VANDERBILT UNIVERSITY
MEDICAL CENTER

What Will it Take to Build an Equitable Precision Health Care System?

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National Academy of Medicine Roundtable
on Genomics and Precision Health
October 12, 2022

@DrCHWilkins

Building an Equitable Precision Health Care System

- Precision medicine has been built on a foundation of inequity
- **Health care is unfair, unjust, racist, and discriminatory**
- What strategies will overcome disinvestments, flawed science?

What is health equity?

The absence of **avoidable, unfair, or remediable differences in health outcomes** among groups of people whether those groups are defined socially, economically, demographically or geographically.

https://www.who.int/topics/health_equity/en/

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WHICH POPULATIONS ARE INCLUDED IN HEALTH EQUITY RESEARCH?

NIH-designated U.S. populations experiencing inequities:

- American Indians/Alaska Natives
- Asian Americans
- Blacks/African Americans
- Hispanics/Latinos
- Native Hawaiians and other Pacific Islanders
- Sexual and gender minorities
- Socioeconomically disadvantaged populations
- Underserved rural populations

As of May 5, 2021 https://www.nimhd.nih.gov/about/overview/

Race is a sociopolitical construct

Race: group a person belongs to (or is perceived to belong to)

- based on physical attributes – skin color, facial features, hair, etc
- fluid (changes over time)
- no biological or scientific basis
- In the U.S., race has been primarily used for oppression

Artist Angélica Dass rethinks the concept of race by showing the diversity of human skin colors in her global photographic mosaic. https://www.angelicadass.com/humanae-project

POLICY FORUM

GENETICS AND SOCIETY

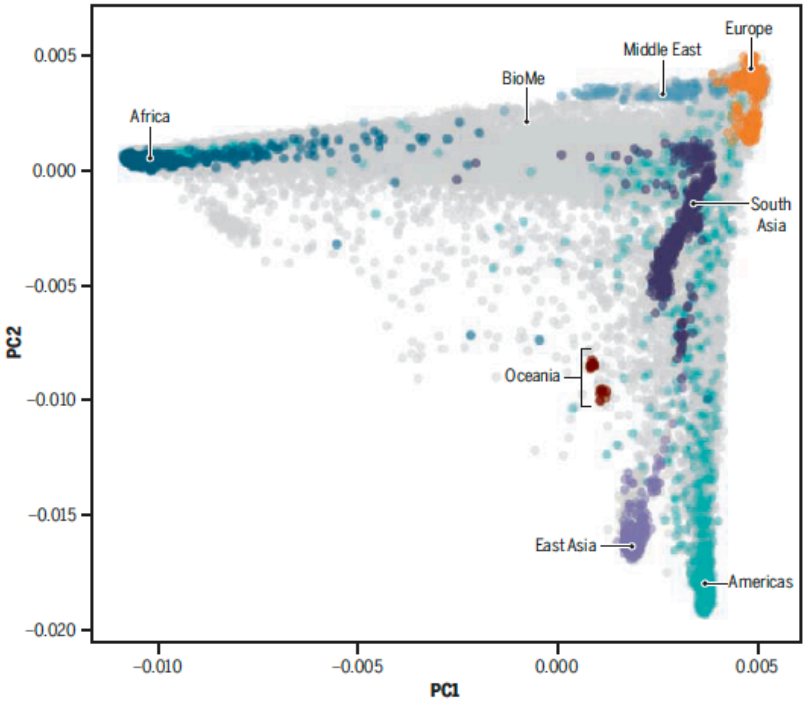
Getting genetic ancestry right for science and society

We must embrace a multidimensional, continuous view of ancestry and move away from continental ancestry categories

