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Research Priorities in Pediatric Asthma Morbidity: Addressing the Impacts of Systemic Racism on Children with Asthma in the United States

An Official American Thoracic Society Workshop Report

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This official workshop report of the American Thoracic Society was approved May 2024

Abstract

Background: In the United States, Black and Latino children with asthma are more likely than White children with asthma to require emergency department visits or hospitalizations because of an asthma exacerbation. Although many cite patient-level socioeconomic status and access to health care as primary drivers of disparities, there is an emerging focus on a major root cause of disparities—systemic racism. Current conceptual models of asthma disparities depict the historical and current effects of systemic racism as the foundation for unequal exposures to social determinants of health, environmental exposures, epigenetic factors, and differential healthcare access and quality. These ultimately lead to biologic changes over the life course resulting in asthma morbidity and mortality.

Methods: At the 2022 American Thoracic Society International Conference, a diverse panel of experts was assembled to identify gaps and opportunities to address systemic racism in childhood asthma research. Panelists found that to examine and address the impacts of systemic racism on children with asthma, researchers and medical systems that support biomedical research will need to 1) address the current gaps in our understanding of how to conceptualize and characterize the impacts of systemic racism on child health, 2) design research studies that leverage diverse disciplines and engage the communities affected by systemic racism in identifying and designing studies to evaluate interventions that address the racialized system that contributes to disparities in asthma health outcomes, and

 address funding mechanisms and institutional research practices that will be needed to promote antiracism practices in research and its dissemination.

Results: A thorough literature review and expert opinion discussion demonstrated that there are few studies in childhood asthma that identify systemic racism as a root cause of many of the disparities seen in children with asthma. Community engagement and participation in research studies is essential to design interventions to address the racialized system in which patients and families live. Dissemination and implementation studies with an equity lens will provide the multilevel evaluations required to understand the impacts of interventions to address systemic racism and the downstream impacts. To address the impacts of systemic racism and childhood asthma, there needs to be increased training for research teams, funding for studies addressing research that evaluates the impacts of racism, funding for diverse and multidisciplinary research teams including community members, and institutional and financial support of advocating for policy changes based on study findings.

Conclusions: Innovative study design, new tools to identify the impacts of systemic racism, community engagement, and improved infrastructure and funding are all needed to support research that will address impacts of systemic racism on childhood asthma outcomes.

Keywords: asthma; racism; health disparities; minority and disadvantaged populations; social determinants of health

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Introduction

Disparities in pediatric asthma prevalence and outcomes across racial and ethnic groups in the United States persist without a precise determination of their cause. Underlying biology cannot explain these differences, because racial categories used in the U.S. census and in research are social definitions of race that lack a biologic. genetic, or anthropologic basis (1, 2). The social concept of race based on perceived differences in individuals' skin color led to the creation of a racialized system that perpetuates inequities in social caste, socioeconomic position, environmental exposures, access to quality health care, and other contextual factors that contribute to health inequities; thus, racism is a root cause of many health disparities, including those in asthma. One example of the racialized system in the United States is redlining, a discriminatory practice created by the federal government's Home Owner's Loan Corporation in the late 1930s to color code maps and identify "high-risk" areas for mortgages and home loans, overwhelming and systematically identified minoritized people and neighborhoods as "high risk" or grade "D," thus discouraging any loans. This practice continued until the Fair Housing

Act was passed in 1968 (3). Studies now show that many historically redlined neighborhoods have low homeownership, poor housing, poor air quality, increased violence, decreased access to health care, poor neighborhood opportunity, and poor respiratory and other pediatric health outcomes, including asthma (4-8). The current residents of those redlined areas are more likely to be from minoritized backgrounds and to have lower incomes. Although this is not true of every urban area, because populations shift, the long-term impacts are clear. As a result of policies such as redlining in societies influenced by a racial caste system, race often approximates social position and contributes to differential access to social determinants of health, including clean environments, quality education, housing, employment, and health care. These tenets of social and environmental justice substantially affect pediatric asthma outcomes (4, 9-14).

Behavioral and social sciences have explored racism and health for decades. In the last decade, there has been a concentration of studies demonstrating clear associations between racism—both interpersonal and structural—and asthma (15–18). Furthermore, interventions

specifically designed to counter the effects of racism show benefits, providing additional evidence for systemic racism as a root cause of pediatric asthma (19). Studies indicate that interpersonal racism leads to biologic changes in inflammatory response, telomere length, and poor mental health (20, 21). Coogan and colleagues showed that everyday and lifetime racism were associated with an increased incidence of adult-onset asthma in Black women and that the association was stronger in Black women who reported persistent racism over a 10-year study period (22). Thakur and colleagues demonstrated that interpersonal discrimination contributes to worse asthma outcomes in children (23-25). Other studies have shown the impacts of racial inequities in the care of children with asthma and the impact on specialist care, medications, and asthma control. Nevertheless, very few studies that examine the effect of racialized policies and the impact on child health outcomes identify systemic racism as the root cause; therefore, the direct impacts of systemic racism on health outcomes for Black, Latino, and other historically marginalized populations have not been well delineated.

There are several barriers to understanding the role of systemic racism in pediatric asthma outcomes. 1) There

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This document has a data supplement, which is accessible at the Supplements tab.

^{*}These authors contributed equally to this work.

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is a lack of consensus on how to quantify systemic racism. 2) There is not a clear methodology for developing and assessing interventions targeting systemic racism. 3) Research teams lack diversity in composition and do not have expertise in the lived experience of children and families experiencing interpersonal or systemic racism. 4) Current research funding together with entrenched institutional research frameworks do not support products that will change the status quo. 5) To understand, identify, and quantify targets to reduce downstream health effects of systemic racism, one needs to include data from several sources and interpret data with multidisciplinary teams. Data from multiple sectors (e.g., education, housing, employment) and community levels (e.g., census tract, block group, state) (26, 27) are required to evaluate unintended impacts. 6) Without the consultation or inclusion of affected populations in interpreting the results, contextualizing multilevel data may lead to inappropriate conclusions (28). Community-based participatory researchers have long advocated for the inclusion of diverse research partners and increased participation of minoritized patient populations. However, a recent systematic review of all published clinical trials reporting patient engagement in research from 2011 to 2016 found heterogeneity in the type and extent of patient engagement. Moreover, in the context of all concurrent clinical trials, less than 1% reported any type of community engagement (29, 30). 7) Current funding models perpetuate this problem by limiting funding for multisector interventions targeting systemic racism and by not enforcing or supporting their own requirements for rigorous community engagement for all health equity research.

