

Reconsidering Race in Clinical Algorithms

Driving Equity through New Models in Research and Implementation

A meeting sponsored by Doris Duke Foundation, in partnership with
the Gordon and Betty Moore Foundation, the Council of Medical Specialty Societies,
and the National Academy of Medicine



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Executive Summary

Race is included as a variable in many clinical algorithms, affecting diagnosis and treatment decisions made by physicians across the U.S. However, a lack of consistency in the consideration of race when clinical algorithms are developed is negatively impacting health equity. This report describes these issues through the lens of a meeting sponsored in June, 2023 by the Doris Duke Foundation in partnership with the Gordon and Betty Moore Foundation, the Council of Medical Specialty Societies, and the National Academy of Medicine.

The impact of including race in clinical algorithms can vary widely, and can be:

- Beneficial, if race is included in an intentional, well-considered effort to reduce inequities and it represents true biological differences based on clinical evidence;
- Neutral/have no impact; or
- Harmful, if the inclusion of race in the algorithm perpetuates race-based medicine that disadvantages historically underserved populations and/or promotes the concept of innate biologic differences between racial groups that do not exist.

As a result, the best path to improving health equity will likely differ for each algorithm. The best option for a particular algorithm may be to update the algorithm to exclude race; to use an alternative to race, such as measures of social determinants of health; to retire the algorithm and replace it with an alternative that promotes equity; or to continue to include race. Further, there are a broad array of methodological approaches to removing race from algorithms, several of which are discussed in this report.

Beyond updating or replacing a particular algorithm, other efforts to minimize the negative impact of algorithms on health equity may include promoting greater transparency regarding the role of race in an algorithm, ensuring clinician awareness of how to interpret results, and educating clinicians and patients about the impact of race in clinical algorithms.

Options for change include working under a set of guiding principles and using a systematic approach to algorithm assessment. However, implementing change brings a broad array of challenges, including acquiring data to model alternatives to existing algorithms; developing adequate evidence to inform change; appropriately adapting clinical decision making; changing clinician habits; communicating clearly with patients about changes to algorithms that affect their health care; and ensuring that updated algorithms are broadly used.

This report includes a series of recommendations from the convening that have been organized using a lifecycle approach to the issue of race in clinical algorithms and include the following key steps:

1. Principles and Guidance: Principles and guidance for the field
2. Evaluate: Identify research methods, standards, and data to evaluate algorithms
3. Implement: Identify implementation approaches
4. Disseminate: Disseminate best practices and provide guidance to major organizations
5. Monitor: Develop approaches to monitor algorithms for bias
6. Adapt: Develop strategies to rapidly adapt problematic algorithms

The current state of the field makes several things clear:

- The impact that algorithms have on equity needs to be systematically assessed and addressed;
- There are multiple methodological options for updating algorithms to improve equity, and there is likely no single approach that will maximize equity for all algorithms;
- There are significant challenges associated with implementing change in response to updated algorithms; and
- Clinicians and patients need to be educated regarding the impact of race on algorithms and the implications of changes to algorithms that are currently in use.

At the same time, there are several open questions to be answered in order to further the field:

- What comprises the optimal approach to algorithm assessment – that is, what questions should be asked and what analyses should be conducted?
- Who is responsible for conducting algorithm assessments and leading change?
- What is the most effective way to disseminate updated algorithms and encourage their use?
- Where should information on algorithm assessments, methods, and recommended updates be stored so that it is widely available?

Ensuring that clinical algorithms promote equity in health care is one essential component of a larger strategy to ensure that the highest quality care is delivered to all patients, and will require broad engagement from across the U.S. health care system.

Introduction

Race is included as a variable in many clinical algorithms, affecting diagnosis and treatment decisions made by physicians across the U.S. However, a lack of consistency in the consideration of race when clinical algorithms are developed is negatively impacting health equity. While race may be a clinically relevant variable in some models, in others race is immaterial at best, and at worst may actually exacerbate health disparities.

To respond to these concerns, the Doris Duke Foundation (DDF), in partnership with the Gordon and Betty Moore Foundation (GBMF), the Council of Medical Specialty Societies (CMSS), and the National Academy of Medicine (NAM), invited thought leaders across medicine, research, technology, patient advocacy, and policy to explore current efforts, challenges, and timely opportunities to bolster actions for more rigorous consideration of race in the design, implementation, and monitoring of clinical algorithms.

The meeting was held on June 27, 2023, in Washington, DC, and included sessions focused on:

- The use of race in research design in algorithms that inform diagnosis and treatment;
- Lessons learned from reassessing race in existing algorithms; and
- Challenges and solutions to de-implementation of harmful race-based algorithms.

Three breakout sessions provided opportunities for deeper conversation in these areas:

- Strategies and data needs required to reassess and remove race from harmful algorithms and offer alternate strategies;
- Implications of including race in artificial intelligence and machine-language-derived clinical algorithms; and
- Opportunities to ensure accountability for fairness in outcomes from health care algorithms before they are deployed.

This report reflects the presentations and conversations from the meeting, and is organized into the following sections:

- An overview, describing history, the impact of race in clinical algorithms, and what race represents;
- Options for change;
- Implementing change
- The unique challenges posed by artificial intelligence;
- Recommendations; and
- Conclusion.

Overview: History, Impact, and What Race Represents

How Race Came to Be Included in Clinical Algorithms

From the earliest days of medicine in the U.S., race – primarily distinctions between Black and white people – has influenced clinical decision making, treatment recommendations and guidelines, and algorithms that support diagnosis and treatment.

