



WISCONSIN DEPARTMENT
of HEALTH SERVICES

The Historical and Contemporary Context of Medical Distrust and What It Will Take to Repair

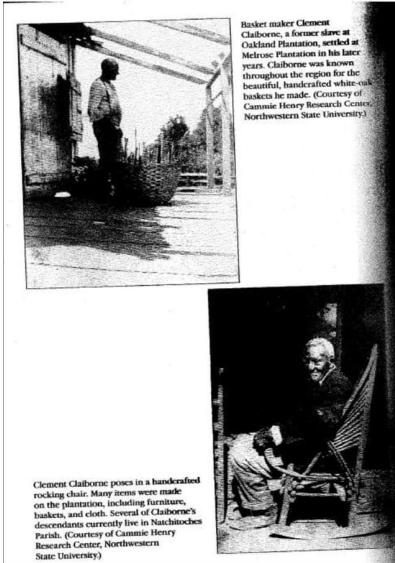
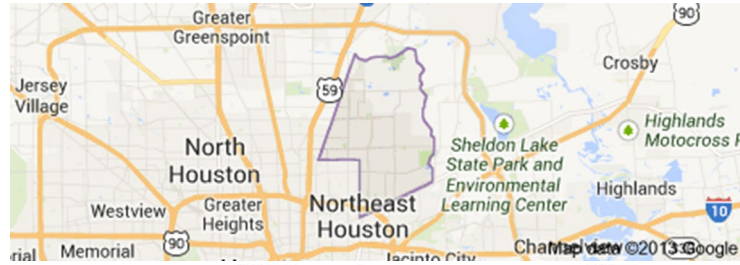
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Director of the Office of Health Equity
June 2, 2023

Who am I?

A bit about me professionally.

- Serving as the inaugural Director of the Office of Health Equity since October of 2021.
- Vice-Chair of the Governor's Health Equity Council
- Consultant to government, non-government organizations and the private sector
- Researcher for Race to Equity/Kids Forward
- Doctorate in Sociology
 - Trained in quantitative and qualitative methods
 - Randomized Control Trials (RCTs), quasi-experimental designs and other inferential statistical methods
 - Ethnography and comparative historical techniques

...and Personally



Setting the Stage

Clinical Trials Composition

- According to the Food and Drug Administration (FDA), in 2020, among clinical trial participants for approved molecular entities and therapeutic biologics:
 - 75% self-identified as white (vs 61.6% of US population)
 - 8% self-identified as Black or African American (vs 12.4% of US population)
 - 11% self-identified as Hispanic (vs 18.7% of US population)
 - 6% self-identified as Asian (vs 6% of US population)

Why Care About Diversity in Clinical Trial Participation?

- Genes
- Age
- Weight
- Height
- Environment
- Social Determinants
 - Race and Ethnicity

Race has been built into medical practice

- Belief that race is biological has shaped healthcare practice and healthcare inequities. Examples include:
 - kidney functioning tests, anemia cut offs in pregnancy, and bone density tests

What is race?

Human Genetic Variation and Categories of Race

- Race has no biological foundation.
- Study: The Apportionment of Human Diversity
 - Evolutionary biologist Richard Lewontin's (1972) work.
 - Tested how much human genetic variation can be attributed to "racial" groupings.
 - Only 6 percent of genetic variation in humans can be attributed.

