignforaction.org/wp-content/uploads/2016/04/SullivanReport-Diversity-in-Healthcare-Workforce1.pdf>.

A. In the United States, implicit and overt medical discrimination contributes to significant disparities in health care on the basis of race.

Studies have shown for decades that discrimination in medicine is a significant reason why Black and white people in America have different access to health care. Black and other patients of color are less likely than non-Hispanic white patients to receive preventive care and routine medical procedures. Matthew Wynia et al., *Collecting and Using Race, Ethnicity and Language Data in Ambulatory Settings: A White Paper with Recommendations from the Commission to End Health Care Disparities* 6 (2011).² And white patients are almost twice as likely as Black patients to receive a referral to a specialist. See Shirley A. Hill, *Inequality and African-American Health: How Racial Disparities Create Sickness* 91 (2016).³

The quality of health care for Black patients is also often different from—and worse than—the care that white people receive. Although Black people are three times as likely to develop cardiovascular disease than white people, and are twice as likely to die from it, they are less likely than white people “to receive . . . newer or more expensive therapies.” Dayna Bowen Matthew, *Just Medicine: A Cure for Racial Inequality in American Healthcare* 57-58 (2015) (hereinafter “Just Medicine”). And studies show that Black patients, including children, are also less likely to receive pain medication than white patients in emergency departments. Kelly Hoffman et al., *Racial Bias In Pain Assessment and Treatment Recommendations, and False Beliefs about Biological Differences Between Blacks and Whites* (2016);⁴ see, e.g., Tiffani Johnson et al., *Association of Race and Ethnicity with Management of Abdominal Pain in the Emergency Department*, 132 *Pediatrics* 851, 853, 855 (2013) (reporting that Black children who go to an

² Available at https://www.ama-assn.org/system/files/corp/media-browser/public/health-policy/cehed-redata_0.pdf.

³ Available at https://books.google.com/books?id=DLSPDQAAQBAJ&pg=PA11&source=gbs_toc_r&cad=4#v=onepage&q&f=false.

⁴ Available at <https://www.pnas.org/doi/10.1073/pnas.1516047113>.

emergency room with stomach pain are less likely than non-Hispanic white children to receive pain medication, and citing studies of similar results for adult patients).⁵

Racial disparities in medical treatment lead to racial disparities in health outcomes. From 2016 to 2018, the all-cause mortality rate among Black populations in the United States was on average 24% higher than among white populations. Maureen R. Benjamins et al., *Comparison of All-Cause Mortality Rates and Inequities Between Black and White Populations Across the 30 Most Populous US Cities* 5 (2021).⁶ These elevated death rates continue from birth through retirement. See David R. Williams, *The Health of U.S. Racial and Ethnic Populations*, 60 J. of Gerontology: Series B S53 (2005).⁷

Racial health disparities cannot be explained away by referencing the economic or educational differences between racial groups. “Racial and ethnic minorities tend to receive a lower quality of health care than non-minorities, even when access-related factors, such as patients’ insurance status and income, are controlled.” Brian D. Smedley et al., *Unequal Treatment: Confronting Racial And Ethnic Disparities In Health Care*, Nat’l Academies Press 1 (2003) (emphasis added).⁸ Indeed, a survey of studies indicates that some racial disparities in health care are due to racism within the medical system. See, e.g., Mathieu Rees, *Racism in Healthcare: What You Need to Know*, Med. News Today (Sept. 16, 2020) (collecting studies); see also Am. Med. Ass’n, *Racism as a Public Health Threat* H-65.952 (2022) (acknowledging that racism causes racial health inequity).⁹

⁵ Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4074647/pdf/peds.2012-3127.pdf>.

⁶ Available at <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2775299>.

⁷ Available at https://academic.oup.com/psychsocgerontology/article/60/Special_Issue_2/S53/2965174.

⁸ Available at <https://pubmed.ncbi.nlm.nih.gov/25032386/>.

⁹ Available at <https://www.medicalnewstoday.com/articles/racism-in-healthcare;>
<https://policysearch.ama-assn.org/policyfinder/detail/racism?uri=%2FAMADoc%2FHOD.xml-H-65.952.xml>.

B. Recent government efforts to remedy health disparities have fallen short.

The federal government's efforts to deter discrimination in health care have been inadequate, particularly for older people of color.

In 2010, Congress enacted the Patient Protection and Affordable Care Act, prohibiting Medicare and other health programs and activities receiving federal funds from discriminating against individuals on any “ground prohibited under title VI of the Civil Rights Act of 1964” (e.g., race). 42 U.S.C. § 18116(a). But Title VI of the 1964 Civil Rights Act does not apply to physicians who receive federal Medicare Part B funds, so they have never been compelled to comply [with the Act] or even submit signed assurances of nondiscrimination. Nondiscrimination in Health Programs and Activities, 87 Fed. Reg. 47,824, 47887 (Aug. 4, 2022) (explaining that “The Department’s longstanding position has been that Medicare Part B funding does not constitute Federal financial assistance for the purpose of Title VI, Title IX, Section 504, the Age Act, and Section 1557,” and “proposing to change that position and treat Medicare Part B funds as Federal financial assistance to the providers and suppliers subsidized by those funds”). Moreover, the Medicare program—designed to ensure that older Americans have access to quality, affordable health care—has in fact led to “increasing re-segregation of care and greater racial disparities in services.” CERD Working Grp. on Health & Env’t Health, *Unequal Health Outcomes in the United States: Racial and Ethnic Disparities in Health Care Treatment and Access, the Role of Social and Environmental Determinants of Health, and the Responsibility of the State* 27 (2008) (explaining that the low out-of-pocket costs associated with some Medicare plans “create financial incentives for low-and-moderate income consumers to select different plans than the more affluent”); *see also, e.g.,* Jennifer Schore et al., *Racial Disparities in Prescription Drug Use Among Dually Eligible Beneficiaries*, 25 Health Care Fin. Rev. 77, 77 (2003) (“Elderly black Medicare

beneficiaries are more than twice as likely as white beneficiaries . . . to not fill prescriptions because they cannot afford them.”).¹⁰

As Plaintiffs acknowledge, CMS has only recently made it a priority to incentivize anti-racism interventions as a means for reducing racial health disparities. Am. Compl. ¶ 41, ECF No. 28 (citing 81 Fed. Reg. 77195).

II. Procedural History

In 2021, CMS proposed and finalized a rule that promotes health equity through the Merit-based Incentive Payment System (“MIPS”), a program of HHS that adjusts reimbursements payments for services covered by Medicare Part B based on the performance of an eligible medical professional. CMS’s new rule—now dubbed the “anti-racism rule¹¹” —allows MIPS-eligible professionals to “create and implement an anti-racism plan” as a high-weighted improvement activity. Medicare Program; CY 2022 Payment Policies Under the Physician Fee Schedule and Other Changes to Part B Payment Policies, 86 Fed. Reg. 64,996, 65,384, 65,969-70 (Nov. 19, 2021). CMS’s rule construes “anti-racism plan” broadly. An anti-racism plan may set goals for preventing and addressing racism, plan trainings on implicit and explicit biases, or otherwise commit to increasing access and accessibility for all individuals seeking care. *Id.*

The anti-racism rule came under Plaintiffs’ fire shortly after its enactment. Plaintiffs’ amended complaint alleges that the Rule exceeds the agency’s statutory jurisdiction and seeks an order from this Court that vacates the rule. Am. Compl. ¶ 6, ECF No. 28. The Agency Defendants filed a motion to dismiss these claims, arguing that Plaintiffs lacked standing, and that § 1395w-

¹⁰ Available at <https://www.prrac.org/pdf/CERDhealthEnvironmentReport.pdf>; <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4194810/pdf/hcfr-25-2-077.pdf>.

¹¹ CMS’s rule does not mandate that any Medicare provider create or implement an anti-racism plan. It merely designates the anti-racism activity as one, of many, *optional* MIPS improvement activities. Medicare Program; CY 2022 Payment Policies Under the Physician Fee Schedule and Other Changes to Part B Payment Policies, 86 Fed. Reg. 39,104, 39,855 (July 23, 2021).

4(q)(13)(B) bars all their claims in any event. ECF No. 37 at 11-28. This Court granted in part and denied in part Defendants’ motion, dismissing one individual plaintiff from the case, but allowing the State Plaintiffs to proceed to the merits of their claims. ECF No. 52 at 47-48. This Court determined that the State Plaintiffs had plausibly alleged standing because the States “alleged that the Anti-Racism Rule will interfere with the enforcement of their anti-discrimination laws.” *Id.* at 35-36. The Court also found that § 1395w-4(q)(13)(B)(iii) does not at the motion-to-dismiss stage bar judicial review of the anti-racism rule because the State Plaintiffs alleged that the anti-racism rule does not qualify as a “clinical practice improvement activity.” *Id.* at 42-47. Arizona voluntarily dismissed its claims with prejudice following the Court’s order. ECF No. 58 at 1.

III. Proposed Intervenor Work to Reduce Racial Disparities in Health Care Outcomes, and to Counteract Discrimination in Health Care.

The NAACP State Conferences and the Greensboro Health Disparities Collaborative seek to intervene and defend the anti-racism rule.

A. The NAACP State Conferences

The NAACP is the nation’s oldest and largest civil rights organization. Ex. 1, Decl. of Robert James ¶ 4 (Mississippi). The NAACP’s state conferences conduct programming at the state and local level to carry out the national NAACP’s mission: “[A]chieve equity, political rights, and social inclusion by advancing policies and practices that expand human and civil rights, eliminate discrimination, and accelerate the well-being, education, and economic security of Black people and all persons of color.” *Id.* Proposed Intervenor include the state conferences in each of the eight states that originally challenged the anti-racism rule: Mississippi, Alabama, Arizona, Arkansas, Missouri, Montana, Kentucky, and Louisiana. Each state conference has Medicare-eligible members (together, thousands of members who rely on Medicare) who benefit from a rule that incentivizes Medicare providers to be more attuned to Black and brown patients’ specific needs. *See* James Decl. ¶¶ 5-6, 9-31 (Mississippi); Ex. 2, Decl. of Benard Simelton ¶¶ 5-18

(Alabama); Ex. 3, Decl. of Danielle Gilliam ¶¶ 6-23 (Arizona); Ex. 4, Decl. of Frank Shaw ¶¶ 5-17 (Arkansas); Ex. 5, Decl. of Nimrod Chapel, Jr. ¶¶ 5-13, 17-23 (Missouri); Ex. 6, Decl. of Portia Prescott ¶¶ 5-8, 12-24 (Montana); Ex. 7, Decl. of Marcus Ray ¶¶ 5-6, 9-17 (Kentucky); Ex. 8, Decl. of Michael McClanahan ¶¶ 6-18 (Louisiana).

The NAACP State Conferences organize programs and activities within their states to counteract the consequences of past and present discrimination against people of color by medical providers. NAACP members from each of the state conferences are either familiar with the state's history of medical racism or have experienced discrimination in the health care system themselves. *See, e.g.*, James Decl. ¶¶ 15, 18, 21, 23, 26, 28 (detailing Mississippi NAACP member complaints of racial discrimination by medical providers); Simelton Decl. ¶¶ 8-9 (explaining how the Tuskegee experiments created distrust between Black Alabamians and medical providers); Chapel Decl. ¶¶ 16, 23 (Missouri) (similar). Years of implicit and overt racial bias within the medical field have led many within the Black community to distrust medical providers and avoid routine, preventative care. *See, e.g.*, James Decl. ¶¶ 15-19 (Mississippi); Simelton Decl. ¶¶ 7-11 (Alabama); Shaw Decl. ¶¶ 14-17 (Arkansas). This history of discrimination and distrust has contributed to rampant health disparities. *See, e.g.*, James Decl. ¶¶ 16-17 (discussing racial disparities in pregnancy-related deaths); McClanahan Decl. ¶¶ 11-13, 16 (discussing racial disparities in COVID-19-related illness and death).

The NAACP State Conferences also work to improve health care access for people of color within their states—members and non-members alike. For example, the Mississippi, Alabama, and Missouri state conferences have spent substantial time and resources advocating for Medicaid expansion in their states—a program that would provide health insurance to thousands of lower wage earners who are currently uninsured. James Decl. ¶¶ 11-14 (Mississippi); Simelton

Decl. ¶ 12 (Alabama); Chapel Decl. ¶ 14 (Missouri). And the Kentucky NAACP collaborated with an organization called Pathways to create a mobile health clinic that delivers medical and mental-health services across around 10 of the State’s rural counties. Ray Decl. ¶ 11 (Kentucky). These activities are possible only with the dues of the State Conference members, the work of local volunteers, and the philanthropic contributions provided by partner organizations. *See* James Decl. ¶¶ 14, 20 (Mississippi); Simelton Decl. ¶¶ 14, 17 (Alabama); Ray Decl. ¶ 11 (Kentucky).

History and experience drive the NAACP State Conferences’ view that rescinding the anti-racism rule will harm their members and jeopardize their organizational partnerships. *See, e.g.,* Ray Decl. ¶¶ 13-14 (discussing how rescinding the anti-racism rule would exacerbate distrust of the medical profession among Black Kentuckians); Simelton Decl. ¶ 17 (explaining how rescission of the anti-racism rule will deter partner organizations from associating with the Alabama NAACP); Chapel Decl. ¶¶ 11-15 (similar). Without the financial incentive provided by the rule, Medicare providers may be less likely to pursue training on how to build trust, encourage preventative care, and communicate treatment options with their Black patients. James Decl. ¶ 15 (Mississippi); Ray Decl. ¶¶ 9, 12-15 (Kentucky); McClanahan Decl. ¶¶ 15, 17 (Louisiana).

B. The Greensboro Health Disparities Collaborative

The Collaborative was founded in 2003 as a group of community leaders, advocates, scholars, clergy, and health care professionals committed to health equity. Ex. 9, Decl. of Kari Thatcher ¶¶ 3, 6; *see also What is Health Equity?*, Ctrs. for Disease Control and Prevention (last visited May 9, 2023) (defining “health equity” as “the state in which everyone has a fair and just opportunity to attain their highest level of health”).¹² The Collaborative connects the public to resources on health equity, delivers presentations on racial equity, and holds multi-day racial

¹² Available at <https://www.cdc.gov/nchhstp/healthequity/index.html>.

equity workshops. Thatcher Decl. ¶¶ 20, 28; *see also* Greensboro Health Disparities Collaborative, *The History of the Greensboro Health Disparities Collaborative* (last visited May 9, 2023).¹³

The Collaborative developed the Accountability for Cancer Care through Undoing Racism and Equity (“ACCURE”) study, an intervention program designed to identify and diminish racial disparities in the quality and completion of treatment for patients with stage 1 or stage 2 breast and lung cancer. Thatcher Decl. ¶ 14. The study implemented four anti-racism interventions at two cancer centers. *Id.* ¶ 15. These interventions eliminated disparities between Black and white patients across several metrics and improved treatment outcomes for *both* Black and white patients. Thatcher Decl. ¶ 16.

In the Collaborative’s view, the anti-racism rule is empirically sound and will advance the organization’s mission to eliminate racial health disparities. *First*, reducing racial health disparities among Medicare recipients will go a long way in reducing racial health disparities across the board. Medicare-eligible people of color are older, more frequently interact with health care providers, and report higher incidents of discrimination than their younger counterparts. *Id.* ¶ 24; Ex. 10, Decl. of Sidney Callahan ¶ 11. *Second*, incentivizing Medicare providers to create and implement anti-racism plans will encourage hospitals and other health care providers to develop and maintain partnerships with health equity groups like the Collaborative. This institutional support is essential for sustaining the Collaborative’s work. Thatcher Decl. ¶¶ 26-29.

ARGUMENT

I. The Proposed Intervenorors are Entitled to Intervene as Defendants of Right.

Rule 24(a)(2) allows intervention as of right any time (1) the motion to intervene is timely, (2) the proposed intervenor asserts an interest in the controversy that the existing parties do not

¹³ Available at <https://greensborohealth.org/history.html>.

adequately represent, and (3) the disposition of the case may impair or impede the potential intervenor's ability to protect that interest. *Texas v. United States*, 805 F.3d 653, 657 (5th Cir. 2015). Courts "allow intervention where no one would be hurt and the greater justice could be attained." *John Doe #1 v. Glickman*, 256 F.3d 371, 375 (5th Cir. 2001) (citation omitted).

Proposed Intervenors are entitled to intervene as of right. Their motion is timely. Moreover, Proposed Intervenors have legally protected interests that are not adequately protected by the Agency Defendants: Plaintiffs' challenge to the anti-racism rule threatens a government program that is intended to benefit the NAACP State Conferences' members and is likely to increase the costs for both the Collaborative and the NAACP State Conferences to conduct programs that advance their missions. The Agency Defendants have not yet adequately defended against Plaintiffs' damaging theory (and may never do so).

A. The intervention is timely.

Rule 24(a)(2)'s timeliness requirement considers: (1) how long the potential intervenor knew or reasonably should have known of her stake in the case; (2) the prejudice, if any, the existing parties may suffer because the potential intervenor failed to intervene when she knew or reasonably should have known of her stake in that case; (3) the prejudice, if any, the potential intervenor may suffer if the court does not let her intervene; and (4) any unusual circumstances. *Id.* at 376 (citation omitted). Here, each relevant factor demonstrates timeliness.

First, the Proposed Intervenors promptly sought to intervene. Indeed, the Collaborative and the NAACP State Conferences filed their motion the same day that the Agency Defendants filed their answer; before any discovery began; and before this Court issued a scheduling order. This timing is consistent with other motions to intervene that the Fifth Circuit has deemed timely. *See, e.g., Wal-Mart Stores, Inc. v. Tex. Alcoholic Beverage Comm'n*, 834 F.3d 562, 565-566 (5th Cir. 2016) (motion timely when filed before discovery); *Sierra Club v. Espy*, 18 F.3d 1202, 1205-06

(5th Cir. 1994) (motion filed promptly after pertinent pre-trial motion was timely even though filed eight years into proceeding).

Second, neither party will be prejudiced by the Proposed Intervenor’s timing. Rather, the Proposed Intervenor’s timing conserved resources for both the parties and the Court. Premature intervention can risk squandering scarce judicial resources and increases litigation costs. *Stallworth v. Monsanto Co.*, 558 F.2d 257, 265 (5th Cir. 1977). The Proposed Intervenor avoided this disfavored result, declining to file their motion when the Agency Defendants’ motion provided a jurisdictional basis for the Court to dispose of Plaintiffs’ suit.

Third, the Proposed Intervenor will be severely prejudiced if their motion to intervene is denied. It is well-established that proposed intervenors are prejudiced when they are unable to be heard on a legal issue for which they have a substantive interest. *E.g.*, *Glickman*, 256 F.3d at 379. That is the case here. Moreover, due to the nature of Plaintiffs’ claims—a challenge to an agency’s rulemaking—the only way private organizations can help defend this rule, and their corresponding interests, is through intervention.

Fourth, this case does not present any unusual circumstances. The process of this case has been entirely typical. In any event, unusual circumstances typically lead courts to be more lenient, not more stringent, about Rule 24(a)’s timing requirement. *See, e.g.*, *Adam Joseph Res. v. CNA Metals Ltd.*, 919 F.3d 856, 866 (5th Cir. 2019) (allowing intervention after parties “settled the case surreptitiously”); *Stallworth*, 558 F.2d at 261-262, 264-267 (allowing intervention after plaintiff “urged the district court to make it more difficult” for intervenors to learn about the suit).

Three of the timing factors decisively favor intervention here, and the fourth factor is neutral. The Proposed Intervenor's motion is timely.

B. Plaintiffs' challenge to the CMS anti-racism rule may impair the Proposed Intervenor's legally protectable interests.

Intervenor must have a "direct, substantial, legally protectable interest" in a case. *Edwards v. City of Houston*, 78 F.3d 983, 1004 (5th Cir. 1996) (quoting *New Orleans Pub. Serv., Inc. v. United Gas Pipe Line Co.*, 732 F.2d 452, 463 (5th Cir. 1984)). This is not a demanding standard: "an interest is sufficient if it is of the type that the law deems worthy of protection, even if the intervenor does not have an enforceable legal entitlement or would not have standing to pursue her own claim." *Texas*, 805 F.3d at 659. Rule 24(a) recognizes a broad range of interests. *Id.* at 658-660 (collecting cases). Moreover, "[t]he interest requirement may be judged by a more lenient standard if the case involves a public interest question or is brought by a public interest group." *Brumfield v. Dodd*, 749 F.3d 339, 344 (5th Cir. 2015) (quotation marks and citation omitted).

The Proposed Intervenor's interests here—preserving a government rule that serves their members and retaining resources that advance their organizational missions—are legally protectable, and may all be impaired by the disposition of this suit. Plaintiffs present the theory that the anti-racism rule violates the APA, in part, because incentivizing anti-racism in medicine is incompatible with § 1395w-4(q)(13)(B)(iii)'s "core mission" of "patients' health and safety." Am. Compl. ¶ 62, ECF No. 28 (citation omitted). A judgment in Plaintiffs' favor will not only remove an incentive for Medicare providers to engage in anti-racism efforts, but affirmatively condemn it. This would impair Proposed Intervenor's interests because it would result in a substantial change in the status quo with respect to those interests. *See Fund for Animals v. Norton*, 322 F.3d 728, 735 (D.C. Cir. 2003) (interest impaired where "reestablishing the status quo . . . will be difficult and burdensome"); *Brumfield*, 749 F.3d at 344-345 (similar).

First, intervenors have a legally protectable interest in receiving the benefits of a government program of which they are the “intended beneficiaries.” *Texas*, 805 F.3d at 660. The NAACP State Conferences have members who are Black, receive Medicare, and will benefit from a program designed to reduce the disparate outcomes that result from overt and implicit racial biases in health care. *Supra* at pp. 1-3. Absent this incentive, racial health disparities may continue and members of the NAACP State Conferences may continue to suffer the consequences of inequitable health care systems. *See, e.g.*, Simelton Decl. ¶ 15 (Alabama) (anti-racism plan would provide members “hope[]” that medical providers “would be fair to them”); Ray Decl. ¶ 13 (Kentucky) (explaining that distrust of medical providers is one obstacle to members accessing routine medical care, and noting that providers’ commitment “to understand and address issues of racial discrimination” would likely reduce that distrust).

In *Brumfield*, the Fifth Circuit recognized a legally protectable interest where parents receiving educational vouchers from Louisiana were allowed to intervene in a challenge to the voucher program. The parents’ interest in continuing to receive the government benefit was legally protectable even though the vouchers were not a legal entitlement. *Brumfield*, 749 F.3d at 344. The NAACP State Conferences have a comparable interest here. Black Medicare recipients—like all patients—are the direct beneficiaries of government programs designed to combat racism in health care. *See* Thatcher Decl. ¶ 16. This is particularly true for Black Medicare recipients who have received disparate treatment because of their race. *See e.g.*, James Decl. ¶ 28 (Mississippi) (discussing how members may travel over an hour to seek routine medical care from Black physicians because of experiences with medical racism and discrimination); Chapel Decl. ¶ 20 (Missouri) (discussing how a member was forced out of an emergency room).

Second, the Proposed Intervenor has an interest in avoiding financial burdens that would interfere with their programming. This type of interest meets Rule 24(a)’s standards. *See La Union del Pueblo Entero v. Abbott*, 29 F.4th 299, 306 (5th Cir. 2022) (committees that “expend resources” recruiting and training election volunteers had legally protectable interest in challenge to law that regulates conduct of those volunteers).

The Collaborative advances its mission by partnering with hospitals and other organizations to conduct research on racial health disparities and how anti-racism interventions can reduce those disparities. Thatcher Decl. ¶¶ 10-29. But promoting anti-racism research and programming to hospitals and medical professionals is challenging because of their competing time and budgetary constraints. *See id.* ¶¶ 19, 26-27. If this Court strikes down the financial incentive provided by the CMS anti-racism rule, there will be less reason for them to engage in partnerships, which in turn may require the Collaborative to expend even more resources to carry out its mission. *Id.* ¶¶ 26-29.

The NAACP State Conferences face the same harm. Many of these organizations partner with hospitals and other health care providers to educate Black communities about health conditions that disproportionately affect Black people. *E.g.*, Shaw Decl. ¶¶ 9-13, 16 (Arkansas); McClanahan Decl. ¶¶ 8, 15 (Louisiana); Ray Decl. ¶ 11 (Kentucky). Plaintiffs’ challenge to the anti-racism rule directly impacts these interests. If Plaintiffs prevail in their theory that physicians discriminate when they consider the needs of particular racial groups, some medical providers might step back from these outreach efforts. The loss of these partnerships would expose the NAACP State Conferences to a greater financial burden for engaging in effective public education and outreach to their members. *See* Simelton Decl. ¶ 17 (Alabama); Ray Decl. ¶ 15 (Kentucky).

C. The Agency Defendants may not adequately represent the NAACP State Conferences’ and the Collaborative’s interests.

The Proposed Intervenor’s satisfy Rule 24(a)’s inadequacy requirement. Any presumption of adequacy implicated by the State Plaintiffs is overcome because their interests are adverse to Proposed Intervenor’s. *Hopwood v. State of Texas*, 21 F.3d 603, 605 (5th Cir. 1994) (presumption overcome when movant’s “interest is in fact different from that of the state” (cleaned up) (citation omitted)). The Agency Defendants are not entitled to a presumption of adequacy at all. They are not “charged by law” to represent Proposed Intervenor’s interests. *Entergy Gulf States La., L.L.C. v. EPA*, 817 F.3d 198, 203 n.2 (5th Cir. 2016). Nor do the Agency Defendants’ interests “align[s] precisely” with those of Proposed Intervenor’s. *See Brumfield*, 749 F.3d at 345. Thus, the Proposed Intervenor’s need only show that their interests “may diverge” from the Agency Defendants’. *Heaton v. Monogram Credit Card Bank of Ga.*, 297 F.3d 416, 425 (5th Cir. 2002).

1. Agency Defendants’ motions to dismiss demonstrate why the Proposed Intervenor’s cannot rely on them for adequate representation. A court can infer from the government’s attempt to dismiss a case on procedural grounds that it would “prefer[] not to resolve the case on the merits.” *Guenther v. BP Ret. Accumulation Plan*, 50 F.4th 536, 546 (5th Cir. 2022) (citing *La Union del Pueblo Entero*, 29 F.4th at 308-309) (recognizing that intervenor’s interest in the “finality and certainty” that accompanies a merits decision may not be adequately protected by a procedural dismissal) (citation omitted). This Court should do so here. The Agency Defendants’ preference for a resolution on procedural grounds is incompatible with Proposed Intervenor’s interests, which require an unqualified rejection of the theory underlying Plaintiffs’ claims.

Twice, the Agency Defendants barely refuted the substance of Plaintiffs’ attempts to equate anti-racism with racism itself, and sought to dispose of this case on standing and immunity grounds instead. ECF No. 16 at 10-19; ECF No. 37 at 11-29. The NAACP State Conferences and the

Collaborative, by contrast, have a distinct interest in and are uniquely positioned to present arguments about how the anti-racism rule is likely to “improv[e] clinical practice or care delivery” and “result in improved outcomes,” 42 U.S.C. § 1395w-4(q)(2)(C)(v)(III), and therefore falls within HHS’s authority to define clinical practice improvement activities. Proposed Intervenor advocates for constituents who have lived, and continue to live, with long-ignored and still-unaddressed health disparities. There is substantial scientific and factual data demonstrating that these disparities have contributed to poor health outcomes, including higher mortality rates among the Black and brown communities in the United States. *See supra* at pp. 1-3. Moreover, the Collaborative would explain how the anti-racism rule will help ameliorate the effects of racially disparate medical treatment and outcomes and how the development of anti-racism plans will improve the quality of care provided to all individuals. *See* Thatcher Decl. ¶ 16.

2. The Agency Defendants’ procedural arguments failed to completely represent Proposed Intervenor’s interests. Unlike the Agency Defendants, Proposed Intervenor is steeped in the Plaintiff States’ anti-discrimination laws and the on-the-ground reality of when (and whether) those laws are enforced to combat discrimination in health care. The NAACP State Conferences arose from and are grounded in the need to end anti-Black violence and discrimination and advance equality across the country. *E.g.* James Decl. ¶ 16 (Mississippi); Chapel Decl. ¶¶ 4, 9 (Missouri). As a result, they have decades of experience and knowledge as to the existence, enforcement and effectiveness of state laws designed to combat racial discrimination. *See* ECF No. 28 at 5; *e.g.* Shaw Decl. ¶¶ 4, 7, 15 (Arkansas); Chapel Decl. ¶ 18 (Missouri).