Claims of health distinctions based on race can be traced back to the early years of colonization. Writings by Thomas Jefferson, for example, stated that Black people had defective pulmonary systems, less kidney secretion, and were more tolerant of heat than white people.¹ These assumptions were used as arguments to justify slavery, such as the idea promulgated by Dr. Samuel Cartwright that Black people should engage in hard slave labor to help strengthen their lungs.²

One striking example: within two months after x-rays were first introduced in 1895, doctors in the U.S. argued that Black people needed higher x-ray exposures, supposedly due to having thicker skin and bones than white people. These beliefs were codified into x-ray device manufacturers' radiation dosing recommendations to radiology technicians, with higher exposures recommended for Black people, and were not questioned until 1968 despite decades of evidence regarding the dangers of radiation exposure.³

OVERVIEW: HISTORY, IMPACT, AND WHAT RACE REPRESENTS

The Impact on Equity

Race has been included in the development of a wide variety of clinical algorithms. Examining algorithms as varied as vaginal birth after cesarean, estimated glomerular filtration rate (eGFR) for assessing kidney function, pulmonary function tests, and the fracture risk assessment tool (FRAX) for osteoporosis, researchers have found that the inclusion of race in clinical algorithms in the U.S. can be traced back to racist arguments, with little or no clinical evidence to support its inclusion in such algorithms.⁴

A review and commentary published in 2020 coincided with heightened public awareness of issues surrounding race in the U.S. and called for a reconsideration of the use of race in clinical algorithms.⁵ The review examined the use of race in 13 algorithms ranging from risk of complication from thoracic surgery to rectal cancer survival and kidney donation failure. The authors found that, among other outcomes, these algorithms have the potential to cause harm to patients who are not white by:

- Dissuading clinicians from offering some types of care;
- Encouraging clinicians to direct fewer clinical resources to patients who are not white because they are deemed lower risk;
- Steering patients who are not white away from potentially beneficial procedures;
- Delaying referrals to specialist care;
- Reducing the likelihood of cancer surveillance; and
- Delaying diagnosis and intervention.

In light of these concerns, in September 2020 members of Congress directed the Federal Agency for Healthcare Research and Quality (AHRQ) to “conduct a review of the use of race-based clinical algorithms in standard medical practice.”⁶

OVERVIEW: HISTORY, IMPACT, AND WHAT RACE REPRESENTS

The review examines two Key Questions:

1. “What is the effect of health care algorithms and algorithm-informed decision tools on racial/ethnic disparities in access to care, quality of care, and health outcomes?”
2. “What is the effect of interventions, models of interventions, or other approaches to mitigate racial and ethnic bias in the development, validation, dissemination, and implementation of health care algorithms?”

Of the 8,500 articles identified through database literature searches, 42 studies met the review’s inclusion criteria, which included examining a clinical algorithm or algorithm-based tool and its effects on race.⁷

Of the 12 studies addressing Key Question 1, four showed that algorithms have the potential to improve equity in access to and quality of care. These findings indicate that algorithms may be associated with improved equity in circumstances where “existing disparities were identified prior to algorithm development and implementation, leading to an intentional effort to tackle disparities.”⁸ One study found no effect on equity. The remaining seven studies demonstrated that algorithms can perpetuate inequities either by the inclusion or exclusion of race from the algorithm.

For Key Question 2, the review found that many mitigation strategies have been used across a wide variety of algorithms. Examples of these mitigation strategies include removing race from the algorithm, replacing race with biological indicators, adding measures of social determinants of health, and a variety of statistical techniques. The researchers found that no single strategy was most successful at mitigating racial and ethnic bias across all algorithms, and that the impact of these strategies varied depending on the patient population, clinical condition, settings, and outcomes assessed.



It's clear that simply omitting race ... or using a colorblind algorithm will not necessarily lead to less harm and more justice.

— Kadija Ferryman, PhD
Johns Hopkins Berman Institute of Bioethics
Johns Hopkins Bloomberg School of Public Health

OVERVIEW: HISTORY, IMPACT, AND WHAT RACE REPRESENTS



In summary, the inclusion of race in algorithms can be:

- Beneficial, if race is included in an intentional, well-considered effort to reduce inequities and it represents true biological differences based on clinical evidence;⁹
- Neutral/have no impact; or
- Harmful, if the inclusion of race in the algorithm perpetuates race-based medicine that disadvantages historically underserved populations and/or promotes the concept of innate biologic differences between racial groups that do not exist. As one example, the inclusion of race in a now-retired algorithm for diagnosing pediatric urinary tract infections led to Black children being underdiagnosed when they had the same symptoms as white children.¹⁰

In other cases, the exclusion of race from algorithms may negatively impact equity. For example, by failing to account for the high likelihood that Black patients have a specific underlying genetic profile, algorithms for interpreting low neutrophil counts have historically led to anxiety for patients and families; specialist visits and extensive clinical workups; and increased out-of-pocket costs – all disproportionately occurring among Black patients.¹¹ A fuller discussion of this example is included in [Appendix 2](#).

OVERVIEW: HISTORY, IMPACT, AND WHAT RACE REPRESENTS

Can an algorithm be racist?

Daniel Yang, MD, Gordon and Betty Moore Foundation, asked a crucial question regarding the role of race in algorithms:

“So I think we’re all in agreement that what we’re trying to root out are racist algorithms. And we heard ... that there’s probably strong correlation of including race in an algorithm ... [and being] a racist algorithm. But my question is, are all algorithms that include race racist algorithms, and does the exclusion of race prevent it from being a racist algorithm?”

In response, Aletha Maybank, MD, MPH, American Medical Association, noted:

“If the algorithm is advantaging white people, for whatever reasons and whatever the outcomes are, and disadvantaging others, then it is creating harm. ... Most of us are not advocating for the removal of race completely, because ... it would cause even greater harm, because that’s just [ignoring the realities] that actually really exist. But we have to ask ourselves critical questions, and you have to evaluate all of these [algorithms], because they have different outcomes and lead to different opportunities.”

She later added that

“Just as policies can be racist, so can algorithms. They are both sets of rules that help determine how resources are allocated. Disparate impact is the main consideration in whether an algorithm is racist. The initial question being asked, the inputs used, the way the instructions or calculations are constructed and by who, and who is interpreting the outputs in what context can all contribute to more or less equitable impact of algorithms.”

And Neil Powe, MD, Priscilla Chan and Mark Zuckerberg San Francisco General Hospital, University of California, San Francisco, commented:

“Many say that we should just expunge race out of everything, and then I say, ‘Well, okay, that would be great to do, but how do we do that? What is the replacement? Could the replacement do more harm than good?’ If we’re going to use race, how do we do it in a conscious way? And a way that is built on evidence?”




OVERVIEW: HISTORY, IMPACT, AND WHAT RACE REPRESENTS

What Does Race Represent in Clinical Algorithms?

Race may serve as a proxy for many concepts in clinical algorithms, such as serving as a proxy for skin color, muscle mass, physical function, or variation based on geographic origin or genetics. In many algorithms, the underlying assumptions about what race represents can be traced back to assumptions used to justify slavery and other forms of oppression,¹² and continuing to include race in these algorithms can perpetuate inequities in health care. Further, a recent report from the National Academies of Science, Engineering and Medicine sponsored by the National Institutes of Health recommends that race should not be used as a proxy for human genetic variation.¹³

In other algorithms, race may have been included because inequities in health and health care were previously observed. Here, race serves primarily as a social rather than a biological construct and may represent accumulated experiences with racism and discrimination.