This workshop report outlines priorities for research addressing the direct impacts of systemic racism on pediatric patients with asthma, by discussing *I*) a conceptualization of systemic racism in pediatric asthma; 2) ethical considerations in designing studies to address disparities in pediatric asthma outcomes; 3) how to design and implement studies to identify inequities due to systemic racism and how to evaluate interventions targeting systemic racism in pediatric patients with asthma; and 4) how funders and institutions can promote racial equity in pediatric asthma research and advocacy to improve health outcomes.

Methods

Formation of the Steering Committee

In 2022, the cochairs convened a diverse group of researchers, clinical scholars, social scientists, and community health workers with expertise in pediatric asthma, asthma research, health disparities, environmental health, epidemiology, population health, social sciences, psychology, and systemic racism to participate in a series of virtual workshop discussions. The goals of the workshop were to 1) evaluate the current evidence for the impacts of systemic racism on children with asthma, 2) identify gaps in understanding of the impacts of racism and a racialized system, and 3) create a framework for researchers to address those gaps in the future.

American Thoracic Society Systemic Racism in Pediatric Asthma Workshop

Meetings were conducted virtually. Prerecorded sessions that addressed fundamental concepts related to the content of the workshop were made available to all participants before the workshop sessions to ensure that all participants were familiar with concepts that may have been outside of their respective disciplines. The initial large committee meeting with all workshop participants was 2 hours long. Follow-up cochair meetings led to the creation of four workgroups, assignment of workgroup leaders, and a draft of a manuscript outline. Each workgroup met at least once virtually, and workgroup leaders met virtually after those meetings to review the content discussed in the meeting and to create a writing plan. The large committee meeting and small workgroup meetings were recorded, and the transcripts were reviewed in preparation for writing the manuscript. A detailed description of workshop participants (see Table E1 in the data supplement) and workshop activities, including background reading, presentations, and description of session activities (Table E2), is provided in the appendix. Potential conflicts of interest were disclosed and managed in accordance with the policies and procedures of the American Thoracic Society (ATS).

ATS Workshop Report Preparation

A comprehensive review of the literature included PubMed and Google Scholar searches for the following in both the healthcare and social sciences literature: race.

racism, ethnicity, disparity, inequity, environmental justice, community-based research, dissemination and implementation (D&I), and asthma. The literature search helped delineate the barriers noted in the introduction and defined the overall workshop goal to create a guide for the design and implementation of studies to investigate systemic racism and pediatric asthma. Please see an abbreviated example of one search in the appendix (Table E3) for studies evaluated for the research design section. Further discussion with subject matter experts, including the cochairs and others, delineated the importance of the other three workshop goals: 1) defining and conceptualizing systemic racism; 2) addressing the complicated ethical issues that are part of working with minoritized and marginalized populations, including building trust, understanding their lived experience, and respecting their goals for health and research; and 3) identifying barriers within institutions and funders to conduct these studies. After the first large committee meeting, the initial outline of the workshop report was authored by the cochairs and workgroup leaders. After each of the four smaller workgroup meetings, workgroup leaders and cochairs worked together to prepare an initial draft of the manuscript. All workshop participants reviewed and edited the complete workshop report, and it was finalized by the cochairs. The final workshop report underwent several cycles of external peer review and revisions, followed by review and approval by the ATS Board of Directors.

Results

Conceptualizing Systemic Racism and the Impacts on Pediatric Asthma

A critical first step in understanding the role of racism in pediatric asthma is to define terms. "Race" is a social construct, the social interpretation of how one looks in a given place and time (31). That is, one's racial and ethnic classification is dynamic and informed by geography, culture, social and political climate, and time in history. The conflation of race and ethnicity, genetic ancestry, and biologic differences is a common misconception. Although there have always been labels to distinguish inhabitants of different countries, tribes, and ethnicities, the current racialized system of identification was developed to facilitate and justify oppression, slavery, and conquest (32–34).

Camara Phyllis Jones defines "racism" as the "system of structuring opportunity and assigning value based on the social interpretation of how one looks (which is what we call 'race'), that unfairly disadvantages some individuals and communities, unfairly advantages other individuals and communities, and saps the strength of the whole society through the waste of human resources" (31, 35). Braveman and colleagues stated, "Racism is the relegation of people of color to inferior status and treatment based on unfounded beliefs about innate inferiority, as well as unjust treatment and oppression of people of color, whether intended or not. Racism is not always conscious, intentional, or explicitoften it is systemic and structural" (36, 37). There are several types of racism. "Interpersonal racism" refers to race-based bias or prejudice between individuals. "Institutional racism" refers to differential access to goods, services, and opportunities by race within a singular institution, such as differential access to quality education in a public school system. Institutional racism is often written into laws or bylaws (e.g., redlining) but could also be behavioral norms (e.g., people with "Black"-sounding names receiving fewer interviews for the same résumé). Systemic and structural racism connects multiple institutions to reinforce racial hierarchy. Structural racism "emphasizes the role of structures (e.g., laws, policies, institutional practices, and entrenched norms)" that are the backbone of our sociopolitical systems and is a subset of systemic racism (36). The term "systemic racism" represents the whole system, including the structures that uphold the systems. It is generally understood to refer to "forms of racism that are pervasively and deeply embedded in and throughout systems, laws, written or unwritten policies, entrenched practices, and established beliefs and attitudes that produce, condone, and perpetuate widespread unfair treatment of people of color" (38). Systemic racism reinforces discriminatory beliefs, values, and distribution of resources and perpetuates historical injustices (36). For example, slavery and Jim Crow laws were designed to disenfranchise Black adults and restrict their right to work and get a quality education (39). Unfortunately, although civil rights legislation made it illegal to discriminate against Black adults in education and employment institutions, systems unintentionally perpetuate historical

injustices and fail to correct inequities (36). For example, voter suppression and gerrymandering are still used to disenfranchise Black adults (36, 40, 41), and banks continue to grant minoritized persons fewer home mortgages and often offer them mortgages with higher rates and fees (3, 42, 43).