For example, the NAACP knows that Mississippi has no state Civil Rights Act or any other civil rights statutory protection related to discrimination in health care. James Decl. ¶ 19 (Mississippi). Moreover, the Collaborative’s roster of physician-members bring expertise in how

medical providers can be conscious of patients' race and the impacts of medical racism without engaging in racial discrimination. Callahan Decl. ¶¶ 9-10, 12; *see also* Prescott Decl. ¶ 21 (Montana) (improving accuracy and specificity of racial demographic data improves health outcomes for people of color). The Agency Defendants lack both areas of expertise and will be ill-equipped to show at summary judgment why Plaintiffs' theory of standing—that an *anti-racism* rule violates state anti-discrimination laws—fails as a matter of law.

3. Proposed Intervenors' and the Agency Defendants' interests diverge even beyond the briefing. The Agency Defendants have an interest in preserving the scope of the agency's rulemaking authority, enhancing the health and well-being of all Americans, and enforcing Federal law, *see About HHS*, HHS.¹⁴ Proposed Intervenors' interest in preserving the anti-racism rule because it will reduce racial disparities in health care access and treatment outcomes is consistent with, *but distinct from*, improving the health of all Americans. *See, e.g.*, James Decl. ¶¶ 16-21 (Mississippi); Simelton Decl. ¶¶ 7-17 (Alabama); *see also* Thatcher Decl. ¶ 16 (explaining how health equity initiatives improve health care outcomes for *all* patients). Moreover, the Agency Defendants' institutional interests make them uniquely unlikely to explain the role that the agency's *own inaction* has played in creating a need for the anti-racism rule. What is more, the Agency Defendants have no reason to take a position in litigation that accounts for the Proposed Intervenors' interest in preserving partnerships with hospitals and medical providers who support the organizations' health equity programming, *supra* at pp. 6-8, or the Collaborative's financial interest in providing hospitals the type of anti-racism trainings that CMS's rule incentivizes, *supra* at pp. 8-9. Across each of these dimensions, the Agency Defendant's defense of the anti-racism rule may fail to encompass or protect Proposed Intervenors' legally protected interests.

¹⁴ Available at <https://www.hhs.gov/about/index.html>.

4. Finally, practical considerations show how the parties' interests may diverge. The next presidential election is 18 months away. There is no guarantee that the next administration will defend CMS's rule before this Court or on appeal—Democratic and Republican administrations have both declined to adopt health equity efforts like the anti-racism rule in the past. *See* ECF No. 28 at 12 (citing 81 Fed. Reg. 77195). This stands as good evidence that the Agency Defendants may not adequately represent Proposed Intervenor's interests in the future. *NextEra Energy Cap. Holdings, Inc. v. D'Andrea*, No. 20-50168, 2022 WL 17492273, at *4 (5th Cir. Dec. 7, 2022) (utility commission may inadequately represent intervenor's interest where commission's litigation position is inconsistent with commission's prior views).

* * *

The Proposed Intervenor's satisfy Rule 24(a)'s requirements. This Court should grant Proposed Intervenor's motion to intervene as of right.

II. Alternatively, Permissive Intervention is Proper Under Rule 24(b).

Permissive intervention is also appropriate. Rule 24(b) allows this Court to “permit anyone to intervene” who has filed a “timely motion” and “has a claim or defense that shares with the main action a common question of law or fact.” Fed. R. Civ. P. 24(b)(1), (B); *Stallworth*, 558 F.2d at 269. “[C]laim or defense” is “construed liberally.” *In re Estelle*, 516 F.2d 480, 485 (5th Cir. 1975); *see also Stallworth*, 558 F.2d at 269. And the “common question of law or fact” requirement is satisfied so long as an intervenor's arguments are “related to” the claims in the lawsuit. *Cf. Trans Chem. Ltd. v. China Nat'l Mach. Imp. & Exp. Corp.*, 332 F.3d 815, 825 (5th Cir. 2003) (common question of law and fact must be “related to” proposed intervenor's arguments). Courts often allow organizations to permissively intervene where, as here, the potential intervenors may provide unique perspective or expertise for a shared legal defense. *See, e.g., League of United Latin Am.*

Citizens, Council No. 4434 v. Clements, 884 F.2d 185, 189 (5th Cir. 1989) (courts should consider permitting intervention when intervenors may “contribute significantly to the development of the underlying factual issues”); *Wachob Leasing Co., Inc. v. Gulfport Aviation Partners, LLC*, No. 1:15cv237-HSO-RHW, 2016 WL 10568063, at *2 (S.D. Miss. Nov. 30, 2016) (same).

The Proposed Intervenors qualify for permissive intervention because, at minimum, the Agency Defendants’ and Proposed Intervenors’ defense of the rule will share a common issue of law. Proposed Intervenors intend to defend the anti-racism rule by using their experience with and expertise in discrimination and racial health disparities to explain why the anti-racism rule falls squarely within CMS’s statutory authority to define clinical practice improvement activities.

CONCLUSION

For the foregoing reasons, this Court should grant the Proposed Intervenors’ motion to intervene as of right or by permission of the Court.

May 11, 2023

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Counsel for Intervenors

** Pro Hac Vice Application Forthcoming*

CERTIFICATE OF SERVICE

I certify that on May 11, 2023, the foregoing document was filed on the Court's CM/ECF system which sent notification of such filing to all counsel of record.

/s/ Robert B. McDuff

EXHIBIT 1

**IN THE UNITED STATES DISTRICT COURT
FOR THE SOUTHERN DISTRICT OF MISSISSIPPI
JACKSON DIVISION**

STATE OF MISSISSIPPI; STATE OF
ALABAMA;
STATE OF ARKANSAS; COMMONWEALTH
OF KENTUCKY; STATE OF LOUISIANA;
STATE OF MISSOURI; and
STATE OF MONTANA,

Plaintiffs,

v.

XAVIER BECERRA, in his official
capacity as Secretary of Health and
Human Services; THE UNITED
STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES;
CHIQUITA BROOKS-LASURE, in her
official capacity as Administrator of the
Centers for Medicare and Medicaid
Services; THE CENTERS FOR
MEDICARE AND MEDICAID
SERVICES; THE UNITED STATES
OF AMERICA,

Defendants.

No. 1:22-cv-113-HSO-RPM

DECLARATION OF ROBERT JAMES

I, Robert James, declare as follows:

1. The facts set forth in this declaration are based on my personal knowledge, and if called as a witness, I could and would competently testify to the following matters under oath.
2. I am the President of the Mississippi State Conference of the National Association for the Advancement of Colored People (“Mississippi NAACP”), a proposed intervenor in the above-captioned matter. The Mississippi NAACP is a nonpartisan, nonprofit organization that is an affiliate of the NAACP.

3. I am authorized to provide this declaration on behalf of the Mississippi NAACP. I have served as the President of Mississippi NAACP for around four years. As president, I often interact with Mississippi NAACP members, and I regularly work with the Mississippi NAACP units (branches, chapters, and committees) and other NAACP units responsible for carrying out the mission of the organization. The Mississippi NAACP typically holds 10 meetings of the State Conference per year. I also periodically attend after-hours meetings and receive phone calls from the branches about their operations and issues that arise, as needed. Before my term as the President of the State Conference, I spent approximately eight years serving as the President of the Stone County Branch of the NAACP. I have also served as the NAACP Membership Committee Chairman. I have been a member of the NAACP since 2013.
4. The NAACP is the nation's oldest and largest civil rights organization, which was founded in 1909. We share the mission of the NAACP, which is to "achieve equity, political rights, and social inclusion by advancing policies and practices that expand human and civil rights, eliminate discrimination, and accelerate the well-being, education, and economic security of Black people and all persons of color."¹ Specifically, we focus on implementing the mission and goals of the NAACP at the state and local level in Mississippi.
5. We currently have over 11,000 members throughout the state, with more than 112 units, including branches, college chapters, and youth councils, across Mississippi. The Mississippi NAACP's membership consists largely of African Americans, and we aim to support all people of color and members of underrepresented and vulnerable populations,

¹ NAACP, *Our Mission*, <https://naacp.org/about/mission-vision> (last visited May 10, 2023).

regardless of membership in the Mississippi NAACP. We advocate for and work with all of our constituents on issues that matter to them.

6. Many of the Mississippi NAACP's members are eligible for Medicare, and a significant number of those eligible for Medicare are Medicare beneficiaries.
7. Dr. Sandra Carr-Melvin, Chief Executive Officer for the Institute for the Advancement of Minority Health, is the Health Committee Chair for Mississippi NAACP. Our Health Committees conduct various forms of Health programming, including health education, and advocacy in the community, and leading our efforts to decrease racial health disparities.
8. We often collaborate with other organizations in our health programming, but the money we receive from our membership dues is also vital to funding our programming and activities.
9. The Mississippi NAACP has strong interests in the stated aims of the Center for Medicare & Medicaid Services ("CMS") 2021 final rule, the rule that adds an improvement activity entitled "create and implement an anti-racism plan" in the health equity subcategory ("anti-racism rule"). The experiences of the Mississippi NAACP's members lead us to strongly disagree with the statements in Plaintiffs' complaint that anti-racism and equity do not belong in medicine. To the contrary, steps such as those promoted by the anti-racism rule are important to correct for the lingering effects of historic racism and persistent racial health disparities.
10. First, the Mississippi NAACP has an interest in preserving the anti-racism rule because many of our members are the intended beneficiaries of the rule and one of our primary

missions is to expand access to affordable, quality healthcare for all Mississippians, including our members. We've undertaken many projects in pursuit of this mission.

11. Currently, one of our largest campaigns involves advocating for Medicaid expansion in Mississippi, which would benefit many thousands of lower wage earners who lack access to medical insurance. Through this campaign, we have learned that many uninsured people forego medical care because they are forced to choose between getting medical care or providing food for their families or other necessities. When Mississippians delay care, they have worse health outcomes and are more likely to end up in the emergency room to receive treatment for their chronic medical conditions.

12. Our Health Chair, Dr. Carr-Melvin, has written about how neglecting preventative care drives up the cost of providing medical care for all Mississippians and burdens hospitals, "making it harder for them to invest in new technologies or equipment, maintain needed capacity to serve patients or even remain open."² Rural hospitals can be particularly affected by this issue: with a large patient population that has no health insurance, or who at best are under insured, many rural hospitals simply do not have the financial ability to continue their mission.

13. Through the Medicaid expansion campaign, we have learned from medical providers, hospital systems, and community members who have had a range of experiences with Mississippi's health care system. They told us about the many barriers that low-income Mississippians face gaining access to quality health care. For example, we have heard about rural hospital closures and how those closures force people living in rural areas to travel

² Dr. Sandra Carr-Melvin, *Medicaid Expansion In Mississippi Closes the Health Insurance Gap*, Miss. Free Press (Mar. 16, 2022), <https://www.mississippifreepress.org/22004/medicaid-expansion-in-mississippi-closes-the-health-insurance-gap>.

long distances for basic medical care. The closure of rural hospitals causes similar hardships for many of our members because Mississippi is a very rural state.

14. In addition to our Medicare expansion campaign, the Mississippi NAACP works with a diverse coalition of stakeholders—including hospital systems, physicians, community members, and advocacy groups—to conduct community education, legislative office visits, press conferences, public forums, op-ed's and other outreach efforts to raise awareness about the importance of access to healthcare. We hired a campaign manager, Dr. Ashley White Jones, and one of the initiatives she led was recording the stories of Mississippians whose lives have been impacted by their lack of medical insurance. Dr. Jones has a master's degree in public health. Her current academic research focuses on health equity and health disparities in the Black community, and she works on a variety of health equity initiatives, including creating a curriculum for nursing and public health studies regarding Black maternal health.
15. Rescinding the anti-racism rule will likely impede the Mississippi NAACP's efforts to increase access to quality health care for Black Mississippians. Our members have told us that they are deterred from overcoming logistical barriers to accessing routine, preventative healthcare when they feel like medical providers are not sensitive or responsive to their needs. The anti-racism rule, if left intact, is designed to incentivize medical providers to implement or instill measures to identify, prevent, and reduce racial health disparities, such as training providers on how to combat implicit biases, respond to the needs of all patients regardless of their race, and overcome the distrust that often exists between medical professionals and Black Mississippians.

16. Second, the Mississippi NAACP has an interest in defending the anti-racism rule because the rule furthers the organization's mission to eliminate racial health disparities. Although Mississippi has some of the worst health outcomes in the country for Black *and* white patients, Mississippi's track record on health outcomes for Black Mississippians is particularly dismal. Public and private discrimination has, for centuries, impeded Black Mississippians' access to quality health care. The resulting racial health disparities are intertwined with and exacerbated by other racial inequities throughout the state. Due to Mississippi's uniquely violent history of racism, the Mississippi NAACP continues to have an interest in overcoming the effects of historic and persistent racism in all aspects of society, including health care. I have discussed these racial health disparities with both experts and lay people within the Mississippi NAACP's membership.
17. Our Health Chair, Dr. Melvin, has stated that Mississippi's Black population has the highest mortality rate due to hypertension, stroke, diabetes, and other chronic conditions, and the highest prevalence of coronary heart disease, hypertension, obesity, and diabetes, compared to Mississippi's Hispanic and non-Hispanic white populations. Moreover, Black women in Mississippi are four times more likely to die from pregnancy-related deaths than non-Hispanic white women.
18. Some of our members have talked about the difference in pain management that Black patients receive as compared to white patients because Black patients' pain is more often ignored or minimized by health care providers. This occurs for several reasons, such as the stereotype that Black people do not feel as much pain and the fact that the medical system fails to account for physical differences between patients who are non-white. The anti-racism rule would likely help reduce bias in the medical profession because it incentivizes

Medicare providers to conduct activities such as providing training so that medical providers are more aware of, and can take into account the shortcomings of some medical equipment and standards of care when used with Black patients.

19. Racial health disparities became even more apparent during the COVID-19 pandemic, in which people of color were disproportionately affected by COVID-19. Due to the many ways that healthcare tends to be less accessible for people of color, as well as inequities in social and economic factors that influence health outcomes, many Black Mississippians are diagnosed with chronic conditions after the condition has worsened, resulting in worse health outcomes and making it more likely that they would die or suffer severe illness from COVID-19. Throughout the pandemic, we called for Mississippi to increase access to the vaccine for communities of color and other vulnerable populations. After the state largely ignored requests by the Mississippi NAACP throughout the pandemic that it develop a plan to distribute vaccines equitably, in March 2022, we filed an administrative complaint for race discrimination with the Federal Emergency Management Administration and the Department of Health and Human Services alleging the state had violated federal antidiscrimination requirements. Mississippi does not have a general civil rights or anti-discrimination law.

20. As we noticed that Mississippi was not working to directly provide assistance to Black communities, the Mississippi NAACP diverted our resources to protect these communities: we worked to promote vaccine campaigns and assisted our members and Mississippians of color in accessing COVID-19 vaccines, personal protective equipment, and other resources. For example, we set up an Emergency Response Program in which we distributed personal protective equipment and set up vaccine clinics. Specifically, the

Jackson City Branch, Panola County Branch, Oktibbeha County Branch, and Pearl River County Branch hosted vaccine clinics, distributed informational materials about the vaccine, and partnered with local organizations and community members to distribute donations such as hand sanitizers and masks, as well as work together to coordinate and publicize their clinics. Also, the Mississippi NAACP hosted a joint rental assistance and vaccine clinic in Greenville, Mississippi, as we found that housing insecure households were more susceptible to COVID-19 transmission.

21. Currently, many of our members continue to experience the consequences of this antipathy toward the health of Black people in Mississippi. For example, our members in the majority-Black city of Jackson, Mississippi went without drinkable running water for over a month in August 2022 after Jackson’s largest water treatment plant failed. This water outage led the National NAACP and the Mississippi NAACP to file a Title VI complaint of race discrimination against the Mississippi State Department of Health and the Mississippi Department of Environmental Quality, citing the state’s repeated failures to allocate federal funds for improvements to the city of Jackson’s water system. Mississippi’s repeated failures caused Jackson’s crumbling water system, which has been an enormous problem for residents of the predominantly Black city, with frequent shutoffs, boil-water notices, and ongoing exposure to toxic lead and harmful bacteria.
22. Our complaint explains that Mississippi, for years, has discriminated on the basis of race against the City of Jackson, Mississippi and “its majority-Black population by diverting federal funds awarded to ensure safe drinking water and unpolluted surface waters and groundwater.”³ Our complaint describes how Mississippi repeatedly “deprived Jackson of

³ Complaint at 2 (Sept. 27, 2022), <https://naacp.org/articles/naacp-files-discrimination-complaint-mishandling-jackson-water-crisis>.

federal funds to maintain its public drinking water system in favor of funding smaller, majority-white communities with less acute needs—despite the fact that Jackson is Mississippi’s most populous city, with a demonstrated need for improvements to water infrastructure. The result is persistently unsafe and unreliable drinking water and massive gaps in the access to safe drinking water[.]”⁴

23. The water crisis is only the latest example of racial disparities that are negatively affecting our members today. On a broader level, we have heard from our members and our chairs about many other examples of how they are still encountering racism and disparities in medical care. The Mississippi NAACP is also taking affirmative steps to identify other ways in which Black people experience disparate health outcomes. For example, we recently began a research project to study Black men’s health and tobacco use.

24. The anti-racism rule is designed to encourage Medicare providers to identify and address health inequities experienced by Black people and other people of color. The rule would likely benefit many of our members, who are Medicare recipients, by encouraging doctors and health care providers to identify racial disparities, create a plan to prevent and address racism, including racism arising from implicit bias and stereotypical assumptions about Black patients, and ensure services are accessible and understandable for those seeking care. Moreover, a rule focused on advancing health equity would improve the quality of care for all patients, and benefit Mississippi NAACP’s members who are not Medicare beneficiaries.

25. In our view, this rule would be especially beneficial for our Medicare-eligible members.

This is because many of our older members hold a distinctive distrust of the healthcare

⁴ *Id.*

system because it was deeply discriminatory for much of their lives. In addition to the racial health disparities that our members face, many of our older members have past trauma from their experiences with the healthcare system. This distrust and trauma deter some older members from pursuing the care they need.

26. Third, the Mississippi NAACP has an interest in seeing more cultural competency and racial sensitivity among medical providers. Our members often seek out medical care from Black physicians or physicians who are culturally competent because of the implicit bias and discrimination they have experienced in the healthcare system. But again, due to the state's history of discrimination, Black physicians in Mississippi are few and far between. In fact, one of our members, Dr. Robert L. Smith, is a medical doctor who experienced segregation and discrimination in his workplace when he began practicing medicine in Mississippi the 1960s. Dr. Smith has said he saw thousands of Mississippians, mostly poor Black families, going without medical care and forced to deal with ailments on their own. For example, Black individuals were refused care at some hospitals or forced into unsanitary wards.

27. Dr. Smith's experience is not unique: the American Medical Association ("AMA") and its Mississippi state affiliate have a long history of discrimination and abuse against Black patients and medical practitioners. Dating back to the 1800s and persisting through much of the 20th century, Black doctors were prohibited from using the same changing rooms, eating in the same dining rooms, or seeing patients in the same hospital rooms as white doctors in Mississippi hospitals.

28. The scarcity of Black physicians leads some rural Black Mississippians to regularly travel more than an hour away to receive routine care, as they have found that doctors are more

likely to be white in rural areas and some, but not all, of those physicians are insensitive to the needs of their Black patients. Many of our members feel they receive better care from Black doctors or white doctors who are culturally competent.

29. The anti-racism rule incentivizes health care providers to create and implement anti-racism plans with the goal of improving medical providers' cultural competencies. Our members would not have to travel so far to receive quality medical care if providers in rural areas were better equipped to meet the needs of Black Mississippians.

30. Ending the anti-racism rule, as Mississippi and other Plaintiffs seek, on the inaccurate grounds that anti-racism efforts are "bad medicine," would pose a significant risk of continuing the exacerbation of racial health disparities and poor health outcomes among Mississippians. In our experience, racial health disparities are a result of racism and discrimination, and we believe that the anti-racism rule is a positive step forward in working to reduce health disparities.

31. In summary, the anti-racism rule is designed to benefit our many members who are Medicare beneficiaries, as well as thousands of other people of color in Mississippi. The rule seeks to improve access to quality healthcare, a goal that the Mississippi NAACP is invested in, and currently spends time and resources on.

I solemnly swear and affirm under the penalties of perjury that the foregoing is true and correct based on my personal knowledge.

/s/ Robert James
Declarant's Signature

5/11/2023
Date

Robert James
Declarant's Printed Name

EXHIBIT 2

**IN THE UNITED STATES DISTRICT COURT
FOR THE SOUTHERN DISTRICT OF MISSISSIPPI
JACKSON DIVISION**

STATE OF MISSISSIPPI;
STATE OF ALABAMA;
STATE OF ARKANSAS; COMMONWEALTH OF
KENTUCKY; STATE OF
LOUISIANA; STATE OF MISSOURI;
and STATE OF MONTANA,

Plaintiffs,

v.

XAVIER BECERRA, in his official
capacity as Secretary of Health and
Human Services; THE UNITED
STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES;
CHIQUITA BROOKS-LASURE, in her
official capacity as Administrator of the
Centers for Medicare and Medicaid
Services; THE CENTERS FOR
MEDICARE AND MEDICAID
SERVICES; THE UNITED STATES
OF AMERICA,

Defendants.

No. 1:22-cv-113-HSO-RPM

DECLARATION OF BENARD SIMELTON

I, Benard Simelton, declare as follows:

1. The facts set forth in this declaration are based on my personal knowledge, and if called as a witness, I could and would competently testify to the following matters under oath.
2. I am the President of the Alabama State Conference of the National Association for the Advancement of Colored People ("Alabama NAACP"), a proposed intervenor in the above-captioned matter. The Alabama NAACP is a nonpartisan, nonprofit organization that is an affiliate of the NAACP.

3. I am authorized to provide this declaration on behalf of the Alabama NAACP. I have held the position of President of the Alabama NAACP for around 13 years. As President, I interact with Alabama NAACP members, and regularly work with the NAACP units (branches, chapters, and committees) that are responsible for carrying out the mission of the organization. Before that, I served as the Limestone County NAACP Branch President for around six years. I have also served as the First Vice Chair and the Education Chair, as well as a general member volunteer. Moreover, when I lived in New Mexico, I was a general member of the New Mexico State Conference of the NAACP.
4. The Alabama NAACP shares the mission of the NAACP, which is to “achieve equity, political rights, and social inclusion by advancing policies and practices that expand human and civil rights, eliminate discrimination, and accelerate the well-being, education, and economic security of Black people and all persons of color.”¹ The Alabama NAACP strives to implement this mission on the local and state level by advancing a variety of social issues, including education, economic opportunity, and health.² We have a Health Committee, which is led by our Health Chair, Brenda Debose.
5. We have thousands of members throughout the state, with more than 40 active units across Alabama. The Alabama NAACP’s membership consists largely of African Americans, and it aims to support all people of color and members of underrepresented and vulnerable populations, regardless of membership in the Alabama NAACP. Currently, many of our members are eligible for Medicare and/or are Medicare beneficiaries.
6. Eliminating racial health disparities is a vital component of the Alabama NAACP’s mission to achieve equity and eliminate discrimination. The 2021 final rule by the Center for

¹ NAACP, *Our Mission*, <https://naacp.org/about/mission-vision> (last visited May 10, 2023).

² The Alabama NAACP, *Our Mission*, <https://alnaacp.org/about> (last visited May 10, 2023).

Medicare & Medicaid Services (“CMS”), which incentivizes Medicare providers to create and implement anti-racism plans (“anti-racism rule”), would work to diminish these disparities by encouraging medical providers to address some of the many factors that contribute to racial health disparities. The Alabama NAACP has strong interests in defending the anti-racism rule because it would likely decrease our members’ distrust of the medical system, increase the quality of care offered by medical providers to our members, and help our partnerships with local medical providers.

7. First, the Alabama NAACP has an interest in defending the anti-racism rule because the rule will likely reduce our members’ distrust of the medical system. This distrust impedes our members’ ability and willingness to access routine medical care.
8. Many of our members express concern about medical racism because of the Tuskegee syphilis experiment, which was conducted in Macon County, Alabama. During the Tuskegee experiment, the government recruited hundreds of Black men as participants for the syphilis study. However, even though penicillin became the recommended treatment for syphilis partway through the study, the health workers, researchers, and physicians intentionally withheld penicillin treatment from the Black participants for decades, stopping only when a whistleblower exposed the study. The decision to withhold treatment caused hundreds of the Black participants to die, go blind, and experience other severe health problems, as well as caused the wives and children to get infected.
9. When the COVID-19 vaccines were approved, many of our members feared that medical providers were again providing incomplete or inaccurate information to the Black community about the vaccine’s efficacy. Others worried that Black communities, like the Tuskegee participants, would be deprived access to life-saving treatments. Lastly, our

members expressed that oftentimes, medications are not tested enough on Black individuals, and so Black individuals can often show adverse reactions to medications. The Alabama NAACP has worked for years to help rectify this distrust. During the COVID-19 pandemic, for example, we held community talks and trainings for our members about the COVID-19 vaccine. We educated the community about the vaccines and provided information about the safety of the vaccines and vaccine access. We also held discussion panels where Black medical providers could speak directly to our members to answer any questions or concerns.

10. The anti-racism rule would help build trust between our members and medical providers throughout Alabama by incentivizing health care providers to create and implement anti-racism plans. By creating and implementing anti-racism plans, medical providers would demonstrate an interest in developing cultural competency and providing equitable care. The Alabama NAACP members are more likely to engage in routine, preventative care when they trust their medical providers.
11. Furthermore, the existence of the rule itself that incentivizes providers to engage in anti-racism efforts would inherently improve the level of trust that our members have in the medical system because it is an action step forward. While we appreciate government officials' acknowledgements of past government responsibility for increasing distrust in the medical profession, acknowledgements are only the very first step to fixing the problem. Establishing this rule is an important action step forward because it incentivizes members of the medical profession to recognize and overcome the hesitancy and suspicion that persists among some of our members. This rule would likely help more of our members

to seek medical care when needed, instead of avoiding routine medical care like vaccinations.

12. Second, the Alabama NAACP has an interest in defending the anti-racism rule as part of its broader interest in expanding access to affordable, quality healthcare for its members. For example, the Alabama NAACP has for years advocated for Medicaid expansion in Alabama, which would benefit many thousands of lower-wage earners who currently lack access to medical insurance.
13. Third, the Alabama NAACP has an interest in improving health outcomes for its members through efforts to eradicate discrimination in health care. Some members have shared that they avoid medical treatment for several reasons, including distrust of the medical field due to past experiences of mistreatment, lack of knowledge over whether they are eligible for Medicare or Medicaid, having a health insurance plan that has large gaps in coverage or high out-of-pocket costs, or concerns over being able to pay the medical bills. For example, several people have told me that they did not receive proper medical attention and think it was because of their race. People's health conditions worsen when they avoid getting the medical care they need. By contrast, providers with greater awareness of racial health disparities and their underlying causes, would likely provide better care for all people.
14. The Alabama NAACP has worked to identify and eliminate discrimination in Alabama's healthcare system for many years. We work with our members to investigate their legal redress complaints. We also try to work with health facilities whose physicians have been accused of discrimination, but policies and regulations surrounding patient privacy often limit our efforts.