... in the absence of that data, it does compromise our ability to use that data to inform our thinking and to generate new hypotheses. So it speaks to how important it is that we develop approaches to be able to ascertain that data rigorously in some way, and that we don't default to the data we have available. [Not having data is] not an acceptable reason to not address social determinants of health and their profound impact on health

— Janine Clayton, MD
NIH Office of Research on Women's Health

OVERVIEW: HISTORY, IMPACT, AND WHAT RACE REPRESENTS

In yet other cases, race serve as a proxy for social determinants of health (SDOH). SDOH are the non-medical factors that influence health, such as income, education, employment, housing, and social inclusion and non-discrimination.¹⁴ Measures of SDOH are frequently proposed in health studies as complements to or as substitutes for measures of race, and this is an active area of research in the field.

One key challenge with using SDOH in clinical algorithms is that clinicians often do not have access to this information when they use algorithms. Options for addressing this challenge include embedding SDOH risk scores within electronic medical records, and developing longitudinal data sets that capture SDOH to enable researchers and clinicians to understand the cumulative experience of SDOH, including exposure to racism, across someone's lifetime.

What Is the Role of Ethnicity?

The algorithms discussed at the meeting were primarily assessed for the impact of race – defined as Black or white – on the outcomes in question. However, issues of race and ethnicity in the U.S. are complex, with individuals from different groups having different experiences and concerns. This complexity is compounded by significant within-group heterogeneity in language, immigration status, country of origin, skin color, and experiences of discrimination.

How are we defining race and how does ethnicity fit into that definition of race?... how do we start thinking about a more holistic view of the way we're approaching this?... how do we bring this all together so that we advance care for everyone and not just focus on Black and white differences?"

— Tina Hernandez-Boussard, PhD, MPH, MS
Stanford University



Options for Change

Guiding Principles and A Systematic Approach to Algorithm Assessment

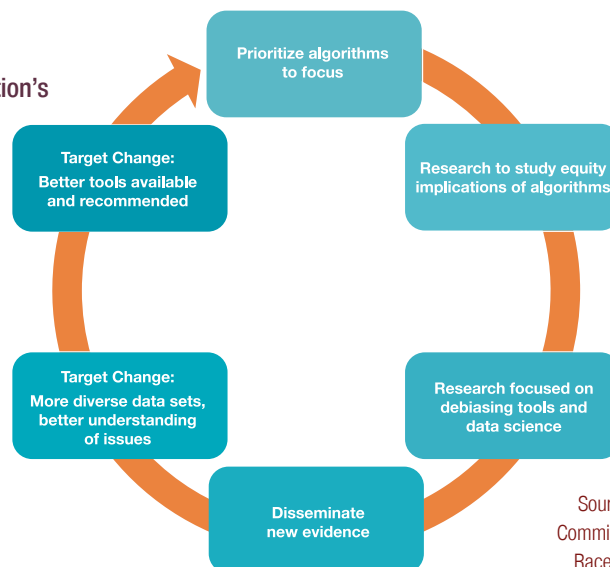
Marshall Chin, MD, MPH, University of Chicago, shared five principles for guiding work on assessing and addressing inequities related to health care algorithms. Supported by the Agency for Healthcare Research and Quality (AHRQ) and National Institute on Minority Health and Health Disparities as a part of a larger effort by AHRQ at the request of members of Congress, these principles include:

- Promoting equity during all phases of the algorithm lifecycle;
- Ensuring the transparency and explainability of algorithms and their use;
- Engaging patients and communities;
- Identifying fairness issues and tradeoffs; and
- Establishing accountability for equity.

Additional details from the nine-person panel that developed these guiding principles will be released in the future.¹⁵

Jennifer Hall, PhD, American Heart Association, shared her organization’s approach to debiasing clinical algorithms under their grant from the Doris Duke Foundation.¹⁶ This life cycle approach, shown in Figure 1, can be applied to algorithms being examined by many organizations, and a systematic approach to considering the assessment of race could be beneficial given the very large number of clinical algorithms that exist.

Figure 1.
American Heart Association’s
Approach to Debiasing
Algorithms



Source: Jennifer Hall. 2023. American Heart Association Commitments to Health Equity. Presented at Reconsidering Race in Clinical Algorithms. Washington, DC. June 2023.

Ideally, such an assessment should result in understanding the impact of current algorithms on equity; whether change to the algorithm is warranted; options for updating the algorithm; and the ideal approach to such updates.

Paths to Improve Equity and Minimize Harm

In theory, any systematic approach to algorithm assessment yields eight possible paths forward to maximize equity and minimize harm, with the optimal path for each algorithm determined by the results of the assessment described above:

If race is currently included in an algorithm	If race is currently excluded from an algorithm
Continue to include race	Update the algorithm to include race
Update the algorithm to exclude race	Continue to exclude race
Use an alternative to race, such as SDOH or clinical measures that are not correlated with race	Use an alternative to race, such as SDOH or clinical measures that are not correlated with race
Retire the algorithm and replace it with an algorithm that promotes equity	Retire the algorithm and replace it with an algorithm that promotes equity

Other efforts to minimize the negative impact of algorithms on equity may include:

- Promoting transparency (e.g., showing both race-specific and race-free results);
- Ensuring clinician awareness of how to interpret race-specific results and combat implicit bias;
- Educating clinicians and patients on the impact of underlying algorithms;
- Including data from diverse populations in reference equations;
- Using multiple tools to assess disease severity or outcomes; and
- Conducting thorough evaluations of alternative algorithms that do not include race.¹⁷

Methodological Approaches to Removing Race from Algorithms

Shazia Siddique, MD, MSHP, University of Pennsylvania, noted that strategies to mitigate the impact of race in clinical algorithms include “replacing race with biological indicators, adding biological input variables, and adding measures of social determinants of health, as well as several statistical techniques.”¹⁸

Dr. Powe described five methodological approaches for removing race from the eGFR algorithm that assess kidney function, considering the advantages and challenges that each pose.¹⁹ These methods, shown below, can be applied to many other algorithms.