The concept that many systems have a racialized foundation is critical to our understanding of differences in pediatric asthma outcomes, because it focuses on the complex historical and current interactions between social systems (e.g., political, legal, educational, economic, health care, media) and their impacts on resources and other social determinants of health shown to have long-term effects on health and health outcomes. Martinez and colleagues provide one conceptual model to explain the pathways by which systemic racism leads to the development and worsening of asthma through modifying biologic processes that lead to altered airway microenvironments and T-helper type 1-type 2 imbalance that contributes to the pathogenesis of atopic diseases (33). The authors show how determinants of health (e.g., culture, societal institutions, health behaviors, biology, ancestry) influence how structural racism is perpetrated and ultimately affects biologic embedding and leads to racial disparities in allergy and immunologic conditions. The authors further break down structural racism into upstream factors (e.g., current and historical racist policies such as redlining) and proximal factors (e.g., physical and social environment) to show how racism affects several important domains known to contribute to asthma disparities.

Building from the conceptual model published by Martinez and colleagues (33), and drawing from other conceptual models showing how racism affects health (44), we propose a revised conceptual model (Figure 1) that 1) incorporates the historical process of racialization by which human biological variation, ancestry, and geographic origin were reduced to perceived phenotypic differences and then mapped to discrete, socially defined "races"; 2) includes colonization as a driving force of historic racialization; and 3) emphasizes the compounding influence of historical racialized policies (e.g., redlining) on current manifestations of systemic racism (e.g., physiologic response to environment) that contribute to asthma outcomes.

Considerations for Ethical Study Design in Research to Address Systemic Racism in Pediatric Asthma

The workshop identified several core ethical considerations in the design of research to address systemic racism and pediatric asthma, including 1) steps to engage communities disproportionately burdened by asthma morbidity in the design of research; 2) how to create diverse research teams, adequately compensating participants for their time; 3) ensuring appropriate representation through flexible recruitment and retention practices; 4) careful collection and analysis of personal data; and 5) thoughtful evaluation in selecting reference populations (see Table 1 for workshop recommendations on ethical conduct of research to address systemic racism and pediatric asthma).

Engaging communities in design of asthma research. Community engagement ensures that research is relevant to the population being studied, aligns the goals of the researchers and the community, addresses community priorities, and results in interventions that are likely to be sustained beyond the project period (30). When research team members who are working with communities and recruiting participants reflect the populations involved, community engagement and recruitment will be more successful (45). Effective engagement encompasses involving, codesigning, cocreating, and cultivating relationships with key partners, particularly those historically underrepresented in research, who are invested in the field of study. Engaging all parties with an interest in the outcome of the research as members of the research team requires building trust, establishing alignment, and recognizing and respecting the knowledge that each party brings. If done well, these partnerships allow "bidirectional learning, mutual benefit and trust, and equitable distribution of power and resources" (46). Building partnerships and mutual trust also limits the risk that racist approaches leading to mistreatment and mistrust are embedded in the research (47). In pediatric asthma research, the lived experience of families and children with asthma and the community partners that support them are required for the iterative process of hypothesis testing and evaluating data in the context of personal experiences needed to identify meaningful metrics of success and solutions to disparities in childhood asthma (48, 49).

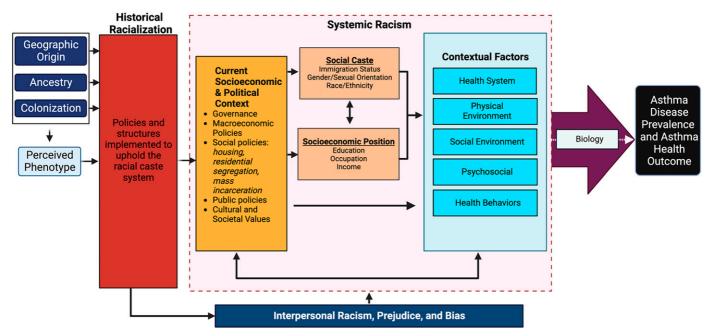


Figure 1. Conceptual model of the impacts of historical racialization and systemic racism on asthma disease prevalence and outcomes. Conceptual model describing how perceived phenotypes led to historical racialization, which led to a system that perpetuates social caste and socioeconomic status positions that exist within a social and political context. The model demonstrates the impacts of systemic racism and interpersonal racism on biology and disease manifestation.

Community engagement can be challenging. Research groups may find that power dynamics within groups (50) and the lingering effects of "historical trauma" stand in the way of meaningful collaboration (51, 52). Mistrust or distrust in medical research and ongoing experiences of racism in the health system are critically important barriers to successful recruitment and retention of exploited communities (45), especially in studies of racism. Although the community members may not have the same academic training, their contribution as experts in the lived experience of the population offers a unique and impactful contribution to the approach and interpretation of outcomes. Employing community members as equal members on asthma research teams, with titles that are commensurate with other members of the research team, is a particularly effective mechanism for building trust and forging connections between researchers and participants (45, 53, 54). Thus, community members' expertise is valued equally to that of principal investigators, and resources can be fairly and adequately shared. Finally, community members should be compensated at levels similar to those of traditional coinvestigators for their participation in research design, conduct, and dissemination and should be included in author bylines (51, 55).

Building diverse, multidisciplinary research teams. Much of the groundbreaking work for the examination of race and racism has been laid by social and behavioral scientists. Anderson showed that multilevel research collaborations that combine the expertise of several disciplines to address complex health concerns is a key component of addressing sociobehavioral effects of disease at the organ system, cellular, and molecular levels (56). Thus, to meaningfully address the impacts of systemic racism on pediatric asthma, we must engage colleagues from diverse disciplines with varied levels of expertise.