Genetic Variation Between Individuals

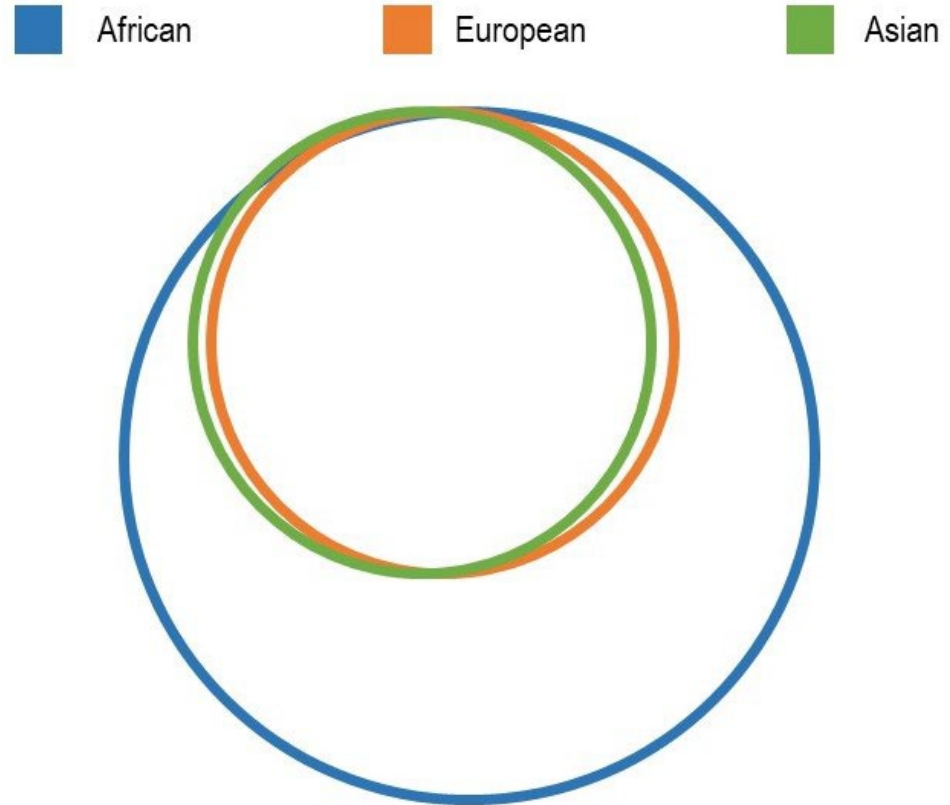
- Race fails to explain a significant amount of human genetic variation.
- Variation between any two individuals is very small.
 - One single nucleotide polymorphism (SNP)
 - A single letter change in our DNA, per 1000.
- Racial categorization could only explain 6 percent of the variation found in 1 in 1000 SNPs.

Genetic Variation Within Categories of Race

Genetic variation can be greater within “race” than it is between “races.”

- Two individuals within a “race” will be more genetically dissimilar from each other than from an individual from a different “race.”

Genetic Diversity by Population



So, what is race then?

“Race is a culturally structured systematic definition of a way of looking at perceiving and interpreting reality.” – Social Anthropologist Dr. Audrey Smedley

- Race is a fluid, political and social construct.
- Race was created and has been used to establish social hierarchies by dividing human populations into groups.

Social and Structural Determinants of Health

Social determinants of health (SDOH) are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.

Social Determinants of Health



Social Determinants of Health
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 Healthy People 2030

The Context of Healthcare Distrust

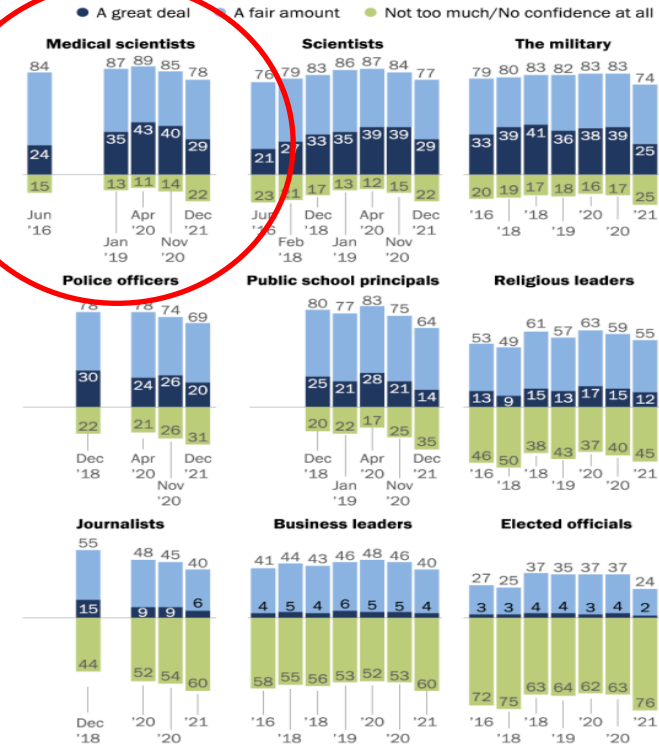
Pew Research Center Poll

Trust in US institutions is on the decline.

- This includes institutional experts.