Methodological Approaches to Removing Race from Algorithms

APPROACH	ADVANTAGES AND CHALLENGES
<p>Dominant (“Normalizing”) Race Standard Discard race coefficient from equations & report “non-Black” estimate for everyone</p>	<p>Is discriminatory because it ignores data on Black persons from studies included in equation derivation; less accurate for Black persons but not for white persons</p>
<p>Racial Phenotyping For example, substitute “low muscle mass” and “high muscle mass” for “non-Black” and “Black”</p>	<p>Assumes race is a proxy for muscle mass, thereby stereotyping all Blacks as having high muscle mass; likely less accurate for Blacks</p>
<p>Raceless Range Reporting Report two values currently generated by algorithm, but do not openly tag them with race descriptors</p>	<p>Recognizes participation of Blacks in derivation studies and imprecision of eGFR; leaves clinical correlation, nephrology consultation, and shared decision-making to ordering physicians</p>
<p>Raceless Markers Use clinical markers not associated with race, such as non-creatinine clearance markers (cystatin C) for eGFR</p>	<p>Possibly less standardization and less accurate than eGFR with creatinine; not tested in sick populations; higher cost</p>
<p>Blended Race Standard Develop new equation from existing data using weighted average of ethnicity coefficients</p>	<p>Requires agreement on appropriate weights. Raises question whether same should be done for all race/ethnic groups; likely less accurate for both Black and non-Black persons but may be equitable and acceptable</p>

It is also important to assess the statistical performance of models with and without race. Ashley Beecy, MD, New York-Presbyterian Hospital, described one algorithm related to post-partum depression that originally included race. When the researcher removed race from the statistical model, it performed equally well.²⁰ As a result, the researchers are implementing the algorithm without including race.

Implementing Change

Challenges to Making Change Happen

Presenters shared multiple case studies regarding the reconsideration and removal of race from clinical algorithms. Common challenges they described are shown here:

Challenges in Reconsidering Race in Clinical Algorithms
People-related challenges <ul style="list-style-type: none">• Behavioral, such as changing clinicians' habits and overcoming discomfort discussing race• Knowledge and education, including the need to educate clinicians and patients about changes to algorithms and the clinical impact of those changes (e.g., patients previously defined as having normal results may now have abnormal results despite no change in their absolute test values)• Clear and understandable communication with patients around the impact of race in algorithms, changes to its inclusion/exclusion in clinical algorithms, and impact on diagnostic and treatment decisions• Health care workforce capacity, including limited staffing and clinician burnout
Resource-related challenges <ul style="list-style-type: none">• Competing leadership priorities distracting from these efforts• Competing IT priorities affecting software updates and installation
Science-related challenges <ul style="list-style-type: none">• Challenges in developing adequate evidence to inform change• Challenges in acquiring data to model alternatives to existing algorithms• Selecting new reporting parameters, such as whether to display results from old algorithms side-by-side with those from new algorithms; whether to recalculate results from old algorithms using new algorithms; and whether and what types of explanations and disclaimers to include for clinicians
Implementation challenges <ul style="list-style-type: none">• Adapting clinical decision making, such as thresholds for treatment, inclusion in clinical trials, and surgical candidacy• Gaining buy-in, engagement, and support from a wide range of stakeholders within a single organization• Diffusion of implementation, as health care systems, hospitals, laboratories, and clinical practices make independent decisions regarding the use of algorithms and provision of clinical care
Social pressure challenges <ul style="list-style-type: none">• Ensuring that committees deliberating changes to the use of race in clinical algorithms are protected from externally imposed urgency and from social pressure to make specific decisions
Policy-related challenges <ul style="list-style-type: none">• Adapting policy making, such as algorithmic thresholds affecting eligibility for specific occupations or for life insurance

IMPLEMENTING CHANGE

Presenters noted a number of approaches to overcoming these challenges, including:

- Developing consensus within broad professional communities, including professional and advocacy associations;
- Having institutional support, such as enterprise-level health equity initiatives, consensus from leadership groups, and clinician advocacy;
- Garnering support from informaticians, information technology teams, and electronic health record programmers;
- Making change incrementally and supporting change with multi-channel educational campaigns;
- Providing team-level support;
- Including patient input;
- Developing broader and more diverse datasets; and
- Engaging in continued monitoring and surveillance after change is made.

Case Studies of Change

Presenters at the meeting shared four case studies of clinical algorithms that have been updated to rectify their detrimental impact on patients from specific racial and ethnic groups:

- Developing a new reference standard for kidney disease;
- Replacing race with a more relevant biological measure for benign ethnic neutropenia;
- Beginning with consensus within a professional association for pediatric urinary tract infections; and
- Implementing a race-neutral approach to pulmonary function testing.

The table below provides a brief overview of the issues with these algorithms and their resolution. [Appendix 2](#) includes a detailed overview of each algorithm and the processes involved in reconsidering and updating them.

Case Studies	
Kidney Disease	
ISSUE	In light of increased attention to institutionalized racism following the murder of George Floyd in 2020, there were public calls to remove race from the calculation of estimated glomerular filtration rate (eGFR), a measure of kidney function that is crucial to diagnosing chronic kidney disease.
RESOLUTION	In 2020, the National Kidney Foundation and the American Society of Nephrology formed a task force to develop recommendations on the best way to remove race from the eGFR algorithm. The task force recommended an updated approach to eGFR estimation that does not include race in its calculation and recommended national efforts to increase the use of an alternative measure that is less problematic with regard to race.
Benign Ethnic Neutropenia	
ISSUE	Diagnoses of benign ethnic neutropenia, while clinically irrelevant, lead to extensive testing and cause significant anxiety for patients and families. These diagnoses are prevalent among patients with sub-Saharan African or Arabian heritage, among whom a gene mutation that is associated with benign ethnic neutropenia is common.
RESOLUTION	Brigham and Women’s Hospital and six affiliated institutions incorporated the new reference ranges into their electronic health record. Choosing Wisely®, a national initiative focused on unnecessary healthcare, developed a recommendation indicating that otherwise healthy patients of African or Middle Eastern ancestry who have neutropenia should not receive extensive clinical workups prior to Duffy-null phenotype testing.
Pediatric Urinary Tract Infection	
ISSUE	The American Academy of Pediatrics’ (AAP) urinary tract infection algorithm included race in a way that made it less likely that Black children would be diagnosed with and treated for a urinary tract infection when presenting with the same symptoms as white children.
RESOLUTION	Following on extensive work under AAP’s Equity and Anti-racism strategy, the algorithm was retired. A subsequent meta-analysis concluded that accurate predictive modeling was possible using additional clinical variables instead of race.
Pulmonary Function Testing	
ISSUE	Patients’ pulmonary function tests had been compared against those of healthy people from the same racial group for more than 15 years, leading to notable differences on multiple measures between white and Black patients and under-diagnosis of pulmonary problems in Black patients.
RESOLUTION	The American Thoracic Society (ATS) convened a committee that recommended that pulmonary function testing laboratories adopt a race-neutral approach to interpreting tests, using a reference based on the average of patients from all racial groups.