Study populations: recruitment and retention of diverse participants. To maximize scientific validity, it is important that researchers appropriately identify and collaborate with the populations most deeply and adversely impacted when designing studies to address systemic racism (57). Recruitment strategies that include outreach in the community (e.g., religious centers, community events) are more likely to be successful at identifying a wide range of individuals who may experience racism. Individuals from racially and ethnically marginalized populations may experience barriers to participating in research because of time and resource constraints (45). Thus, investigators who cannot provide flexible

times, visit lengths, and locations for visits should be cognizant of potential sampling bias. For example, some parents may not be able to take time off from work or secure transportation, resulting in unintentionally disproportionate recruitment from unemployed or underemployed households. Study visits that take place at participants' homes, local community centers, or schools may be more convenient and comfortable for the participants and their families and more representative of the community of interest (58–62). These steps to ensure diversity in the study population will optimize the scientific output of the research findings.

Data collection: allowing participants to self-identify and communities to define the problems. To address systemic racism in research, it is essential to have accurate data that reflect the impacts of policies and other aspects of systemic racism that led to inequities in health and health care. At the foundation is collecting accurate selfidentified race, ethnicity, ethnic background, and language data for the populations being studied and served. It is also notable that although there is correlation between selfidentified race and genetic ancestry, individuals frequently are unaware of their true origins (63). It is important to understand how these data, together with other demographic factors, are collected in

Table 1. Recommendations and considerations for conducting ethical research to address systemic racism and pediatric asthma

Considerations	Descriptions
Evaluate use of race as a variable (119)	 Evaluate why race (e.g., shared social experience or exposure) is included in your research. State your reason for including race, a social construct, in your methods and interpret race-related findings. Acknowledge that race and ethnicity are social constructs and differences in outcomes by race and ethnicity do not necessarily indicate biological differences. Understand that genetic ancestry is a better way to assess potential biological differences and that race does not measure genetic ancestry. Acknowledge and learn how to measure racism as a possible root cause of the disparity being studied. Acknowledge the connections between race and social class that are perpetuated by institutionalized racism and explicitly measure social class in addition to race.
Use a restorative justice approach to systemic inequities	 Include populations harmed in the development, implementation, and evaluation of solutions. Consider a framework such as the acknowledgement, redress, and closure (ARC) model to acknowledge inequities and include community partners and harmed populations when developing solutions and evaluating effectiveness of interventions.
Establish multidisciplinary teams and diverse research teams	 Include community members and invite academic partners outside of health care, including those with expertise in sociology, psychology, education, transportation, environmental services, housing, etc., when designing research studies, writing grant applications, and evaluating results. Collaborate with health equity experts to increase the methodologic rigor. Recruit and retain study staff and investigators from the community of interest. Adequately compensate community members engaged in research activities.
Collect accurate and inclusive data	 Collect accurate self-identified race, ethnicity, ethnic background, and language data in the electronic health record and research databases. Allow multiple identities to be self-identified (e.g., multiple races, ethnicities, gender identities) and consider how intersectionality may amplify the impacts of racism in individuals. Measure "socially assigned race" ("How do OTHER people usually classify you in this [country/city/place]?"), including as possible response options all of the "on the street" categories pertinent to that locale, to capture the substrate on which racism operates day to day (31). Include patients and community members in determining and defining the outcomes to be measured. Consider collecting data from multiple sources (e.g., emergency room use, patient-reported outcomes) and from multiple sectors (e.g., transportation access, neighborhood safety, local air quality) to better understand the context of the problem and sites for intervention. Collect data to understand barriers and unintended consequences of study enrollment and of the interventions being evaluated. Collect data to show success as defined by short- and long-term goals set by the population being evaluated and members of the community they live in (e.g., key partnerships to establish mail order pharmacy delivery short term and increased adherence long term). Collect data on racism, social class, and culture to help determine root causes of differences within the sample. Collect data to support policies identifying the structural changes needed to address the root cause of the condition under investigation. Include geospatial data to understand how key exposures for asthma
Decenter Whiteness in the evaluation	 are distributed across a community. Evaluate whether the scientific question requires a White population as a comparator or whether the outcomes can be compared with the whole population. Assess if a comparator population is needed at all.

the electronic health records before using them to identify inequities and disparities in health. For example, using the question, "How do OTHER people usually classify you in this country? Would you say White, Black or African American, Hispanic of Latino, Asian, American Indian or Alaska Native, Native Hawaiian or Other Pacific Islander, or some other group?" allows more direct measurement of the substrate on which racism operates day to day (31). In addition, it is important to recognize the importance of intersectionality, or the complex and cumulative ways that multiple different identities experienced by an individual (e.g., multiple races, ethnicities, gender identities) may amplify the impacts of racism. Once race and ethnicity data have been collected, investigators should thoughtfully consider the best approaches to including these variables in analysis. Several approaches exist, including the hierarchical model that combines all Hispanic participants, regardless of race, versus the additive model that sets multiple categories for Hispanic participants, depending on identified race (64).

Communities at the center of a research project or intervention should be consulted to understand additional data elements, including markers of success, desired short- and long-term outcomes, how the data/results should be disseminated, and what data are needed for sustained change, including policy goals. Quantitative studies are helpful in identifying where racism may be contributing to disparities. However, qualitative research is critical to understanding how racism is operating and being experienced by community members (65, 66). Indeed, Jones has introduced the question, "How is racism operating here?" as a tool for identifying the mechanisms of systemic racism in our structures, policies, practices, norms, and values. These mechanisms are actually the elements of decision making: Structures are the "who," "what," "when," and "where" of decision making; policies are the written "how" of decision making; practices and norms are the unwritten "how" of decision making; and values are the "why." By engaging with communities in asking "How is racism operating here?" with regard to differential pediatric asthma morbidity in various settings, we can identify promising levers for intervention and early targets for action (67).