15. Reducing racial discrimination and insensitivity in the medical profession would likely improve the quality of care that some of our members receive. The Alabama NAACP members have expressed that they would be interested in receiving medical care from a provider who has an anti-racism plan in place—they would be hopeful that the provider would be fair to them.
16. Fourth, the Alabama NAACP has an interest in defending the anti-racism rule because combatting racism and discrimination is at the core of our mission. Our activities seek to reduce racial disparities and combat discrimination. For example, we recently called on an Alabama Council member to resign after he used the phrase “house n-----” during a council meeting, and we stated unequivocally that we believe “there is no place for racist white supremacists to hold office and conduct business in our public meeting spaces.”³
17. If the Court agrees with Alabama’s position in this case that anti-racism plans are “bad medicine,” it will remove an incentive for healthcare providers to create anti-racism plans and may cause some healthcare providers to be hesitant about associating with the type of anti-racism efforts that the Alabama NAACP undertakes. The Alabama NAACP has an interest in preserving and expanding our connections to medical partners, especially given the importance of our partnerships with medical providers during the COVID-19 vaccine trainings and community discussions.
18. Overall, this anti-racism rule supports the Alabama NAACP’s mission, our Health Committee efforts, and many of our members.

³ Elisha Fieldstadt, *Alabama Lawmaker Uses Racist Slur in Recorded Council Meeting, Faces Calls to Resign*, NBC News, <https://www.nbcnews.com/news/us-news/alabama-lawmaker-uses-racist-slur-recorded-council-meeting-faces-calls-n1274603> (last visited May 10, 2023).

I solemnly swear and affirm under the penalties of perjury that the foregoing is true and correct based on my personal knowledge.

/s/ Benard Simelton
Declarant's Signature

5/11/2023
Date

Benard Simelton
Declarant's Printed Name

EXHIBIT 3

**IN THE UNITED STATES DISTRICT COURT
FOR THE SOUTHERN DISTRICT OF MISSISSIPPI
JACKSON DIVISION**

STATE OF MISSISSIPPI; STATE OF ALABAMA;
STATE OF ARKANSAS; COMMONWEALTH OF
KENTUCKY; STATE OF
LOUISIANA; STATE OF MISSOURI;
and STATE OF MONTANA,

Plaintiffs,

v.

XAVIER BECERRA, in his official
capacity as Secretary of Health and
Human Services; THE UNITED
STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES;
CHIQUITA BROOKS-LASURE, in her
official capacity as Administrator of the
Centers for Medicare and Medicaid
Services; THE CENTERS FOR
MEDICARE AND MEDICAID
SERVICES; THE UNITED STATES
OF AMERICA,

Defendants.

No. 1:22-cv-113-HSO-RPM

DECLARATION OF DANIELLE GILLIAM

I, Danielle Gilliam, declare as follows:

1. The facts set forth in this declaration are based on my personal knowledge, and if called as a witness, I could and would competently testify to the following matters under oath.
2. I am the Health Chair of the Arizona State Conference of the National Association for the Advancement of Colored People (“Arizona NAACP”), a proposed intervenor in the above-captioned matter. This is a volunteer position. The Arizona NAACP is a nonpartisan, nonprofit organization that is an affiliate of the NAACP.
3. I am employed as a field-based Executive Medical Liaison with Novo Nordisk Inc. covering the Southwest region. Novo Nordisk is a global healthcare company, founded

in 1923 and headquartered just outside Copenhagen, Denmark, whose purpose is to drive change to defeat diabetes and other serious chronic diseases such as obesity, and rare blood and rare endocrine diseases.

4. I studied Chemistry at Xavier University and obtained my Master's Degree in Public Health Policy and Administration and a Doctorate in Pharmacy from the University of Illinois Chicago. I have experience as a clinical pharmacist, health educator, researcher, and community advocate. My area of expertise is cardiometabolic disease. I am also certified in health disparities, health education, and medical writing and editing. I have received several awards for my work in diversity, inclusion, and belonging, including the American Diabetes Association Phoenix Chapter Lily Hines-Marbley Memorial Outreach Award (2012, 2013), Arizona State Conference NAACP Committee Chair Person Award (2018), Novo Nordisk CMR Drive Change Award – DEI¹ in Clinical Trials (2022), AZ Pharmacy Association Pharmaceutical Associate of the Year (2022), and Novo Nordisk Office of D&I² Engaged Enthusiast Award (2019, 2020) and Novo Nordisk Circle of Excellence (2023).
5. I am authorized to provide this declaration on behalf of the Arizona NAACP. I have been the Arizona NAACP Health Chair since 2016. Before serving in my current role, I was the East Valley Branch NAACP Health Chair. As Health Chair, I interact with Arizona NAACP State Conference leadership and members about carrying out the mission of the organization related to health equity. The Arizona NAACP shares the mission of the NAACP, which is to “achieve equity, political rights, and social inclusion by advancing policies and practices that expand human and civil rights, eliminate discrimination, and

¹ DEI is an acronym for Diversity, Equity, and Inclusion.

² D&I is an acronym for Diversity and Inclusion

accelerate the well-being, education, and economic security of Black people and all persons of color.”³ The Arizona NAACP strives to implement this mission at the state level by advancing a variety of social issues including health justice.

6. The Arizona NAACP is a grassroots organization. We have 11 adult units, 5 college chapters, and 4 youth councils across the state. Altogether, the Arizona NAACP has thousands of members. Our membership consists largely of African Americans, but we aim to support all members of underrepresented and vulnerable communities. Many of our members are eligible for Medicare and/or are Medicare beneficiaries.
7. The Arizona NAACP has an interest in defending the Center for Medicare & Medicaid Services’ (“CMS”) anti-racism rule—a rule that seeks to diminish racial-health disparities by incentivizing Medicare providers to create and implement anti-racism plans.
8. *First*, the Arizona NAACP has an interest in defending the anti-racism rule because eliminating racial health disparities is an indispensable component of our mission to achieve equity and eliminate discrimination. Racism can have a significant impact on the health outcomes of patients who are members of marginalized communities. Studies have shown that racism can contribute to health disparities, including higher rates of chronic illness, mental health issues, and maternal and infant mortality. An anti-racism plan can help health care providers recognize and address health disparities by promoting diversity and inclusion in their practices, providing culturally sensitive care to all patients, and taking steps towards eliminating bias and discrimination. By implementing an anti-racism plan, health care providers can help to ensure that all patients receive the highest quality of care, regardless of their race or ethnicity.

³ NAACP, *Our Mission*, <https://naacp.org/about/mission-vision> (last visited May 8, 2023).

9. The Arizona NAACP Health Committee regularly demonstrates its interest in reducing racial health disparities by conducting health equity programming. We participate in and organize community events and health fairs. I often participate in these events to help educate our members and the community about health issues that disproportionately affect Black people and other people of color. As Health Chair, I sometimes meet with the chairs of other state conference NAACP health committees as well the national NAACP's Director of Health and Wellness to discuss ways in which we can address health disparities.
10. For example, the Arizona NAACP participated in the Dialysis Health Imperative for Access, Choice, and Equity ("ACE") program, a collaboration among Baxter, the NAACP, and the Alliance for Home Dialysis with the goal of informing individuals within African American communities in the U.S. about access to kidney care and the disproportionate impact kidney disease has on African Americans and other people of color. The program included a series of town hall events to discuss kidney health and identify the needed resources so patients would be more aware of their options earlier in the process.
11. There are many environmental, medical, and social factors that contribute to an increased risk of developing kidney disease, also known as chronic kidney disease ("CKD"). These factors include: having more than one disease (for example, high blood pressure or diabetes), your family's medical history, where you live, where you work, where you play, how you are perceived by others, and (in the case of people of color) how you have personally experienced discrimination. According to the National Kidney Foundation, while Black people make up about 13% of the population, they account for 35% of the

people with kidney failure in the United States.⁴ A growing number of Hispanic people are diagnosed with kidney disease each year — since 2000, the number of Hispanic people with kidney failure has increased by more than 70%.⁵ Diabetes is the leading cause of kidney failure among Indigenous people. “Black and Latinx patients are less likely than non-Latinx white patients to be treated with home dialysis: 7.3% of Black patients and 7.4% of Latinx prevalent patients with kidney failure are treated with home dialysis therapies, compared with 9.3% of non-Latinx white patients. The lower rates of home dialysis use in the Black and Latinx communities are not completely explained by geographic, demographic, and clinical factors.”⁶ Based on the limited studies of this issue, provider bias often leads to people of color being referred to dialysis centers rather than being offered home dialysis. They are often not told about home dialysis which has the potential to allow them to continue full time employment with little disruption to their regular routine.

12. In 2018, the Health Committee organized a health and wellness fair in Mesa, Arizona in partnership with the Arizona Kidney Foundation, the American Diabetes Association, and South Phoenix Baptist Church, where they had a comprehensive kidney screening and panel discussion with a nephrologist, Arizona state legislator, home dialysis representative, and a person living with kidney disease on home dialysis. A chronic

⁴ Nat’l Kidney Found., *Social Determinants of Kidney Disease*, <https://www.kidney.org/atoz/content/kidneydiscauses> (last visited May 8, 2023).

⁵ *Id.*

⁶ Katherine Rizzolo et al., *Racial and Ethnic Disparities in Home Dialysis Use in the United States: Barriers and Solutions*, 33 J. of the Am. Soc’y of Nephrology 1258, 1258 (2022), <https://journals.lww.com/jasn/pages/articleviewer.aspx?year=2022&issue=07000&article=00012&type=Fulltext> (citation omitted).

kidney disease lecture and interactive demonstration of an in-home dialysis machine was held at The Word Church in Mesa, Arizona.

13. As part of the Dialysis Health Imperative for ACE media campaign, I was interviewed on the Alvin Galloway show on RadioPhoenix.org, where I discussed kidney disease and its impact on communities of color. As a result of our efforts, the communities of color in the greater Phoenix metro area have an increased awareness around treatment options for End Stage Renal Disease including the benefits of home dialysis.

14. Black maternal and infant mortality is a key social justice focus among the NAACP.

Black women are three times more likely to die from pregnancy related complications than their White counterparts. In Arizona “Black/African American and American Indian/Alaska Native infants have consistently had the highest rates of infant mortality from 2010-2019 In 2019, the infant mortality rate for Black/African Americans was 12.3 deaths per 1,000 live births and among American Indian/Alaska Natives was 6.1 deaths per 1,000 live births, whereas, the infant mortality rate among [w]hites was 3.6 deaths per 1,000 live births.”⁷ Social determinants of health play a role in Black maternal and infant morbidity and mortality, however, research has shown there are other factors at play like structural racism and implicit bias. On September 6, 2019, the CDC reported in their *Morbidity and Mortality Weekly Report (MMWR)*, the pregnancy related mortality ratios “(PRMRs) for black and AI/AN women with at least some college

⁷ Ariz. Child Fatality Review Team, *Twenty-Seventh Annual Report* (2020), <https://www.azdhs.gov/documents/prevention/womens-childrens-health/reports-fact-sheets/child-fatality-review-annual-reports/cfr-annual-report-2020.pdf>.

education were higher than those for all other racial/ethnic groups with less than a high school diploma.”⁸

15. As Health Chair, I am committed to representing the voice of my membership. I

collaborated with an Arizona House of Representative legislator and a policy advisor identifying policies/laws that created or exacerbated disparities in maternal and infant health care. In 2021–2022, I was on the planning committee for the Arizona Department of Health Services (“AZDHS”) Bureau of Women’s and Children’s Health Mortality Review Program. In 2021, I presented *Maternal Health Outcomes: Chronic Health Conditions* at the Maternal and Infant Mortality Summit. Currently, I am a steering committee member on the AZDHS Maternal and Child Health Needs Assessment.

16. Also, the Arizona NAACP held a series of four townhall programs for the general public discussing SARS-CoV-2, COVID-19, and vaccines. People of all ages within and outside of Arizona participated virtually. I contacted one of the two Black FDA advisory committee members reviewing the Pfizer-BioNTech and Moderna COVID vaccine for emergency use authorization. I was honored when the committee member accepted my request to speak during our townhall on vaccines. I participated on a panel discussing the future of pandemics at the University of Arizona Honors College speaker series *Big Ideas, Grand Challenges* on September 29, 2021. On November 18, 2021, I presented on COVID-19 and Health Disparities to the Arizona Pharmacy Association. Then on February 10, 2022, I presented to the African American Conference on Disabilities sponsored by the Arizona Center for Disability Law regarding the rights of persons with

⁸ CDC, *Morbidity and Mortality Weekly Report (MMWR), Racial/Ethnic Disparities in Pregnancy-Related Deaths – United States, 2007-2016* (Sept. 6, 2019), https://www.cdc.gov/mmwr/volumes/68/wr/mm6835a3.htm?s_cid=mm6835a3_w.

disabilities unable to receive COVID vaccines. There were over 15,000 virtual attendees from across Arizona, almost every state in the US, US Virgin Islands, Canada, Africa, and Europe.

17. As a trusted messenger in the Black community, it was imperative that I provided unbiased, evidence-based information about the pandemic to encourage the CDC's recommendations to control the spread of SARS-CoV-2, especially to Black Arizonians. The residents of Arizona were less likely to wear masks, practice social distancing, and get vaccinated. Arizona's death rates were similar to the countries with the highest COVID-19 deaths. Black and Hispanic people died from COVID-19 more than other racial groups.⁹
18. *Second*, the Arizona NAACP has an interest in defending CMS' anti-racism rule because it is likely to make medical providers more sensitive to the specific concerns of their Black patients, particularly older Black patients. Racism against Black people in health care has a sordid past, present, and future if drastic steps are not taken soon. Dr. Marion Sims, considered the father of OB/GYN for his vaginal fistula invention, experimented on Black women over 40 times without their consent or anesthesia. Sara Baartman was a full-figured woman whose naked body was exhibited for entertainment. Her brain and sexual organs were displayed in a Paris museum until 1974.
19. The most infamous medical racism against Black people occurred when the United States Public Health Service, began a study in 1932 to record the natural history of syphilis originally called the "Tuskegee Study of Untreated Syphilis in the Negro Male." Almost

⁹ Thomas J. Bollyky et al., *Assessing COVID-19 Pandemic Policies and Behaviours and Their Economic and Educational Trade-offs Across US States from Jan 1, 2020, to July 31, 2022: An Observational Analysis*, 401 *Lancet* 1341 (2023), [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(23\)00461-0/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(23)00461-0/fulltext).

400 Black men, who did not give consent, were not treated for syphilis even when penicillin became widely used as a treatment in 1943. The study finally ended October 1972 mainly due to an article written a year earlier by the Associated Press. I often wonder how long the study would have proceeded had a light not been shown on the unethical treatment of those men.

20. More recently, less than four years ago, two former Black football players sued the NFL for race-based adjustments in dementia testing.¹⁰ The NFL dementia testing policy used “race-norming” which assumed Black players start with lower cognitive function. This makes it harder to qualify for financial payouts.¹¹ Even more disturbing, if a claim was submitted without “race-norming” the results, the claim was denied.¹² Seventy percent of the NFL players are Black.¹³

21. I have been in the health care industry for over 20 years. I have witnessed and experienced medical racism personally. Our health care system needs advocates for those whose voices are often muted. For anyone to say that racism does not exist in the health care system only solidifies it more. Medical racism has a direct effect on the health of our members and Black people across the state and nation. In order to have a holistic approach to the health and wellness of a person, the health care professional needs to address socioeconomic factors, physical environment, health behaviors, in addition to health care. Only 20% of health comes from physical health, the remaining percentage of our health outcomes is dictated by social determinants. Fifty percent of your health can

¹⁰ *NFL Agrees to End Race-based Brain Testing in \$1B Settlement on Concussions*, The Associated Press (Oct. 20, 2021), <https://www.npr.org/2021/10/20/1047793751/nfl-concussion-settlement-race-norming-cte>.

¹¹ *Id.*

¹² *See id.*

¹³ *Id.*

be traced to your zip code. The CDC defines social determinates of health as “the nonmedical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.”¹⁴ For instance, discrimination, racism, and microaggressions cause a low-grade inflammation response in our bodies. Many diseases result from inflammation like heart diseases, diabetes, obesity, breast cancer, and other illness disproportionately impacting people of color. “Allostatic load refers to the cumulative burden of chronic stress and life events. It involves the interaction of different physiological systems at varying degrees of activity. When environmental challenges exceed the individual ability to cope, then allostatic overload ensues.”¹⁵

22. The Arizona NAACP and its members will suffer if Plaintiffs succeed in striking down the anti-racism rule because of the disparities that exist in healthcare for people of color. Racism, discrimination, and bias among providers negatively affect the health of our members. Implicit racial bias in the health care system leads to “diagnostic uncertainty and, for Black patients, negative ratings of their clinical interactions, less patient-centeredness, poor provider communication, undertreatment of pain, views of Black patients as less medically adherent than White patients, and other ill effects.”¹⁶ Almost half of U.S. medical students surveyed reported having heard negative comments about Black patients by attending or resident physicians, resulting in those students

¹⁴ CDC, *Social Determinants of Health at CDC* (Dec. 8, 2022), <https://www.cdc.gov/about/sdoh/index.html>.

¹⁵ Jenny Guidi et al., *Allostatic Load and Its Impact on Health: A Systematic Review*, 90 *Psychother Psychosom* 11 (2020), <https://www.karger.com/Article/FullText/510696>.

¹⁶ Janice A. Sabin, *Tackling Implicit Bias In Health Care*, 387 *New England J. Med.* 105 (2022), <https://www.nejm.org/doi/full/10.1056/NEJMp2201180> (citation omitted).

exhibiting significantly greater implicit racial bias in year four than year one.¹⁷ The American Medical Association, the largest medical association representing the interests of physicians, recognizes racial bias in the health system and has implemented an equity plan to embed racial justice and advance health equity. AMA Trustee Willarda V. Edwards said, “[s]ystemic racism in medicine is the most serious barrier to the advancement of health equity and appropriate medical care.”¹⁸

23. This anti-racism rule supports the NAACP’s mission and its members. Rescission of the rule will likely impede the NAACP’s mission and goal in advancing health equity for its members. Numerous studies have shown that Black and brown patients have overwhelmingly suffered worse outcomes in the United States than white patients. Studies have also shown that at least part of the reason for those outcomes is racial stereotyping, implicit bias, and lack of understanding of the needs of Black and brown patients. A finding that this rule violates the law would not only discourage health care providers from learning and attempting to address these issues, but also paint such efforts as themselves discriminatory. That would be an injustice for the NAACP’s Medicare beneficiaries as well as Black and brown patients generally.

I solemnly swear and affirm under the penalties of perjury that the foregoing is true and correct based on my personal knowledge.

/s/ Danielle Gilliam
Declarant’s Signature

5/11/2023
Date

Danielle Gilliam
Declarant’s Printed Name

¹⁷ *Id.*

¹⁸ Timothy M. Smith, *AMA Guidelines Offer Path to Prevent Discrimination In Medicine* (June 15, 2021), <https://www.ama-assn.org/delivering-care/health-equity/ama-guidelines-offer-path-prevent-discrimination-medicine>.

EXHIBIT 4

**IN THE UNITED STATES DISTRICT COURT
FOR THE SOUTHERN DISTRICT OF MISSISSIPPI
JACKSON DIVISION**

STATE OF MISSISSIPPI;
STATE OF ALABAMA;
STATE OF ARKANSAS; COMMONWEALTH OF
ARKANSAS; STATE OF
LOUISIANA; STATE OF MISSOURI;
and STATE OF MONTANA,

Plaintiffs,

v.

XAVIER BECERRA, in his official
capacity as Secretary of Health and
Human Services; THE UNITED
STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES;
CHIQUITA BROOKS-LASURE, in her
official capacity as Administrator of the
Centers for Medicare and Medicaid
Services; THE CENTERS FOR
MEDICARE AND MEDICAID
SERVICES; THE UNITED STATES
OF AMERICA,

Defendants.

No. 1:22-cv-113-HSO-RPM

DECLARATION OF FRANK SHAW

I, Frank Shaw, declare as follows:

1. The facts set forth in this declaration are based on my personal knowledge, and if called as a witness, I could and would competently testify to the following matters under oath.
2. I am the immediate past President of the Arkansas State Conference of the National Association for the Advancement of Colored People (“Arkansas NAACP”), a proposed intervenor in the above-captioned matter. The Arkansas NAACP is a nonpartisan, nonprofit organization that is an affiliate of the NAACP.

3. I am authorized to provide this declaration on behalf of the Arkansas NAACP. I held the position of president from 2018 to 2021, and I currently serve on the Executive Committee in the Arkansas NAACP. In performing my past duties as president, I interacted with Arkansas NAACP members, and regularly worked with the NAACP units (branches, chapters, and committees) that are responsible for carrying out the mission of the organization. In performing my current duties on the Executive Committee, I also regularly work with NAACP units and members. Before my presidency, I was a NAACP member, and have been a NAACP member for many decades.
4. The NAACP is the nation's oldest and largest civil rights organization, which was founded in 1909. We share the mission of the NAACP, which is to "achieve equity, political rights, and social inclusion by advancing policies and practices that expand human and civil rights, eliminate discrimination, and accelerate the well-being, education, and economic security of Black people and all persons of color."¹
5. We currently have thousands of members throughout the state, with around 27 active units across Arkansas. The Arkansas NAACP's membership consists largely of African Americans, and it aims to support all people of color and members of underrepresented and vulnerable populations, regardless of membership in Arkansas NAACP.
6. Currently, we estimate that over 60% of our members are eligible for Medicare and that most of them are Medicare beneficiaries.
7. We focus on implementing the mission of NAACP at the state and local level in Arkansas. We work on a variety of issues that advance our mission and are of concern to our members,

¹ NAACP, *Our Mission*, <https://naacp.org/about/mission-vision> (last visited May 10, 2023).

such as voting, education, and health. The Arkansas NAACP has a Health Committee, which is led by our health chair.

8. The Arkansas NAACP and its members will be negatively affected if Plaintiffs succeed in striking down the Center for Medicare & Medicaid Services (“CMS”) 2021 final rule, the rule that adds an improvement activity entitled “create and implement an anti-racism plan” in the health equity subcategory (“anti-racism rule”). The rule complements the Arkansas NAACP’s work to educate our members about common health conditions in the Black community and encourage them to engage in routine preventative care. If CMS’s anti-racism rule is rescinded, we are concerned that it will exacerbate existing distrust of medical providers among many Black Arkansans. The rule also aims to improve health care for older Arkansans, including older Black Arkansans and older members of Arkansas NAACP. The rule works to reduce racial health disparities, and the rule’s rescission would make it less likely that Medicare providers will adopt measures that aim to reduce racial health disparities.
9. First, the Arkansas NAACP has an interest in preserving the anti-racism rule because the rule furthers one of our primary missions, which is to eliminate racial health disparities. Our work on improving access to healthcare and eliminating racial health disparities is a result of the fact that so many of our members and the citizens of Arkansas who are people of color have had to confront health inequities, including lack of access to health care, racial stereotyping, and encounters with racism.
10. Accordingly, the Arkansas NAACP organizes a wide range of health-focused programming. For example, in September 2022, the Arkansas NAACP hosted Blue Cross Blue Shield representatives at our annual convention. Blue Cross Blue Shield gave a

presentation about health conditions that disproportionately affect the Black community. In 2022, and in years past, many of our physician-members gave presentations to the state conference membership. These presentations educate members of the Arkansas NAACP about health issues affecting the community and about where to access health care in Arkansas.

11. Several local Arkansas NAACP branches also host annual health fairs, coordinate COVID-19 vaccination clinics, and partner with clinics to provide blood glucose screenings. Members of the Lee County branch, for example, volunteer with the Lee County Cooperative Clinic. This clinic has to meet a significant portion of the County's health care needs because there are no hospitals in the area.
12. Arkansas is a rural state, and in many of our counties, there are no hospitals or clinics, or hospitals have closed, causing our members to have to travel very far to see a healthcare provider. When there is a hospital closure or a sale of a hospital that used to be run by the county in an area, the Arkansas NAACP branch in the area typically holds a community event open to all where there is discussion from providers and community members about how these hospital closures or sales will affect the community. Through these events and through our membership, we have learned that hospital closures and lack of access to quality healthcare is a substantial barrier for low-income Arkansans to live healthier lives. Additionally, the Arkansas Minority Health Commission identified that the quality of healthcare in many rural areas is poor, and that many patients in rural parts of the state have a lack of trust in the healthcare system.

13. Although our membership and other Arkansans of color face many barriers to equitable healthcare, this anti-racism rule represents an important step to address and work on eliminating health disparities.
14. Second, the Arkansas NAACP has an interest in defending CMS's anti-racism rule because it creates an incentive for Medicare providers to become culturally competent and deliver medical care that is sensitive to the needs of Black individuals and other individuals of color. Many culturally and racially diverse Arkansans fall below the poverty line and live in rural areas where accessing routine medical care is difficult. In our experience, Arkansas NAACP members are more likely to overcome those barriers and access medical care when they trust their providers.
15. The Arkansas NAACP has designed programming throughout the years to rebuild trust between Black Arkansans and the medical community. For example, in 2020, the Arkansas NAACP partnered with the state's Minority Health Commission to conduct better education and outreach efforts regarding the COVID-19 pandemic. Black Arkansans sometimes distrust the medical community because of the long history of intentional and inadvertent racial discrimination—discrimination that continues today. For example, the Arkansas NAACP has a legal redress line, which allows Black Arkansans and other Arkansans to report incidents of discrimination within the state, and we have received complaints from Arkansans reporting encounters with medical racism over the years.
16. Some members have told me that they feel like they experience barriers in communicating their medical needs to their medical providers because of cultural differences. Others have expressed concern that their doctors treat the experiences of their white patients as the “default,” instead of being attentive to the varying experiences of patients of all races and

ethnicities. However, overall, Arkansas NAACP has found that medical providers deliver better care to our members when they are attentive to cultural differences and our members' specific needs.

17. The anti-racism rule is designed to combat the implicit biases among the medical community that interfere with our members' ability to access quality health care from responsive medical providers. Recission of the anti-racism rule will likely impede the Arkansas NAACP's ability to realize progress in our mission of eliminating health disparities and rebuilding trust between Black Arkansans and the medical community.

I solemnly swear and affirm under the penalties of perjury that the foregoing is true and correct based on my personal knowledge.

/s/ Frank Shaw
Declarant's Signature

5/11/2023
Date

Frank Shaw
Declarant's Printed Name

EXHIBIT 5

**IN THE UNITED STATES DISTRICT COURT
FOR THE SOUTHERN DISTRICT OF MISSISSIPPI
JACKSON DIVISION**

STATE OF MISSISSIPPI;
STATE OF ALABAMA;
STATE OF ARKANSAS; COMMONWEALTH OF
KENTUCKY; STATE OF
LOUISIANA; STATE OF Missouri;
and STATE OF MONTANA,

Plaintiffs,

v.

XAVIER BECERRA, in his official
capacity as Secretary of Health and
Human Services; THE UNITED
STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES;
CHIQUITA BROOKS-LASURE, in her
official capacity as Administrator of the
Centers for Medicare and Medicaid
Services; THE CENTERS FOR
MEDICARE AND MEDICAID
SERVICES; THE UNITED STATES
OF AMERICA,

Defendants.

No. 1:22-cv-113-HSO-RPM

DECLARATION OF NIMROD CHAPEL, JR.

I, Nimrod Chapel, Jr., declare as follows:

1. The facts set forth in this declaration are based on my personal knowledge, and if called as a witness, I could and would competently testify to the following matters under oath.
2. I am the President of the Missouri State Conference of the National Association for the Advancement of Colored People ("Missouri NAACP"), a proposed intervenor in the above-captioned matter.
3. I am authorized to provide this declaration on behalf of the Missouri NAACP. I have held the position of President for the Missouri NAACP for approximately eight years. I am also

the President of the Jefferson City Branch of Missouri, and I have served as President of the branch since around 2006. Before my presidency, I was a member of the Missouri NAACP, involved in the Kansas City NAACP branch, and served as the chair of the Young Adult Committee in Kansas. In performing my duties as both the President of the Missouri NAACP and the Jefferson City Branch, I often interact with Missouri NAACP members. I also regularly work with the Missouri NAACP units and other NAACP units responsible for carrying out the mission of the organization.

