HISTORY OF RACISM AND CLINICAL TRIALS

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Defining “Race”

- Merriam-Webster dictionary definition: “a category of humankind that shares certain distinctive physical traits”
  - However, a person’s race is often based on society and culture rather than physical traits also known as phenotypic traits
    - Example: “one-drop rule”
  - There are more genetic differences within a race than there are genetic differences between racial groups

- There is a troubling legacy of discrimination against people of color throughout American and world history
  - This has been increasingly recognized and addressed throughout the last few decades through policies and cultural change
  - However, racism is still deeply embedded in our institutions and society

- Merriam-Webster is updating its definition of “racism” to include structural racism as well as personally mediated racism

- In this presentation, we will critically examine the history of racism in medical research so that we may progress towards full, consenting participation of people of color in research that advances scientific knowledge
The Gardener’s Tale: Allegory for Racism

TEDx Emory video entitled “Allegories on Race and Racism” by Dr. Camara Jones:
https://www.youtube.com/watch?v=GNhcY6fTyBM

Jones C. Levels of Racism: A Theoretic Framework and a Gardener’s Tale. AJPH 2000
Defining Racism

Institutionalized racism
- Initial historical insult
- Structural barriers
- Inaction in face of need
- Societal norms
- Biological determinism
- Unearned privilege

Internalized racism
- Reflects systems of privilege
- Reflects societal values
- Erodes individual sense of value
- Undermines collective action

Personally mediated racism
- Intentional
- Unintentional
- Acts of commission
- Acts of omission
- Maintains structural barriers
- Condoned by societal norms
Does Racism Still Exist?

- Among Black women with lupus, unfair treatment and discrimination is associated with more severe disease
  - *Discrimination may lead to increased stress which can increase inflammation and disease damage*

- Black and Hispanic women with lupus who are pregnant have higher than expected rates of poor outcomes such as preterm birth
  - *Likely related to decreased access to care, social determinants of health, and differential treatment by health care providers*

- Black and Hispanic patients presenting to the emergency department with pain are less likely to receive pain medications than White patients presenting with pain
  - *Likely related to racial biases regarding pain tolerance and communication/language barriers*

The Black Lives Matter Movement and Healthcare

- The Black Lives Matter Movement was begun by Alicia Garza, Patrisse Cullors, and Opal Tometi in response to the murder of 17-year-old Trayvon Martin by George Zimmerman.
  - They created the #BlackLivesMatter hashtag in 2013 and Black Lives Matter has grown to represent a new civil rights movement.
  - The recent murders of Breonna Taylor, Ahmaud Arbery, Tony McDade, George Floyd, Riah Milton, Dominique “Rem‘Mie“ Fells, and Elijah McClain have made many healthcare workers question their biases and examine what they can do to help dismantle institutionalized racism in the healthcare system.

- Medical students created the White Coats for Black Lives Organization in 2014.
  - Aims to “dismantle racism in medicine and promote the health, well-being, and self-determination of Black and Indigenous people, and other people of color.”

- Racism is still deeply engrained in the healthcare system. With the Black Lives Matter Movement, information about racism and healthcare is reaching a wider audience.
Racism and COVID-19

- In Boston, Black residents account for 25% of the city’s population but approximately 37% of confirmed COVID-19 cases and 35% of deaths
- In Chicago, Black residents account for 32% of the city’s population, 32.1% of confirmed COVID-19 cases, and 47.5% of deaths
  - This reflects national data: the CDC reports that non-Hispanic Blacks account for 13% of the US population, but they make up about 25% of COVID-19 deaths

According to the CDC, “Long-standing systemic health and social inequities have put some members of racial and ethnic minority groups at increased risk of getting COVID-19 or experiencing severe illness, regardless of age”
Cases of COVID-19 in Boston and Chicago Neighborhoods

- Maps include data through April 23, 3030 (Boston) and July 13, 2020 (Chicago)
- Darker colors = More COVID-19 Cases

DATA ANALYSIS: Boston Public Health Commission, Research and Evaluation Office
Historical Context of Racism in Medical Research in the U.S.

- Racism is a process rather than a sequence of events, therefore the following examples provide only a small snapshot of how racist research projects in the U.S. have caused harm:

- **Tuskegee Syphilis Study**
  - 600 Black men followed over 40 years (1932-1972)
  - Goal of the study was to understand the natural course of syphilis
  - These men were not told that they had syphilis and were not treated, though treatment was available

- **Henrietta Lacks**
  - 31-year-old Black woman whose cervical cancer cells were removed in 1951 without her consent
  - Her cells were used to create the first immortal cell line for medical research
  - Neither she nor her family were compensated
“My friends always say “Don’t do it. Don’t forget your history...It haunts a lot of us...Any person of color.”

“A lot of the clinical trials, we would like to do them, but a lot of times, we don’t qualify... most of the time, with African American women, we don’t qualify for a lot of the studies unless you lie.”

“A lot of minorities, especially Black families, ‘cause we don’t go to the hospital, we wait until the very last minute, so when we do go to the hospital, we die. Then you’ll have people say, “Don’t go to the hospital. They kill you...”
“For me that [the race of the researcher] doesn’t matter. I just want to know that the person is truthful...if the person seems truthful and open and whatever, that’s fine.”

“It’s needed. It’s needed. It’s needed. Because every time you look around, they’re always doing cancer research. Lupus is just as prevalent out there as cancer. It’s mainly in our community...the Black community.”

“It’s a catch 22. We’re more predominantly affected. If we don’t participate in trials that benefit us, even more of us will be affected.”
Safeguards to Prevent Racism in Clinical Trials

- **1974 National Research Act:**
  - Voluntary informed consent
  - Institutional Review Boards
  - Federal oversight
    - Presidential Commission for the Study of Bioethical Issues

https://www.cdc.gov/tuskegee/after.htm
https://bioethicsarchive.georgetown.edu/pcsbi/index.html
Non-White People are Under-Represented in Clinical Trials

- 43% of people with lupus are Black, but only 14% of lupus clinical trial participants are Black

- Why is this the case?
  - Mistrust of physicians and researchers
  - Lack of authentic academic-community partnerships
  - Strict inclusion criteria

This is Also True in Boston...

■ Dana Farber Cancer Institute:

- 2 in every 5 White residents receive their cancer care there compared to 1 in 5 Black residents

- Boston Medical Center, where Black Bostonians are more than three times as likely to get care, listed 7 clinical trials for breast cancer and 6 for lung cancer in 2017 compared to 63 for breast cancer and 45 for lung cancer at the Dana-Farber
Why is it Important to Have Racial Diversity in Clinical Trials?

- To study new interventions across all populations that they will be used to treat
  - If differences are found by race/ethnicity, the reason why must be investigated so that EVERYONE benefits

- Certain conditions, such as lupus, are more common in people of color. We want to make sure that the people who are most affected by a disease are the ones benefiting from clinical trials, in order to get patients more effective treatments more quickly

- Unequal enrollment in clinical trials perpetuates systemic racism in healthcare
QUESTIONS?

THANK YOU!
Additional Reading

- Racial health disparities
  - [www.cdc.gov/minorityhealth/index.html](http://www.cdc.gov/minorityhealth/index.html)

- Tuskegee Syphilis Study
  - *Bad Blood: The Tuskegee Syphilis Experiment, book by James H. Jones*
  - [www.cdc.gov/tuskegee](http://www.cdc.gov/tuskegee)

- Henrietta Lacks
  - *The Immortal Life of Henrietta Lacks, book by Rebecca Skloot*
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