Thoughtful evaluation in selecting reference populations: decentering Whiteness in research. White normativity, the notion that Whiteness is the standard racial identity, pervades medical research, where participants identified as White have historically been designated as the reference group with which other racial and ethnic groups are compared (68, 69). The use of White race as the norm reinforces and perpetuates the notion that Whiteness is the standard for optimal health. Pediatric asthma disparities research traditionally identifies differences in access, treatment, and outcomes among children from minoritized groups and compares these data with data for children in a White reference group for the purpose of quantifying and closing gaps in disparities to achieve health equity. Centering on White race as the standard for optimal health focuses attention on racial deficits rather than focusing on root causes, such as racism and its effects on health as the source of disparate asthma outcomes (70). In addition, when trying to understand how an exposure or risk factor operates in a single community, including other groups can be a distractor and may not allow appropriate understanding of how the exposure influences that specific population. A recent systematic review of pediatric clinical practice guidelines concluded that race was frequently used in ways that could have a negative impact on healthcare inequities (71). Many scholars note that current reporting of health disparities places the burden and responsibility of the outcomes on marginalized, minoritized populations rather than focusing the analytic lens on institutional policies and practices that have propped up a system where disparities thrive (72).

To decenter Whiteness, researchers will need to pivot away from White de facto reference groups and adopt other comparators, such as the whole population, multiple reference groups, or nondominant race groups, depending on the outcome of interest. When the inclusion of a reference group is appropriate, there should be explicit justification for using a privileged versus historically marginalized population. These approaches will require adequate representation with diverse study populations based on relative advantage and disadvantage experienced between different groups in the community of interest (70). Also, reviewers of grants and manuscripts should be discouraged from reflexively

asking for White "control" or comparator groups, and, if they do, they should be required to provide justification for doing so. In addition, race-neutral reference ranges should be adopted to ensure that measures are not artificially scaled to normalize disparities, as was recently recommended by the American Thoracic Society Statement on Race and Ethnicity in Pulmonary Function Test Interpretation (73).

Using Dissemination and Implementation Science to Apply an Antiracism Lens to Addressing Pediatric Asthma Disparities

D&I science evaluates how evidence-based practices and policies are effectively communicated and/or adapted to real-world settings, including clinical practice and residential communities. The workshop participants agreed that D&I science provides an ideal study design for interventions targeting systemic racism in childhood asthma (19, 74). Research to address the impacts of systemic racism in children with asthma should be grounded in frameworks that allow a multilevel evaluation of the impacts of racism on asthma outcomes as well as the barriers to the adoption, acceptance, sustainability, or implementation of evidence-based interventions (see Table 2). Moreover, interventions targeting racial disparities in childhood asthma should contain upstream implementation targets such as historical policies or embedded social norms that contribute to the social, physical, economic, or political environments influencing health (74). Shelton and colleagues describe five core elements of implementation science through which researchers should apply an antiracism lens: 1) community and partner engagement; 2) conceptual frameworks/models; 3) development, selection, and/or adaptation of evidencebased interventions; 4) evaluation approaches; and 5) implementation strategies (46). Another approach is a "natural experiment" design that can be a common and powerful way of studying the impact of a policy implementation (19). Here we describe several strategies that adopt an antiracism lens toward D&I research strategies in the study of pediatric asthma.

Community-based participatory research and community engagement as a basis for social justice research. Including those who directly experience the unfair disadvantages created and perpetuated by

Table 2. Recommendations for design and evaluation of research to address systemic racism and pediatric asthma

Considerations Descriptions

Engage community members and partners from other sectors

Study design/framework

Choose effective intervention methodology

Evaluation: data

Evaluation: methods

- Include community members and academic partners outside of health care, including education, transportation, environmental services, housing, etc., in the design, evaluation, and preparation of grant applications.
- Work with communities to understand context and to identify possible unintended consequences.
- Apply dissemination and implementation research frameworks that will allow the community partners and researchers to evaluate the barriers to and the outcome of implementing interventions to address systemic racism.
- Take advantage of "natural experiment" study design that can provide an
 opportunity to study the impacts of a policy implementation.
- Incorporate an antiracism lens and frameworks in a variety of methodologic approaches (e.g., epidemiology, randomized controlled trials).
- Implement multisector interventions that allow investigators to analyze the impacts of systemic upstream (e.g., policy) factors and downstream (e.g., housing) factors that affect health outcomes.
- Use an antiracism lens to evaluate the effects of racism on the process and the outcomes of the study.
- Collect accurate self-identified race, ethnicity, ethnic background, and language data in the electronic health record and research databases.
- · Collect additional data on socially assigned race.
- Consider collecting data from more than one sector to elucidate the systemic impacts (e.g., air quality, housing violations, and hospitalizations in the same census track).
- Collect data to understand the impacts of racism and unintended consequences from study enrollment and from the intervention.
- Collect data to show community-defined success in short- and long-term goals.
- Collect data to support policies identifying structural changes needed to address root causes of race-associated disparities.
- Consider a tool to measure the impacts of systemic racism on the outcome.
- · Consider mixed methods to include qualitative evidence.

racism as part of the research process results in research questions and study outcomes that are better tailored to impact those outcomes most important to the participants themselves (51, 55). Community-based participatory research and participatory action research approaches are well poised to help define and address research questions surrounding social justice (75–77). Appropriately sustained engagement of members of the community requires involvement at each stage of research, including formulation of the research questions, data collection, analysis, interpretation, and reporting of results broadly, including to the affected communities (78). The foundational work to build trust and the involvement in research needs to occur before pursuing traditional grant funding mechanisms, which calls for a new national funding model that includes funded planning phases for community work as discussed above (55). Communityengaged studies should be a colearning experience: The academic team learns from and about the community (community strengths, problem definitions, approaches to

solving those problems), and the community team learns from and about academia (scientific methods, grant applications, publication) (79). Study teams should consider the time it may take for community members to complete any required training on the responsible conduct of research that they might not otherwise do except to be able to meaningfully participate on the research team. Community team members will need to be compensated for that time and might benefit from research team support in the completion of any required training. Research teams also need to pursue additional funding that supports patient and community engagement as a fundamental aspect of the research process; The Patient-Centered Outcomes Research Institute engagement award program is an example of a federal grant for community-engaged research (80).