4. The NAACP is the nation's oldest and largest civil rights organization, which was founded in 1909. The Missouri NAACP is a nonpartisan, nonprofit organization that is an affiliate of the NAACP. We share the mission of the NAACP, which is to "achieve equity, political rights, and social inclusion by advancing policies and practices that expand human and civil rights, eliminate discrimination, and accelerate the well-being, education, and economic security of Black people and all persons of color."¹
5. We currently have several thousand members throughout the state, with more than 30 active units across Missouri. The Missouri NAACP's membership consists largely of African Americans, and the organization supports all people of color and all members of underrepresented and vulnerable populations, regardless of their membership in the Missouri NAACP.
6. A large percentage of the Missouri NAACP members residing in Missouri are Medicare beneficiaries or are eligible for Medicare.
7. The Missouri NAACP has a Health Committee led by our Health Chair, Dr. Cheryl Avant, PhD, MBA, MHA. Our Health Committee consists of members who are medical providers,

¹ NAACP, *Our Mission*, <https://naacp.org/about/mission-vision> (last visited May 10, 2023).

advocates, professors, researchers, and other community members who have expertise in or interest in health justice issues.

8. We hold quarterly meetings for state conference members, which frequently include presentations or remarks by our Health Chair, who relays information about important health matters that the Missouri NAACP is working on.
9. The Missouri NAACP is uniquely well-positioned to understand the enduring effects of a long history of structural and individual racism. Missouri was founded as a “slave state,” during the Missouri Compromise—a national compromise designed to protect slavery throughout major areas of the United States. Missouri’s laws later served as a springboard for the *Dred Scott* decision—a case that ultimately concluded that African-Americans were not and could never be citizens of the United States. Even though *Dred Scott* has since been reversed and repudiated, Black Missourians continue to face overt and implicit racial discrimination, including in health care.
10. The Missouri NAACP has broad interests in the Center for Medicare & Medicaid Services’ (“CMS”) rule that adds an improvement activity entitled “create and implement an anti-racism plan” in the health equity subcategory (“anti-racism rule”).
11. First, the Missouri NAACP has an interest in defending the anti-racism rule because of its potential to reduce racial disparities in health outcomes, particularly for our older members. Our Health Chair, Dr. Avant, co-authored the State of Missouri’s – Office of Minority Health’s report entitled, *State of Missouri Health Disparities Report: Promoting Health Equity and Reducing Disparities in Missouri*,² which found that there were large health

² Mo. Dep’t of Health and Senior Servs., Mo. Office of Minority Health, *State of Missouri Health Disparities Report: Promotion Health Equity & Reducing Health Disparities in Missouri* (2008), <https://health.mo.gov/living/families/minorityhealth/pdf/DisparityReport.pdf>.

disparities in both the United States and Missouri. The report explains that health disparities (also called health inequalities) are “population-specific differences in the presence of disease and health outcomes, as well as differences in access to and quality of health and health care across racial, ethnic, gender, age and socioeconomic groups.”³ Unfortunately, in the years since the report was published, health disparities have continued in the United States and in Missouri.

12. As a result of these persistent racial health disparities across the state, we consider our Health Committee work to be a significant component of our efforts to implement the NAACP’s mission at the state level in Missouri.
13. One example of our Health Committee’s work is our initiative to draft health policy and health advancement recommendations to the Missouri Office of Minority Health. We plan to focus our report on sickle cell anemia research, but the report will also cover related conditions like heart disease and respiratory illness. As part of our research for the report, we are distributing questionnaires to our members and other individuals in the community regarding their exposure and experience with common health conditions and their knowledge of treatment and/or prevention measures.
14. The Missouri NAACP also advocated for Medicaid expansion, which the Missouri legislature passed into law in 2020. This advocacy spanned many years. We held panels featuring health experts discussing the importance of expanding Medicaid; drafted, shared, and collected petitions signed by community members; disseminated informational mailings; partnered with clergy and community groups to educate community members; discussed the issues with constituents, hosted town halls for Missouri NAACP members

³ *Id.* at 6.

and the general public; and collaborated on a variety of communications to members and the public. Over the years, Black Missourians across the state told us about the importance of federal health insurance programs, including Medicare, in their everyday lives. Being able to access quality healthcare through Medicaid and Medicare is a critical issue to Black people in Missouri, including members of the Missouri NAACP.

15. The Missouri NAACP's COVID-19-related activities and efforts are another example of the health justice programming that is spearheaded by our Health Committee. First, we held several town halls and webinars about COVID-19. These provided the public with a wide range of information—from safety measures to disparities in accessing COVID-19 tests and treatments. Second, we worked diligently on partnerships with churches, such as churches affiliated with conventions and independent churches, to provide information on COVID-19 and on vaccines. Third, our Health Chair worked to secure more than 900 masks to distribute throughout Missouri, after we heard that individuals in Missouri were having mask access issues. Fourth, we partnered with local churches and Missouri community health centers on immunization clinics and mobile units, and supported their efforts to obtain vaccines. Fifth, we regularly released COVID-19 educational materials on our social media platforms to educate our community. Finally, our Health Committee researched and disseminated a report on COVID-19 to our members and community.
16. Notwithstanding these efforts, Black Missourians, including our members, died from COVID-19 at disproportionately higher rates than white Missourians. In the first few months of the COVID-19 pandemic, the disparity in death rates between Black individuals and white individuals was five to one. Accordingly, we believe that our Health Committee

work is very important to advance our mission, and we have a firm interest in defending this anti-racism rule that would work to reduce health disparities.

17. Second, the Missouri NAACP has an interest in CMS's anti-racism rule because it is likely to reduce the amount of implicit bias and overt discrimination that Black Missourians experience when seeking medical care.
18. The Missouri NAACP strives to listen to and amplify the interests of all Black Missourians, regardless of whether they are members of the Missouri NAACP. In doing so, we accept legal redress complaints from all Missourians. We have helped refer Missourians to a variety of resources, discussed potential solutions with the hospital or clinic directly, and engaged in policy advocacy and support of initiatives that we feel will improve health disparities.
19. Our members, and other Missourians of color, frequently face a variety of obstacles reflecting implicit structural biases that result in disparate access to quality healthcare. Our Health Chair, Dr. Avant, has written about barriers to accessing healthcare such as medical providers' limited locations and hours of operation, lack of transportation, lack of affordable healthcare, and language barriers.⁴
20. Black Missourians, including some of our members, also face overt medical racism on an individual level. Several Missouri NAACP members have confided in me about their experiences where they felt like they were treated differently than white patients. For example, one of our members told me that he went to the emergency room after a car accident. After being treated, he waited in the waiting room for his car ride back home. As he was waiting, the emergency room forced him to leave and then called the police on him.

⁴ Mo. Dep't of Health and Senior Servs., *supra* note 2, at 8-9.

He was forced outside, even though it was December and cold outside. The member is a Black man, and he observed that no white patients were forced outside or reported to the police for waiting in the waiting room.

21. Third, we have an interest in seeing more cultural competency and racial sensitivity among medical providers, which the anti-racism rule promotes. As our Health Chair, Dr. Avant, found in her research, some Missourians of color have shared that, if the healthcare provider “was competent and had a genuine concern, warm spirit, and respect for the client,” they have had good interactions when being seen by the provider, regardless of whether the provider was of a different nationality, race, or cultural background.⁵ The anti-racism rule incentivizes health care providers to create and implement anti-racism plans with the goal of improving the provider’s cultural competency and racial sensitivity. If more providers develop increased cultural competency, we believe our members and other Missourians of color will then experience better healthcare interactions.
22. The Missouri NAACP believes that it is important to provide medical care to patients on an equitable basis. The anti-racism rule plays an important role in advancing that objective. If, however, Plaintiffs succeed in striking down the anti-racism rule, Medicare providers will lose an important incentive to deliver culturally sensitive care. Rescission of the rule could also be harmful to the Missouri NAACP’s efforts to pursue our organizational mission through our work to reduce health disparities.
23. Moreover, if the rule is rescinded on the grounds that anti-racism measures conflict with antidiscrimination laws, or that such efforts do not improve health care or outcomes, providers are likely to rescind existing anti-racism efforts. Such a result would require the

⁵ *Id.* at 9.

Missouri NAACP to spend more resources on our health programming as we would need to address the deepening divide between the medical field and the communities we serve.

The Missouri NAACP has spent its own resources through its Health Committee work to help facilitate better delivery of healthcare in the Black community. The rule would help accomplish these goals as well. Over time, this would allow the Missouri NAACP to spend less of its dues and resources on addressing medical distrust, outreach and other health programming, as the medical profession becomes better at serving all of the community.

I solemnly swear and affirm under the penalties of perjury that the foregoing is true and correct based on my personal knowledge.

/s/ Nimrod Chapel, Jr.
Declarant's Signature

5/11/2023
Date

Nimrod Chapel, Jr.
Declarant's Printed Name

EXHIBIT 6

**IN THE UNITED STATES DISTRICT COURT
FOR THE SOUTHERN DISTRICT OF MISSISSIPPI
JACKSON DIVISION**

STATE OF MISSISSIPPI;
STATE OF ALABAMA;
STATE OF ARKANSAS; COMMONWEALTH OF
KENTUCKY; STATE OF
LOUISIANA; STATE OF MISSOURI;
and STATE OF MONTANA,

Plaintiffs,

No. 1:22-cv-113-HSO-RPM

v.

XAVIER BECERRA, in his official
capacity as Secretary of Health and
Human Services; THE UNITED
STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES;
CHIQUITA BROOKS-LASURE, in her
official capacity as Administrator of the
Centers for Medicare and Medicaid
Services; THE CENTERS FOR
MEDICARE AND MEDICAID
SERVICES; THE UNITED STATES
OF AMERICA,

Defendants.

DECLARATION OF PORTIA PRESCOTT

I, Portia Prescott, declare as follows:

1. The facts set forth in this declaration are based on my personal knowledge, and if called as a witness, I could and would competently testify to the following matters under oath.
2. I am the President of the Colorado-Montana-Wyoming State Conference of the NAACP (“Rocky Mountain NAACP”), and I am authorized to provide this declaration on behalf of the Rocky Mountain NAACP. I have been involved with a variety of NAACP branches for decades, such as the Denver, Colorado branch and the Beverly Hills, California branch, and I am a lifetime member of NAACP. In performing my duties as president, I interact

with Rocky Mountain NAACP members often, and I regularly work with NAACP units (branches, chapters, and committees) responsible for carrying out the mission of the organization.

3. The Rocky Mountain NAACP is a nonpartisan, nonprofit affiliate of the NAACP, based in the Colorado, Montana, and Wyoming area (“tri-state area”). We share the mission of the NAACP, which is to “ensure the political, educational, social, and economic equality of rights of all persons and to eliminate race-based discrimination wherever it exists.”¹ We also share the vision of a “society in which all individuals have equal rights without discrimination based on race.” The Rocky Mountain NAACP works to implement this vision at the tri-state-level by advancing a variety of social issues, including issues related to health. We collect member dues from our members, which go towards covering Rocky Mountain NAACP costs, including the costs of our programming.
4. The Rocky Mountain NAACP’s Health Committee is led by our Health Chair, Dr. Sheila Davis, MD. Dr. Davis completed her medical training at the University of Pennsylvania and McGill University in Montréal and has over 20 years of experience in health equity work at the national and local level.
5. We currently have hundreds of members. As one of the fastest growing state conferences in the NAACP, we have members throughout the three states in the State Conference, Montana, Colorado, and Wyoming. Many of our members are Medicare beneficiaries and/or are eligible for Medicare. Our membership consists largely of Black and Hispanic individuals, but we aim to support all people of color and all members of underrepresented and vulnerable populations.

¹ NAACP, *Our Mission*, <https://naacp.org/about/mission-vision> (last visited May 10, 2023); CO-MT-WY NAACP, *Vision*, <https://rmnaacp.org/> (last visited May 10, 2023).

6. The Rocky Mountain NAACP has significant interests in defending the Center for Medicare & Medicaid Services' ("CMS") anti-racism rule. The anti-racism rule would likely decrease racial health disparities by incentivizing Medicare providers to implement antiracism plans, which will likely lead to improved care for Black patients and other patients of color and advance our mission to advance equity and eliminate discrimination in the tri-state area. We believe the anti-racism rule is an important step to take, and likely helps our members, many of whom are direct beneficiaries of this rule.
7. First, the Rocky Mountain NAACP has an interest in preserving the anti-racism rule because eliminating racial health disparities is an integral part of our mission to advance equity and eliminate discrimination. The anti-racism rule works to decrease these disparities by incentivizing Medicare providers to create and implement anti-racism plans. The adoption of anti-racism plans by medical providers would likely benefit Rocky Mountain NAACP members, including members in Montana.
8. One of our top priorities is addressing health disparities with respect to Black maternal mortality. Pregnancy-related mortality rates among Black women are over three times higher compared to the rate of white women, and Black women have disproportionately higher shares of low birthweight births, preterm births, or births for which they received no prenatal care or late prenatal care compared to white women.² Concerningly, there has not only been an increase in maternal death rates during the COVID-19 pandemic, but also an increase in the racial disparities experienced by Black women.³

² James W. Collins, et al., *Very Low Birthweight in African American Infants: The Role of Maternal Exposure to Interpersonal Racial Discrimination* (2004), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1448603/> (last visited May 10, 2023).

³ Donna L. Hoyert, *Maternal Mortality Rates in the United States, 2021*, (2023) <https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2021/maternal-mortality-rates-2021.pdf> (last visited May 10, 2023).

9. April is Black Maternal Health Month. Examples of our April 2023 programming to spread awareness and visibility of this issue include a webinar regarding Black maternal health, entitled *Black Mamas Matter - Our Bodies Belong to Us: Restoring Black Autonomy and Joy*, and an event featuring the streaming the documentary film, *Aftershock: For Black Women, Pregnancy Can Be Deadly*, followed by a facilitated discussion between a panel and the audience. These events are open to our members and members of our co-sponsors, including Sister-to-Sister: International Network of Professional African American Women, Inc. and the Center for African-American Health, as well as to the general public. These events advance our mission and help expose the intersections between different issues of concern, such as the connections between racial health disparities and environmental justice⁴ and the links between Black maternal health and other facets of healthcare.
10. An example of the Rocky Mountain NAACP's past health-related programming is our COVID-19 programming, where we held vaccine clinics that reached out to marginalized communities such as Black individuals and other individuals of color, as well as LGBTQ individuals.

⁴ For example, climate change has contributed to rising temperatures and other adverse climate-related events, increasing air pollution, which is associated with an increased risk of dying from cancer and increasing the rates of heat related illnesses. Am. Ass'n for Cancer Rsch., *Air Pollution May be Associated with Many Kinds of Cancer*, <https://www.aacr.org/patients-caregivers/progress-against-cancer/air-pollution-associated-cancer/> (last visited May, 2023). These adverse health outcomes have a disproportionate negative impact on people of color: from 2005 to 2015, the rates of emergency room visits for heat-related illnesses increased by 67% for Black individuals and 63% for Hispanic individuals, compared to 27% for white individuals. KFF, *Extreme Heat and Racial Health Equity* (Sept. 8, 2021), <https://www.kff.org/policy-watch/extreme-heat-racial-health-equity/>.

11. An example of future health-related programming that we are currently planning is our programming addressing the Fentanyl crisis.⁵ The Fentanyl crisis is adversely affecting the tri-state area. For example, from 2016 to 2020 the number of Fentanyl-related overdose deaths is estimated to have increased by 167% in Montana,⁶ and we have seen an increase in drug overdose related deaths. Our goal is to help our members, as well as other community members in the tri-state area, become more knowledgeable about the prevalence and danger of Fentanyl abuse, as well as solutions to address the Fentanyl crisis. The Rocky Mountain NAACP is seeking to partner with organizations that will train healthcare providers to conduct medication-assisted treatments. We plan to encourage people in our network, such as medical providers of color and other culturally competent providers, to receive training on medication-assisted treatments for Fentanyl abuse. We also plan to partner with state health departments, associations of medical providers, and nonprofit organizations that work with diverse populations to increase the reach of our community education and training.
12. The anti-racism rule incentivizes healthcare providers to create and implement anti-racism plans, which will likely reduce racial health disparities because providers who choose to implement anti-racism plans will become more culturally competent and improve their practice as a whole.

⁵ Fentanyl is a synthetic opioid analgesic that is sometimes sold via illicit drug markets and mixed with other drugs for its euphoric effects; Fentanyl related overdoses can oftentimes be reversed with Naloxone. MTN News, *28 Fentanyl Overdoses, 8 Deaths Reported in Montana Over 10 Day Period*, 8KPAX, <https://www.kpax.com/news/montana-news/28-fentanyl-overdoses-8-deaths-reported-in-montana-over-10-day-period> (last updated Jan. 25, 2023).

⁶ Mont. Dep't of Just. Div. of Crim. Inv., *Montana Fentanyl Trends 2021* 3 (2021), https://leg.mt.gov/content/publications/fiscal/2023-Interim/IBC-D/MT_Fentanyl_Trends_2021.pdf.

13. If this rule is rescinded, then Medicare providers will have less incentive to implement anti-racism plans, which would be counter-productive to our work to reduce racial health disparities.
14. Plaintiffs' challenge to the anti-racism rule is based on the premise that health equity and anti-racism approaches to healthcare are "bad medicine" and "encourage[] doctors to elevate faddish theories about race above patient care." ECF No. 28 at 3. Our health chair, an MD and public health expert, disagrees strongly with this characterization. She has stated that public health literature and evidence supports the importance of health equity measures for improving racial health disparities and improving health outcomes for all. Moreover, the idea that anti-racism measures are "bad medicine" is antithetical to our mission as an organization and our history.
15. Second, the Rocky Mountain NAACP has an interest in defending the anti-racism rule because our members will likely benefit from the anti-racism rule's intended effects. Our members raise complaints to the Rocky Mountain NAACP leadership through our legal redress form, phone calls directly to Executive Committee members, and referrals from other Chapter presidents. Some members have reported that they have been mistreated in the healthcare system.
16. We have seen firsthand how problematic stereotypes based on race are still very prevalent in the tri-state area. Some members have told me that they have been treated negatively based on stereotypes, including in the healthcare setting. For example, members told me about a NAACP member, who was Black, who died at home after he was denied care at the hospital emergency room at least three consecutive times because medical staff repeatedly told him that he did not look sick enough. I have also heard accounts from other

members who were turned away from the hospital during the COVID-19 pandemic because they were told they did not look sick enough.

17. Rocky Mountain NAACP members have also told me that they have faced problems with receiving care during pregnancy. At least two members had complications during pregnancy and were in imminent risk of harm—their families had to advocate in the emergency room for them to receive care to treat them for their pregnancy complications. Some members have told me that they felt like the medical providers were treating them differently based on racial stereotypes, assuming that they did not need help in recovery from childbirth and in developing lactation plans, and not advising them adequately. Some Rocky Mountain NAACP members have reported, and I have personally perceived, a variety of other negative racial stereotypes in healthcare settings, such as the myth that Black people do not feel as much pain, leading to less thorough pain management by healthcare professionals. These racial stereotypes are not limited to hospitals and are pervasive within healthcare settings, including clinics that treat Medicare patients.

18. Furthermore, our Health Chair, Dr. Davis, has worked to document the experiences of Black women in the healthcare setting after she saw gaps in how healthcare providers were collecting medical data from Black women patients. This led her to engage with several focus groups consisting of Black women who had been patients or were current patients and compiled accounts of their experiences. She said that many of the patients reported mistreatment by healthcare professionals. For example, some of the Black women in the focus groups reported that they had been seen by medical students or assistants, while observing that white women in the same facility were seen by doctors. In another example, a Black woman who was at a high risk for pregnancy complications went to the emergency

room but was told to return home while she was in labor, where she then was forced to give birth without medical assistance. After she experienced complications during childbirth and post-partum bleeding, she returned to the hospital, but still had to wait hours to be seen by a physician.

19. These examples are just some of the many stories we hear from our members and other people of color in the tri-state area about substandard healthcare they receive. This rule is an important step to improving the quality of health care our members receive. Many of our members will likely receive better care and have improved health outcomes if more providers have taken steps to identify and address discrimination and health disparities in their practices.
20. Our health chair has years of experience providing trainings to health care providers about implicit bias and anti-racism practices. She has found that after the training, healthcare providers have reported a better understanding of how to provide culturally responsive care and are able to implement lessons learned to provide better care to their patients, especially their patients from marginalized communities.
21. Additionally, our members benefit as a whole from an improved healthcare system. Anti-racism plans can include efforts beyond facilitating anti-racism training for medical staff. For example, collecting more reliable and more nuanced demographic health data can also improve health outcomes for people of color. Our health chair has engaged with Black community members who would have benefited from better data collection; our members and broader community of color will likely benefit from these and other anti-racism measures that Medicare providers implement to reduce racial health disparities.

22. Third, the Rocky Mountain NAACP has an interest in defending this anti-racism rule because we believe that government has a role in improving health outcomes and increasing health equity in the healthcare system. Our members and other Black people, Indigenous people, and People of Color (BIPOC) in the tri-state area have benefited from government intervention previously, such as with the Affordable Care Act, which helped many people across racial and ethnic groups gain more health coverage. However, the Affordable Care Act, while a step forward, does not fully address the racial health disparities in the nation and the tri-state area, especially given the exacerbation of health disparities due to the COVID-19 pandemic.

23. The anti-racism rule is an example of an important step that the government can take to address racial health disparities and encourage medical providers to continue to improve their healthcare practices.

24. Overall, the Rocky Mountain NAACP believes that the anti-racism rule should not be rescinded. Otherwise, we will likely be taking a step back in advancing health equity for Rocky Mountain NAACP members. This rule is important because we still see racial disparities in life expectancy and throughout the lives of patients of color. We are committed to antiracism efforts and believe this rule will reduce the terrible costs and negative outcomes experienced by some of our members and many people of color in the tri-state area.

I solemnly swear and affirm under the penalties of perjury that the foregoing is true and correct based on my personal knowledge.

/s/ Portia Prescott
Declarant's Signature

5/11/2023
Date

Portia Prescott
Declarant's Printed Name

EXHIBIT 7

**IN THE UNITED STATES DISTRICT COURT
FOR THE SOUTHERN DISTRICT OF MISSISSIPPI
JACKSON DIVISION**

STATE OF MISSISSIPPI;
STATE OF ALABAMA;
STATE OF ARKANSAS; COMMONWEALTH OF
KENTUCKY; STATE OF
LOUISIANA; STATE OF MISSOURI;
and STATE OF MONTANA,

Plaintiffs,

v.

XAVIER BECERRA, in his official
capacity as Secretary of Health and
Human Services; THE UNITED
STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES;
CHIQUITA BROOKS-LASURE, in her
official capacity as Administrator of the
Centers for Medicare and Medicaid
Services; THE CENTERS FOR
MEDICARE AND MEDICAID
SERVICES; THE UNITED STATES
OF AMERICA,

Defendants.

No. 1:22-cv-113-HSO-RPM

DECLARATION OF MARCUS RAY

I, Marcus Ray, declare as follows:

1. The facts set forth in this declaration are based on my personal knowledge, and if called as a witness, I could and would competently testify to the following matters under oath.
2. I am the President of the Kentucky State Conference of the National Association for the Advancement of Colored People ("Kentucky NAACP"), a proposed intervenor in the above-captioned matter. The Kentucky NAACP is a nonpartisan, nonprofit organization that is an affiliate of the NAACP.

3. I am authorized to provide this declaration on behalf of the Kentucky NAACP. I have held the position of president since being elected to the position in 2019. In performing my duties as president, I interact with Kentucky NAACP members, and regularly work with the NAACP units (branches, chapters, and committees) that are responsible for carrying out the mission of the organization. Before my presidency, I was a NAACP member, and have been a NAACP member for many decades.
4. The NAACP is the nation's oldest and largest civil rights organization, which was founded in 1909. We share the mission of the NAACP, which is to "achieve equity, political rights, and social inclusion by advancing policies and practices that expand human and civil rights, eliminate discrimination, and accelerate the well-being, education, and economic security of Black people and all persons of color."¹
5. We currently have thousands of members throughout the state, with more than 30 active units across Kentucky. The Kentucky NAACP's membership consists largely of African Americans, and it aims to support all people of color and members of underrepresented and vulnerable populations, regardless of membership in the Kentucky NAACP.
6. Currently, we estimate that over 50% of our members are eligible for Medicare and most of them are Medicare beneficiaries.
7. We focus on implementing the mission of NAACP at the state and local level in Kentucky. We work on a variety of issues in furtherance of our mission, such as education, criminal justice reform, and health justice. The Kentucky NAACP has a Health Committee, which is led by our Health Chair.

¹ NAACP, *Our Mission*, <https://naacp.org/about/mission-vision> (last visited May 10, 2023).

8. Our work on health matters is motivated and informed by the experiences of many of our members and other people of color in Kentucky who have had health justice issues, including lack of access to health care, racial stereotyping, and encounters with racism. Two of Kentucky NAACP's areas of focus are issues related to improving access to healthcare and emphasizing the importance of preventative care. Additionally, I serve on several healthcare-focused committees on behalf of Kentucky NAACP.
9. If Plaintiffs succeed in striking down the Center for Medicare & Medicaid Services ("CMS") 2021 final rule, the rule that adds an improvement activity entitled "create and implement an anti-racism plan" in the health equity subcategory ("anti-racism rule"), it will very likely cause negative effects on the Kentucky NAACP and our members.
10. First, the Kentucky NAACP has an interest in furthering quality health care for its members, as well as for Kentuckians of color generally. Quality preventive healthcare is especially valuable in facilitating better health outcomes and longevity. However, many of Kentucky NAACP's members lack access to quality preventative care. Members often explain that they cannot afford to access preventative care and do not go to the hospital until it is too late. Some of our members do not even go to the hospital at all because they cannot afford to pay the medical bills and do not want to burden their families with the financial stress. Thus, a large component of our health-related work involves annual health fairs organized by local Kentucky NAACP chapters. At our health fairs, medical professionals conduct check-ups and hospitals send out mobile laboratories for health testing. The health fairs are well attended by Kentucky NAACP members, as well as members of the general public.

11. The Kentucky NAACP recognizes that quality preventative care includes mental health.

So, the Kentucky NAACP recently partnered with Pathways, a behavioral healthcare provider, to support a mobile health clinic in our community. The mobile clinic started service around 10 counties out of Boyd county, a rural area of Kentucky that our members and Pathways determined was an underserved area. The mobile health clinic focuses on providing mental health services and contains an educational component to facilitate overcoming the stigma of seeking help for mental health.

12. The anti-racism rule would benefit many of our members, who are Medicare recipients, by encouraging doctors and health care providers to identify racial disparities, create a plan to prevent and address racism, and ensure services, including quality preventative care, are accessible and understandable for those seeking care.

13. Second, the Kentucky NAACP has an interest in addressing medical distrust in our community. Members have told me that they avoid medical treatment because of several reasons, including wariness of the medical system due to past negative experiences with the medical system, lack of knowledge over whether they are eligible for Medicare or Medicaid, difficulties with insurance coverage, or concerns over being able to pay the medical bills. I have heard from some Kentucky NAACP members that they do not seek medical care until they are forced to by their families because of debilitating pain. If our members understand that there is a commitment among at least some health care providers to understand and address issues of racial discrimination in health care and health disparities, it will likely build their confidence in the medical system. Providing an incentive to medical providers to create and implement anti-racism plans is a valuable step to build trust in the medical system.

14. On the other hand, an order from this Court condemning health equity measures like the anti-racism rule will likely exacerbate distrust and skepticism of medical providers throughout the state amongst Kentucky NAACP members and other Kentuckians of color. We think it is very important to work to change the view of our members and community of the medical system, so the generation after us understands how important and life-changing quality medical care can be. A successful challenge to the anti-racism rule by the Plaintiffs will likely create another barrier to achieving that goal.
15. Third, the Kentucky NAACP has an interest in preserving medical providers' current anti-racism efforts. Rescission of the anti-racism rule on the grounds that anti-racism is "bad medicine" will likely delegitimize and diminish anti-racism measures in healthcare. This could cause some healthcare providers to abandon anti-racism plans and other measures aimed at overcoming health disparities in order to avoid potential litigation. If healthcare providers abandon anti-racism efforts, the Kentucky NAACP may have to spend more resources on our health programming and education efforts.
16. Fourth, the Kentucky NAACP has a strong interest in reducing barriers to healthcare and advancing better access to healthcare. For example, the Kentucky NAACP believes it is important to provide insurance plans with more coverage and healthcare options to under-resourced communities, increase quality healthcare, and work to fix pollution and environmental quality problems that cause illness in our communities. One of the reasons why this is a priority for the Kentucky NAACP is because Kentuckians of color are disproportionately more likely to lack health insurance. These problems affect many Kentucky NAACP members. The adoption of anti-racism plans by health systems would

benefit many Kentucky NAACP members because anti-racism plans are designed to reduce barriers and increase access to healthcare.