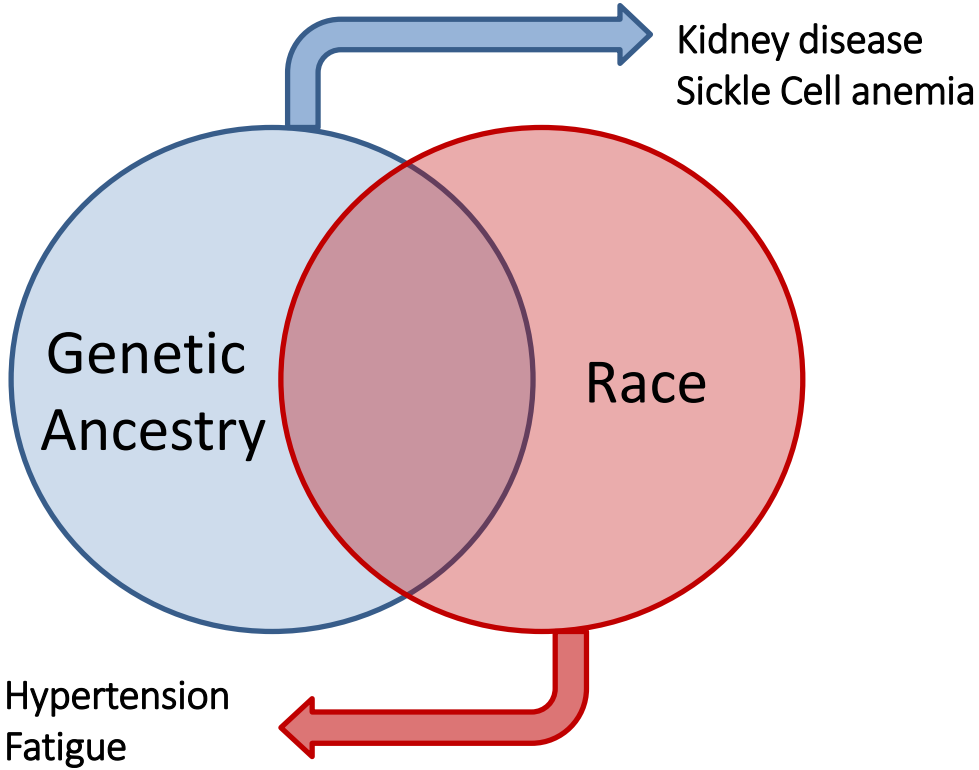
By **Anna C. F. Lewis, Santiago J. Molina, Paul S. Appelbaum, Bege Dauda, Anna Di Rienzo, Agustin Fuentes, Stephanie M. Fullerton, Nanibaa' A. Garrison, Nayanika Ghosh, Evelynn M. Hammonds, David S. Jones, Eimear E. Kenny, Peter Kraft, Sandra S.-J. Lee, Madelyn Mauro, John Novembre, Aaron Panofsky, Mashaal Sohail, Benjamin M. Neale, Danielle S. Allen**

The continuous, category-free, nature of genetic variation

Colored dots (n = 4149) are reference panel individuals from 87 populations representing ancestry from seven continental or subcontinental regions projected onto the first two principal components (PC1 and PC2) of genetic similarity. Gray dots (n = 31,705) are participants from BioMe, a diverse biobank based in New York City. Clearly delineated continental ancestry categories (the islands of color) are shown to be a by-product of sampling strategy. They are not reflective of the diversity in this real-world dataset, which is made evident by the continuous sea of gray.