Public confidence in scientists and medical scientists has declined over the last year

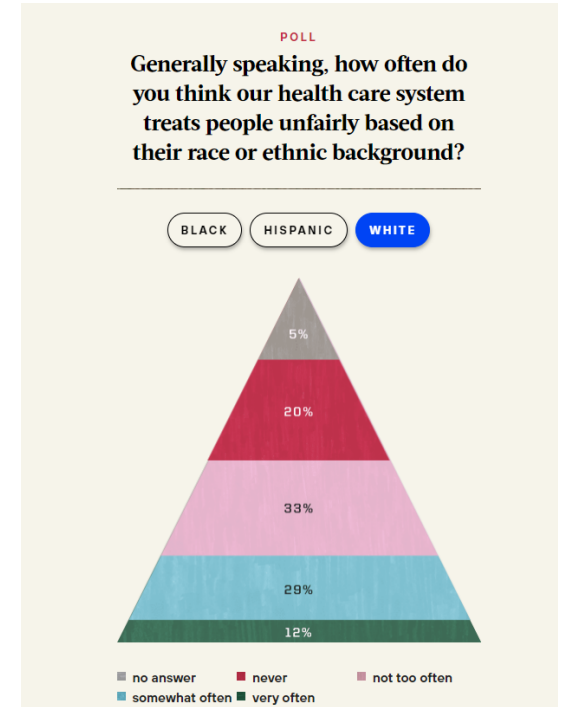
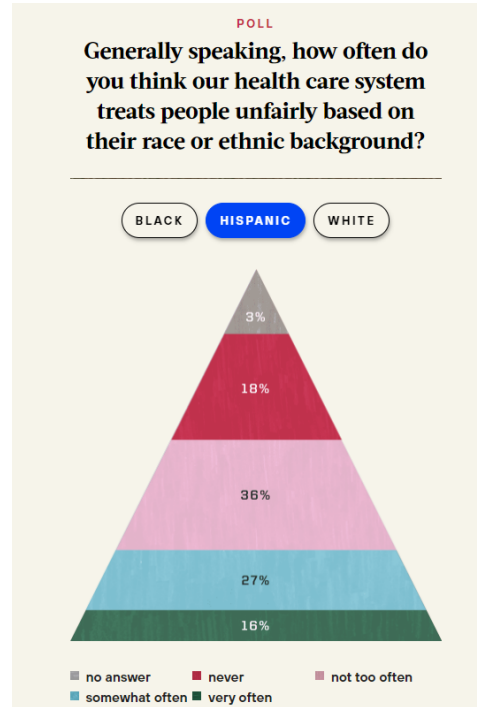
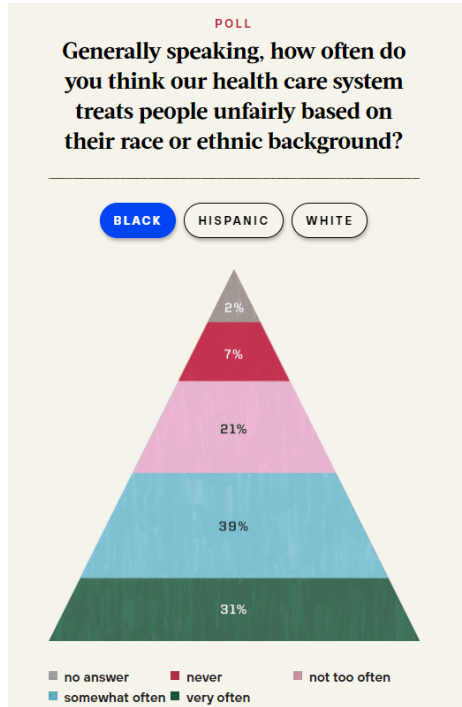
% of U.S. adults who have ____ of confidence in the following groups to act in the best interests of the public



Note: Respondents who did not give an answer are not shown.
Source: Survey conducted Nov. 30–Dec. 12, 2021.
“Americans’ Trust in Scientists, Other Groups Declines”

PEW RESEARCH CENTER

The Undefeated and Kaiser Family Foundation (KFF) Poll



The Undefeated and Kaiser Family Foundation (KFF) Poll

POLL

Was there a time in the last twelve months when you felt you were treated unfairly in the following places because of your racial or ethnic background?

BLACK

HISPANIC

WHITE

AT YOUR PLACE OF WORK

28%

IN A STORE WHERE YOU WERE SHOPPING

40%

IN DEALINGS WITH THE POLICE, SUCH AS TRAFFIC INCIDENTS

26%

WHILE GETTING HEALTH CARE FOR YOURSELF OR A FAMILY MEMBER

20%

POLL

Was there a time in the last twelve months when you felt you were treated unfairly in the following places because of your racial or ethnic background?

BLACK

HISPANIC

WHITE

AT YOUR PLACE OF WORK

17%

IN A STORE WHERE YOU WERE SHOPPING

24%

IN DEALINGS WITH THE POLICE, SUCH AS TRAFFIC INCIDENTS

18%

WHILE GETTING HEALTH CARE FOR YOURSELF OR A FAMILY MEMBER

19%

POLL

Was there a time in the last twelve months when you felt you were treated unfairly in the following places because of your racial or ethnic background?