A final tenet that has historically been difficult for many research teams is to ensure that findings are sensitively communicated back to the participating communities so that outcomes can be addressed. Ensuring that study results are shared with community

members also illustrates the degree to which research studies are not only coproduced but also co-owned. However, mistrust in data sharing may be founded on concerns about confidentiality and sensitive information sharing. At the beginning and end of the study, community partners should participate in any discussion of data safety and how best to sensitively share results with participants and key partners.

Dissemination and implementation science and frameworks. D&I science evaluates the gap between research and realworld application or practice using tools including frameworks, theories, and models. There are several conceptual frameworks used to plan and execute D&I research studies. These conceptual frameworks and models highlight multilevel context with respect to disseminating and implementing research; however, none underscore the importance of the extraorganizational or social context, including racism, that shapes our institutions, communities, and provision of care (e.g., racism). We recommend a select group of frameworks that effectively allow researchers to use an antiracism lens

Table 3. Research methods and dissemination and implementation frameworks with antiracism lens

Considerations	Descriptions
Nationally available framework	National Institutes on Minority Health and Health Disparities (NIMHD) research framework (102).
	This framework provides an invaluable visual depiction of the numerous and complex levels and domains that influence the health of historically minoritized populations. We recommend that researchers use the NIMHD framework to thoroughly reflect on the necessary components that should be included in their intervention and evaluation approaches.
Research frameworks that	Public Health Critical Race Framework (120, 121) and Healing ARC (122, 123).
embed critical race theory	These frameworks are vital for research interventions at the institution level because they center on medical restitution and guide researchers to move beyond typical, indirect interventions such as bias training. The Healing ARC—acknowledgment, redress, and closure—is a pragmatic framework for addressing institutional racial inequities in health care delivery and treatment.
Research frameworks that consider context	Health Equity Implementation Framework and race(ism) Consolidated Framework for Implementation Research (CFIR) (124).
Consider Contox	This framework uses the Public Health Critical Race Praxis to adapt CFIR to delineate how health equity may be concomitantly assessed and addressed in planning the implementation of an evidence-based intervention.
	Exploration Preparation, Implementation, and Sustainment (EPIS) framework (125–127).
	This framework describes the phases of and factors that lead to implementation intervention. It can be expanded to examine the intersectional lens of racism and sexism.
Qualitative design	Qualitative research and study designs used by other disciplines (e.g., public health and sociology) provide foundational work, including qualitative and focus group work, that helps identify problems with the intervention that can be disseminated and implemented.

(Table 3). In particular, the National Institute on Minority Health and Health Disparities framework presents a structure for researchers to use as they consider the impacts of multiple interacting layers of factors on different domains of minority health and health disparities at the levels of the patient, family/organization, community, and population. Implementation of these frameworks can be bolstered by using tools such as the action-oriented community diagnosis tool that is centered on understanding communities and context to implement meaningful solutions (81).

Development, selection, and/or adaptation of evidence-based interventions. To reduce disparities in pediatric asthma morbidity, research questions and study objectives must focus on interventions that address aspects of systemic racism, such as institutional racism, structural racism, and discrimination (82). Study teams will need to consider how intervention studies can be designed not only to understand the impacts of a racialized system on asthma outcomes but also how best to maximize the impacts of the findings on policy. For example, a growing body of research demonstrates that institutional racist policies such as historical redlining contributed to differences in environmental exposures and asthma outcomes (4, 7, 8). These data have been

used in California to drive air pollution legislation such as the creation of the California Air Resources Board (https://ww2.arb.ca.gov/capp).

Research questions that address systems and policy change have the potential for meaningful long-term impacts. One example is the Allies Against Asthma Program that was funded by the Robert Wood Johnson Foundation and included seven coalitions of community organizations in low-income communities of color across the United States (83, 84). This 5-year program was created to support communities in targeting effective asthma management and led to 45 policy changes and 44 system changes related to childhood asthma across their communities, including changes in institutional policies and statewide legislation. Examples of institutional policy and system changes included establishing community health worker programs, legislation to prevent diesel truck idling, and expansion of asthma education. Children who lived in communities that were part of the coalition reported improvement in asthma symptoms (83), thus demonstrating that upstream interventions designed to address policies and systems can have significant impacts on personal clinical outcomes. For studies that do not directly attempt to address the impacts of racism on

the outcome, investigators need to consider how racism contributes to the observed findings.

Tools for evaluating the impacts of systemic racism in clinical research. The evaluation of studies that identify racism as a root cause for inequities in care and/or disparities in outcomes will vary on the basis of the study. Any assessment of systemic or structural racism and asthma will need to include the multiple layers of factors that may impact the outcomes. For example, analyzing current and historical data across sectors may further the researchers' understanding of the interacting exposures that lead to the downstream impacts of systemic racism (85). Coupling publicly available current data (e.g., claims data) with deprivation indices allows researchers to understand the intersection of multiple factors with race and ethnicity. The Index of Concentrations at Extremes can be used to evaluate the extremes of deprivation and how income is disparately distributed across race in a neighborhood (86). The Child Opportunity Index integrates multiple neighborhood-level factors to evaluate opportunity within a neighborhood for children and can be coupled with race and ethnicity data to understand those opportunities for children unfairly disadvantaged by systemic and structural

racism (87). The Structural Racism Effect Index is a promising new indicator designed to capture the totality of the downstream impacts of systemic racism across society and associated with life expectancy (88). Qualitative data can help the research team understand the context and barriers of the problem to be considered in data collection and analysis (e.g., using a mixed-methods model that includes the qualitative data gathered). Working with experts outside of health care, such as epidemiologists, social and behavioral scientists, public health researchers, and others, may also be important to design and complete the analysis of the data.

The growing body of research dedicated to measuring racism has provided tools that can be applied to pediatric asthma research. In a recent review, Groos and colleagues outlined over a dozen unique measures of structural racism that have been used in recent research related to residential neighborhood and housing, social institutions, socioeconomic status, and other domains (26). Most of the studies focused on Black versus White racial comparisons; however, measures of racism related to immigration and border enforcement have also been described (26). Validated tools such as the Everyday Discrimination Scale can be used to measure racial discrimination and have been used in pediatric research (25, 89, 90).