De-Implementing Algorithms

Challenges

There can be significant challenges associated with de-implementing existing algorithms. For example, consider a patient whose kidney function is tested several times per year as part of their long-term treatment for kidney disease. After multiple eGFR tests showing a consistent result, one day their result changes, looking significantly worse than it had previously. While this change may be solely due to a change in the underlying algorithm to remove race, it could in part also reflect changes in their health. This could cause significant worry for the patient and can pose challenges for the quality of their care if their clinician changes their treatment plans in response to an apparent but artificial change in the algorithm results.

Another example of challenges associated with de-implementing algorithms relates to pulmonary function testing, where patients could gain or lose disability benefits, priority for health care services, and/or eligibility for clinical trials based on changes to the algorithm that do not reflect any changes in their actual health.

Local Change Leadership for De-Implementing Algorithms

Launched in 2021, the New York City Coalition to End Racism in Clinical Algorithms (CERCA) brings together 10 health systems under the auspices of the city health department's Chief Medical Officer with the goal to "end race adjustment, monitor the impact on racial health inequities, and engage patients whose care was negatively impacted by it."²¹

Each health system committed to ending race adjustment (de-implementing existing algorithms) in one of three race-based clinical algorithms: eGFR kidney function testing, pulmonary function tests, and/or vaginal birth after cesarean, working together in a learning collaborative to which they will deliver a work plan, an evaluation plan, and a patient engagement plan.

... it's important for us to consider how racial algorithms are expanding and building structures that can be oppressive. We may be able to remove race or use a different algorithm, but what structures of discrimination, marginalization, or oppression do these algorithms leave in their wake?

— Dr. Kadija Ferryman

IMPLEMENTING CHANGE

By the end of CERCA's first year, the coalition had discussed topics including the historical and legal implications of race adjustment; current research and debate on existing algorithms; and the impact of existing algorithms. As of September 2022, the city health department planned to supplement the coalition's efforts with educational programs in medical schools; policy and advocacy to change existing medical standards and guidelines; engagement with patient advocacy and support groups; and exploration of reparative paradigms to guide institutional racial equity initiatives.²²

The intensity of CERCA's efforts exemplifies the depth of work and investment of resources that are needed to change algorithms that are embedded in routine medical processes.

Incentivizing Change

Incentives from funders and journal editors provide one approach to encouraging investigation into the impact of algorithms on racial equity and the de-implementation of harmful algorithms.

Funders have several mechanisms they can use to incentivize change by ensuring that funding announcements support:

- Both (1) research to develop or update algorithms to minimize their negative impact on bias and fairness and (2) implementation of changes that may result from the research; and
- Development of new algorithms that include discussion of specific expectations regarding the impact on equity and the development of mitigation approaches when necessary.

Further, journal editors could announce that as of a certain date, they will no longer publish research that lacks an adequate level of sophistication in how it addresses race, ethnicity, ancestry, and social determinants of health. To be effective, this change would need to be announced several years in advance of the actual change to enable researchers to update their data collection and analytic approaches.

The Unique Challenges Posed by Artificial Intelligence

Artificial intelligence (AI) introduces a host of complications into any discussion of racial bias in health care algorithms. These challenges include data accessibility and the ethical use of data; the lack of transparency of AI models (the “black box” effect); algorithmic bias, which has been demonstrated in use cases from health care to human resources; and the technical and operational challenges associated with AI deployment.²³

The black box effect can be particularly disturbing in health care. For example, AI can identify a person’s self-reported race with a high level of accuracy from medical images, something humans are unable to do. Concerningly, researchers have been unable to identify the reasons why and the mechanisms AI uses to do so, and AI can identify patient race even when the medical image has been corrupted, cropped, or distorted, creating significant risks to safety, fairness, and equity.^{24,25}

AI requires special considerations when assessing equity, with particular attention to identifying where bias could be introduced at each point in the lifecycle of AI and algorithm development. Biases that arise in the real world may be reflected in the data sets used to train AI models; the algorithms themselves may be biased; and the algorithm output may be used in ways that are biased.



If we see really powerful predictions [from AI algorithms] and we're able to establish some sort of fairness and reliability... at what point is it okay, or under what circumstances is it okay to use a prediction where we don't fully understand what the explainability or the intentionality of the deep learning model is?

— Tommy Wang, PhD
Gordon and Betty Moore Foundation

THE UNIQUE CHALLENGES POSED BY ARTIFICIAL INTELLIGENCE

Presenter Brett Beaulieu-Jones highlighted five steps in the AI process in which inequities can emerge, shown in Figure 2. He noted the importance of specifying in advance what actions will be taken if AI-based algorithms are shown to be unfair; of exploring potential mitigation strategies such as resampling or reweighting training data sets; and of including health equity considerations in the model training process.²⁶

Figure 2. Inequity Can Emerge at Many Steps in the AI Process



Source: Brett Beaulieu-Jones. 2023. Mitigating the Risks Machine Learning Presents to Health Equity. Presented at Reconsidering Race in Clinical Algorithms. Washington, DC. June 2023.

Dr. Beecy also highlighted the need to apply the same level of rigor to third-party AI solutions that health care providers may purchase, focusing on transparency of the underlying data, features of the AI model, and an ethics review.

Dr. Ferryman noted the possibility of using a framework for assessing and testing algorithms that is akin to the stepwise approach used in clinical trials. In this approach, as AI tools are implemented, potential biases are evaluated and solutions identified before proceeding to the next stage.

Recommendations

The recommendations from the convening are described here using a lifecycle approach to the issue of race in clinical algorithms and include the following key steps:

1. **Principles and Guidance:** Develop principles and guidance for the field;
2. **Evaluate:** Identify research methods, standards, and data to evaluate algorithms;
3. **Implement:** Identify implementation approaches;
4. **Disseminate:** Disseminate best practices and provide guidance to key organizations;
5. **Monitor:** Develop approaches to monitor algorithms for bias; and
6. **Adapt:** Develop strategies to rapidly adapt problematic algorithms.