BLACK

HISPANIC

WHITE

AT YOUR PLACE OF WORK

5%

IN A STORE WHERE YOU WERE SHOPPING

8%

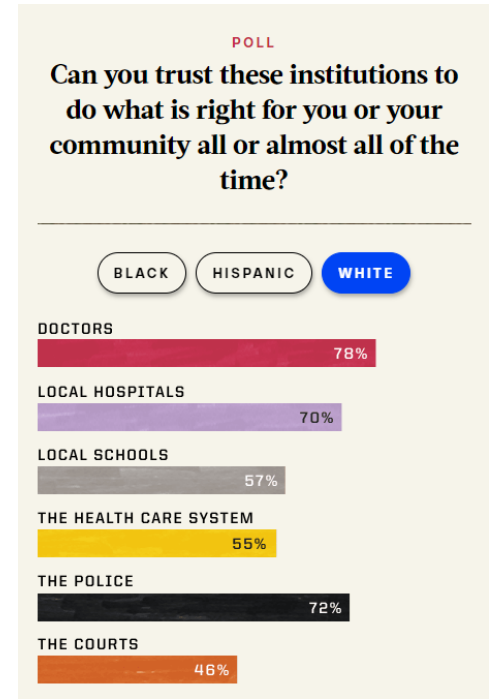
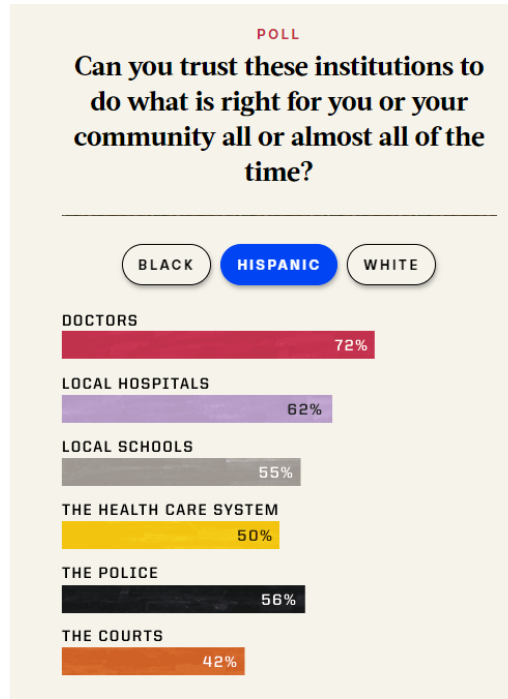
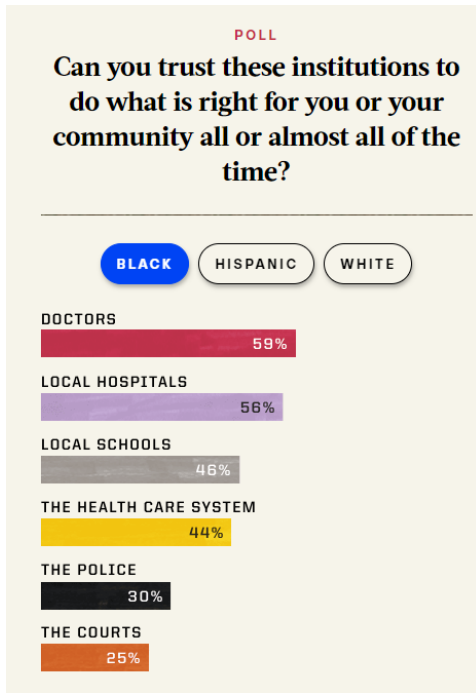
IN DEALINGS WITH THE POLICE, SUCH AS TRAFFIC INCIDENTS