Unfortunately, although many pediatric asthma studies identify and address disparities in exposure to negative risk factors, few evaluate systemic racism as the root cause of those disparities or of the inequities in exposures and resources that lead to them. This important knowledge gap persists.

Funding and Institutional Priorities for Research to Address the Impacts of Systemic Racism on Pediatric Asthma

The agencies and foundations that fund asthma research and the institutions that provide physical and intellectual research infrastructure have a unique platform to promote antiracism change in research. Systemic racism is, by definition, a set of structural problems built into society. Resolving such fundamental inequities will require deliberate and coordinated efforts at the institutional and societal levels. Federal and other funding agencies have the power to insist that research priorities align with dismantling racism. Funders can frame

specific research initiatives to better understand and, most important, address systemic racism and its effect on childhood asthma. In addition, they can forge and foster changes in the scientific community that address the pervasiveness of structural inequities and impacts on patient experiences (*see* Table 4 for workshop recommendations).

Fomenting specific research initiatives. The research funding process can be biased at many levels, and systemic racism and discrimination have contributed to disparities in who is awarded grants (91-94). Racially and ethnically minoritized investigators tend to be underfunded even when their score is above the pay line, regardless of the investigator's degree. In a National Science Foundation study, racial disparities (racism) were found to be widespread; non-Hispanic White principal investigators were consistently funded at higher rates than most principal investigators of color across all disciplinary directorates (95). Similarly, Ginther and colleagues studied National Institutes of Health (NIH) funding from 2001 to 2006 and found that Black applicants were 1.7 times less likely than White applicants to be funded (96), a racial funding gap that was unchanged on subsequent evaluation of funding from 2011 to 2015 (97) and persisted even after accounting for other applicant and application factors (92).

Funders need to be intentional in dismantling racist practices and policies by incorporating specific mandates for funding proposals (98, 99). Implicit biases that are not intentionally dismantled can lead to studies that do not include the patients who are most impacted by the diseases studied and therefore in most need of improved treatments. For instance, monoclonal antibodies ("biologics") for asthma have advanced treatment for severe asthma; yet, many studies do not even list race in their results. For grant applications, investigators should explicitly discuss how they will ensure that the population studied is representative of the population served; it should no longer suffice to state that "no racial/ethnic groups will be excluded."

In response to the substantial health inequities for patients with asthma, federal agencies have developed several programs to improve racial and ethnic disparities in asthma outcomes and improve workforce diversity. The Coordinated Federal Action Plan to Reduce Racial and Ethnic Asthma

Disparities (100) resulted in the 2012 President's Task Force on Environmental Health Risks and Safety Risks to Children, which led to additional funding to assess community needs for children with asthma (RFA HL 15-028) and encourage clinical trials to reduce childhood asthma disparities (RFA HL 17-001). The NIH UNITE initiative was established to identify and address structural racism within the NIHsupported community and the greater scientific community. It aims to establish an equitable and civil culture within the biomedical research enterprise and reduce barriers to racial equity in the biomedical research workforce (101). The NIH has a site dedicated to diversity-related funding opportunity announcements (https:// extramural-diversity.nih.gov/guidedata/ data), and the National Institute on Minority Health and Health Disparities has several programs that directly or indirectly support asthma research in minority populations (102). ComPASS (Community Partnerships to Advance Science for Society), an NIH Common Fund initiative, specifically funds a consortium of "Community-led, Health Equity Structural Intervention (CHESI) projects that intervene on structural factors that create and perpetuate health inequities and Health Equity Research Hubs to provide localized technical assistance to the community-led health equity structural interventions" (103).

Additional efforts by the NIH continue to address some of the barriers to equitable research (104), but more is needed to address systemic racism. For example, the DECIPHER (Disparities Elimination through Coordinated Interventions to Prevent and Control Heart and Lung Disease Risk) Alliance promotes late-stage implementation research, specifically calls out "the persistent, significant health inequities" that exist for patients from underrepresented racial and ethnic backgrounds, and requires participation of community organizations (105). This announcement could make a stronger impact on racism in research by calling for and empowering community investigators to collaborate with the academic researchers and have equal standing instead of simply calling for a community advisory board. A recent NIH funding opportunity, "Addressing the Impact of Structural Racism and Discrimination on Minority Health and Health Disparities" (106), specifically focuses on intervention research that addresses

Table 4. Recommendations for funding and institutional practices for research to address impacts of systemic racism on pediatric asthma

Considerations	Descriptions
Investigative team	 Require diverse patient or community partner representation on the investigator team.
Study design	 Criteria for diversity should have its own score line with specific criteria as part of scientific review. Require the study populations to be those most impacted by disease studied. All requests for applications should have a requirement to include evaluation of social determinants of health.
Responsible conduct of research Review	 Investigators should be required to explicitly consider disparities in outcomes, racism, the effects of racism, and contextual factors in the design of studies focused on childhood asthma. Mandatory training in systemic racism for all grantees. Establish a framework for evaluating investigators' treatment of and approach to systemic racism in asthma research proposals. Ensure review committees have adequate expertise to evaluate multidisciplinary (e.g., social and biomedical sciences) research proposals.

structural racism and discrimination to improve minority health or reduce health disparities. Unfortunately, this announcement calls for collaboration but does not specifically require that a community and/or patient participate as a leader in the project. Until individuals from minoritized populations are treated as an essential part of the research team and their efforts are appropriately supported with research funds, it will be difficult to address racist practices that lead to incomplete science and poor health outcomes.