RECOMMENDATIONS	KEY ROLE	SUPPORTING ROLE(S)
Principles and Guidance		
<p>PG1 – Develop a set of working principles to guide organizations and committees seeking to address and mitigate the role of race in algorithms and clinical practice guidelines, including: essential skills and personnel needed from clinical sciences, social sciences, and informatics backgrounds; governance recommendations; approaches to developing consensus and managing disagreement; transparency; communications; and ensuring appropriate accountability.</p>	CMSS	Researchers
<p>PG2 – Provide guidance and training in health equity to guideline and algorithm developers, including the Grading of Recommendations Assessment, Development and Evaluation (GRADE) equity guidelines.</p>	Specialty Societies, CMSS, other guideline developers	
<p>PG3 – Ensure that funding announcements:</p> <ol style="list-style-type: none"> 1. Include support for research to develop or update algorithms to minimize their negative impact on bias and fairness; 2. Include support for implementation of changes that may result from the research and require the inclusion of implementation plans in relevant grant applications; 3. Include discussion of specific expectations regarding the impact on equity and the development of mitigation approaches when necessary as new algorithms are developed; 4. Include best practices for engaging diverse research and implementation teams and require a discussion focused on the diversity of the research team in relevant grant applications; and 5. Include guidance regarding best practices for considering race/ethnicity in algorithm design. 	Funders (Public and Private)	

RECOMMENDATIONS

RECOMMENDATIONS	KEY ROLE	SUPPORTING ROLE(S)
Principles and Guidance		
PG4 – Provide guidance to review committee members and training to grant reviewers regarding the impact of clinical algorithms on health equity, approaches to the assessment of bias and fairness, and methods for minimizing the potential negative impact of algorithms on health equity.	Funders	
PG5 – Ensure that applications are reviewed using a definition of scientific rigor that explicitly includes an assessment of study design for bias or the potential to create bias, as well as ways in which race may be directly or indirectly embedded in study designs.	Funders	
Evaluate		
E1 – Identify approaches to assessing the impact algorithms have on health equity, including defining measures for assessing bias and fairness.	Researchers	
E2 – Define the minimum set of analyses that should be conducted for each algorithm under consideration.	Informaticians, Biostatisticians	
E3 – Identify data sets and available information sources on minoritized populations that may be excluded from traditional data sets.	Researchers	HBCUs HSHPS
E4 – Catalog all known methodological approaches to removing race from algorithms and/or mitigating its impact. Include the known advantages and limitations of each method, and essential attributes/criteria/measures to evaluate each approach for a given algorithm.	Federal agencies	Researchers
Implement		
I1 – Drawing from the field of implementation science, develop an implementation and change management toolkit or playbook that describes best practices for implementing changes to algorithms/deimplementing algorithms, including: <ul style="list-style-type: none"> • Leadership • Roll-out processes • Addressing barriers to change • Education • Role of rewards or penalties 	Research community Specialty society community	AI/ML community

RECOMMENDATIONS

RECOMMENDATIONS	KEY ROLE	SUPPORTING ROLE(S)
Implement		
<p>I2 – Develop guidance on considerations in reporting the clinical results of algorithms that are changed to remove race or otherwise increase health equity, including:</p> <ul style="list-style-type: none"> • How results are reported to clinicians and to patients; and • How to address longitudinal change in clinical results that are due solely to changes in the algorithm. 	Clinical community	Hospital and laboratory community
Disseminate		
<p>D1 – Develop recommended content and layout for reporting the results of algorithm assessments. Promulgate this report format for use by smaller hospitals, health care providers that may not have the resources to perform their own assessments, and all providers that use algorithms from third-party developers.</p>	Informaticians	Hospitals
<p>D2 – Build and make publicly available a compendium of algorithms that have been assessed for equity.</p>	Federal agencies	CMSS
<p>D3 – For those algorithms with a negative impact on health equity, include available recommendations regarding approaches to minimizing such impact.</p>	CMSS	
<p>D4 – Develop educational modules for clinicians across the continuum, including medical students, residents, fellows, and practicing clinicians, focusing on:</p> <ul style="list-style-type: none"> • The role of race in algorithms and clinical practice guidelines and the importance of ensuring equity in their development, application, and use; • The use of implementation science and change management approaches for de-implementing biased algorithms; and • Leadership of change processes in this area. 	CMSS	AAMC
<p>D5 – Develop an education campaign and equitable approach to the development of clinical guidelines and algorithms by all medical specialty societies.</p>	CMSS	
<p>D6 – Coordinate efforts among multiple specialty societies through the Council of Medical Specialty Societies (CMSS) as societies pursue this agenda, beginning with a joint policy statement regarding the need to reconsider the use of race in clinical algorithms.</p>	CMSS	

RECOMMENDATIONS

RECOMMENDATIONS	KEY ROLE	SUPPORTING ROLE(S)
Disseminate		
D7 – Journal editors should identify characteristics and guidelines for rigorous consideration of race and ethnicity in the design and validation of algorithms for publication. They should provide guidance to reviewers, including the impact of clinical algorithms on health equity, approaches to assessment for bias and fairness, methods for minimizing negative impact, and appropriate engagement of multidisciplinary teams and of communities.	ICJME	Researchers
Monitor		
M1 – Use hackathons and similar mechanisms to assess the equity impact of a wide range of algorithms using publicly available data.	ONC	AMIA HIMSS
Adapt		
A1 – Coordinate efforts to de-bias algorithms with Medicare, Medicaid, and private insurers to prepare for changes to approvals or reimbursement for alternative tests (e.g., Cystatin-C).	CMS	AHIP AHA
A2 – Consider incentives and performance measures to remove race from clinical algorithms.	CMS State Medicaid Agencies	
A3 – Develop additional local collaborations focused on removing race from clinical algorithms, learning from existing models of local collaboration (e.g., New York City CERCA model).	States and local public health	NACCHO



Conclusion

The underlying goal of assessing the impact of race on clinical algorithms is simple: to ensure the greatest possible equity in the health care provided to patients from all racial and ethnic groups. Conducting such assessments and taking action based on their results, however, is a far more complex endeavor.