4%

WHILE GETTING HEALTH CARE FOR YOURSELF OR A FAMILY MEMBER

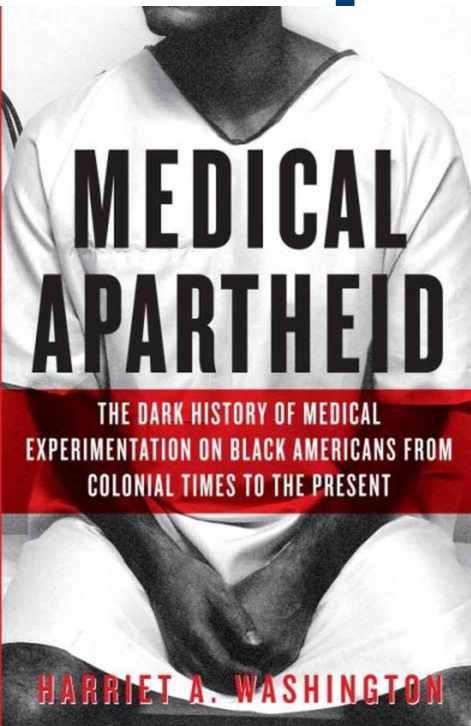
5%

The Undefeated and Kaiser Family Foundation (KFF) Poll



Historic and Contemporary Drivers of Distrust

Abuse, Mistreatment and Exploitation in Healthcare



Sterilization rates per 1000 institutionalized patients

In the first half of the twentieth century, approximately 20,000 people – many of them Latino – were forcibly sterilized in California.

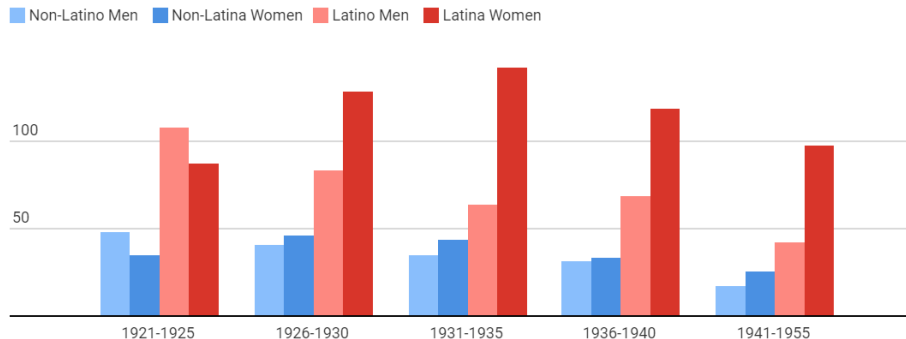


Chart: The Conversation, CC-BY-ND • Source: [California Eugenic Sterilization Dataset, University of Michigan](#) • [Get the data](#)

The Indian Health Service and the Sterilization of Native American Women

JANE LAWRENCE

A young Indian woman entered Dr. Connie Pinkerton-Uri's Los Angeles office on a November day in 1972. The twenty-six-year-old woman asked Dr. Pinkerton-Uri for a "womb transplant" because she and her husband wished to start a family. An Indian Health Service (IHS) physician had given the woman a complete hysterectomy when she was having problems with alcoholism six years earlier. Dr. Pinkerton-Uri had to tell the young woman that there was no such thing as a "womb transplant" despite the IHS physician having told her that the surgery was reversible. The woman left Dr. Pinkerton-Uri's office in tears.¹

Two young women entered an IHS hospital in Montana to undergo appendectomies and received tubal ligations, a form of sterilization, as an added benefit. Bertha Medicine Bull, a member of the Northern Cheyenne tribe, related how the "two girls had been sterilized at age fifteen before they had any children. Both were having appendectomies when the doctors sterilized them without their knowledge or consent." Their parents were not informed either. Two fifteen-year-old girls would never be able to have children of their own.²

What happened to these three females was a common occurrence during the 1960s and 1970s. Native Americans accused the Indian Health Service of sterilizing at least 25 percent of Native American women who were between the ages of fifteen and forty-four during the 1970s. The allegations included: failure to provide women with necessary information regarding sterilization; use of coercion to get signatures on the consent forms; improper consent forms; and lack of an appropriate waiting period (at least seventy-two hours) between the signing of a consent form and the surgical procedure. This paper investigates the historical relationship between the IHS and Indian tribes; the right of the United States government to sterilize women; the government regulations pertaining to sterilization; the efforts of the IHS to sterilize American Indian women; physicians' reasons for sterilizing American Indian women; and the consequences the sterilizations had on the lives of a few of those women and their families.³

400 Lawrence: The Sterilization of Native American Women

Entrenched Health Disparities

Infant Birth and Mortality Outcomes in Wisconsin, 2020

	White (Non-Hispanic)	Black (Non-Hispanic)	AIAN (Non-Hispanic) ²	Asian (Non-Hispanic)	Hispanic	WIC Recipient*	WI Total
Low birthweight, %	6.25%	16.82%	7.40%	6.27%	8.06%	10.30%	7.73%
Premature birth, rate per 1,000 births	89.6	162.6	134.3	70.8	100.5	116.4	99.2
Infant mortality, rate per 1,000 births	4.4	14.3	6.9	5.9	7.9	5.8	6.0

**Birthing parent received Women, Infants, and Children Program during pregnancy*

(Wisconsin Dept. of Health Services, Division of Public Health, Office of Health Informatics. Wisconsin Interactive Statistics on Health query system, <http://dhs.wisconsin.gov/wish/>, Low Birthweight Module, accessed 6/28/2022.)