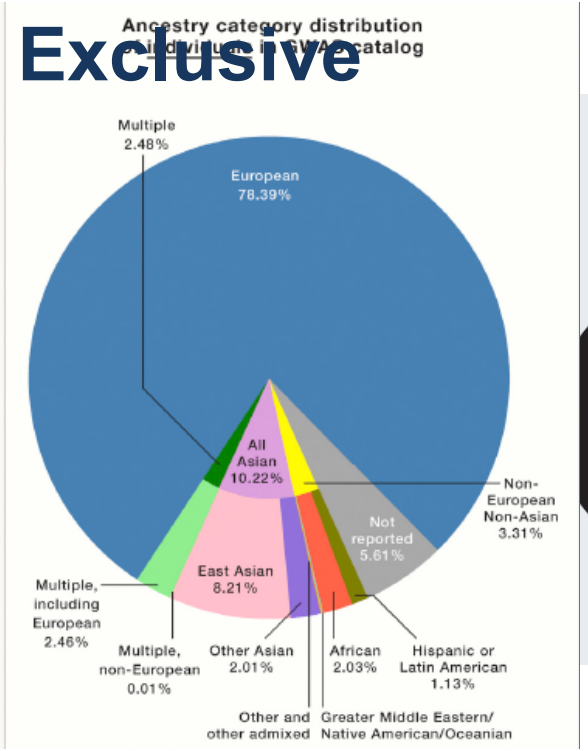


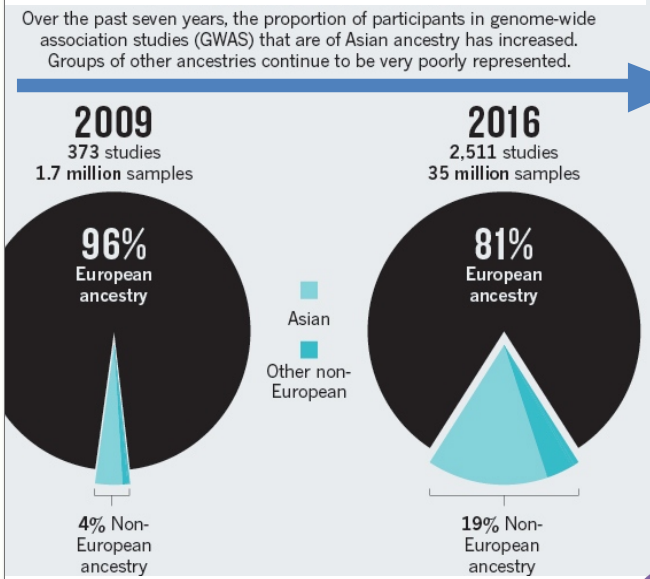
BioVU Study: 30,000+ patients

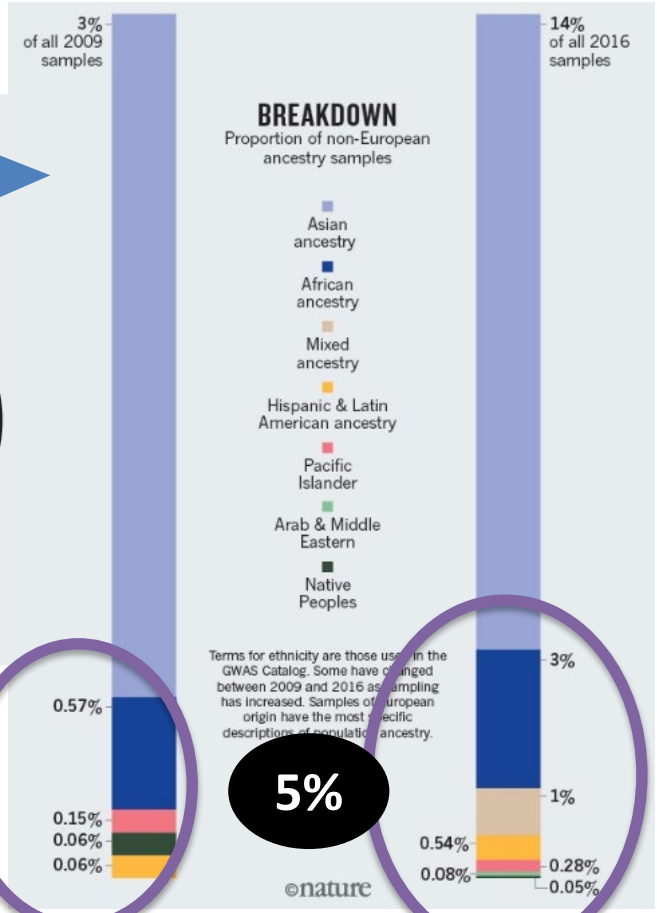


Acktins et al; Using electronic health records to identify health disparities. Manuscript in progress.