17. The anti-racism rule supports the Kentucky NAACP's mission, programming efforts, and individual members. Rescission of the rule threatens harm to all three by taking Kentucky NAACP a step back in advancing health equity for its members, likely worsening some Kentucky NAACP members' distrust of the medical system, and discouraging anti-racism efforts.

I solemnly swear and affirm under the penalties of perjury that the foregoing is true and correct based on my personal knowledge.

/s/Marcus Ray
Declarant's Signature

5/11/2023
Date

Marcus Ray
Declarant's Printed Name

EXHIBIT 8

**IN THE UNITED STATES DISTRICT COURT
FOR THE SOUTHERN DISTRICT OF MISSISSIPPI
JACKSON DIVISION**

STATE OF MISSISSIPPI;
STATE OF ALABAMA;
STATE OF ARKANSAS; COMMONWEALTH OF
KENTUCKY; STATE OF
LOUISIANA; STATE OF MISSOURI;
and STATE OF MONTANA,

Plaintiffs,

v.

XAVIER BECERRA, in his official
capacity as Secretary of Health and
Human Services; THE UNITED
STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES;
CHIQUITA BROOKS-LASURE, in her
official capacity as Administrator of the
Centers for Medicare and Medicaid
Services; THE CENTERS FOR
MEDICARE AND MEDICAID
SERVICES; THE UNITED STATES
OF AMERICA,

Defendants.

No. 1:22-cv-113-HSO-RPM

DECLARATION OF MICHAEL MCCLANAHAN

I, Michael McClanahan, declare as follows:

1. The facts set forth in this declaration are based on my personal knowledge, and if called as a witness, I could and would competently testify to the following matters under oath.
2. I am the President of the National Association for the Advancement of Colored People Louisiana State Conference (“Louisiana NAACP”), a proposed intervenor in the above-captioned matter. The Louisiana NAACP is a nonpartisan, nonprofit organization that is an affiliate of the NAACP.

3. I am authorized to provide this declaration on behalf of the Louisiana NAACP. I have held the position of President for Louisiana NAACP for the past six years. In performing my duties as the President of Louisiana NAACP, I often interact with Louisiana NAACP members, and I regularly work with the Louisiana NAACP units (branches, chapters, and committees) and other NAACP units responsible for carrying out the mission of the organization. We hold quarterly meetings for state conference members, and where committee chairs report on their committee activities. Additionally, I have a standing meeting every week for members from across the state to bring any concerns to me on an ad hoc basis.
4. Before my term as president of the Louisiana NAACP, I served as the president of the Baton Rouge branch and also as an active member. In total, I have been an active member of the NAACP for more than a decade.
5. The NAACP is the nation's oldest and largest civil rights organization, which was founded in 1909. We share the mission of the NAACP, which is to "achieve equity, political rights, and social inclusion by advancing policies and practices that expand human and civil rights, eliminate discrimination, and accelerate the well-being, education, and economic security of Black people and all persons of color."¹ Although Louisiana NAACP's membership consists largely of Black people, we aim to support all people of color and all members of underrepresented and vulnerable populations.
6. The Louisiana NAACP has more than 40 active units and several thousand members across the state of Louisiana. Thousands of Louisiana NAACP's members are eligible for Medicare, and a significant number are Medicare beneficiaries.

¹ NAACP, *Our Mission*, <https://naacp.org/about/mission-vision> (last visited May 10, 2023).

7. The Louisiana NAACP's efforts to implement the mission of NAACP have led us to conduct and support efforts on a wide range of social issues. This includes our work on health issues, which is spearheaded by our Health Committee. The Louisiana NAACP's Health Committee is led by our Health Chair, Mrs. Alma Stewart Allen, who is a registered nurse and public health policy advocate.
8. We often collaborate with other organizations in our health programming. The money we receive from our membership dues is also an important part of how we fund our programming and activities, including on health matters.
9. The Louisiana NAACP strives to advocate for our members on issues that matter to them. Louisiana NAACP members, and others throughout Louisiana, raise questions and concerns through our legal redress line, during monthly meetings, and at office hours. Over the years, the Louisiana NAACP has received a broad range of complaints, including health-related complaints. The Louisiana NAACP has responded to concerns in different ways, such as helping individuals write a statement or fill out a complaint form, conducting informal investigations into the problem, sending letters to the medical board, and engaging in legislative advocacy.
10. The Louisiana NAACP has strong interests in the stated aims of the Center for Medicare & Medicaid Services ("CMS") 2021 final rule, the rule that adds an improvement activity entitled "create and implement an anti-racism plan" in the health equity subcategory ("anti-racism rule"). Many of our members, as Medicare recipients, are the direct beneficiaries of this rule. The anti-racism rule incentivizes doctors and health care providers to identify racial health disparities, create a plan to prevent and address racism, and ensure services are accessible and understandable for those seeking care.

11. First, the Louisiana NAACP has an interest in defending the anti-racism rule because the rule helps to advance our mission to eliminate racial health disparities. I served on the Louisiana COVID-19 Health Equity Task Force, on behalf of the Louisiana NAACP. This Task Force was convened by the governor and was designed to examine how health inequities are affecting communities most impacted by COVID-19. As part of this Task Force, we prepared a report on health equity in 2020, which identified grave disparities in health care across Louisiana, especially for Black communities and other communities of color.² For example, in the state of Louisiana, 33% of the population is Black. But in 2020, they accounted for a disproportionate share of positive cases, hospital admissions, and deaths from COVID-19.³

12. The report also found that inequities in Louisiana's health care system disproportionately harm Black communities in Louisiana. For example, racial segregation in some Louisiana's cities place predominantly Black communities in areas with "[s]ubstandard housing, abandoned buildings, [and] vacant lots," where they suffer from over-exposure to environmental harms.⁴ "[T]he location of highways, polluting industries, and the development of flood-prone property" have a similar effect, further contributing to Black communities' "greater susceptibility to illness and disease."⁵ This stress on Black communities is compounded by the lack of access to healthy food, quality affordable

² La. COVID-19 Health Equity Task Force, *Subcommittee Reports*, https://www.sus.edu/assets/sus/LAHealthEquityTaskForce/June-COVID-Task-Force-Subcommittee-Reports.pdf?fbclid=IwAR00GlvB8HrmW_Lo1YQoyFa0SfV9o-B3uAINdJ9dRdfGj3LnyUQHsH0jbyI (last visited May 10, 2023).

³ *Id.* at 11 (Excluding individuals whose race was recorded as unknown, 60% of positive cases, 63% of hospital emissions, and 54% of deaths occurred among Black individuals in 2020).

⁴ *Id.* at 62.

⁵ *Id.*

housing, and green space.⁶ These factors make it all the more important that health care providers consider ways to improve care.

13. The report also explained that racial inequities in Louisiana lead to “inter-generationally transferred black poverty and disadvantage” and have “a direct link to public health problems, as is evident through the COVID-19” pandemic.⁷

14. The Louisiana NAACP believes that one of the best ways to improve health outcomes and work to fix these racial health disparities is by supporting measures to identify, prevent, and correct disparities and discriminatory practices in healthcare. This includes incentives for medical providers to improve the care they provide, such as their care for communities of color, who are historically disenfranchised and are more likely to experience the effects of medical racism.

15. Second, the Louisiana NAACP has an interest in preserving the anti-racism rule because the rule seeks to increase access to affordable, quality healthcare in Louisiana. My experiences as president of the Louisiana NAACP and on the Louisiana COVID-19 health equity Task Force contribute to my knowledge of the many shortcomings in Louisiana’s provision of health care, which have led to persistent racial health disparities. By creating financial incentives for Medicare providers to provide improved and more consistent care, regardless of a patient’s race, the anti-racism rule may decrease these, and other, racial health disparities.

16. Third, the Louisiana NAACP has an interest in defending the anti-racism rule because the rule is designed to increase cultural competency and racial sensitivity among medical providers. Our members have experienced implicit bias and discrimination in the

⁶ *Id.*

⁷ *Id.*

healthcare system. They have shared that they feel they receive better care from Black doctors or white doctors who are culturally sensitive. Some of our members have experienced and warned others about medical providers who use racial epithets to insult Black people and treat marginalized people of color differently. They have expressed concerns about going to a medical provider who is not culturally sensitive or who may harbor negative stereotypes, such as the stereotype that Black patients do not feel as much pain as white patients, that could cause the provider to provide a lower level of care.

17. Medicare providers who choose to implement the anti-racism rule would be indicating to prospective Black patients who are concerned about physicians' cultural sensitivity that they are aware of these concerns and working to improve health disparities. Conversely, rescinding the anti-racism rule on the basis that anti-racist activities are somehow racially discriminatory, or do not improve healthcare or health outcomes, will likely discourage medical providers from taking measures to identify and resolve racial health disparities.

18. Reducing barriers to healthcare, including through measures to address racial discrimination in healthcare such as anti-racism rules, is a worthy endeavor that the Louisiana NAACP and our members believe in. This anti-racism rule is needed and should not be rescinded. If rescinded, it will be a step backwards in advancing health equity for Louisiana NAACP members and negatively impact on the NAACP's mission to ensure that our members, particularly those eligible for Medicare, receive better health care.

I solemnly swear and affirm under the penalties of perjury that the foregoing is true and correct based on my personal knowledge.

/s/ Michael McClanahan
Declarant's Signature

5/11/2023
Date

Michael McClanahan
Declarant's Printed Name

EXHIBIT 9

**IN THE UNITED STATES DISTRICT COURT
FOR THE SOUTHERN DISTRICT OF MISSISSIPPI
JACKSON DIVISION**

STATE OF MISSISSIPPI;
STATE OF ALABAMA;
STATE OF ARKANSAS; COMMONWEALTH OF
KENTUCKY; STATE OF
LOUISIANA; STATE OF MISSOURI;
and STATE OF MONTANA,

Plaintiffs,

v.

XAVIER BECERRA, in his official
capacity as Secretary of Health and
Human Services; THE UNITED
STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES;
CHIQUITA BROOKS-LASURE, in her
official capacity as Administrator of the
Centers for Medicare and Medicaid
Services; THE CENTERS FOR
MEDICARE AND MEDICAID
SERVICES; THE UNITED STATES
OF AMERICA,

Defendants.

No. 1:22-cv-113-HSO-RPM

DECLARATION OF KARI THATCHER

I, Kari Thatcher, declare as follows:

1. The facts set forth in this declaration are based on my personal knowledge, and if called as a witness, I could and would competently testify to the following matters under oath.
2. As Co-Chair of the Greensboro Health Disparities Collaborative (the “Collaborative”), I am authorized to provide this declaration on behalf of the Collaborative, a proposed intervenor in this case. I have been the Co-Chair of the Collaborative since 2017 and a member of the Collaborative since 2015.

3. I also serve as the Board Chair of The Partnership Project, Inc.—an organization which helped create and is affiliated with the Collaborative. The Partnership Project began in 1993 to promote community building through training and the formation of relationships between fragile communities and outside resources. It formed the Collaborative in 2003 to address issues of racial and ethnic disparities in health care in Greensboro, North Carolina and across the United States. In the same year, The Partnership Project reorganized as a 501(c)(3) non-profit to better support the work of the Collaborative.
4. I received my master's degree in Public Health from the University of North Carolina in 2015. I received a bachelor's degree from Chapman University in 2001.
5. I am currently a free-lance consultant on issues relating to health equity and public health. I spend most of my time working with the Collaborative and the Partnership Project. I occasionally receive stipends for the work I do with the Collaborative. The Partnership Project pays me on a Form 1099 for organizing a racial equity presentation known as A Groundwater Approach to Understanding Racial Inequity.

Background on the Collaborative

6. The Collaborative has approximately 50 members, which include health care providers, health care and public health scholars, representatives of community organizations, and other representatives from the Greensboro community. Our membership also includes people who are eligible for Medicare and receive health coverage through Medicare, as well as physicians who provide medical services to Medicare recipients. Absent a financial-hardship exception, each member of the Collaborative pays \$35 annually in dues.
7. The Collaborative has six officers: two co-chairs, a vice chair, a secretary, an assistant secretary, and a treasurer. All of the Collaborative's officer positions are volunteer

positions. As the Co-Chair of the Collaborative, my duties include providing strategic direction for the organization, cultivating strong relationships with partner organizations, and fostering leadership and project-management skills among the Collaborative's members.

8. The Collaborative also has several volunteer committee chairs. Our standing committees center around outreach, social media, membership, and publications and dissemination. Periodically, the Collaborative convenes ad hoc committees for special projects.
9. The Collaborative grew out of the Partnership Project's recognition that unequal treatment based on race and ethnicity exists in the healthcare system across the United States and that inequality in healthcare literally has life-and-death consequences. As just one example, a 2003 report by the Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care and commissioned by Congress documented substantial evidence that (1) the quality of health care in America varies across racial and ethnic groups, even when controlling for other factors such as insurance status and income, and (2) disparities in treatment, including provider attitudes, and policy choices contribute to health inequalities. Specifically, the report found that people of color received lower quality healthcare than white people and that these racial disparities in health care are associated with higher death rates for Black Americans across a range of health conditions.¹ The study showed that Black women died of breast cancer at much higher rates than white women, even though white women were diagnosed with breast cancer at much higher rates

¹ Brian D. Smedley, Adrienne Y. Stith, & Alan R. Nelson, eds., *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, Inst. of Medicine on Understanding & Eliminating Racial & Ethnic Disparities in Health Care 1-2 (2003), <https://pubmed.ncbi.nlm.nih.gov/25032386/>.

than Black women at the time.² The study also found that the discriminatory treatment of Black women is a contributing factor in these disparate outcomes.

The Collaborative's Involvement in Health Equity Research

10. The Collaborative and its members conduct and support research on racial and ethnic health care disparities.³ The Collaborative has a particular interest in researching disparities in cancer treatment and in outcomes from that treatment because Black patients have the highest death rates and shortest survival of any racial group in the United States for most types of cancer.⁴ The American Cancer Society has reported that Black women are 40 percent more likely to die of breast cancer than white women.⁵ Most people living with cancer are older adults; many are Medicare recipients.

11. In 2006, the Collaborative obtained a two-year grant from the National Institutes of Health (NIH) for a Cancer Care and Racial Equity Study (CCARES) to investigate the complexities of institutional racism and how it relates to disparities experienced by Black and white breast cancer survivors within a local community. The Collaborative worked with the Cone Health Cancer Center on this study. Cone Health is a private, not-for-profit healthcare delivery system based in Greensboro that operates hospitals and various care

² *Id.* 54-55.

³ *E.g.*, Chandra Ford, et al., *Racism: Science & Tools for the Public Health Professional*, Am. Pub. Health Ass'n (2019); 01/01/2019; Kristin Z. Black, et al., *'It's Like You Don't Have a Roadmap Really': Using an Antiracism Framework to Analyze Patients' Encounters In the Cancer System*, Ethn Health (2018) (attached as Exhibit A); Katrina R. Ellis, et al., *Racial Differences in the Influence of Healthcare System Factors on Informal Support for Cancer Care Among Black and White Breast and Lung Cancer Survivors*, Fam Cmty. Health (2020).

⁴ *See* Am. Cancer Soc'y, *Cancer Facts and Figures for African Americans 2019-2021* 1 (2021), <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-facts-and-figures-for-african-americans/cancer-facts-and-figures-for-african-americans-2019-2021.pdf>.

⁵ *Id.* at 14.

centers. It employs more than 10,000 physicians and other medical providers caring for tens of thousands of residents of North Carolina, many of whom are Medicare recipients.

12. CCARES collected qualitative data from Black and white breast cancer survivors within the Greensboro community about challenges that those patients experienced during their cancer treatment. CCARES collected this data using the Critical Incident Technique—a system of semi-structured interviews that are designed to aid recall of past critical events or incidents.

13. The study revealed that Black survivors of breast cancer were not adequately supported by the existing peer-support organizations.⁶

14. After CCARES revealed disparate cancer care treatment experiences, the Collaborative sought to obtain a more robust understanding of the “pressure points” in the cancer care journey where these patterns of racial disparities in treatments arose, and real-time data to make it possible to intervene as they were happening, therefore the Collaborative began developing interventions with these goals in mind.⁷ We applied for and received in 2012 a second five-year grant from NIH’s National Cancer Institute to conduct the Accountability for Cancer Care through Undoing Racism and Equity (ACCURE) study. The ACCURE study was a collaborative effort with the University of North Carolina at Chapel Hill, The Partnership Project, Inc., Cone Health, and the University of Pittsburgh Medical Center. The Collaborative developed and implemented the study, which collected information on 89,454 Black and white patients with stage 1 or stage 2 breast cancer or lung cancer. The study involved breast cancer and lung cancer patients because breast cancer kills more

⁶ Yonas, Michael et al., *Cancer Care and Racial Equity Study (CCARES): An Innovative Community and Academic Model for Investigating Disparities in Systems of Breast Cancer Care* (2008).

⁷ Ex. A at 5-8.

Black women than any other cancer and lung cancer kills more Black men than any other cancer. Many of the patients in the study were Medicare recipients. The goal of the study was to test whether a multipronged intervention that changed the systems of care could improve the experiences of Black patients undergoing treatment.

15. The ACCURE study incorporated four major interventions at Cone Health and Hillman Cancer Center. *First*, each cancer center’s “nurse navigator” received a two-day racial equity training (the same one that is required to join the Collaborative). Nurse navigators also received training from Dr. Sam Cykert—a member of the Collaborative—on how to identify and address challenges that limit care for Black cancer patients, such as medical mistrust, low self-efficacy, and communication barriers. In addition to these trainings, the nurse navigator received ongoing education about implicit bias, unintentional attitudes, and institutional racism and how these concepts manifest in policies, practices, and cultural norms. *Second*, the study developed an electronic alert system based on patient electronic health records for each cancer center to use. The system alerted the nurse navigator when a patient participating in the study missed an appointment or did not reach an expected milestone in care (i.e., scheduling diagnostic testing, undergoing surgery, beginning chemotherapy). Around 300 patients who were diagnosed with cancer from April 1, 2013 to March 31, 2015 agreed to include their information in the electronic system and work with a nurse navigator. *Third*, each cancer center selected a “physician champion.” The physician champion received anti-racism training, garnered buy-in from other physicians for the philosophy of anti-racism in medicine, and served as a liaison between the nurse navigator and other physicians during the study. *Fourth*, the staff of each cancer center were offered continuing education sessions on implicit bias, unintentional attitudes, and

institutional racism, known as Health Equity and Education Training (HEET) sessions. Periodically, these continuing education sessions also included reporting the hospitals' own data on patient outcomes disaggregated by race back to them for review.

16. The ACCURE study findings (attached as Exhibit B) showed that a racial equity plan had a substantial impact on successful treatment. For example, before the program, 79.8% of Black patients and 87.3% percent of white patients completed treatment. But for those who received the benefit of ACCURE's interventions, the treatment completion rates increased for both racial groups: 88.4% of Black patients and 89.5% of white patients completed treatment. In short, race-related differences were resolved while both Black and white patients had improved outcomes. And after considering patients' income, health insurance and diagnosis of other illnesses, the Black-white difference was reduced by 8%. Reducing disparities in treatment completion rates is critical, because studies show that differences in treatment completion play a major role in explaining racially disparate mortality rates for lung cancer and breast cancer.⁸ The ACCURE study projected that the study's interventions could yield similar benefits for other common chronic illnesses, including other types of cancer.⁹

17. The ACCURE study involved anti-racism training called Health Care Equity and Training (HEET) that focused on issues of racial and ethnic health disparities. That training was provided to Cone Health and University of Pittsburgh Medical Center staff members, including the nurse navigators and oncology physicians. HEET was developed with the participation of the Collaborative's members. Members of the GHDC also served as HEET trainers.

⁸ Ex. B at 14 (collecting studies).

⁹ *Id.* at 15.

18. The results of the ACCURE study have sharpened the Collaborative's focus on recruiting more hospitals to develop and implement anti-racism interventions, and on providing consulting services for those hospitals. ACURE4Moms is one example of those efforts. ACURE4Moms is a randomized controlled trial that aims to improve maternal health outcomes, satisfaction, and communication, particularly for Black moms. The Principal Investigator of ACURE4Moms is a member of the Collaborative and a researcher at the University of North Carolina Chapel Hill. Additional members of the Collaborative support ACURE4Moms in various capacities. For example, I plan to work as an Observer for the ACURE4Moms' MHEET (Maternal Health Equity Education Trainings) and collect process evaluation data.
19. The Collaborative is striving to increase its membership base and financial resources in order to extend its reach geographically and to wider range of health conditions.

The Collaborative's Involvement in Health Equity Programming

20. In addition to CCARES and the ACCURE study, the Collaborative assists in grassroots programming to advance health equity, including racial equity workshops. Members of the Collaborative often serve as trainers in anti-racism trainings facilitated by a national organization called the Racial Equity Institute, and routinely hosted by The Partnership Project. Participation in one of these anti-racism trainings is a pre-requisite for joining the Collaborative. The Collaborative cannot fulfill its mission unless health care providers understand racial inequity and how to eliminate it. For this reason, the Collaborative believes that anti-racism training is important for *all* health care providers—even those who are not consciously racist.

21. “Phase 1 Racial Training” is a two-day, 16-hour seminar where a team of facilitators leads a small group (approximately 30 people) through a series of exercises are designed to develop the capacity of participants to better understand racism in its institutional and structural forms. Moving away from a focus on personal bigotry and bias, this workshop presents a historical, cultural, and structural analysis of racism.
22. The Partnership Project hosted ten Phase 1 trainings in 2022, typically attended by about 35-40 people. A wide range of people with varying backgrounds attend the training, including teachers, physicians, nurses and others in medicine, administrators of non-profits organizations, and members of community groups. The registration fees for these trainings supply The Partnership Project’s primary source of annual revenue. The Partnership Project sets regular, group, and student rates for these trainings, however we adhere to a “pay what you can” model and maintain a scholarship fund in memory of one of our founders, Mrs. Nettie Coad, to support access for anyone wishing to attend; the organization never turns anyone away due to an inability to pay. Phase 1 training is a prerequisite to membership in the Collaborative.
23. At least one of the Collaborative’s members is a physician in Greensboro and shared with me that his medical practice has meaningfully improved as a result of attending the Phase 1 and Phase 2 anti-racism trainings. The Greensboro physician shared that he was once skeptical of and offended by the notion that medical professionals provide disparate care based on implicit racial biases, and that most physicians that he works with share this mentality. His viewpoint began to change when an investigator came to Cone Health to begin laying the framework for the ACCURE study. The results of the ACCURE study led the Greensboro physician to become a member of the Collaborative and cemented his

assessment that affirmative anti-racism efforts are necessary to reduce racial disparities in health care and improve treatment outcomes for all patients. He told me that he realized that the existence structural racism makes systemwide anti-racism efforts especially important. Structural changes, as opposed to simply correcting individual biases, are required to overcome racism in the healthcare system as a whole precisely because disparate treatment is present even when bigotry is not. He shared with me that he believes that all medical providers would benefit from anti-racism training, but that many providers are unlikely to overcome their inherent skepticism of anti-racism programming without appropriate incentives like the Merit-Based Improvement Payment System.

24. Another member of the Collaborative, Dr. Sidney Callahan, provides medical care to individuals who are eligible for and receive Medicare. Dr. Callahan shared with me that efforts by the Department of Health and Human Services (HHS) to improve Medicare services for people of color, such as the MIPS anti-racism plan improvement activity, are especially important for older patients as that segment of the population is more likely to have experienced overt and government-sanctioned discriminatory policies including segregated housing, education and healthcare that have led to disparities in health outcomes.

The Collaborative's Interest in Anti-Racism Incentives for Health Care Providers

25. The availability of the MIPS anti-racism plan improvement activity will significantly advance the Collaborative's mission to resolve issues related to health disparities. The improvement activity gives to health care providers an incentive to assess racial and ethnic gaps in their provision of healthcare and identify ways they can intervene and resolve such

disparities. The benefits of these evaluations and interventions have been the core subject of the Collaborative's research and the aim of its trainings.

26. By contrast, the elimination of the MIPS anti-racism plan improvement activity would have a detrimental impact on our programs and ability to accomplish our mission to empower and establish structures to resolve racism. Financial incentives are necessary to overcome the time, financial, and psychological barriers to creating and implementing anti-racism plans in the medical profession. Without the anti-racism plan improvement activity, fewer health care providers are likely to work with us and develop programs to advance our mission.
27. Absent financial incentives from the MIPS anti-racism improvement activity, the Collaborative will have to divert financial resources from research and other programming and put those resources toward increasing clinician buy-in for anti-racism planning.
28. Plaintiffs' suit, if successful, will also inevitably divert resources from the Collaborative's mission. In recent years, the Collaborative's primary source of funding has been the fees that the Collaborative charges to hospitals and other organizations for health equity consulting and health equity presentations. Plaintiffs' challenge to the MIPS anti-racism improvement activity rests on the premise that the anti-racism philosophy that the Collaborative endorses and teaches to others, including medical providers, is "bad medicine" and "encourages doctors to elevate faddish theories about race above patient care." If the Court strikes down the MIPS anti-racism improvement activity on this basis, then health care providers, philanthropists, and health insurance companies will likely be deterred from seeking out and paying for the type of health equity education that the Collaborative provides. Without this funding, the Collaborative will have to increase its

membership dues, increase the cost of its anti-racism trainings, or substantially divert its focus on research and education to fundraising.

29. The Collaborative has interests in defending the MIPS anti-racism improvement activity that diverge from HHS, the Centers for Medicare and Medicaid Services, and the individual defendants (“Agency Defendants”) in this case. The Agency Defendants have a general interest in maintaining the breadth of the Department’s rulemaking authority and defending the scope of the immunity conferred by 42 U.S.C. § 1395w-4(q)(13)(B). By contrast, the Collaborative has a specific interest in refuting the premise of Plaintiffs’ theory: that encouraging Medicare Part B providers to create and implement an anti-racism plan is detrimental to the health of white patients. Left unrefuted, Plaintiffs’ theory will undermine the research that the Collaborative conducts and supports, will increase antagonism toward anti-racism in health care, and will dissuade health care providers from participating in the anti-racism trainings that the Collaborative’s members help facilitate – and importantly, will result in preventable human suffering and death.

I solemnly swear and affirm under the penalties of perjury that the foregoing is true and correct based on my personal knowledge.

/s/ Kari Thatcher

Declarant’s Signature

5/11/2023

Date

Kari Thatcher

Declarant’s Printed Name

EXHIBIT A



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'It's like you don't have a roadmap really': Using an antiracism framework to analyze patients' encounters in the cancer system

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Abstract

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Background: Cancer patients can experience healthcare system-related challenges during the course of their treatment. Yet, little is known about how these challenges might affect the quality and completion of cancer treatment for all patients, and particularly for patients of color. Accountability for Cancer Care through Undoing Racism and Equity is a multi-component, community-based participatory research intervention to reduce Black-White cancer care disparities. This formative work aimed to understand patients' cancer center experiences, explore racial differences in experiences, and inform systems-level interventions.

Methods: Twenty-seven breast and lung cancer patients at two cancer centers participated in focus groups, grouped by race and cancer type. Participants were asked about what they found empowering and disempowering regarding their cancer care experiences. The community-guided analysis used a racial equity approach to identify racial differences in care experiences.

Results: For Black *and* White patients, fear, uncertainty, and incomplete knowledge were disempowering; trust in providers and a sense of control were empowering. Although participants denied differential treatment due to race, analysis revealed implicit Black-White differences in care.

Conclusions: Most of the challenges participants faced were related to lack of transparency, such that improvements in communication, particularly two-way communication could greatly improve patients' interaction with the system. Pathways for accountability can also be built into a system that allows patients to find solutions for their problems with the system itself. Participants' insights suggest the need for patient-centered, systems-level interventions to improve care experiences and reduce disparities.