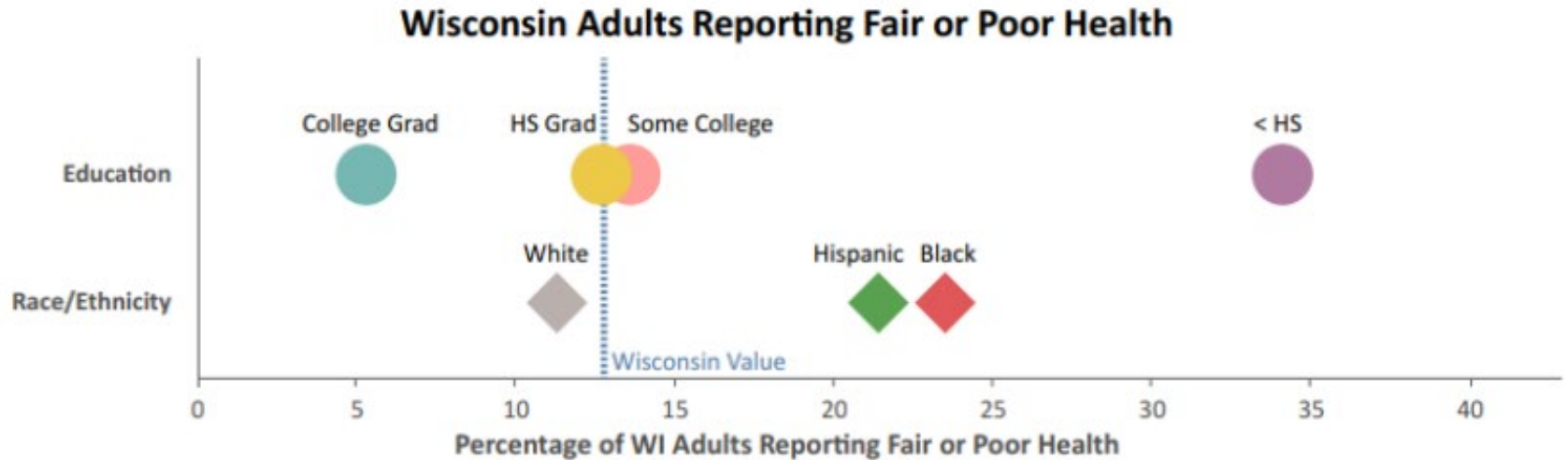
Infant Birth and Mortality Outcomes in Wisconsin, 2020

	Black (Non-Hispanic) number of deaths (IMR)	White (Non-Hispanic) number of deaths (IMR)	Risk ratio (Black vs. White)
Birthing parent education (years)			
8th grade or less	X (12.8)	12 (8.6)	1.49
Some high school	20 (19.3)	13 (10.0)	1.93
High school graduate/GED	38 (12.9)	46 (5.6)	2.32
Some college	19 (11.2)	55 (4.5)	2.50
College graduate	X (8.6)	43 (3.2)	2.70
Postgraduate	. (.)	15 (2.5)	.
Missing	10 (73.5)	X (12.7)	5.81

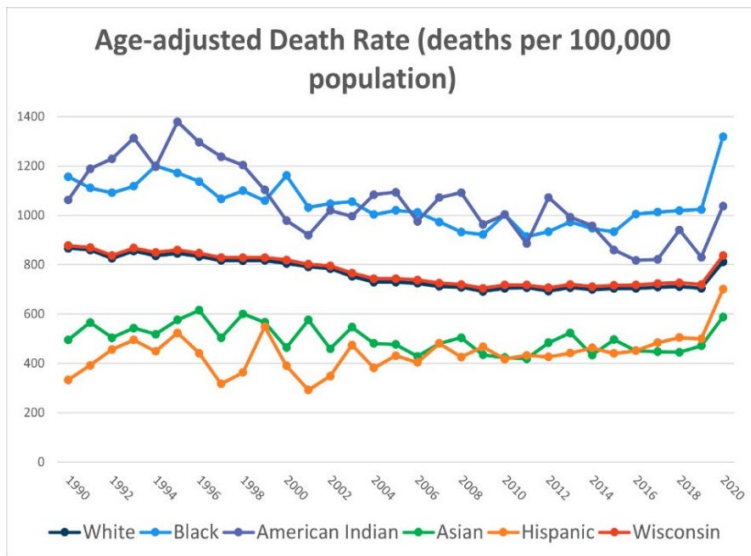
An "X" indicates a value that is less than 5 (but more than zero) and has been suppressed to protect confidentiality. A period (.) indicates there are zero cases in that cell.

