CAN DATA BE RACIST?

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On Racism: A New Standard For Publishing On Racial Health Inequities

Rhea W. Boyd, Edwin G. Lindo, Lachelle D. Weeks, Monica R. McLemore

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WHAT IS RACISM?

• “…any prejudice against someone because of their race, when those views are reinforced by systems of power.” (Oluo I 2019)

• “Racist policies” (Kendi (2019) How to be an Antiracist)

• “Structural racism”
WHAT IS YOUR ROLE?

- Research Questions
- Study design
  - Recruitment
  - Inclusion/exclusion
- Data collection tools
- Data analysis decisions

- Research coordinator
- Clinician
- Principle Investigator
- Data analyst
- Research assistant

- Interpretation of quantitative findings
- Peer review
- Evidence review
- Interpretation of published research
- Synthesizing literature
THE TUSKEGEE SYPHILIS STUDY
BLACK-WHITE MORTALITY DIFFERENCES BY GENDER


Tuskegee Study Leaked to Press

Men

Women
COVID-19 HAS BROUGHT RACISM INTO FOCUS

Nationwide, Black people are dying at 2.3 times the rate of white people.

Deaths per 100,000 people by race or ethnicity:
- Black or African American: 101
- American Indian or Alaska Native: 67
- Hispanic or Latino: 67
- Native Hawaiian and Pacific Islander: 53
- White: 45
- Asian: 42
- Other: 37
- Two or more races: 4

Notes:
We've lost at least 41,583 Black lives to COVID-19 to date. Black people account for 20% of COVID-19 deaths where race is known.
“Compared with non-Hispanic white patients, African Americans had 2.7 times the odds of hospitalization, after adjusting for age, sex, comorbidities, and income...

...one hypothesis is that there may be some unknown or unmeasured genetic or biological factors that increase the severity of this illness for African Americans.”


*Text shown here was included in the Ahead-of-Print version of this article. The final published version of the paper has been revised to clarify the authors’ conclusion that the disparities are most likely explained by societal factors.
Figure 1. Pathogen, host, environment interplay in racial disparities in COVID-19. Abbreviations: COVID-19, coronavirus disease 2019; SARS-CoV-2, severe acute respiratory syndrome coronavirus-2.
MYTH: It’s just biological Race!

![Graph showing birth weight distribution for African-born blacks, U.S.-born blacks, and U.S.-born whites.](Image)


RACISM NOT RACE
MYTH: It's just biological Race!


- African-born blacks
- U.S.-born blacks
- U.S.-born whites

Babies born to Black African-born moms have a similar birth weight distribution to babies born to white US-born moms.
MYTH: It’s just poverty/social class!

Babies born to Black mom’s with graduate degrees die at a higher rate than babies born to white moms with high school degrees

RACISM IS A FUNDAMENTAL CAUSE OF DISEASE

Root Causes
- White Supremacy & Racism
- Class Oppression
- Gender Discrimination & Exploitation

Power and Wealth Imbalance
- Labor Markets
- Housing Policy
- Education Systems
- Social Safety Net
- Tax Policy
- Social networks
- Globalization & Deregulation

Social Determinants of Health
- Safe affordable housing
- Living wage
- Quality education
- Transportation
- Job security
- Social connection
- Safety
- Food availability

Psychosocial stress/unhealthy behaviors

Inequities in the distribution of disease, illness, and well-being

Black Former N.F.L. Players Say Racial Bias Skews Concussion Payouts

The players say doctors use two scales — one for Black athletes, one for white — to determine eligibility for dementia claims.
Hidden in Plain Sight — Reconsidering the Use of Race Correction in Clinical Algorithms

Darshali A. Vyas, M.D., Leo G. Eisenstein, M.D., and David S. Jones, M.D., Ph.D.

Table 1. Examples of Race Correction in Clinical Medicine.

<table>
<thead>
<tr>
<th>Tool and Clinical Utility</th>
<th>Input Variables</th>
<th>Use of Race</th>
<th>Equity Concern</th>
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<tbody>
<tr>
<td><strong>Nephrology</strong></td>
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<tr>
<td>Estimated glomerular filtration rate (eGFR)</td>
<td>Serum creatinine</td>
<td>The MDRD equation reports a higher eGFR (by a factor of 1.210) if the patient is identified as black. This adjustment is similar in magnitude to the correction for sex (0.742 if female).</td>
<td>Both equations report higher eGFR values (given the same creatinine measurement) for patients identified as black, suggesting better kidney function. These higher eGFR values may delay referral to specialist care or listing for kidney transplantation.</td>
</tr>
<tr>
<td>MDRD and CKD-EPI equations¹¹ (<a href="https://ukidney.com/nephrology-resources/egfr-calculator">https://ukidney.com/nephrology-resources/egfr-calculator</a>)</td>
<td>Age and sex</td>
<td>The CKD-EPI equation (which included a larger number of black patients in the study population), proposes a more modest race correction (by a factor of 1.139) if the patient is identified as black. This correction is larger than the correction for sex (1.018 if female).</td>
<td></td>
</tr>
<tr>
<td>Estimates glomerular filtration rate on the basis of a measurement of serum creatinine.</td>
<td>Race: black vs. white or other</td>
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</tbody>
</table>
May 29, 2020