Keywords

cancer health disparities; systems-level interventions; community-based participatory research; racial equity

It is well documented that cancer patients can experience healthcare system-related challenges during the course of their treatment (Institute of Medicine 1999, 2008). Poor patient-physician communication and lack of emotional and instrumental support have been commonly reported by breast cancer patients (Carroll et al. 2010; Kranick et al. 2010; Roberts et al. 1994). Lung cancer patients have reported high levels of unmet physical, psychological, and informational supportive care needs (Li and Girgis 2006; Sanders et al. 2010). In addition, navigating cancer care across multiple providers and clinical settings have been noted as burdensome for cancer patients (Freeman and Rodriguez 2011).

Systems-level challenges warrant greater attention given racial/ethnic disparities in cancer care. Compared with White cancer patients, Black cancer patients are less likely to be diagnosed at early stages (Bradley, Given, and Roberts 2001; Howlader et al. 2013; DeSantis, Naishadham, and Jemal 2013), undergo guideline-concordant treatments (Samuel et al. 2014; Lathan, Neville, and Earle 2008; Keating et al. 2009), report trust and shared decision-making with providers (Siminoff, Graham, and Gordon 2006; Gordon et al. 2006), and receive palliative and supportive care (Cleeland et al. 1994; Payne, Medina, and Hampton 2003; Smith, Earle, and McCarthy 2009). Despite decades of documenting racial disparities in cancer survival, Black breast cancer patients continue to initiate treatment later

(Gorin et al. 2006) and be treated less completely than their White counterparts (Voti et al. 2006; Hershman et al. 2005; Bickell et al. 2006; Berry et al. 2009). Moreover, Black lung cancer patients are more likely than Whites to make a decision, either independently or mutually with their physicians, to not pursue surgical resection, which is the only reliable curative treatment (McCann et al. 2005; Farjah et al. 2009; Cykert et al. 2010). Reasons for racial variations in quality and completion of cancer care are not well conceptualized or documented, and they vary by type of condition, socio-demographic variables, economic factors, and various cultural preferences, attitudes, and reservoirs of knowledge about disease etiology, prevention, and treatment (Rimer 2000; Van Ryn and Burke 2000; Tejeda et al. 2017; Haozous and Knobf 2013). Despite the clear need, interventions that address systems-level challenges to enhance equity, quality, and completion of cancer treatment are missing from cancer prevention and control research. This paper shares findings from formative work aimed to understand patients' cancer center experiences, explore racial differences in experiences, and inform systems-level interventions.

Background

Background on ACCURE Partnership and Intervention

To address this gap, our community-academic-medical partnership implemented and evaluated Accountability for Cancer Care through Undoing Racism and Equity (ACCURE), a systems-change intervention aimed at reducing race-specific gaps in treatment initiation and completion among early stage Black and White breast and lung cancer patients. Funded by the National Cancer Institute (NCI), ACCURE utilized a community-based participatory research approach (CBPR) (Schaal et al. 2016; Oh et al. 2016; Israel et al. 1998) with guidance and governance provided by the Greensboro Health Disparities Collaborative (GHDC), a 15-year old CBPR partnership of community, academic, and medical organizations. GHDC's mission is 'to establish structures and processes that respond to, and build the capacity of, communities and institutions in defining and resolving issues related to racial and ethnic disparities in health' (Schaal et al. 2016; Yonas et al. 2006; Yonas, Aronson, Coad, et al. 2013; Yonas, Aronson, Schaal, et al. 2013). GHDC is committed to using an antiracism approach informed by the Undoing Racism (UR)[®] framework (The People's Institute for Survival and Beyond 2015). All members of GHDC have completed a two-day antiracism training based on that model. The foundation of this training is to provide participants with a common understanding of antiracism language and to establish a lens for analyzing the structure of power in US institutions and systems. ACCURE, GHDC's second NCI-funded study, built on findings from prior research, the Cancer Care and Racial Equity Study (CCARES), which, using critical incident analysis, an innovative interviewing technique, with Black and White cancer survivors, identified systems-level gaps, such as lack of race-specific data related to treatment completion (Yonas, Aronson, Schaal, et al. 2013).

ACCURE was developed by the GHDC as an intervention to respond to the systems-level gaps identified in the literature and our CCARES research findings. ACCURE included four innovations with the goal of reducing gaps in treatment initiation and completion between Black and White cancer patients and tested the intervention in two cancer centers, one a

regional cancer center in the south and the second a large academic cancer center in the northeast. Innovations included, first, a nurse navigator, specially trained in utilizing a racial equity lens to work with Black and White breast and lung cancer patients to identify and address practical, emotional, and communication issues. The goal was for the navigator to serve as a two-way conduit between the patient and the cancer care system to address issues during the full continuum of care. Second, a real-time patient registry was developed to alert the navigator when patients did not reach timely treatment milestones (e.g., attending appointments, completing radiation treatments), allowing the navigator to address issues early enough to prevent compromises of quality and completion of care. The registry also aggregated provider-level and practice-level data, allowing clinicians to examine race-stratified care quality metrics (e.g., time between diagnosis and first treatment, percentage of early stage lung cancer patients referred for lobectomy) of their own patient panels as compared to practice averages and to published literature. Third, the nurse navigator collaborated with specific Physician Champions at each site for each cancer type to bring these race-specific clinical performance reports to the attention of practitioners to ensure equity in quality and completion of care. Finally, ACCURE offered quarterly Healthcare Equity Education and Training (HEET) sessions for medical and administrative staff members at each site. These interactive sessions were designed to introduce the staff to: systems-level issues of transparency and accountability, a racial equity lens, and concepts of unconscious bias and its effect on patient care.

Principles of Undoing Racism® Informing ACCURE

The concepts of antiracism are at the core of ACCURE and its focus on systems-level change to reduce gaps in cancer care and outcomes between Black and White patients. Antiracism training has grounded our partnership in the history of racism in the US and the laws, policies, and procedures which have perpetuated a system of power that advantages some (White people) and disadvantages others (primarily people of color). The legacy of this structural racism is evident in all of the systems that affect people's lives and opportunities (e.g., education, criminal justice, healthcare) and the disparate outcomes (e.g., achievement gap, mass incarceration, health disparities) that disproportionately burden people of color (Hayes-Greene and Love 2016). The antiracism framework promotes understanding and a common language, and also provides a racial equity lens and tool (the analysis of power and authority) to gain understanding of how power shapes our institutions/systems as a first step towards generating systems-level strategies to intervene.

In particular, ACCURE draws on the antiracism principles of transparency (technocratic protocols and narrow knowledge) and accountability (technical language and fragmented power) which affect how systems operate, and the roles of gatekeepers who can impede or advance access, resources, policies, and procedures which affect how individuals experience and are treated in institutions or systems. ACCURE's intervention components were designed with an antiracism lens to address specific exposures and circumstances that make cancer care vulnerable to institutional racism (James et al. 1984; Geronimus 2000), interrupt the pathways through which these occur (McEwen 1998; Wadhwa et al. 2001; Lu and Chen 2004), with the explicit goal of changing structures that obstruct transparency and accountability. The absence of transparency and accountability in a system can lead to

unequal access to information and resources, therefore exacerbating racial inequities (The People's Institute for Survival and Beyond 2015).

Practices of Undoing Racism® Informing ACCURE Focus Group Analysis

In the research described here, we drew on a critical practice within the UR® framework, an analysis of power and authority. The goal of this analysis is to examine the relationships between communities and institutions, and facilitate a critical analysis of structural racism by addressing issues of transparency and accountability, which affect equitable treatment. According to the People's Institute for Survival and Beyond (PISAB), which initiated these principles and practices, 'the world is controlled by powerful systems with historically traceable roots. Once people are shown how they benefit from or are oppressed by those systems, they can work together to change the system' (Shapiro 2002, 100). PISAB's analysis of power and authority process also brings to light the role of gatekeepers within systems who can grant access to resources and who have power over the individuals who enroll in the system.

To inform intervention development, particularly the Healthcare Equity and Education Training sessions for providers and staff at our partner cancer centers, ACCURE conducted a formative study engaging Black and White cancer survivors in an examination of the cancer care experience. The goal of this investigation, carried out through focus group discussions, was to explore patients' perspectives on treatment and identify places in the cancer care system where patients encountered critical incidents, also referred to as pressure points (Yonas, Aronson, Schaal, et al. 2013), that influenced the quality and completion of their cancer treatment.

Once the focus group data were collected, we sought to apply the principles and practices of antiracism by using the analysis of power and authority as a tool and a lens to analyze the transcripts and identify pressure points, or encounters within the care and treatment experience of Black and White breast and lung cancer patients at two different cancer centers, that affected their ability to navigate the cancer care system and complete their care plan. In doing so, we focused on the UR® principles lack of transparency (e.g., obtuse vocabulary/jargon, inconsistent information, impersonal communication modes, inflexible protocols, unclear procedures) and lack of accountability (e.g., unclear procedures for collecting and monitoring information on standards of care and for decision-making, not knowing about deviations from standards of care) from the cancer care system to the patients.

Few studies have applied CBPR principles (Israel et al. 1998) to examine patient perspectives on their cancer care experiences. Moreover, no studies to our knowledge have examined these experiences through an antiracism lens. This paper reports on the findings from the focus groups we conducted with cancer patients and analyzed with an antiracism lens. In this paper we: (1) describe our approach to applying the Undoing Racism® framework's analysis of power and authority (Schaal et al. 2016) as a tool to understand the experiences of Black and White stage 1-2 breast and lung cancer patients at two cancer centers; (2) discuss our findings on pressure points during care that influenced the quality and completion of their cancer treatment; and (3) highlight race-specific differences that are

critical to attend to if we are to improve transparency and accountability for equity in cancer care experiences.

Methods

Participant Selection and Data Collection

To elicit experiences of cancer patients during their journey through the cancer care system, we conducted eight focus groups with non-Hispanic Black and White breast and lung cancer survivors. Patients were recruited through their oncologists at the Cone Health Cancer Center (CHCC) and UPMC Hillman Cancer Center (UPMC CC). The CHCC is part of a regional hospital system and UPMC CC is a university teaching hospital. The requirements for participation were: (1) diagnosed with stage 1-2 breast (women only) or lung cancer (women and men); (2) received cancer care at CHCC or UPMC CC; and (3) completed treatment in the previous 12 months. Four race and cancer type specific focus group sessions were conducted (i.e., Black patients with breast cancer, White patients with breast cancer, Black patients with lung cancer, and White patients with lung cancer) at each cancer center for a total of eight focus groups.

The goal of the focus groups was to probe patients' experiences for pressure point encounters in which they felt encouraged (or discouraged) to continue their treatment and empowered (or disempowered) by the treatment process in order to understand systems-level protocols, procedures, and encounters that affect patients' treatment experiences, decisions, and completion rate and, ultimately, differential outcomes (Table 1). We used a journey diagram (Figure 1) to jog their memories in recalling aspects of their treatment and interactions with the cancer system and as a tool for our analysis of power and authority within the cancer care system.

Our uniquely inclusive CBPR process explicitly addressed racial equity and power sharing at each step of the project, a process described thoroughly elsewhere (Schaal et al. 2016). ACCURE's community, academic, and medical partners collaborated to develop the analysis of power and authority materials, including the journey diagram and focus group guide. Two community members were selected by GHDC as racially concordant facilitators for the focus group sessions. A person of color (Japanese-African American) facilitated sessions with Black participants at each cancer center, while a White moderator took notes. They reversed roles for the sessions with White participants. Sessions were audio-recorded and transcribed verbatim. The Institutional Review Boards at the University of North Carolina at Chapel Hill and the University of Pittsburgh approved the ACCURE study.

Focus Group Analysis using the Analysis of Power and Authority

To analyze the data in adherence to our CBPR and antiracism principles, each step involved racially diverse community, academic, and medical center partners from GHDC working together (Schaal et al. 2016). All members of the team had been through antiracism training. A Coding Coordinating Team (CCT), a subgroup of community and academic members of the GHDC that included people of color and White representatives, developed guidelines and protocols for analyzing the transcripts. To ensure that community, academic, medical,

and racially diverse perspectives were included in the analysis, volunteer coders were solicited from the GHDC membership. The CCT developed a codebook, conducted qualitative analysis training with GHDC members, and organized GHDC volunteers into diverse coding pairs who: reviewed an assigned transcript together; assigned topical codes to relevant text; and defined and assigned interpretive codes to relevant text (Schaal et al. 2016). The CCT reviewed coded transcripts, created a consolidated codebook that included topical and interpretive codes, applied these codes to all transcripts, and produced code reports of extracted text.

Informed by the antiracism framework's analysis of power and authority, the CCT reviewed these code reports to identify the pressure points encountered by cancer care patients along the cancer journey and generated a matrix for Black and White participants, respectively. This matrix provided detailed descriptions of patients' experiences on both challenging and uplifting interactions. From that matrix, the CCT literally mapped these experiences, both positive and negative, onto the journey diagram (Figure 1) as a way to visualize encounters at the systems level. Subsequently, the CCT used the patient encounter journey diagram to generate conversations first with GHDC members and ultimately with cancer center providers and staff about how these systems-level encounters did or did not exhibit transparency and accountability and what affect these experiences might have on cancer patients.

Results

A total of 27 breast and lung cancer patients participated in eight focus group sessions. Of the 27 participants, 12 were Black and 15 were White. Table 2 shows the breakdown of the participants by race, cancer type, and cancer center.

Six overarching, interrelated themes emerged across racial and cancer groups (Table 3): (1) fear was disempowering and discouraged continuation of care; (2) uncertainty and lack of information were disempowering and hindered care; (3) trust in the medical team was crucial to continuing care; (4) communication was empowering when providers shared information and were also good listeners; (5) navigating complex, impersonal healthcare systems was often confusing, overwhelming, and disempowering; and (6) in these impersonal systems, small interpersonal interactions were enormously important in helping patients feel cared for or disregarded. When patients were asked during their focus group discussions whether they felt they were treated differently due to their race, few explicitly described experiences of differential treatment. Despite these commonalities, implicit differences emerged in Black and White participants' descriptions of their cancer care experiences and pressure points they encountered along the way. We describe these commonalities and differences across four phases of care: diagnosis, course of treatment, daily grind in a complex system, and when treatment ends. These phases were where our patients' pressure point experiences clustered. Table 3 exhibits how the six overarching themes manifested within these four encounters.

The Diagnosis Encounter

The moment of delivery of the diagnosis of cancer is a stressful experience for cancer patients. Black and White participants in this study shared the ways they received this news at two different cancer centers. At one cancer center, this news was largely delivered in person, while at the other it was routinely delivered by telephone without regard for whether the patient was at home or work or had a supportive individual with them. The reactions of participants to these different modes of communicating difficult, life-changing news highlighted ways that patients experienced pressure points at the outset of the cancer journey. Both Black and White breast cancer patients expressed dismay when such critical information was delivered by telephone, especially at work. Receiving such news in locations or circumstances where they did not have a safe space to express themselves emotionally or a caring source of support at their side was overwhelming and disempowering. These impersonal modes of communicating critical information at the beginning of the cancer journey typify a system not accountable to patients' needs for establishing trust with the cancer care system; and exemplify how the system lacked transparency in its two-way communication by not considering how the mode of delivering critical information may impact the patients' experience in receiving that information. For the cancer centers, this represents a missed opportunity to begin establishing trust through transparency in communication and accountability for the important nature of this first communication.

Racial Differences—Although both Black and White patients expressed dismay at receiving their cancer diagnosis by phone, Black patients reported concerning delays in communication. For example, one Black breast cancer patient received a voice message about her biopsy results on a Friday and had to wait five days until she could speak with her provider regarding the results. Delayed information and uncertainty were exceedingly stressful for her. Another Black breast cancer patient described a delayed diagnosis because the technician administering her mammogram did not listen to her. The patient's primary care physician (PCP) found a small mass underneath the patient's right arm and scheduled a mammogram. The patient informed the technician about this mass, identified its location, and was assured that the mammography would detect a mass if present. She later discovered from her surgeon that the area of concern was not included in the field of the image, so the mammogram was negative. Subsequently, she was retested with an ultrasound-guided biopsy that ultimately confirmed the breast cancer diagnosis originally suspected by her PCP. The Black breast cancer patient described her anger about this delay in diagnosis and, therefore, treatment:

I was angry for a while because the doctor [mammography technician] that was here at [hospital]...I thought that she would've listened to me better. If...she would've listened to what I was trying to tell her about the spot here...then I probably would not have had to go through that... So, if she would've listened maybe we could've stopped it before, but she just wouldn't listen.

This patient felt strongly that her breast cancer would have been diagnosed more quickly and treated sooner if the mammography technician had listened to her and investigated her concern. Through its lack of accountability, missing the mass so that her diagnosis and

treatment were delayed, the system in effect failed this patient. The technician served as a gatekeeper whose control of the interaction (i.e., not accepting the patient's insights and communication of the issue) resulted in inadequate follow through and critical delay in diagnosis and treatment. While only two among many, these experiences demonstrate how lack of two-way transparent communication interferes with the patient-provider relationship and lack of system accountability has potentially serious consequences for patient diagnosis, treatment, and care.

The Treatment Encounter

The issue of transparency also arose in regard to building trust and facilitating two-way communication during the course of treatment. Once diagnosed, the participants found the processes before and during treatment to be challenging and stressful due to the lack of information and uncertainties of what to expect. Patients experienced difficult treatments, which caused problematic fatigue and noxious side effects. The pressure points they described most often were interactions with physicians as gatekeepers, which either successfully facilitated care, or failed to do so. Both Black and White patients reported that the information they received was sometimes inadequate and often too overwhelming to understand clearly. In addition, pain and side effects were not always satisfactorily managed or addressed. For example, a White breast cancer patient's crippling pain was dismissed for over a year before her doctors agreed to discontinue a medication that caused her suffering. A Black participant described her skin pain during radiation treatment as follows:

And so...I had start burning real, real bad and I couldn't stand to have anything on me...so I wanted to stop, but...because of him being a nice doctor...he heard me. ...'Cause this one day I, I said 'I refuse to go'...when they called me to go I said, 'I'm not going! I'm burning.' ...And so they called the doctor down and he came and he said, 'You're a feisty little thing.' He said, 'And I'm gonna listen to you and I'm giving you a week off.' ...and when I came back...I only had three more days to go...and I was ready to...deal with it even though...it was still painful, but I was ready to deal with it.

Clear, transparent communication and careful listening on the part of the provider was essential in creating a space for patients to question, disagree, and provide input. Our participants made it clear that patients want regular, open, clear communication and to know what to expect in terms of treatment and appointment schedules. Black and White patients both described challenging interactions with doctors when they did not feel they were listened to or consulted. Pivotal pressure points and causes for distress for cancer patients included: (1) waiting and uncertainty about aspects of their treatment; (2) inflexibility in scheduled care plans; (3) lack of preparation for and communication before procedures or treatments; and (4) unexpected changes for which patients were not well informed. These pressure points are all indicators of the lack of transparency within the cancer care system.

In spite of these negative experiences, our analysis of pressure points in the cancer care system revealed that patients were grateful for the amount and quality of support from their cancer care teams. Overall, patients felt included in the decision-making process regarding their treatment. Some patients established trusting relationships with physicians, nurses, and

support staff, even to the point where the cancer care team members and the patients themselves used humor to communicate and to bring joy to an otherwise difficult situation. There were several instances where physicians used much-appreciated humor to build rapport with patients and put them at ease.

Racial Differences—Whereas White patients' main issues concerned not receiving adequate post-operative care information, such as reconstructive surgery information for breast cancer patients, Black patients expressed more concern about how standard procedures or the implications of procedures were not always fully explained to them. For example, they described experiencing delays in the scheduling of surgery, as well as delays in receiving pathology or staging results after a lumpectomy. Although they tried to advocate for themselves, there was no mechanism in place to ensure the system and the procedures initiated were transparent or to hold the system accountable for timely communications.

Although patients of both races at both cancer sites expressed that their pain and side effects were not always satisfactorily managed or addressed, Black patients felt particular dissatisfaction with how their cancer treatment-related symptoms were managed. Pain and symptom control were issues for Black patients in multiple settings and from multiple causes during the course of their cancer treatment. Issues mentioned by Black patients included painful venipuncture, radiation skin problems, medication side effects, and invasive un-anesthetized procedures. When they did receive information about potential side effects, some Black patients suggested, it was insufficient, inaccurate, or late, resulting in undue pain and suffering from treatable side effects.

One Black lung cancer patient described the experience:

I was disappointed mostly in the side effects...that...is the part that really got me, ...I didn't think that you could go through all of that, because, they would tell you a certain part of it...and a few other things that wasn't mentioned... They gave me some...prescription to get the right medication, but there are certain things that I called in about... they weren't givin' me the right information I needed...at the time.

A Black breast cancer patient described a particularly harsh experience:

Cause I had a boil to come up...the provider said 'let me take a look at it' and then the next thing I knew he asked for something and he immediately lanced it. He didn't prepare me. He didn't tell me what he was doing. Nothing. And I had to actually literally grab my pants because I was getting ready to cold cock him... That's how bad it was.

Insensitivity to or even disregard for patients' pain tolerance, as the boil experience suggests, has the potential to sever the patient-doctor relationship at a time when patients are particularly in need of support and empathy. Failure to prepare patients for procedures and treatments led to excess pain and unmanaged side effects among Black patients. The lack of transparency manifested in these experiences disempowers and discourages patients, increasing the potential for discontinuation of care.

Although it is important to acknowledge how individual interactions between patients and providers influence patient health outcomes, it is critical to understand these interactions from a systems perspective. For example, the inflexibility of the protocols and procedures for scheduling surgery/treatment appointments and managing pain and symptoms reflect the failure of the *system* to maintain the transparency necessary for optimal care. Patients' experiences during treatment played a critical role in how and when they followed their treatment plan. Racial differences that emerged from our analysis of the system suggest that some Black patients were not receiving the care they needed in a timely or sensitive manner.

The Encounter of the Daily Grind of Navigating the System

Navigating a large, complex, impersonal system without clear mechanisms for transparency and accountability was overwhelming and disempowering for the participants. Challenges faced by participants included medical and non-medical issues reflecting a lack of transparency, such as: (1) not having well-coordinated care, which led to confusion about which provider to call for which issues; (2) problems with acquiring information or support from billing offices; and (3) lack of support from social workers even in times of dire need for transportation, financial, or psychosocial support. Furthermore, these patients' challenges were a reflection of how the cancer care system can provide uneven, haphazard care. Some patients shared how they were not aware that educational and social support resources were available at their cancer center, while others had been connected with an array of resources and services. Although communication was clear at times, it was not always transparent, and the mechanisms in place did not hold the system accountable. Breast cancer participants provided one example of how such differential access to resources was experienced by patients. Some told of receiving a '*black bag*' full of breast cancer resources and information at the onset of diagnosis, while others had never heard of or been offered such a resource.

Another dominant theme among the participants was the importance of small interpersonal interactions. Participants acknowledged the crucial role their physicians played in encouraging them to initiate or continue treatment. Patients valued their interactions with staff and described them as '*welcoming*' and '*like old friends*' who '*knew their names*.' A Black lung cancer participant summed up the kind of experience expressed by participants:

So...between the cancer center, the therapist that they have there...the smallest person, even the greeters when you come in the door...they go above and beyond their job. Because I think you have to be a special kind of person to work there, you just can't be like a regular doctor's office, because they are compassionate, they understand people are going through some serious stuff, mentally, physically, and emotionally.

Despite these positive interactions, both Black lung and White breast cancer patients also described negative experiences with nursing staff and oncologists at both cancer centers. Seemingly minor interactions were perceived as critically important in making patients feel comfortable, encouraged, or empowered. Both Black and White patients gave examples of the challenges they encountered, for example, in negotiating the financial/ billing system. Patients also described stress-inducing experiences with the oncology center, including long initial visits, lack of return calls from the scheduler, and difficult interactions with '*rude*'

staff or a doctor who had no *'bedside manner.'* Patients recognized during those encounters that the quality of care was sub-optimal but did not know who was in charge or where to voice a complaint. The mechanisms for accountability of the system to the patients were not clear. A White breast cancer patient described the frustration of such an interaction she had at the front desk:

...And I actually left here in tears one day because of the rudeness of the people that worked here. It wasn't the nurse, it was like mainly the...people at the desk... and I don't know whether it was a bad day, it was just everyone was so rude. And I felt that, well you know I thought it was unprofessional, but you know if any place where you need to be kind and caring, it should be here because not only are the patients under a lot of stress, but their families are under stress. And I actually did call somebody about this and reported it.

Similarly, a Black breast cancer patient described a pressure point encounter with a White woman at the front desk:

I could get food down more and better than I had. But...there was another woman that told me about the mints and the...Lemonheads...up there at the chemo place. And when I come in there for my treatment...I would grab a handful and throw them in my purse. There was this one lady up there at that desk, she knew I was coming. Every time I came she would move 'em... And I asked her where's the Lemonheads at? {imitating lady at front desk} 'Oh, they haven't put any out today.' ...She was at the front desk on floor three. ...I went back to where the chemo people were, they always had their Lemonheads out, so I grabbed a handful of them... But for her to move them Lemonheads that really like, just took me...

Racial Differences—The examples above speak to individual incidences experienced by both Black and White patients. While these occasional negative experiences were dwarfed by the participants' overall positive impressions of the cancer centers, the tenor of incidents described by Black participants raise questions about whether innocuous interactions may be related to unconscious bias (Hall et al. 2015; Nolan et al. 2014; Burgess et al. 2006), a critical underpinning that may affect the quality of patient care. Whereas the White patient experienced a kind of universal rudeness from the front desk staff, the Black patient experienced a very targeted and intentional denial of a small bright spot in her chemotherapy treatment experience. While she did not explicitly describe this as an example of when she was treated differently due to her race, it emerged from our analysis as a potential racial microaggression. Microaggressions, or 'brief and commonplace daily verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial slights and insults toward people of color,' (Sue et al. 2007, 273) could affect patients' treatment experiences whether or not they recognize them as racially-motivated. The very staff members whose role was to facilitate the patients' care journey were in fact preventing patients from progressing smoothly through the system; an example of how a gatekeeper controlling access to resources and procedures can affect the quality of care and patient experience. Moreover, each patient's response raises interesting questions about who feels empowered within the cancer system. In this case, the White patient felt empowered enough to complain and report the rude behavior. The Black patient

acknowledged that she found this behavior distressing, but she did not describe taking any action. From our antiracism lens, these encounters suggest the privilege a White patient may feel (and the reluctance a Black patient may feel) in challenging the negative treatment within a system that is not accountable to all of its patients.

In a few cases, cancer treatment-related side effects were so severe that patients reported going to the emergency department (ED) to seek care. Navigating the ED system was frustrating for cancer patients, especially the Black patients who reported more negative experiences. Black breast and lung cancer patients reported receiving inadequate information and care from the ED medical staff. There was a lack of coordination and transparency between the ED triage and the cancer care system. One Black lung cancer patient said that he was told to go to another section of the hospital after reporting to the ED located near his cancer center. Unlike a White patient who described feeling empowered during her ED visit, a majority of Black patients spoke about their experiences in the ED as a challenging and frustrating aspect of their cancer journey because they were not able to navigate the ED to receive the care they needed to manage residual pain from cancer treatment. They felt they were given insufficient treatment that only temporarily managed their pain. When they were told to schedule visits with their cancer care teams, it felt like a dismissal since it was not clearly communicated that this was the path to long-term pain management resolutions.

Navigating the cancer center system is a difficult journey for many patients, so the guidance and service that patients received from oncology and other hospital staff had a powerful effect on their overall experience. Many patients expressed how attentive and caring the cancer center staff was, while others, particularly Black patients, shared incidents of microaggressions that left them feeling disempowered by the very gatekeepers who were in place to assist them. This attests to the need for cancer center staff to engage positively with patients and for systems to be in place so that when patients, regardless of race, do not feel welcomed, respected, or well supported, they know where to go to address those issues.