Wisconsin Dept. of Health Services, Division of Public Health, Office of Health Informatics. Wisconsin Interactive Statistics on Health (WISH) data query system, www.dhs.wisconsin.gov/wish/index.htm, Infant Mortality Module, accessed 6/29/2022.

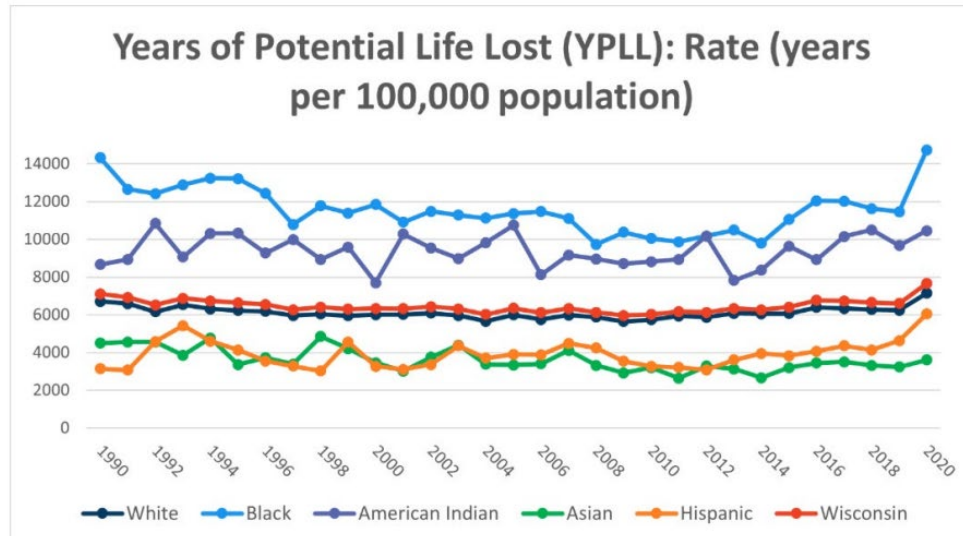
Entrenched Health Disparities



Entrenched Health Disparities



Wisconsin Dept. of Health Services, Division of Public Health, Office of Health Informatics. Wisconsin Interactive Statistics on Health (WISH) data query system, <https://www.dhs.wisconsin.gov/wish/index.htm>, Mortality Module, accessed 9/21/2022.



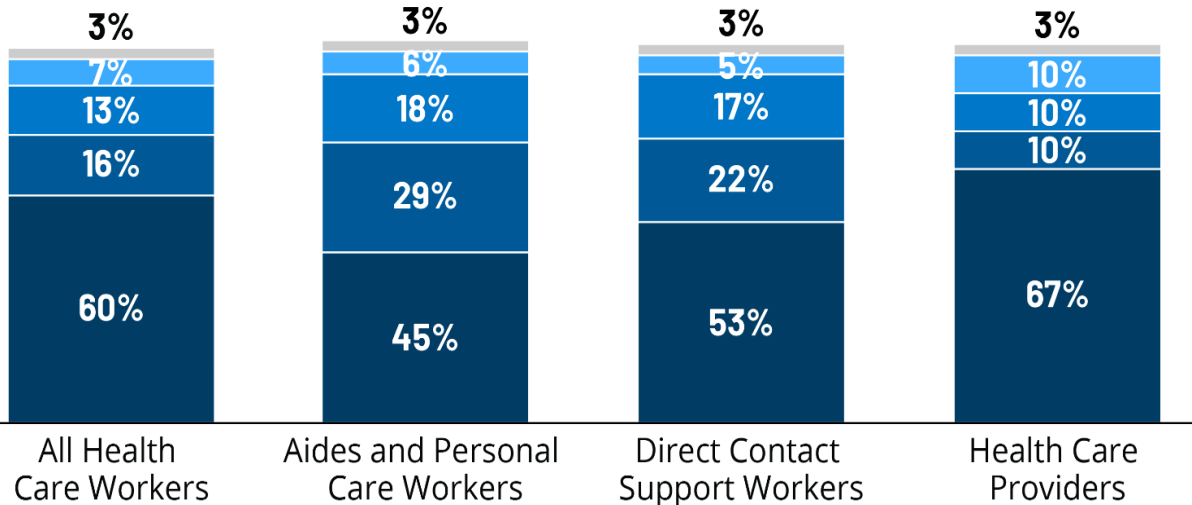
Wisconsin Dept. of Health Services, Division of Public Health, Office of Health Informatics. Wisconsin Interactive Statistics on Health (WISH) data query system, www.dhs.wisconsin.gov/wish/index.htm, Mortality Module, accessed 9/21/2022.