Foundational Inequity: Genomics is Exclusive







% Non-European, Non-Asian

1%

5%

Popejoy and Fullerton 2016
Quansah and McGregor 2017
Sirugo, Williams and Tishkoff 2019

Foundational Inequity: Variants of Undetermined Significance More Common in Minoritized Groups

Original Report:
Cancer

Next Generation Sequencing Reveals High Prevalence of BRCA1 and BRCA2 Variants of Unknown Significance in Early-Onset Breast Cancer in African American Women

Luisel Ricks-Santi, PhD[1]; J. Tyson McDonald, PhD[1]; Bert Gold, PhD[2]; Michael Dean, PhD[2]; Nicole Thompson, MS[3]; Muneer Abbas, PhD[4]; Bradford Wilson, PhD[4]; Yasmine Kanaan, PhD[5]; Tammey J. Naab, PhD[3]; Georgia Dunston, PhD[4,5]

Inequities in multi-gene hereditary cancer testing: lower diagnostic yield and higher VUS rate in individuals who identify as Hispanic, African or Asian and Pacific Islander as compared to European

Mesaki K. Ndugga-Kabuye[1] · Rachel B. Issaka[2,3,4]

Published online: 17 September 2019

Equitable Expanded Carrier Screening Needs Indigenous Clinical and Population Genomic Data

Simon Easteal,[1,*] Ruth M. Arkell,[2] Renzo F. Balboa,[1] Shayne A. Bellingham,[1] Alex D. Brown,[3,4] Tom Calma,[5] Matthew C. Cook,[6] Megan Davis,[7] Hugh J.S. Dawkins,[8,9,10,11,12] Marcel E. Dinger,[13] Michael S. Dobbie,[1,2] Ashley Farlow,[1,14] Kylie G. Gwynne,[5,15] Azure Hermes,[1] Wendy E. Hoy,[16] Misty R. Jenkins,[17,18] Simon H. Jiang,[6] Warren Kaplan,[19] Stephen Leslie,[1,14] Bastien Llamas,[1,20] Graham J. Mann,[2] Brendan J. McMorran,[2] Rebekah E. McWhirter,[21] Cliff J. Meldrum,[22] Shivashankar H. Nagaraj,[23] Saul J. Newman,[24] Jack S. Nunn,[25] Lyndon Ormond-Parker,[26] Neil J. Orr,[5] Devashi Paliwal,[1,2] Hardip R. Patel,[1] Glenn Pearson,[27] Greg R. Pratt,[28] Boe Rambaldini,[5] Lynette W. Russell,[29] Ravi Savarirayan,[30] Matthew Silcocks,[1,14] John C. Skinner,[5] Yassine Souilmi,[1,31] Carola G. Vinuesa,[2] The National Centre for Indigenous Genomics, and[1] Gareth Baynam[32,33,34,*]

Hall et al 2009; Caswell-Jin et al 2018; Ndugga-Kabuye and Issaka 2019; Chapman-Davis et al 2020; Kwon et al 2020; Roberts et al 2020.