In addition to including individuals from minoritized populations in the research team, funders should also modify their scientific review mechanisms by 1) requiring a framework for evaluating investigators' treatment of and approach to systemic racism in asthma research proposals and 2) developing a review system that has adequate and diverse expertise to evaluate multidisciplinary (e.g., social and biomedical sciences) research proposals. Finally, dismantling the effects of systemic racism on asthma (and other multifactorial diseases) will require long-term investment and should be reflected in appropriate timelines and metrics. Historical racism over the past 400 years has impacted the health outcomes of Black, Brown, and Indigenous patients for many generations. Therefore, funders must be intentional in establishing metrics that can be tracked over time and not hold unrealistic expectations for solutions that can be studied or implemented in 4- or 5-year project periods. Federal funding and regulatory agencies such as the NIH and Food and Drug Administration should also consider

ways to ensure that pharmaceutical and biotechnology companies have structured long-term initiatives to ensure equitable access to new medications and treatments and then hold those companies accountable. A systematic approach to evaluating the treatment of race, ethnicity, disparities, and contextual factors in proposals should be developed and used to inform funding decisions. This includes issues such as the role of racism in measurement (e.g., survey tools, physiologic and biologic measurements) and the interpretation of study results focused on genetics and ancestry.

Forging general awareness. Addressing racism in research is integral to all aspects of training. Beyond providing incentives for specific research on systemic racism in asthma, calls for federal funding at any level should include requirements for best practices to address racism in research. The NIH and Agency for Healthcare Research and Quality current recommended topics are shown in Box 1 (107). We suggest adding required modules on understanding the effects of systemic racism on health equity and on proven approaches to incorporating antiracism methodologies into all aspects of human research (whether or not a research project is specifically focused on racism or health inequities). These could either stand alone as independent training modules or be incorporated into the existing suite of modules. For example, institutional review boards and ethics committees mandate Collaborative Institutional Training Initiative training and periodic recertification for researchers participating in human research.

Additional Collaborative Institutional Training Initiative modules should be required on structural health disparities, systemic racism, and the importance of incorporating antiracism approaches in ethical clinical research. Trainings on health equity, racism awareness, and antiracism approaches should not be suggested, recommended, or preferred; it should be mandatory and expected before investigators at all career levels can participate in federally funded human research. Required trainings will help trainees and early career investigators become more aware of the problem and better equipped to address it, and the hope is that these younger generations will internalize and propagate these lessons.

Academic institutions and clinical research organizations have similar oversight and responsibility for the conduct of research. Organizations must ensure that their research offices include the necessary expertise to advise investigators. Institutions provide resources for biostatistics and study design; they should also facilitate consultation with experts on antiracism methodologies during the development phase of a study or proposal. Institutional review board committees should include representatives with adequate expertise as well. Importantly, the advice and support provided by these experts should be properly recognized with protected time, recognition for promotion and tenure, and adequate compensation. Institutions should offer continuous training on social determinants of health, history of systemic racism and its impacts on health outcomes, how to recruit

Box 1. Current topics recommended for responsible conduct of research training, together with potential new topic suggestions (denoted by bold font) as standalone modules or integrated into current modules

- Conflict of interest
- Policies on research with human subjects and vertebrate animals
- Mentor/mentee responsibilities
- Safe and inclusive research environments
- Collaborative research
- Peer review
- Data acquisition and analysis
- · Secure and ethical data use and confidentiality
- Research misconduct
- Responsible authorship
- Scientist as responsible members of society
- The effects of systemic racism on health disparities and inequities
- Incorporating antiracism methodologies into research on human subjects

and train community investigators, and research-to-policy implications.

Racially and ethnically marginalized researchers face structural barriers to successful funding, and funding agencies should take initiatives to reverse such disparities. Several mechanisms have begun to foster the career development of underrepresented minorities in biomedical research. Funders may consider supporting institutions that share the same priorities, such as historically Black colleges and universities and Hispanic-serving institutions. Moreover, racially and ethnically marginalized investigators and scholars should be sufficiently supported by their institutions rather than being taxed with fighting structural inequities within and outside of the organization (108-113). Examples of institutional supports include investing in financial support for professional development activities, providing opportunities and support for multiple levels of mentoring (e.g., affinity groups, peer and near-peer mentoring teams), supporting and facilitating cross-disciplinary mentoring and collaboration, attaching value to health equity work and research that is commensurate with "traditional" scholarship activities, attaching value to the additional mentoring and advising responsibilities that many investigators from marginalized groups engage in, providing financial support to alleviate additional burdens, and providing competitive startup packages and bridge funding supports. Institutions can also

be intentional about mentoring investigators from backgrounds underrepresented in health care by encouraging applications to internal pilot award programs, multiyear internal institutional grants, T32 training grants, NIH Stimulating Access to Research in Residency R38, internal and national K12 programs, the NIH Programs for Inclusion and Diversity Among Individuals Engaged in Health-related Research Program (114), NIH loan repayment programs, and foundation award programs such as the Amos Medical Faculty Development Award Program (115). In addition, institutions should be actively engaged in promoting pathways to health care for individuals from marginalized groups starting as early as elementary and middle school through science training programs and observerships (108, 116-118). Regulatory agencies should systematically require that pharmaceutical industries, foundations, and other funders include underrepresented investigators in their funding calls, research programs, and clinical trials.

Finally, academic institutions and healthcare systems need to begin to collaborate in bringing research outcomes to policy recommendations. Researchers' and clinicians' voices can strengthen calls for policy change to address inequities in health care at multiple levels. Further training in best practices for sharing results and advocacy with institutional, local, or federal policy makers will increase the impact of the research on system-level change.

Conclusions

Systemic racism is the most pervasive cause of the differential distribution of the social determinants of health in the United States. Childhood asthma is a prominent example of a host-by-environment condition that disproportionately affects urban, minoritized children. Progress in dismantling the structures, policies, practices, norms, values, systems, beliefs, and attitudes that created and perpetuate societal inequity and disparities in health outcomes is challenging. Medical research develops new knowledge and establishes factual relationships in human health and disease and therefore must ensure equitable, unbiased practices in the planning and execution of scientific discoveries. All research and research funding that aims to understand and mitigate the impact of systemic racism on children with asthma should include a plan to dismantle the policies that perpetuate the inequities created by systemic racism. The ATS workshop identified key gaps and recommendations to advance identification, study, and mitigation of systemic racism in pediatric asthma research that can be broadly applied.

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