Several things are clear following the meeting described in this report:

- The impact that algorithms have on equity needs to be systematically assessed and addressed;
- There are multiple methodological options for updating algorithms to improve equity, and there is likely no single approach that will maximize equity for all algorithms;
- There are significant challenges associated with implementing change in response to updated algorithms; and
- Clinicians and patients need to be educated regarding the impact of race on algorithms and the implications of changes to algorithms that are currently in use.

At the same time, there are several open questions to be answered in order to further the field:

- What comprises the optimal approach to algorithm assessment – that is, what questions should be asked and what analyses should be conducted?
- Who is responsible for conducting algorithm assessments and leading change?
- What is the most effective way to disseminate updated algorithms and encourage their use?
- Where should information on algorithm assessments, methods, and recommended updates be stored so that it is widely available?

Ensuring that clinical algorithms promote equity in health care is one essential component of a larger strategy to ensure that the highest quality care is delivered to all patients, and will require broad engagement from across the U.S. health care system.

Appendix 1: Resources

Reconsidering Race in Clinical Algorithms: Driving Equity through New Models in Research and Implementation was held on June 27, 2023 in Washington DC.

Additional information is available at these links:

- [Meeting home page](#)
- [Agenda](#)
- [Speakers](#)
- [Attendees](#)

Appendix 2: Case Studies

Presenters shared four case studies focused on:

- Developing a new reference standard for kidney disease;
- Replacing race with a more relevant biological measure for benign ethnic neutropenia;
- Beginning with consensus within a professional association for pediatric urinary tract infections; and
- Implementing a race-neutral approach to pulmonary function testing.
- Each case study illustrates the complexity of the issues and describes the unique approaches to their resolution.

Developing a New Reference Standard: Kidney Disease ²⁷

The algorithm used to estimate creatinine clearance – a key measure in assessing kidney function – was developed in 1976 and was based on a small sample of white men. The results were then extrapolated to women and Black patients.

Research based on data from the late 1980s through the 1990s demonstrated the existence of substantial inequities in treatment for chronic kidney disease:

- Black patients were less likely to be placed on waitlists for kidney transplantation within one year of kidney failure diagnosis, giving them less access to transplants than white patients;²⁸
- Black patients with kidney disease were more likely to have a late evaluation by a nephrologist, leading to less specialist care;²⁹ and
- Serum creatinine, a key measure of kidney function, was shown to be greater in Black Americans, indicating that “the use of a single cutpoint to define elevated serum creatinine values may be misleading.”³⁰

As a result of this and other research, in 1999 race was introduced into the algorithm that is used to calculate estimated glomerular filtration rate (eGFR), a key measure of kidney function that is crucial to the diagnosis of chronic kidney disease. The new algorithm spread widely, with adoption by 90 percent of clinical laboratories in the U.S. by 2013.

In 2020, calls for the removal of race from the eGFR algorithm accelerated in light of public discussion of institutionalized racism following the murder of George Floyd. These calls were based on the argument that eGFR is a biological construct while race is a social construct, and therefore that including race in the eGFR perpetuates racism and inequities.

Some institutions removed race from eGFR reporting, but not from the algorithm itself, and did so without an evidence base. One method for doing this was discarding the race variable from the algorithm’s equations and reporting the non-Black estimate for everyone, resulting in an

APPENDIX 2: CASE STUDIES

increased number of Black persons diagnosed with chronic kidney disease and at more severe disease stages. While this had potential benefits, such as increased referral to specialists and greater access to the transplant waitlist, it also carried harms including the decreased use of certain medications (including those that can prevent chronic kidney disease), decreased use of imaging procedures with contrast fluids, and decreased access to clinical trials.

In 2020 the National Kidney Foundation and the American Society of Nephrology formed a joint task force to develop recommendations regarding the best way to remove race from the eGFR algorithm. The task force identified 26 potential approaches and evaluated 5 approaches in depth, including in their deliberations input from experts, patients, trainees, and providers, as well as existing evidence and emerging research.

The task force made three recommendations:

- Immediate adoption of an updated approach to eGFR estimation that does not include race in its calculation and uses the weighted average of ethnicity coefficients as the new reference standard;
- National efforts to increase the use of cystatin C, an alternative measure that is less problematic with regard to race, particularly for confirming eGFR in adults for clinical decisions; and
- Investment in further research to develop measures that support the elimination of inequities in care for kidney disease.³¹

It was important to find a sound path to eliminate race, as early attempts to eliminate race were not evidence-based, did not reflect diversity, and were not free from harm. And a path and a process was established to recognize both evidence and values that will lead to changes for everyone, not just African Americans.

— Dr. Neil Powe



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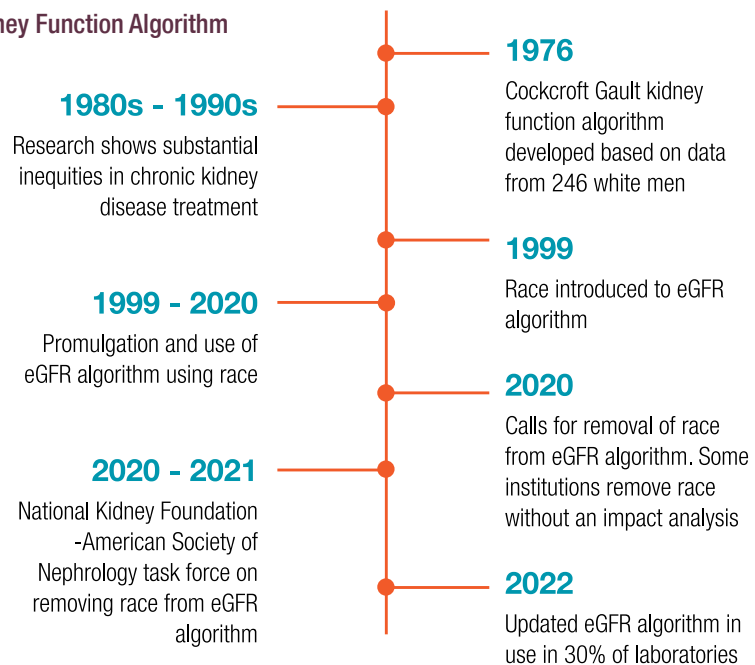
Immediately after the recommendations were issued, the National Kidney Foundation formed a laboratory engagement committee comprised of laboratory directors. This committee was actively involved in the dissemination of the new recommendations, and also developed and shared a toolkit for laboratories providing detailed guidance on reprogramming their systems to support efforts to implement the new algorithm.