Popular Latest

The Atlantic

POLITICS

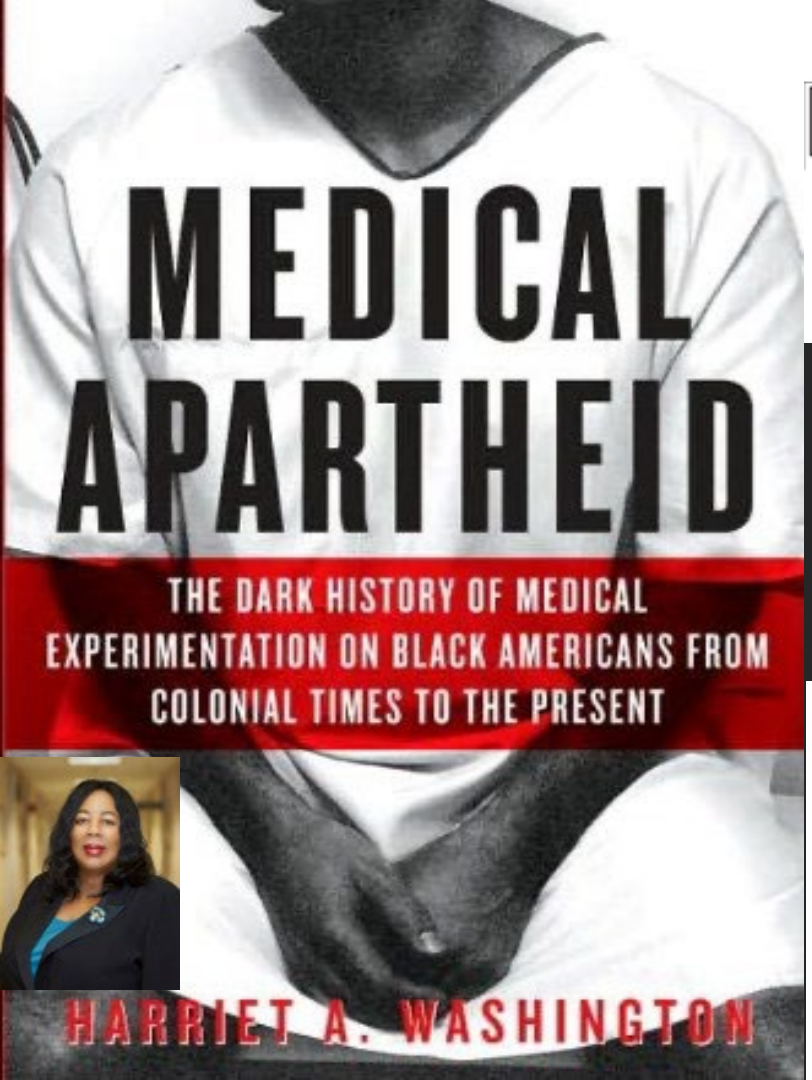
America's Health Segregation Problem

Has the country done enough to overcome its Jim Crow health care history?

VANN R. NEWKIRK II MAY 18, 2016

A doctor's office in Merigold, Mississippi in 1939 (MARION POST WOLCOTT / LIBRARY OF CONGRESS)

Wilkins CH. Slide created April 2018.



The NEW ENGLAND JOURNAL of MEDICINE

MEDICINE AND SOCIETY

Debra Malina, Ph.D., *Editor*

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.

Black people were less likely than white people to be sent for personalized care, a study found.

MILLIONS AFFECTED BY RACIAL BIAS IN HEALTH-CARE ALGORITHM

Study reveals widespread racism in decision-making software used by US hospitals.

| Nature | Vol 574 | 31 October 2019

Original Investigation

July 11, 2022

Asian, Black, and Hispanic patients received less supplemental oxygen than White patients

Assessment of Racial and Ethnic Differences in Oxygen Supplementation Among Patients in the Intensive Care Unit

Eric Raphael Gottlieb, MD, MS[1,2,3]; Jennifer Ziegler, MD, MSc[4]; Katharine Morley, MD, MPH[2,5]; et al