The Encounter When Treatment Ends

The participants' cancer-related experiences extended beyond their cancer care team since they often interacted with other areas of the hospital post-treatment, including the ED, radiology, and support groups. There were reports from both Black and White patients about positive experiences they had with receiving a post-treatment MRI (magnetic resonance imaging) and visits to the ED. One White patient emphasized how empowered she felt when she received the care she needed in the ED. A Black patient shared that she was able to advocate for herself in the ED when she insisted that the medical staff not use the port, which had been inserted for use during her cancer treatments. Another Black patient reported how appreciative she was when the person conducting her X-rays allowed a break in the scan to increase her comfort.

Yet, several patients felt the strong support they received during treatment completely dissipated once they finished their chemotherapy or radiation. This left patients feeling abandoned and ill-prepared to navigate the post-treatment issues they experienced, such as continued radiation-induced skin changes, side-effects from anti-estrogen medications, and persistent residual effects of chemotherapy. Post-treatment care was a major concern for

Black and White breast cancer patients. Patients found the system was not set up to provide continuing transparent communication after their active treatment ended, although they were expected to attend scheduled follow-ups. As one White breast cancer patient explained, *'When treatments end, the support ends.'* In the same regard, a Black breast cancer patient shared:

If I had to change something or suggest a change, it would be after treatment. I found that to be very difficult. Matter fact I fell apart... After treatment it's like what do you do? Where do you go? ...And some real high anxiety like over-the-chart anxiety issues came up after my treatment. Just like out of nowhere, which I later found out it was very typical, very normal, but I'm like I didn't know what to do... And so it wasn't until I saw...the [physician assistant] that you know if it's certain things you just call the center... You know if you got a headache, your leg hurt, your head you know go to my primary physician. But anything else so...I'm still not real clear on that.

This uncertainty about whom to contact (e.g., primary care or cancer care physician) to address post-treatment medical needs left many patients confused about who should be their primary provider following completion of cancer treatment. At one cancer center, patients mentioned that chemotherapy classes were offered. They appreciated these classes because they provided information about what to expect during treatment. Patients desired to have similar resources that offered more widespread support post-treatment. They desired reliable sources to contact to address their questions and to assist them with navigating the medical system after the completion of active cancer treatment.

The care of cancer patients extends beyond the actual cancer center. Patients need flexible and compassionate care from gatekeepers in all sections of the hospital that they interact with. Even after the patients' care plans have been completed, they experience residual medical issues for weeks or months related to their cancer treatment. All cancer patients need well-defined instructions on steps to take when they have pain or symptom management concerns after treatment ends.

Discussion

Our analysis of power and authority focus group findings provide important considerations for how cancer centers in the US can improve transparency and accountability for quality and completion of treatment within their system. As one patient eloquently described the challenges of navigating the cancer system for her treatment and care, *'it's like you don't have a roadmap really.'* Our findings shed important light on what the experience of treatment was like for cancer survivors and suggest critical areas where cancer systems could change their procedures and policies, as well as better educate and prepare gatekeepers, to improve care for all patients. As described by our patient participants, most of the pressure point encounters were related to lack of transparency, such that improvements in communication, particularly two-way communication could greatly improve patients' interaction with the system. Pathways for accountability can also be built into a system that allows patients to find solutions for their problems with the system itself. Seen through an antiracism lens, the experiences these participants shared about their

diagnoses, treatments, and dealings with complex cancer centers suggest eight patient-centered systems-level interventions that could address common pressure points and potentially improve cancer center experiences for all patients:

- (1) Participants said learning of their diagnosis was enormously stressful. The stress was intensified for those who had received the news by telephone, because it was impersonal, and did not allow for the opportunity to absorb information or formulate questions. Following-up with patients in person after diagnostic imaging and procedures would address this problem.
- (2) Some participants found a first visit with a multi-specialty oncology clinic to be informative, streamlined, and reassuring, but others found that approach overwhelming because of the length of the visit and the sheer amount of information conveyed by multiple providers. Centers might offer options for the first visit format based on patient preferences.
- (3) Systematizing provision of informational resources, triaging for social service needs at regular intervals, and documenting these interventions in the electronic health record could help to ensure every patient has access to needed support services.
- (4) While reducing wait times might be difficult, appointments might be made less stressful by allowing patients to wait in common spaces, rather than in gowns in exam rooms.
- (5) Our participants reminded us that procedures clinicians consider minimally invasive are often aversive experiences for patients. Protocols that limit venipuncture attempts and appointment systems whereby patients might have their intravenous lines placed or indwelling catheters accessed by known, trusted phlebotomists and nurses might reduce the distress associated with these procedures.
- (6) Protocols for timely communication among ED staff, on-call oncologists, and patients might alleviate some of the stress associated with unexpected complications that result in visits to the ED.
- (7) Health systems can establish clear protocols to communicate the plan for follow-up or identify community resources for survivorship education and support for every patient transitioning out of active treatment. Our participants' concerns align with a growing conversation about the need to provide survivorship care plans for all patients that are post-treatment.
- (8) Finally, consistent policies that *explicitly* address the mechanisms patients have to address institutional problems should be clear. Guiding patients through the system with accessible policies will clearly establish the institution's commitment to accountability to patients.

Our findings have been crucial to informing ACCURE's groundbreaking intervention components and to engaging cancer center providers and staff in the effort to increase their own cancer care systems' mechanisms of transparency and accountability. Using the

analysis of power and authority tool for this formative research also emphasized the importance of using an antiracism lens to understand and intervene on racial inequities in health. In order for this type of analysis to be effectively used, community and academic researchers must gain the shared understanding, language, and lens offered by an antiracism training to fully comprehend and appropriately apply the analysis of power and authority to research. Efforts should be made to increase access to antiracism trainings to enable more researchers to learn about this framework for examining systems. A limitation of this formative study is our findings are specific to the care systems at two cancer centers and may not be transferrable to other cancer centers. Nonetheless, our two partnering cancer centers were specifically selected as ACCURE sites to reflect a range of cancer centers in the US (i.e., those that are affiliated with regional hospitals and academic medical centers), as well as the racial gap in patients' outcomes exhibited in cancer centers across the country (DeSantis, Naishadham, and Jemal 2013; Samuel et al. 2014; Lathan, Neville, and Earle 2008; Keating et al. 2009; Smith, Earle, and McCarthy 2009; Cykert et al. 2010; Farjah et al. 2009). Hence, our findings are likely relevant to other cancer centers.

A major strength of this formative research is the central role that our community partners in the GHDC played in holding academic and medical center partners accountable and transparent throughout the research and intervention process. The GHDC members led the effort to pinpoint pressure points that might be related to differential treatment by race, discussed preliminary findings, and once the findings were finalized, suggested ways to incorporate them into the larger project, fine-tune ACCURE navigators' work goals, and shape content of the Healthcare Equity and Education Training sessions for cancer center providers, staff, and administrators. Another strength is that our team included cancer survivors whose perspective was essential, and feedback was taken into account at every step of the research process. Our CBPR approach to planning, data collection, analysis, interpretation, and writing of this manuscript integrated multiple perspectives throughout the process, including Black and White cancer survivors, community members, healthcare workers, and academic researchers.

Our analysis of power and authority of the cancer care system has shown that:

- (1) There are several key pressure points along the cancer care continuum where patients encounter barriers to care and feel disempowered. These pressure points are where the healthcare system can be improved to facilitate more empowering experiences for patients.
- (2) The Undoing Racism[®] framework's analysis of power and authority serves as an effective tool for analyzing pressure point encounters and identifying equity issues within the healthcare system.
- (3) The concepts of transparency and accountability provide a starting point for the fields of public health and medicine in general, and cancer health disparities in particular, to understand and address how structural issues contribute to persistent cancer disparities.

In sum, our findings from patients' encounters with the cancer care system underscore the need for new ways to ensure transparency and accountability for cancer care through clear,

two-way communication systems and well-integrated policies and procedures that serve as a roadmap to guide patients, clinicians, and staff through the cancer care journey. The use of the antiracism framework to achieve systems change may assist in eliminating Black-White inequities in the quality and completion of cancer treatment.

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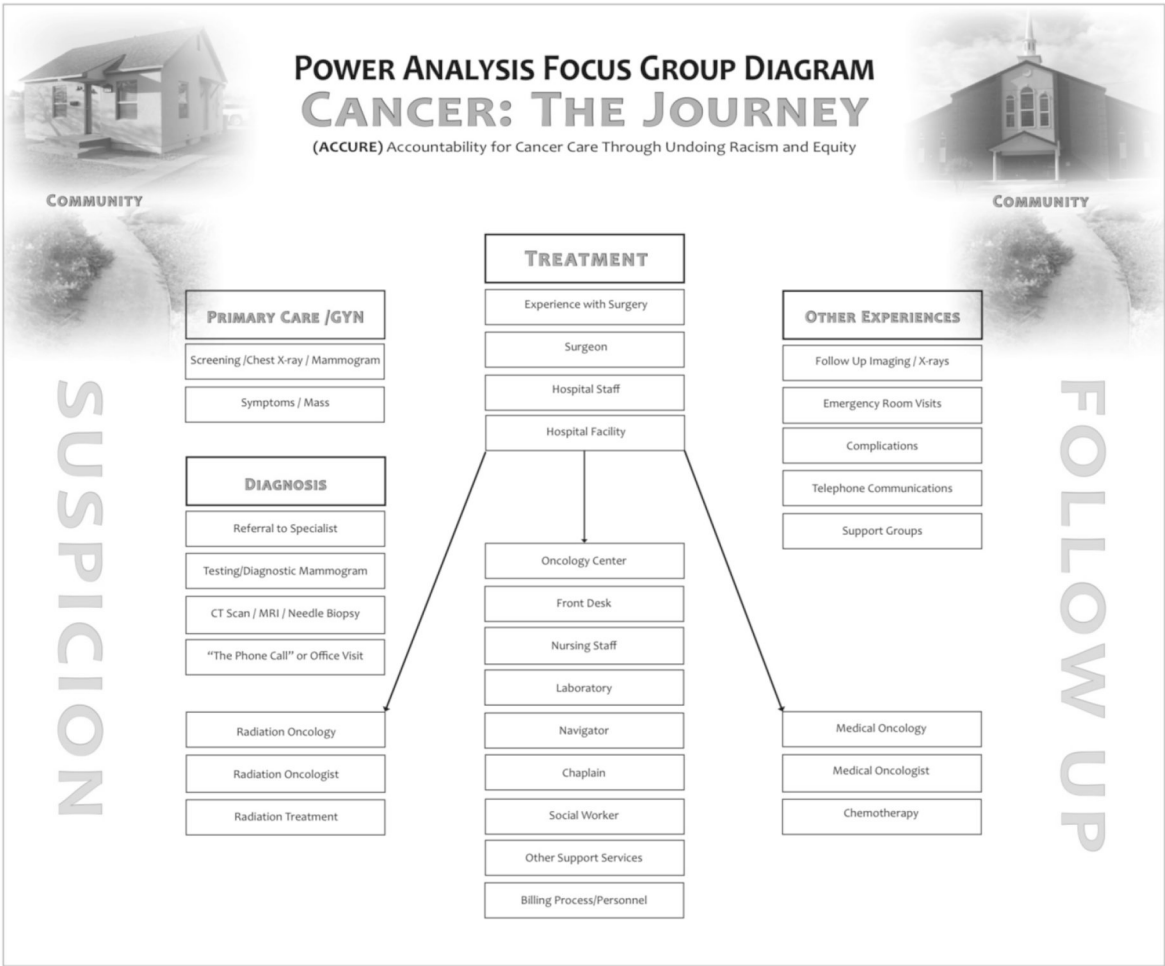


Figure 1.
Cancer Journey Diagram^a
^aThe cancer journey diagram, developed by GHDC and Sisters Network Greensboro NC, a local affiliate of a national African American breast cancer survivorship organization, was a focal point for analysis of power and authority discussions and data analysis. It depicts a patient’s journey through cancer care, beginning in the community, from diagnosis through therapy and return to the community following treatment.

Table 1.

Analysis of Power and Authority Focus Group Guide

#	Question and Additional Prompts
Introduction	We've put together this diagram to jog memories of the 'journey through the cancer care system.' Each person's journey is a bit different, but we can hopefully use this as way to remind us of all the different parts of the system. You can also let us know as we go along if we need to change or add anything to this diagram to better reflect the treatment experience at your cancer center.
1	We can start with a quick walk through the diagram to review the many important points in a cancer treatment process. We show progression from initial testing through diagnosis to the cancer center and through treatment. At each point there are multiple medical and non-medical experiences that can influence the quality of your experience. For example, I would like to hear your experiences with services, paper work, unfamiliar medical vocabulary, rules and regulations, schedules, preparation and follow-up procedures, or experiences when medication side effects may not have been explained. There may be: <ul style="list-style-type: none"> • Points (encounters with the medical system) where you felt 'stuck'; that you did not know how to move forward in the system • Points where you were sent 'back and forth'; or going in circles like a merry-go-round • Points of particular confusion {STOP to allow time for the participants to add to the diagram and reflect on these points.}
2	Now that we've got the system mapped out and you are thinking about your experiences, let's begin by describing: <ul style="list-style-type: none"> • What led you to start your cancer treatment at your cancer center instead of another place? • What made it easy or hard for you to DECIDE to start your treatment at your cancer center? • And then, tell me about particular points in this journey, or situations, where you felt EMPOWERED (meaning that you fully understood the plan, your opinions were respected, that you were a full partner in your own cancer treatment)? • What about that experience made you feel empowered?
3	And what about experiences in the journey or situations where you did NOT feel EMPOWERED / that you were a full partner in your own cancer care? <ul style="list-style-type: none"> • What about that experience made you feel disengaged, discouraged, and/or disappointed?
4	Tell me about times when you felt you had a part in making decisions about your care. <ul style="list-style-type: none"> • How was your participation 'invited'? • How welcome do you think your participation was in that instance?
5	And what about times when you felt you were NOT allowed to participate in making decisions about your care? <ul style="list-style-type: none"> • What happened to make you feel like you weren't allowed to participate? • Were there times when you did not feel welcome to participate in decision-making but you did/tried to participate anyway? What happened?
6	Were there any incidents or points along this journey that made you want to stop treatment? Tell me about that... <ul style="list-style-type: none"> • Did you tell any medical staff that you wanted to stop treatment? What happened? • Why did you decide to continue? • How do you think the cancer care system should handle issues like this?
7	Describe any incidents or points along this journey that really built up your courage to continue your care. <ul style="list-style-type: none"> • Tell me more about that...
8	Were there barriers to YOU for getting the best care? <i>(Give a long pause for silence to wait for answers before giving these examples: any challenges regarding paper work, unfamiliar medical vocabulary, rules and regulations, schedules, preparation and follow-up procedures.)</i> Tell me about those. <ul style="list-style-type: none"> • Did you know of anything or anyone in the cancer center system that might have been able to change that situation? • How were those barriers dealt with, or were they?
9	Do you feel you were treated differently (positively or negatively / better or worse) because of your race or other elements of your cultural or ethnic background? If so, what gave you this feeling or impression?
10	What was helpful to you in getting the quality of care YOU needed? <ul style="list-style-type: none"> • What was helpful about the way the procedures/services were organized? • How did this help you?
11	What were the points in this system that made your experience especially difficult or frustrating? <ul style="list-style-type: none"> • (If answers are personal—family, relationships, work, etc.) Did you know of anything or anyone in the cancer center system that might have been able to help with that situation, or anyone you could go to for advice? • Did you communicate these struggles to your providers? How?
12	Based on your experience with cancer diagnosis and treatment system, if you had the power to improve the system, what would you change?

Table 2.

Analysis of Power and Authority Participant Profile By Race, Cancer Type, and Cancer Center

Race	Cancer Type	Cone Health Cancer Center (Regional Hospital)	UPMC Hillman Cancer Center (Teaching Hospital)
Black	Lung	3	1 ^a
	Breast	4	4
White	Lung	5	1 ^a
	Breast	5	4

^aConducted as one-on-one in-depth interview using the same focus group questions

Table 3.

Encounters in the Cancer Care System Where the 6 Overarching Themes Manifested

THEMES	ENCOUNTERS			
	<i>Diagnosis</i>	<i>Treatment</i>	<i>Daily Grind</i>	<i>Treatment Ends</i>
1: Fear was disempowering and discouraged continuation of care	X	X	X	X
2: Uncertainty and lack of information were disempowering and hindered care	X	X	X	X
3: Trust in the medical team was crucial to continuing care		X	X	
4: Communication was empowering when providers shared information and were also good listeners		X	X	
5: Navigating complex, impersonal healthcare systems was often confusing, overwhelming, and disempowering	X	X	X	
6: Small interpersonal interactions were enormously important in helping patients feel cared for or disregarded	X	X	X	

EXHIBIT B

A Multi-Faceted Intervention Aimed at Black-White Disparities in the Treatment of Early Stage Cancers: The ACCURE Pragmatic Quality Improvement Trial

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ABSTRACT

Reports continue to show that Black patients with curable lung or breast cancer complete treatment less often than similar White patients resulting in worse survival. The Accountability for Cancer Care through Undoing Racism and Equity trial was designed as a pragmatic, quality improvement trial comparing an intervention group to retrospective and concurrent controls in an effort to reduce treatment disparities. Patients with early stage breast or lung cancer aged 18 to 85 were enrolled (N = 302) at 2 cancer centers between April 2013 and March 2015 for the intervention component. Data from patients seen at these sites between January 2007 and December 2012 were obtained to establish baseline completion rates. Concurrent data for non-study patients were used to monitor for any secular trends. The intervention included: a real time registry derived from electronic health records to signal missed appointments or unmet care milestones, a navigator, and race-specific performance feedback. The primary outcome was “Treatment Complete”, a composite variable representing completion of surgery, recommended radiation and chemotherapy for each patient. The mean age in the intervention group was 63.1 years and 37.1% of patients were Black. Treatment completion within retrospective and concurrent controls showed significant Black-White differences (Blacks (B) 79.8% vs. Whites (W) 87.3%, $p < 0.001$; 83.1% B vs. 90.1% W, $p < 0.001$, respectively). The disparity was much smaller within the intervention (B 88.4% and W 89.5%, $p = 0.77$). Multivariate analyses confirmed the reduction in treatment gap. The odds ratio (OR) for Black-White disparity within the intervention group was 0.98 (95% CI 0.46 – 2.1); between group analyses showed Black completion in the intervention compared favorably to Whites in both the retrospective (OR 1.6; 95% CI 0.90 – 2.9) and concurrent (OR 1.1; 95% CI 0.59 – 2.0) groups. We conclude that a system-based intervention consisting of a real time registry combined with feedback and

navigation improved completion of cancer treatment for everyone and narrowed Black-White disparities.

Keywords: cancer disparities; institutional racism; intervention; quality improvement

1.0 INTRODUCTION

Inequalities in the treatment of early stage breast and lung cancer have been consistently documented for Black patients compared to similar White patients for decades¹⁻⁴. These treatment differences are extremely important because lung cancer is the leading cause of cancer death for both men and women⁵ nationally and breast cancer is second to only lung cancer in women⁵. While Bach and Hershman demonstrated a direct contribution of disparities to excess mortality for Blacks more than a decade ago^{1,2}, recent data show that lung cancer survival disparities persist while breast cancer survival disparities have actually widened⁶. Even after controlling for confounders, such as comorbidity, health insurance, and socioeconomic status, studies still report less care and increased mortality for Blacks^{1,2,7,8}. Factors such as implicit bias, mistrust, and poor communication have been associated with treatment variability^{4,9-11} but interventions to address these issues have been sparse^{12,13}. In response to these gaps in research and persistent unequal outcomes, the Greensboro Health Disparities Collaborative (GHDC), the UPMC Hillman Cancer Center, the University of Pittsburgh School of Medicine, Pittsburgh Pennsylvania, and Cone Health Cancer Center, Greensboro, North Carolina joined together to test a system change intervention to enhance racial equity in the completion of cancer treatment. We conducted a trial, Accountability for Cancer Care through Undoing Racism and Equity (ACCURE), using a multi-faceted intervention designed to address barriers identified in our preliminary studies and informed by community-based participatory research. In this report, we describe the intervention and the clinical results.

2.0 MATERIALS AND METHODS

2.1 Study Design and Intervention

We performed a 5-year study to examine the effect of an intervention on disparities in treatment completion for Black patients with stages 1 and 2 lung or breast cancer compared to similar White patients. Our study was a pragmatic trial as assessed by the PRECIS-2 definition¹⁴; specifically, the patients were community based with broad enrollment criteria, treated by usual care providers in a typical cancer care setting using tools and personnel that could easily fit into routine clinic workflows. Study diagnoses were selected because of our community partners' awareness that these cancers were very common and often fatal among people in their communities with similar racial and socioeconomic backgrounds.

The ACCURE intervention study utilized the People's Institute for Survival and Beyond (PISAB) Undoing Racism™ framework as a conceptual model for medical care. Recognized by the Aspen Institute (2004) as one of the top 10 anti-racism training programs in the U.S., the PISAB Undoing Racism™ framework suggests that the world is controlled by powerful systems with historically traceable roots. Once people are shown how they benefit from or are oppressed by those systems, they can work together and lead system change. Therefore, transparency in measuring system effects and accountability to implement change become the key concepts for undoing institutional racism and establishing racial equity¹⁵. In this vain, all consented patients received the intervention which consisted of a real time warning system derived from automated uploads of data from electronic health records (EHRs) to enhance transparency, feedback to clinical teams on completion of cancer treatments according to race (enhance both transparency and accountability), and a nurse navigator with access to the warning system (to formalize accountability). Health equity training sessions covering concepts such as implicit bias,

gatekeeping, and institutional racism were offered to all staff and providers quarterly to make them aware of these concepts. See Figure 1 which demonstrates the relationship of the real time registry derived from EHR downloads leading to transparency of substandard or delayed care within a window of actionable intervention connecting to the accountability provided by the interactions of the navigator and physician champion with patients and the relevant clinical team resulting in quality improvement for all.

Because of the ubiquitous nature of EHRs and the pervasiveness of quality improvement (QI) work in practice, we felt it was unethical to randomize patients to a “control” group devoid of data feedback and electronic tools so we used a QI approach. We established 2 statistical control groups. The first group included all patients diagnosed with stages 1 and 2 breast cancer or non-small cell lung cancer at UPMC and Cone from January 1, 2007 to December 31, 2012 to establish baseline treatment completion rates and racial differences. The second control was the concurrent population of stage 1 and 2 breast and lung cancer patients who were diagnosed in 2014 and 2015 and not enrolled in the intervention. The latter group ensured that improvement documented in the intervention did not represent spontaneous improvement in the participating centers thus eliminating the possibility of secular trends. Variables collected in all groups included site, gender, age, race, health insurance status, marital status, zip code, cancer stage at diagnosis, and co-morbid illnesses. We recorded whether patients received surgical treatment, radiation therapy (and dose), or chemotherapy (and number of treatments) and the dates of all treatments. Within the intervention group, we conducted a small, pre-planned randomized trial in which half received standard nurse navigation consisting of nurse availability for patient initiated contacts on an as needed basis and half received a specially trained nurse navigator who attended a racial equity training delivered as a 2 day workshop by the Racial Equity Institute (Greensboro,

NC) that included components on the culture and history of racism, institutional aspects of racism, the role of implicit bias, and systematic approaches to establish “anti-racism”. These special navigators also received case-based training on barriers more specific to the Black community such as medical mistrust, lack of self-efficacy, poor communication, and beliefs that negatively influence care (e.g. “air will cause the spread of cancer during surgery”). This latter training was delivered by one of the principal investigators (Cykert) during two 1-hour sessions during the first 3-months of recruitment and was based on findings of a prospective cohort study that explored factors leading to disparities in receipt of lung cancer surgery⁴. The special ACCURE Navigator protocol was proactive and not dependent on patient initiation. It required 2 navigator initiated face-to-face meetings within the first month of diagnosis; then monthly contact was scheduled, usually by telephone, to assess progress in addition to any patient initiated communications. The real time registry system generated reminders for these visits until the visit was documented by the navigator. These meetings occurred for all patients randomized to the special navigator regardless of patient race. A priori, we estimated that by enrolling 270 patients (162 White and 108 Black) that we had 80% power to detect a treatment completion difference of 14% in the special navigator group above usual care navigation.

Other important features of the intervention are described. For the real time registry, we received automated nightly uploads of EHR data including patients’ appointments for clinician visits, tests, treatments, and procedures. The registry was configured to deliver alerts when a patient either missed a scheduled appointment or did not reach an expected milestone in care. Programmed milestones were determined a priori with cancer center clinicians and are shown in Table 1. To monitor intervention fidelity, we logged all warnings and navigator responses in the registry system.

For each cancer center, we selected a practicing oncologist to serve as the ACCURE physician champion. The champion made other clinicians and staff aware of the study through scheduled staff meetings and was responsible for delivering quarterly reports that included surgical rates and completion rates for chemotherapy and radiation therapy of the cancer center population and intervention group stratified by race. Note that the study team did not determine whether actual initiation of adjuvant chemotherapy was appropriate. Once chemotherapy was started the number of completed cycles were ascertained again through automated EHR uploads. We assumed that all patients who received breast conserving surgery (BCS) should start and complete adjuvant radiation.

2.2 Patient Enrollment

Patients with the new diagnosis of stage 1 or 2 breast or lung cancer between the ages of 18 and 85 were eligible for intervention. Exclusions included pregnancy, inability to speak English, and cognitive impairment. Enrollment occurred from April of 2013 until March of 2015. Our goal was to recruit consecutive patients at the participating centers as quickly as possible so that everyone experienced 2 to 3 years of follow-up. To identify eligible patients, research assistants (RA) screened patient schedules from breast surgery, thoracic surgery, oncology, pulmonary, and multi-disciplinary cancer clinics. All these schedules were available through the EHR. Most patients screened were not eligible because of a non-cancer diagnosis, a follow-up visit rather than an initial diagnostic visit, a cancer diagnosis other than breast or lung, or a stage more advanced than stage 2. See Figure 2 for a schematic representation of enrollment. The top row of this Consort diagram represents all the patients screened regardless of eligibility. The second row shows the number of eligible patients identified by race and those refusing consent. When

eligible patients shared simultaneous appointment times, RA's were trained to prioritize Black patients for enrollment as a method of oversampling. Informed consent was given by all participants. Institutional Review Board approval was obtained from each study institution. ACCURE was registered with ClinicalTrials.Gov (NCT01954641).

2.3 Primary Outcome

The primary outcome reflecting a full course of treatment for both cancers is the composite, "Treatment Complete". Treatment Complete is defined: (1) for lung cancer, a patient must receive resection surgery or a full course of stereotactic radiation calculated for potential cure. If chemotherapy was started for stage 1B or stage 2 patients, then administration of at least 3 of 4 cycles had to have occurred to be deemed complete. (2) For breast cancer, any patient who did not undergo surgery received a, "no" for Treatment Complete. If surgery was BCS, then adjuvant radiation had to be completed. If chemotherapy was initiated either in the setting of complete mastectomy or BCS plus radiation, then a patient must have received at least 4 cycles.

3.0 THEORY / CALCULATION

Patient characteristics including gender, age, median household income by zip code, race, and marital status were summarized using descriptive statistics and compared across study groups and within study groups between races using chi-square and F-tests for categorical and continuous variables, respectively. Since we were interested in estimating treatment completion differences between Black and White race for each study group, a logistic regression model including a combination of study group and race variables was used to estimate treatment

completion percentages and differences in treatment completion percentages for each study group by race. The retrospective data were used to define baseline treatment disparity between Black and White patients. Concurrent data were used to assess the disparity during the intervention period and therefore assess secular trends or spillover effects for non-enrolled patients. In order to control for bivariate differences across study samples and between races within each study sample, a similar logistic regression model that included age, marital status, health insurance status, median household income, study site and Charlson Comorbidity Score in addition to study group by race combinations was employed to estimate differences in treatment completion between Black and White patients within each study group. Subsequently, using the same model and data from all 3 study groups, we compared estimates of racial differences between baseline (retrospective) and intervention and between concurrent and intervention study groups to further assess effectiveness of the intervention.

4.0 RESULTS AND DISCUSSION

During the recruitment period, 132 Black and 265 White patients eligible for the study were identified and 92.4% and 77%, respectively, agreed to participate. Ten Black (8.2%) and 18 White (8.7%) patients withdrew prior to ascertainment of clinical outcomes and were removed from the analyses. See Figure 2. For characteristics of the 3 study groups, see Table 2. Black patients in the intervention group were intentionally oversampled. Patients in the intervention group were older, had less private insurance, and there were proportionally more males and fewer married individuals than in the other cohorts.