A survey conducted in March 2022, six months after the task force recommendations were released, showed that 77 percent of clinical laboratories were aware of the updated eGFR algorithm that does not include race adjustment factors. Thirty percent of laboratories reported having adopted the updated algorithm – rapid uptake described by Dr. Neil Powe as “rocket speed for implementation in medicine.” Laboratories also reported significant barriers to adopting updated methods, including limited options for cystatin C testing, cost of testing, and staffing resources.³²

Lessons learned from this effort include:

- Be very clear on the charge to the task force, and consider having a narrow charge so they can appropriately scope their work;
- Ensure engagement of top institutional leadership;
- Create opportunities to involve students, residents, and other trainees; and
- Have open discussions about plans to address social determinants of health and issues of justice in health care.

Figure 3. Removing Race from Kidney Function Algorithm



Source: Neil R. Powe. 2023. Race-Free Estimation of Kidney Function: The Wrath, Path and Aftermath. Presented at Reconsidering Race in Clinical Algorithms. Washington, DC. June 2023.

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Replacing Race with a More Relevant Biological Measure: Benign Ethnic Neutropenia³³

A diagnosis of benign ethnic neutropenia occurs when blood tests yield an absolute neutrophil count less than 1,500 and no cause can be found. While this diagnosis is clinically irrelevant, it causes anxiety for patients and families; referrals to hematology; extensive workups, potentially including bone marrow aspiration and biopsy, to rule out other causes; and increased out-of-pocket costs for patients and families. Further, the diagnosis can result in denial of certain prescription medications and participation in clinical trials.

In 2009, research demonstrated that benign ethnic neutropenia is strongly associated with the Duffy-null phenotype, a gene mutation that is prevalent in upwards of 80 percent of individuals of sub-Saharan African heritage and up to 70 percent of those from the Arabian peninsula. As a result, individuals from these groups are disproportionately diagnosed with benign ethnic neutropenia and suffer the consequences of that diagnosis even though it poses no risk to their health.

In 2020, a research team at Brigham and Women's Hospital studied the prevalence of the Duffy-null phenotype among their healthy Black patients, finding that those with the Duffy-null phenotype were far more likely than those without to have low absolute neutrophil counts. The study specifically identified a new reference range of absolute neutrophil counts between 1,200 and 5,300 for Duffy-null individuals, lower than the previous reference range used by the hospital.

Working closely with the hematology and pathology departments at the hospital, the team incorporated this information into the electronic health record at Brigham and Women's Hospital and six affiliated institutions, implementing new reference ranges that should result in far less unnecessary follow-up testing for low absolute neutrophil counts among Duffy-null individuals, who are disproportionately Black.

Beyond this, the team worked with Choosing Wisely[®], a national initiative, to develop a recommendation that physicians in the U.S. should not “perform an extensive workup in otherwise healthy neutropenic patients of African or Middle Eastern ancestry prior to Duffy-null phenotype testing.”³⁴

Beginning with Consensus: Pediatric Urinary Tract Infection Algorithm³⁵

In August 2019, the American Academy of Pediatrics (AAP) issued a landmark statement entitled “The Impact of Racism on Child and Adolescent Health.” The statement defined an extensive evidence base constituting the most authoritative publication on the issue at the time.³⁶

APPENDIX 2: CASE STUDIES

Over the following three years, the AAP Board of Directors, Executive Committee, and Board Committee on Equity were directly engaged in accelerating AAP's Equity and Anti-Racism strategy agenda, publishing multiple policy pieces.^{37,38,39} This work culminated in an amendment to the association's bylaws, which garnered significant attention among pediatricians and in the media and continued the organization's commitment to eliminating race-based medicine.

As a result of this focus, one particular Academy-sponsored algorithm was challenged by the Academy's membership, and a strong case was made for removing race from AAP's urinary tract infection algorithm, noting that race had been inappropriately inserted as a default proxy for other factors that were not well understood.⁴⁰ The resulting algorithm had discriminated against black children, making it less likely that they would be diagnosed with and treated for a urinary tract infection when presenting with the same symptoms as white children.



One of the things that we're learning in the unwinding of race-based algorithms is that it requires a thorough understanding of the history of their derivation and a deep dive into the reference literature that supports them.

— Joseph L. Wright

The guideline that used this algorithm was retired⁴¹, and a subsequent meta-analysis concluded that accurate predictive modeling was possible using additional clinical variables instead of race.⁴²

Following this change, the AAP went through a similar process with regard to the algorithm that governs its clinical practice guideline for the management of hyperbilirubinemia in newborns, which led to the University of Maryland Medical System updating its electronic health record to capture the new algorithm.

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Implementing a Race-Neutral Approach: Pulmonary Function Testing⁴³

From 1991 to 2005, the American Thoracic Society (ATS) measured the lung function of patients using a race-adjusted algorithm. This involved comparing the lung function of patients of any race with measurements taken from a healthy white patient population and then adjusted for race. Beginning in 2005, the ATS switched to a race-specific algorithm, where patients from each racial group were compared with measurements taken from healthy people in that same racial group.

A panel convened in 2021 by ATS was asked to review the use of race and ethnicity in the interpretation of pulmonary function tests, evaluate its clinical implications, and provide guidance to inform clinical decision making. The panel released its recommendations in 2023, noting that pulmonary function testing laboratories should adopt a race-neutral approach to test interpretation by using a reference based on the average of patients from all races. Their rationale was that notable differences on multiple measures between white and Black patients occur when race-specific equations are used, but not when average reference equations were used. The panel also felt that their recommended change would prevent under-diagnosis of Black patients and mitigate perceptions that race can be used to infer biological characteristics.

The panel noted challenges to achieving consensus on balancing the potential desirable vs undesirable effects of removing race from the algorithm, and noted a paucity of data, particularly related to alternatives to race-specific interpretation.

Desirable effects of removing race	Undesirable effects of removing race
Increasing rate of diagnosis among Black patients, potentially providing more access to medical care by identifying more abnormalities	Potentially being cut off from certain surgical options, employment, and life insurance policies

The ATS felt they needed to shield the committee from external influences so they could focus on science and patient care rather than politics and advocacy. There was significant social media pressure on the committee to adopt a specific position before the experts had completed their work, with frequent pushes to issue guidance faster than the committee was ready to. The ATS also expects significant challenges related to implementation of the new approach and new thresholds, including clinician education and clinical decision-making.

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Reconsidering Race in Clinical Algorithms

Driving Equity through New Models in Research and Implementation

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