» Author Affiliations

JAMA Intern Med. 2022;182(8):849-858. doi:10.1001/jamainternmed.2022.2587

Unequal Treatment

- Published in March 2002 by Institute of Medicine
- Refers to racism >150 times

The National Academies of SCIENCES ENGINEERING MEDICINE

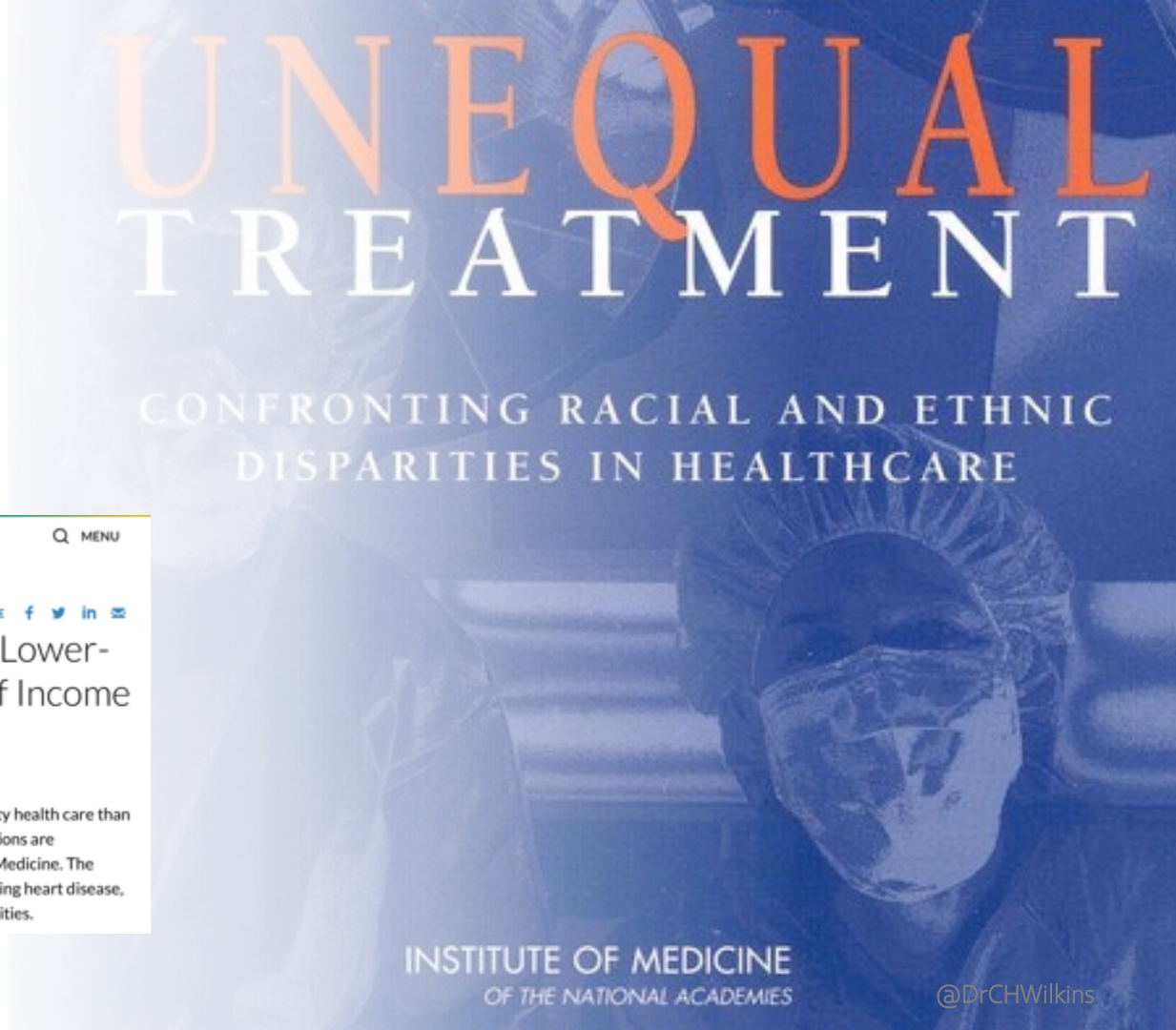
MENU

SHARE

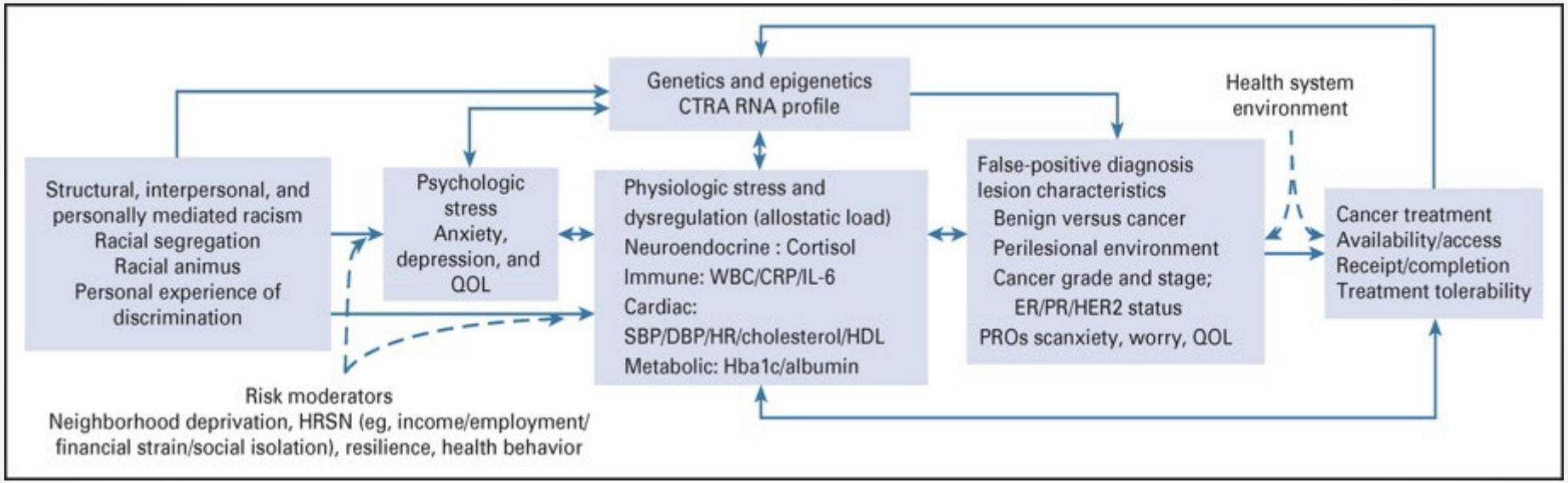
Minorities More Likely to Receive Lower-Quality Health Care, Regardless of Income and Insurance Coverage

News Release | March 20, 2002

WASHINGTON -- Racial and ethnic minorities tend to receive lower-quality health care than whites do, even when insurance status, income, age, and severity of conditions are comparable, says a new report from the National Academies' Institute of Medicine. The committee that wrote the report also emphasized that differences in treating heart disease, cancer, and HIV infection partly contribute to higher death rates for minorities.



Linking Structural Racism and Discrimination and Breast Cancer Outcomes: A Social Genomics Approach



Carlos RC, Obeng-Gyasi S, Cole SW ... Wilkins CH. Linking Structural Racism and Discrimination and Breast Cancer Outcomes: A Social Genomics Approach. J Clin Oncol. 2022 May 1;40(13):1407-1413.

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Building Equitable Precision Health Care

- Bolus of funding for higher quality reference data, identify novel variants, accurate sets
- Acknowledge some racial/ethnic groups benefit less from precision medicine; commit to remedying
- Include social and structural determinants of health data; prioritize diverse teams; engage marginalized communities
- Center the needs & preferences of minoritized groups; health & science must be trustworthy; acknowledge differing risks

Consuelo H. Wilkins, MD, MSCI; Senior Vice President and Senior Associate Dean for Health Equity; Professor of Medicine; Vanderbilt University Medical Center