Diversity in Healthcare

Racial/Ethnic Distribution of Health Care Workers

Total and Select Occupations, 2019

● White ● Black ● Hispanic ● Asian ● Other



Statistics Showing the Need for Diversity Among US Physicians

When it comes to diversity in medicine, there's progress to be made. The below facts illustrate the need for change.

GENDER DIVERSITY



Only 36% of US physicians are female.¹

Less than 10% of physicians in the following fields are female:²



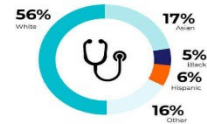
- Interventional cardiology
- Thoracic surgery
- Neurological surgery
- Urology
- Orthopedic surgery
- Vascular and interventional radiology
- Sports medicine

RACIAL AND ETHNIC DIVERSITY



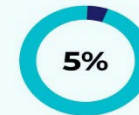
There were fewer Black male medical students in 2014 than in 1978.³

Of all US physicians⁴



SOCIOECONOMIC DIVERSITY

Only 5% of medical students' families are in the lowest household income quintile.



Less than 25% of medical students' families are in the bottom three household income quintiles.⁴

St. George's University

Citation:
 1. Association of American Medical Colleges, "Diversity in Medicine: Facts and Figures 2009" (<https://www.aamc.org/data-reports/diversity-in-medicine-facts-and-figures-2009>)
 2. Association of American Medical Colleges, "2020 Active Physician Specialty Data Report" (<https://www.aamc.org/data-reports/2020-active-physician-specialty-data-report>)
 3. Association of American Medical Colleges, "Altering the Course: Black Males in Medicine" (<https://www.aamc.org/data-reports/altering-the-course-black-males-in-medicine>)
 4. Association of American Medical Colleges, "An Updated Look at the Economic Diversity of U.S. Medical Students" (<https://www.aamc.org/media/2019/06/2019-economic-diversity>)

What can we do?

Long-term Goals

- Identifying and implementing strategies that diversify healthcare, public health, and clinical/academic workforces.
- Address the social and structural determinants of health, eliminate health disparities and improve overall population health.
- Build/re-build public trust in healthcare systems and medical/biomedical research.

Strategies to Build Trust

- Establish research/practice governance structures that brings underrepresented groups into study development implementation and dissemination.
 - **Examples:**
 - **Carbone Cancer Center's Community Advocacy Boards** (CAB) – Cancer Health Disparities Initiative
 - **Community Advisors on Research Design and Strategies (CARDS)** – Wisconsin Network for Research Support (WINRS)
 - **Dane County Health Council** and the **Black Maternal Child Health Alliance**

Strategies to Build Trust

- Invest in, and partner with, researchers from underrepresented groups from the start of a potential project and through every phase.
 - **Children, Families and Schools Study** – *Can FAST Build Social Capital Among Low-Income, Urban Latino Families?*
 - National Institute of Child Health and Human Development (NICHD) Grant
 - 5-year study
 - 3000+ Families, 52 Schools, 2 School Districts

Strategies to Build Trust

- Provide scientifically accurate training and professional development on race and health and cultural humility to healthcare professionals and researchers.
 - **Examples:**
 - Dr. Tiffany Green – Race in US Obstetrics and Gynecology
 - Beverly Hutcherson – Courses on biology, race, epigenetics

Final Thoughts

In Summation

- Race is not a biology.
 - Is race the best way of capturing the variation of concern?
- Contemporary distrust is a function of historic and contemporary experiences with medical research, healthcare systems and health outcomes.
- Ultimately, addressing distrust requires addressing power imbalances as well as the drivers and outcomes of these imbalances.

In Summation, cont.

- In the meantime, strategies that support the co-development and leadership of research with members of underrepresented groups, or groups of interest can create localized structures of trust.
- Improving experiences with healthcare providers and systems will go along way to improve trust.