**UW Medicine to exclude race from calculation of eGFR (measure of kidney function)**

UW medical students initiate one of the first of its kind transition to the calculation of estimated glomerular filtration rate that is not adjusted by race.
INTERROGATE RACISM AS A CRITICAL DRIVER OF HEALTH INEQUITIES

Structural “rules of the game”: laws, policies and rules that explicitly or implicitly discriminate adversely against the targeted group (i.e. Black people) and privilege the dominant group (i.e. white people)

Structural/Institutional

Discriminatory practices and beliefs directed at persons in the targeted social group by persons in the privileged social group

Interpersonal

Self-subordinating practices and beliefs by persons in the targeted social groups (i.e. Black folks)

Internalized

MISTRUST IS JUST A SYMPTOM, MISTREATMENT IS THE DISEASE

Demonstrators march outside at the Los Angeles County USC Medical Center in 1974 at a protest organized by "The Committee to Stop Forced Sterilization." [accessed at: https://www.cnn.com/2020/09/16/us/ice-hysterectomy-forced-sterilization-history/index.html]
Predicted probabilities for analgesic and opioid administration by race in children with appendicitis and severe pain seen in Emergency Departments. JAMA Pediatr. 2015 November; 169(11): 996–1002
EVERY STUDY OCCURS WITHIN A RACIAL CONTEXT

Understand and explicate how aspects of the racial context may influence your study.

• Refute colorblind ideologies
• How might race have shaped your study aims?
• Which structural factors are at play (eg, funding opportunities that imply a particular racial frame)?
• How does this factor into your conceptual framework?
• Refine the study based on what you learn.

The data generation process “[is] an inherently subjective enterprise in which a discipline’s norms and conventions help to reinforce existing racial (and other) hierarchies”

- “[D]ata never speak for themselves. It is the questions we pose (and those we fail to ask) as well as our theories, concepts and ideas that bring a narrative and meaning to marginal distributions, correlations, regression coefficients, and statistics of all kinds.”
- “Question the question.”

Without an explicit focus on social equity, the concerns of the most privileged members of society are overrepresented in data and research.

Whitney R Robinson, Audrey Renson, Ashley I Naimi, Teaching yourself about structural racism will improve your machine learning, Biostatistics, Volume 21, Issue 2, April 2020, Pages 339–344
The findings should do more than merely support a research industrial complex.

- Use the knowledge obtained through your studies to help disrupt one or more causes of the inequities. Action steps may include:
  - expanding the vocabulary with which to discuss poorly understood racial and power relations
  - using storytelling that is centered in the margins to describe a problem
  - directly challenging identified injustices (e.g., direct action, lawsuits)
- To the extent possible, research should benefit communities directly

The conduct of antiracist research, data collection and analysis, necessitates shifting away from centering on whiteness

- Promote more inclusive research teams
- Decolonize data
- #citeblackwomen
WHAT CAN WE (RESEARCHERS) DO?

- **Define race** during the experimental design and **specify a reason** for its use in the study. Reasons should be couched within a **sociopolitical framework** (not biologic).
- **Name racism**, identify the **form**, the **mechanism** by which it may be operating, and **other intersecting forms of oppression** that may compound its effects.
  - Form: interpersonal, institutional, internalized
  - Intersecting forms: e.g. sex, sexual orientation, age, rationality, nationality, religion, income
- **Never offer genetic interpretations of race** because such suppositions are not grounded in science.
- **Solicit patient input**. Use community review boards or form patient panels.
- **Identify the stakes**: “All policy is health policy”
- **Cite the experts**, particular scholars of color whose work forms the basis of the field’s knowledge on racism and its effects.

• The rest of our Antiracism in Data and Analysis planning team
  • Janne Boone-Heinonen
  • Amy Laird
• OCTRI’s Biostatistics, Epidemiology, Research, and Design (BERD) Core