The unadjusted rates for Treatment Complete in the retrospective group were 79.8% for Black patients (B) and 87.3% for White patients (W), ($p < 0.001$); in the concurrent group treatment

completion rates also significantly favored White patients – 83.1% B vs. 90.1% W, ($p < 0.001$) – suggesting persistence of disparities. In contrast, Black patients in the intervention group achieved a Treatment Complete rate of 88.4% compared to 89.5% for Whites ($p = 0.77$). Bivariate comparisons within the retrospective and concurrent whole population groups showed that in addition to Black race, lower median income, a lack of private insurance, and being unmarried were associated with lower treatment completion. Within the intervention group, these variables were not associated with significant treatment differences. For the intervention, Site 1 had a completion rate of 88.3% compared to 91.0% for Site 2 ($p = 0.44$). See Table 3 for full bivariate results.

Multivariate analysis within study groups confirmed reduced treatment completion for Black compared to White patients for the retrospective (OR 0.79; 95% CI, 0.65 – 0.96) and concurrent control (OR 0.69; 95% CI 0.49 – 0.96). There was no Black-White disparity demonstrated within the intervention group (OR 0.98; 95% CI 0.46 – 2.1). Between group comparisons using the combined model examining race-group interactions showed completion rates for Black patients in the intervention compared favorably to Whites in the retrospective group (OR 1.6; 95% CI 0.90 – 2.9) and the concurrent group (OR 1.1; 95% CI 0.59 – 2.0). Patients without private insurance and unmarried had lower completion rates in the overall model and a site effect was noted (See Table 4).

The small randomized study within the intervention cohort did not show a statistically significant difference in favor of the special navigator (91% vs. 87%, $p = 0.38$).

Fidelity monitoring for the real time registry revealed 3,340 missed appointment warnings; all but 45 were resolved through appointment rescheduling and completion. 111 milestone warnings were triggered; 59 were resolved by achieving treatment completion. Nineteen of these missed

milestones were for “no lung cancer surgery in 130 days” but these actually represented patients who received definitive treatment with stereotactic radiation and completed treatment. Therefore, 40 warnings did not lead to advancements in care.

When interpreting the results of ACCURE, some of the history concerning racial disparities must be considered. As noted by the Sullivan Commission (2004)¹⁶, the more visible racial barriers of the U.S. health care system were eradicated by the Civil Rights Era, but today’s effects from “institutional racism” are subtle. Institutional racism has been defined as a process of oppression, unconscious or not, functioning as “a system of structuring opportunity and assigning value based on race phenotype, that unfairly disadvantages some and undermines the potential of the whole society”¹⁷. Examples include: lack of providers within reasonable traveling distance, poor institutional understanding of how to mobilize community organizations that principally serve Black residents, and racial discordance between patients and clinicians that may affect care-seeking behaviors¹⁸⁻²⁰. Our previous work demonstrating that Blacks with higher comorbid risk, poor perceptions of communication, or no regular source of care were less apt to receive cancer surgery served as a poignant example of how unintended, institutional biases can be operationalized⁴.

Given the many factors contributing to treatment disparities and lack of data supporting a single intervention, the research team and community partners determined that a multi-faceted approach utilizing transparency of clinical data and care team accountability achieved through race-specific audit and feedback was required for the highest probability of success. With the diffuse prevalence of EHRs since passage of the HITECH Act of 2009, we hypothesized that digital data available at nearly all cancer centers could rapidly populate a real time registry and generate warnings providing the transparency needed to identify barriers to treatment completion

whether attributable to patient factors (e.g. missed appointments) or clinical inertia (e.g. unmet milestones in the context of appointment adherence). Bickell et al. previously demonstrated that a registry could narrow undertreatment disparities for adjuvant breast cancer care intended for Black and Hispanic patients¹². Their registry was populated with hand entry by RAs who called the offices of patients' providers including surgeons, oncologists, and primary care physicians asking about consultations obtained and adjuvant treatments started. These tedious steps were followed by supplemental, manual chart reviews. Similar "hand-entered" systems would be untenable as a population-based, real time tool. The system built for ACCURE mimicked the treatment categories of the Bickell intervention but accomplished this in a fully automated manner translatable to widespread use. Given the demonstrated effectiveness of QI approaches such as audit and feedback, this accountability piece was added^{21,22}. To disentangle the structural issues of race and social class, community partners advocated making feedback race-specific. In addition, we presented the results stratified by comorbid conditions and race to address concerns about implicit bias in decision-making associated with the uneven interpretation of comorbidities highlighted in our prior work⁴. Lastly, given past barriers to patient adherence such as poor perceptions of communication, negative beliefs (e.g. air exposure spreads cancer), religiosity, and low health literacy, we included assessment and discussion of these issues in navigator training. Although race-related navigation has not been shown to specifically improve cancer treatment disparities, reports have described improvements in screening and diagnosis²³⁻²⁵. Navigation in ACCURE worked regardless of concordance in navigator-patient pairs suggesting that training related to the harsh realities and histories of the African American experience results in enhanced communication regardless of the race of the trainee. A more formal analysis of this result could be considered in future work in order to maximize the navigation effect.

As noted, all ACCURE components are supported in the literature, but which interventions really worked? An unintended limitation of the study helped answer this question. One cancer center experienced high clinician turnover mid-intervention. This turnover limited opportunities for effective audit and feedback. Despite this circumstance, improvement in the affected center was strong though not quite as robust as the second center. This result suggested high efficacy of the real time registry and the nurse navigators who acted on registry warnings. The efficacy of registry function plus navigation was further supported by the high rate of rescheduling action noted for missed appointments and the resolution of most deficient milestones in care. Regarding the health equity training sessions, if they played a major role in improvement, we should have seen a spillover effect through narrowing of racial differences in the concurrent control group. This effect did not occur.

Another important observation concerns the nurse navigators. In the small randomized portion of the study comparing navigators according to training, we saw no significant treatment completion increase favoring the ACCURE navigator compared to the usual care nurse navigator. This result could have several explanations. First, the ACCURE navigator did interact with the other nurse navigators so there could have been some adoption of ACCURE principles by the usual care nurses. Also, the ACCURE navigator did not specifically target patients of Black race, lower socioeconomic status, or low health literacy. Therefore, the effectiveness of the special training may have been diluted by including patients that didn't need more intense engagement. Conversely, it is possible that nurse navigators perform equally well when supported by real time tools that identify patients who need more engagement to complete difficult treatment regimens.

Given the shallow pool of evidence for effective system change interventions, the potential impact of ACCURE's promising results is two-fold. First, the ACCURE use of a real time registry derived from multiple EHRs can directly incorporate digital data to impact completion of important treatments. Second, race-specific feedback delivered during the actual course of care can be complementary to evolving registry systems such as the American Colleges of Surgeons (ACOS) *Rapid Quality Reporting System* and, ultimately, drive sustainable transformations within the 1,472 cancer facilities already accredited by the ACOS *Commission on Cancer*²⁶⁻²⁸. This process of systematically combining real time informatics support, data usage, and appropriate role responsibilities for using these data is crucial.

Since the time of Bach's report on lung cancer disparities, despite sharp definition of the problem and the application of individual level interventions such as culture competence education, recent data demonstrate little progress^{1,4,11}. In fact, 2016 cancer statistics show lung cancer mortality remained 20% higher for Black than White men⁶ and the Black-White mortality gap for breast cancer is actually widening⁶. Although social determinants and comorbid illness can all contribute to these survival differences, a significant part of the chasm for both cancers are directly attributable to the lack of treatment completion for Black patients. Specifically, Black lung cancer patients receive surgery and curative radiotherapy less often than similar White patients^{1,4,29}; Black breast cancer patients undergo less surgery, radiation, and chemotherapy than White patients^{30,31}. Even when chemotherapy is prescribed, completion rates are lower for Black women and lower completion rates are independently associated with worse survival^{2,32}. These data make the case for systematic, practice transformation interventions like ACCURE all the more compelling.

5.0 IMPLICATIONS

A multifaceted, system-based, practical intervention applied to patients with either early stage breast or lung cancer resulted in improved treatment completion for Black and White patients and reduced the racial disparity demonstrated in historic and concurrent controls. If applied broadly, this intervention could potentially improve cancer treatment and reduce disparities in over 1400 cancer centers in the U.S. As the intervention incorporates a real time electronic registry and other simple tools to promote transparency and accountability in care, future research using this approach could focus on improving treatment of cancers and common chronic illnesses with longer therapeutic horizons. Success in applying similar system based approaches to these areas of care could potentially mitigate disparities and result in substantial gains in quality of life and survival for Black patients and the population at large.

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Figure Legends

Figure 1. ACCURE Conceptual Model

Figure 2. Patient Enrollment, Randomization, and Progression in ACCURE.

Table 1. Unmet milestones used to trigger warnings in the real time registry for study patients

<u>Lung Cancer</u>
No clinical appointment, diagnostic test, or treatment scheduled within 30 days of the index visit
No surgery or radiation scheduled within 90 days of the index visit
No surgery performed by day 130 from the index visit
<u>Breast Cancer</u>
No clinical appointment, diagnostic test, or treatment scheduled within 30 days of the index visit
No breast cancer surgery completed within 30 days of the initial visit
No chemotherapy or radiation appointments scheduled within 21 days of breast cancer surgery
No chemotherapy treatments actually received within 90 days of breast cancer surgery
No radiation treatments actually received within 90 days of breast cancer surgery

Table 2. Characteristics of stage 1 and 2 breast and lung cancer patients by study group

Characteristics	Retrospective Whole Population Cohort (Control Group) N = 8945 (percent, 95% CI) [†]	Concurrent Whole Population Cohort (Control Group) N = 2717 (percent, 95% CI)	Intervention Group N = 302 (percent, 95% CI)
Mean Age (years)	61.7 (61.4, 61.9)	62.7 (62.2, 63.1)	63.1 (61.8, 64.4)
Female Gender	88.0 (87.3, 88.7)	89.3 (88.2, 90.5)	83.1 (78.9, 87.3)*
Married or Lives with Significant Other	60.4 (59.4, 61.4)	58.3 (56.5, 60.2)	47.4 (41.7, 53.0)*
Black Race	11.8 (11.1, 12.5)	12.5 (11.2, 13.7)	37.1 (31.6, 42.5)*
Private Insurance	51.7 (50.7, 52.8)	47.0 (45.1, 48.0)	30.8 (25.6, 36.0)*
Mean of Median Household Income by Zip Code (\$)	53.6K(53.3K,54.0K)	54.1K(53.5K,54.8K)	49.2K(47.2K,51.0K)*
Mean Charlson Score	2.8 (2.70, 2.82)	2.7 (2.55, 2.77)	2.6 (2.33, 2.97)
Clinical Stage 1 at Diagnosis	64.7 (63.7, 65.7)	64.5 (62.7, 66.3)	74.5 (69.6, 79.4)*
Breast Cancer	76.2 (75.3, 77.1)	78.0 (76.5,79.6)	59.6 (54.1, 65.1)*

*Difference statistically significant comparing the intervention cohort to the whole population cohorts, p<0.05

[†]CI = confidence interval

Table 3. Bivariate treatment completion results according to patient characteristics within each study group

Patient Characteristic	Retrospective Whole Population Cohort (Control Group) N = 8945	Concurrent Whole Population Cohort (Control Group) N = 2717	Intervention Group N = 302
Mean Age (years)			
Treatment Complete			
Yes	62.4	62.8	62.7
No	63.7	63.2	66.5
p-value	0.004	0.59	0.07
Median Income (\$)			
Treatment Complete			
Yes	54,442	54,810	48,524
No	51,489	50,303	54,468
p-value	<0.001	<0.001	0.13
Married (% TC*)			
Yes	88.2	90.9	90.9
No	83.8	88.6	87.4
p-value	<0.001	0.05	0.33
Private Insurance (% TC)			
Yes	89.3	91.3	89.3
No	83.6	88.7	89.0
p-value	<0.001	0.03	0.95
Charlson Score (% TC)			
≤1	86.8	91.9	93.3
>1	86.1	88.5	88.4
p-value	0.39	0.005	0.22
Race (% TC)			
White	87.3	91.9	89.5
Black	79.8	83.1	88.4

TC = Treatment Complete

Table 4. Results from multivariate logistic regression of treatment completions including all race-group combinations; within and between group comparisons are shown

Variable	Beta	Odds Ratio (95% Confidence Interval)	p-Value
Age	0.004	1.00 (0.99, 1.01)	0.15
Charlson Score (> 1 vs. < or =1)	-0.12	0.89 (0.79, 1.0)	0.06
Median Zip Code Income	0.003	1.00 (1.0, 1.01) ³	0.15
Marital Status Not Married vs. Married	-0.22	0.80 (0.71, 0.90)	<0.001
Private Insurance No vs. Yes	-0.29	0.75 (0.65, 0.86)	<.0001
Site	-0.74	0.48 (0.42, 0.54)	<0.001
Race and Study Group			
Black-Retrospective*	-0.24	0.79 (0.65, 0.96)	0.02
Black-Intervention*	0.48	1.6 (0.90, 2.9)	0.11
Black-Concurrent†	-0.37	0.69 (0.49, 0.96)	0.03
White-Intervention*	0.50	01.6 (1.03, 2.7)	0.04
Black-Intervention†	0.08	1.1 (0.59, 2.0)	0.80
Black-Intervention**	-0.02	0.98 (0.46, 2.1)	0.95

*White retrospective cohort is the referent group.

†White concurrent cohort is the referent group.

**White intervention cohort is the referent group

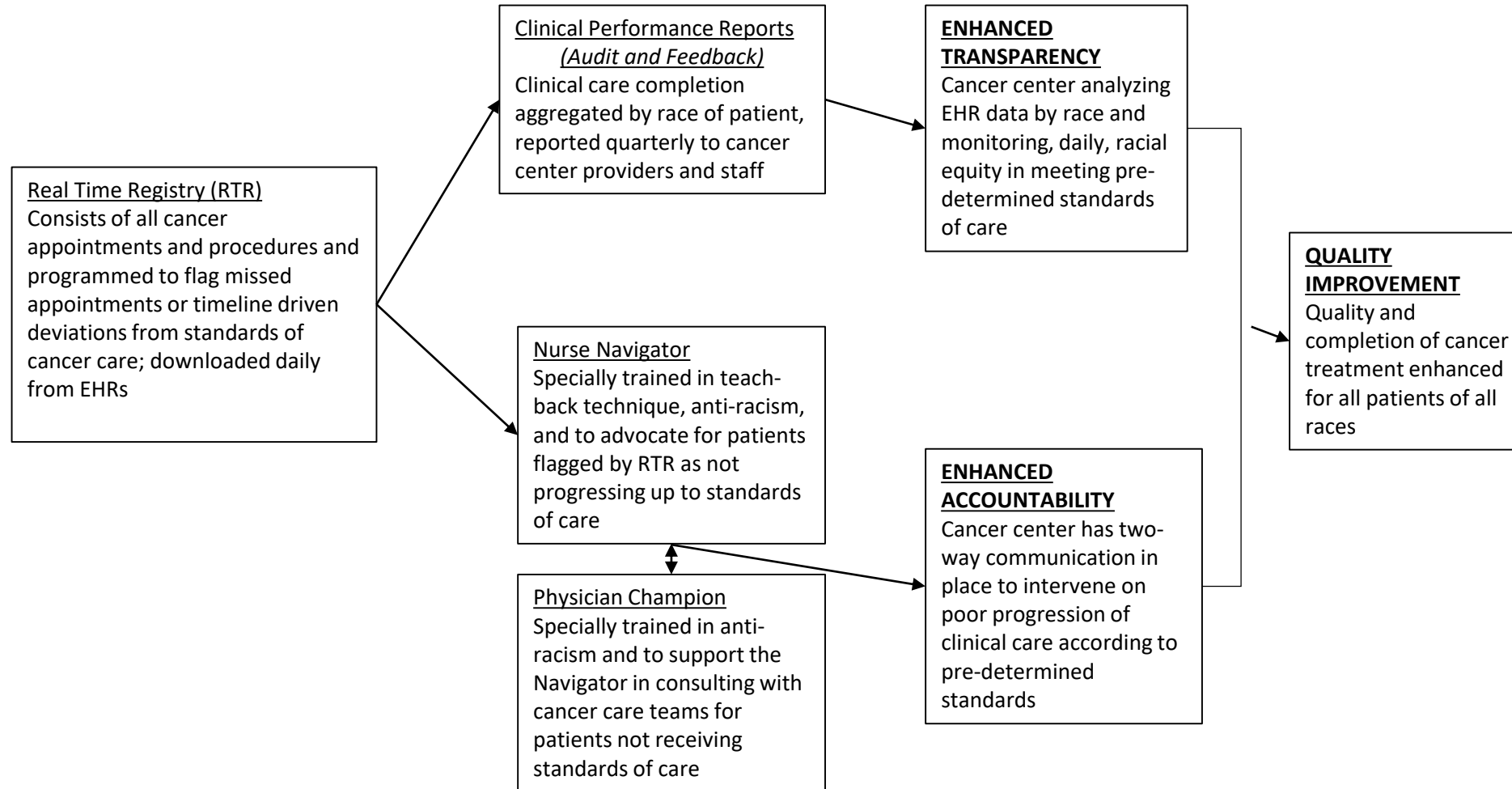


Figure 1. Patient Enrollment, Randomization, and Progression in ACCURE.

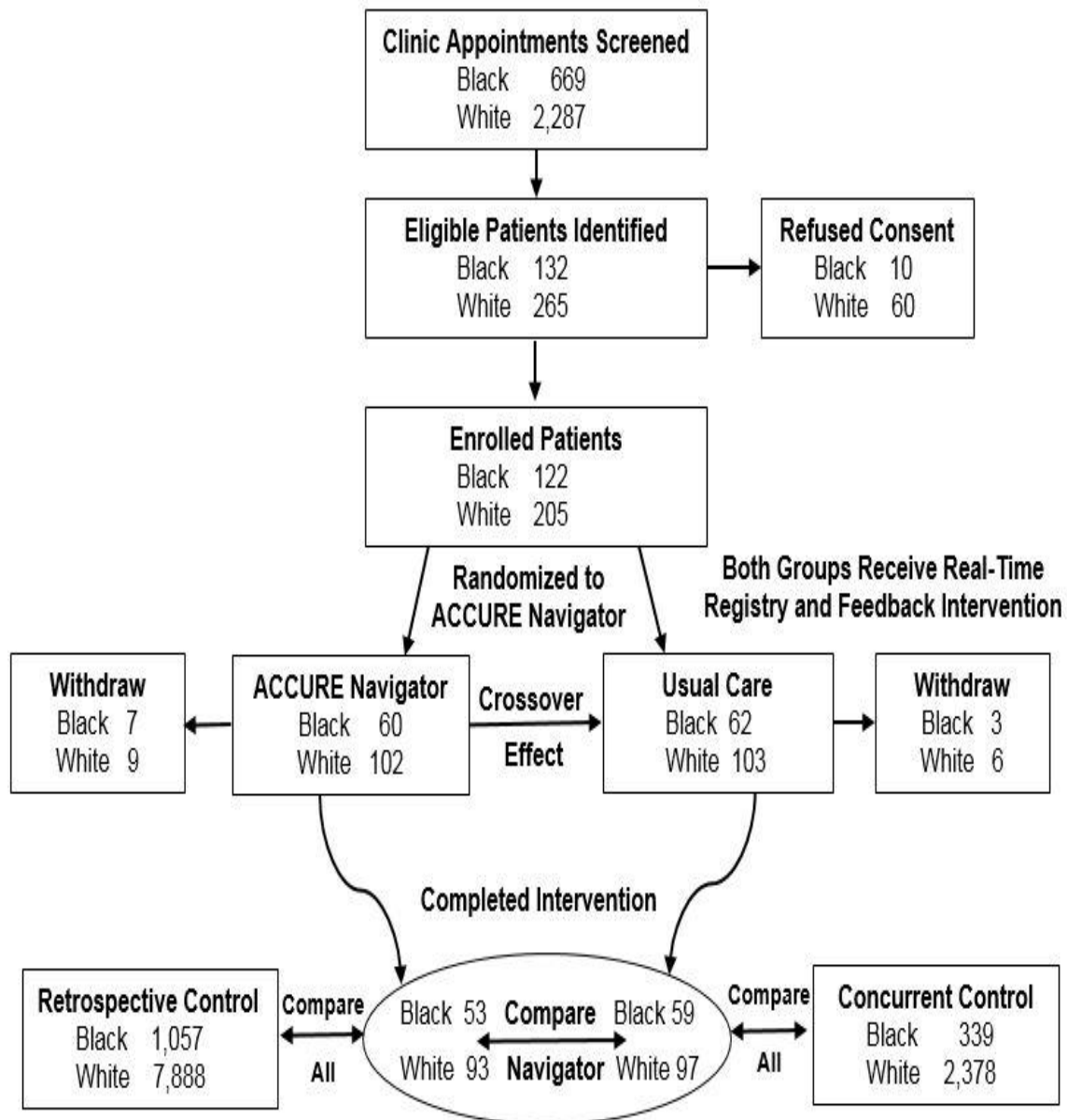


EXHIBIT 10

**IN THE UNITED STATES DISTRICT COURT
FOR THE SOUTHERN DISTRICT OF MISSISSIPPI
JACKSON DIVISION**

STATE OF MISSISSIPPI;
STATE OF ALABAMA;
STATE OF ARKANSAS; COMMONWEALTH OF
KENTUCKY; STATE OF
LOUISIANA; STATE OF Missouri;
and STATE OF MONTANA,

Plaintiffs,

No. 1:22-cv-113-HSO-RPM

v.

XAVIER BECERRA, in his official
capacity as Secretary of Health and
Human Services; THE UNITED
STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES;
CHIQUITA BROOKS-LASURE, in her
official capacity as Administrator of the
Centers for Medicare and Medicaid
Services; THE CENTERS FOR
MEDICARE AND MEDICAID
SERVICES; THE UNITED STATES
OF AMERICA,

Defendants.

DECLARATION OF DR. SIDNEY CALLAHAN

I, Dr. Sidney Callahan, declare as follows:

1. The facts set forth in this declaration are based on my personal knowledge, and if called as a witness, I could and would competently testify to the following matters under oath.
2. I am a board-certified Obstetrician-Gynecologist at Green Valley OB/GYN, a private practice that is owned by Unified Women's Health—a single specialty group with practices across multiple states. I joined Green Valley after graduating from the University of New England College of Osteopathic Medicine and completing my residency at Abington

Memorial Hospital in Abington, Pennsylvania. While attending the University of New England, I also obtained a master's degree in Public Health from Johns Hopkins University in Baltimore, Maryland.

3. I work with a very diverse range of patients. Nearly half of my patients are Black. A number of my patients speak English as a second language. And the ages of my patients range from teenagers to 90-year-olds. Some of my older patients rely on Medicare as their sole source of medical insurance.
4. I am familiar with the concept of disparity in health care outcomes because of the academic focus of my graduate education and the range of experiences I have had while practicing medicine in Greensboro, North Carolina. In my view, disparity in health care refers to differences in medical outcomes that patients experience even though they share the same underlying medical condition.
5. During my graduate program, I spent a substantial amount of time studying global health disparities. My interest in addressing global health disparities led me to provide voluntary medical care in several different countries. For example, I spent three years volunteering with a project in Cap-Haïtien, Haiti that strives to reduce maternal mortality. Most recently, I spent three weeks in Nepal to help develop a health care system in the Himalayas. I have also provided voluntary medical care in Uganda and India.
6. I became more familiar with racial disparities in health care when I moved to Greensboro, North Carolina and began practicing medicine at Green Valley OB/GYN. My time in Greensboro has been an awakening in how much work remains to be done in reducing health disparities that people of color, particularly Black people, experience in communities across the United States.

7. I became a member of the Greensboro Health Disparity Collaborative to support community efforts toward reducing racial disparity in health care throughout Greensboro, North Carolina. I first learned about the Collaborative through a guest speaker who came to Moses Cone Hospital to discuss the Collaborative's work. The Collaborative's mission is to establish structures and processes that respond to, empower and facilitate communities in defining and resolving issues related to disparities in health. As a member of the Collaborative, I attend monthly meetings and participate in the Collaborative's research, fundraising, and other programing efforts. I have been a member of the Collaborative for nearly three years.
8. As a prerequisite to membership in the Collaborative, I participated in "Phase 1" of the Collaborative's anti-racism training program. The training involved a two-day seminar where a facilitator led a small group (approximately 20 people) through range of exercises to identify and discuss people's perceptions of race. The facilitator also explained how policies throughout the United States' history have diminished Black Americans' access to resources and opportunities in an ongoing, systemic way. For example, the facilitator explained how low rates of Black home ownership today are a modern byproduct of decades of redlining.
9. I have attended the Collaborative's Phase 1 training multiple times and believe that it has had a positive effect on the way that I practice medicine. The lessons I learned about structural racism and cultural differences provide me with a reminder that, because of the implicit biases we all have, simply ignoring the race of my patients may actually lead to racially disparate health outcomes. For example, I have worked with Black patients who have vocalized their suspicion toward medicine and medical professionals. If I ignore the

historical reasons why a Black person in America may be suspicious of medical providers, I lose trust with my patient and hinder my ability to design a treatment plan that my patient is likely to complete.

10. I think that medical professionals would provide better care to *all* of their patients if they participated in anti-racism training. In my experience, the vast majority of doctors believe they provide equal care to all of their patients, regardless of race. But I have observed some of those same providers discuss or complain about their patients using racial stereotypes. For example, I have heard providers disparage Black patients who own expensive sneakers or other accessories but have not spent money on preventative health care measures. I have frequently encouraged my colleagues to participate in anti-racism training because I believe that this training teaches empathy for and understanding of the many reasons why people of color may be reluctant or unable to engage with providers of routine, preventative medical care.
11. Anti-racism training is particularly important for medical professionals who serve Medicare recipients. Older people of color who are eligible for and aging into Medicare are most likely to have suffered from some of the most extreme forms of overt racism, including at the hands of medical professionals. If healthcare providers ignore how those experiences may have influenced their patient's medical history, they cannot develop a treatment plan that fully suits their patient's needs.
12. I do not provide worse medical care to white patients because I have participated in the Collaborative's anti-racism trainings or because I am sensitive to the distinct needs of my patients of color. In fact, the Collaborative recently completed a five-year study in connection with the University of North Carolina at Chapel Hill, The Partnership Project,

Inc., Cone Health, and the University of Pittsburgh Medical Center which showed that implementing various anti-racism measures improved outcomes for *all* patients with Stage 1 or 2 breast or lung cancer. The results of this study, Accountability for Cancer Care Through Undoing Racism and Equity (ACCURE), also fortify my belief that encouraging doctors to participate in anti-racism training is not tantamount to “reverse racism”—the concept that being mindful of and attempting to eliminate implicit bias against Black people will necessarily result in discrimination against white people. The Collaborative applied for and obtained a grant for this study from the National Cancer Institute, which is part of the National Institutes of Health.

13. My practice is collaborating with UNC to complete a follow-on study to the ACCURE.

The study, called ACURE4Moms will examine whether implementing anti-racism measures in the obstetrics and gynecology context will similarly eliminate racial health disparities and improve health care outcomes for all patients.

14. A critical part of the Collaborative’s mission is to encourage as many health care providers as possible to understand the importance of addressing racial disparities in health care and to help them develop approaches and methods to accomplish that goal. If Medicare providers have an option to adopt anti-racism plans as part of the Merit-Based Incentive Payment System, this will help us accomplish our mission. On the other hand, if that option is prohibited, this will present an obstacle and force us to find other ways to persuade health care providers to adopt plans without government support and encouragement. In short, it will make our mission more difficult and indeed, more expensive, as we work with health care providers and encourage them to acknowledge and address the impact of race on providing the highest level of medical care.

I solemnly swear and affirm under the penalties of perjury that the foregoing is true and correct based on my personal knowledge.

/s/ Sidney Callahan
Declarant's Signature

5/11/2023
Date

Sidney Callahan
Declarant's Printed Name