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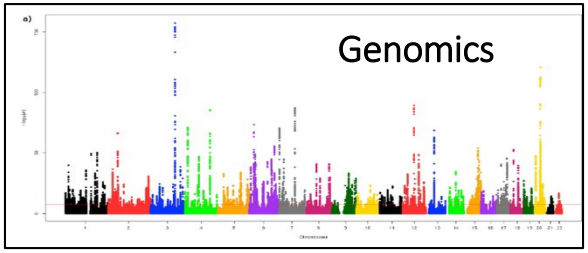
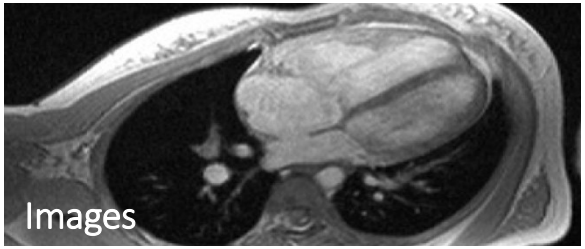
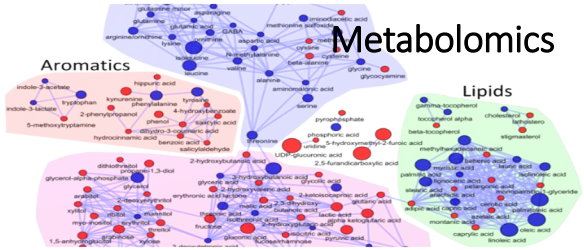
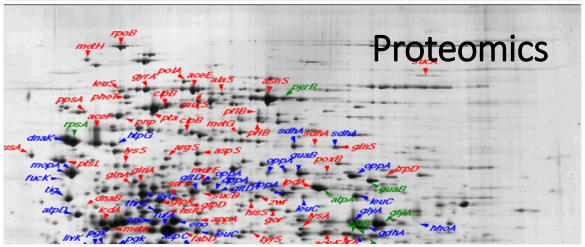
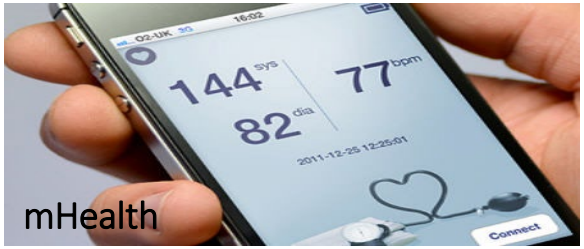
Are we including the right data?

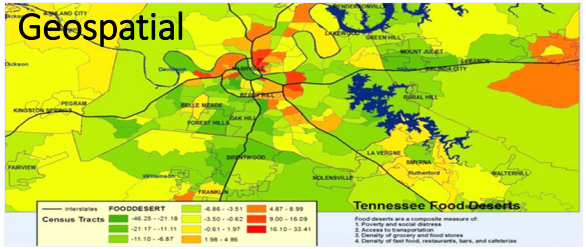


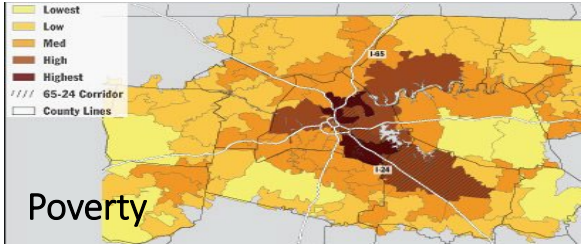


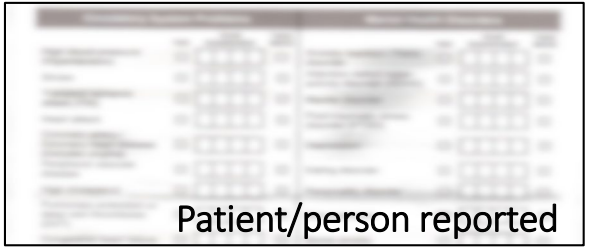












Twitter: @DrCHWilkins

Slide adapted from Josh Denny 2017