Big Data
For or Against
Health Disparities

Deborah Guadalupe Duran, PhD
Director, Office of Science Policy, Planning Reporting and Data
National Institute of Minority Health and Health Disparities

National Institute
on Minority Health
and Health Disparities

OVERVIEW

"Imagine most of the world is getting healthier because of some new technology, but you're getting left behind"

- NIMHD Mission
- Need for Big Data – Minority Health/Health Disparities
- Big Data: Structured and Unstructured (Use with Caution)
- Big Data: Importance for Health Disparities Research and Clinical Care
- NIMHD - Big Data into Health Disparities Research

NIMHD Mission

NIMHD'S MISSION

- To improve minority health
- To reduce health disparities

To achieve:

- Plans, coordinates, reviews, and evaluates NIH minority health and health disparities research and activities
- Conducts and supports research in minority health and health disparities
- Promotes and supports the training of a diverse research workforce
- Translates and disseminates research information
- Fosters innovative collaborations and partnerships

MINORITY AND *HEALTH DISPARITIES POPULATIONS

- Racial/Ethnic Minorities
  - American Indian or Alaska Native
  - Asian
  - Black or African American
  - Hispanic/Latino American
  - Native Hawaiian or Other Pacific Islander

- *Low socio-economic status
- *Rural
- *Sexual and gender minorities
- *Others subject to discrimination who have poorer health outcomes

Source: Duran DG, Perez-Stable, EJ, Novel Approaches to Advance Minority Health and Health Disparities Research, *AJPH* Supplement 1, 2019

MINORITY HEALTH DEFINITION

"Health characteristics and attributes of racial and/or ethnic minority groups who are socially disadvantaged due in part by being subject to potential discriminatory acts."

Minority health research examines singularly and in combination the attributes, characteristics, behaviors, biology, and other factors that influence the health outcomes of minority racial and ethnic groups, including within-group or ethnic subpopulations, with the goal of understanding mechanisms and improving health.

HEALTH DISPARITIES DEFINITION

A health difference that adversely affects defined disadvantaged populations, based on one or more health outcomes.

HD OUTCOMES:

- Higher incidence/prevalence, including earlier onset or more aggressive progression
- Premature or excessive mortality
- Greater global burden
- Worse self-reported outcomes measures that reflect daily functioning or symptoms from specific conditions
- Poorer health behaviors and clinical outcomes (related to above)

Source: Duran DG, Perez-Stable, EJ, Novel Approaches to Advance Minority Health and Health Disparities Research, *AJPH* Supplement 1, 2019

CAUSES

EFFECTS

***Health Determinants**

- Behaviors
- Biology
- Sociocultural
- Physical Environment
- Health Care & Systems

These influence health Disparities

*With substantial evidence, may be used as a proxy outcome measure

Health Disparity Outcomes

- Higher Incidence prevalence, including earlier onset or more aggressive progression
- Premature or excessive mortality from specific conditions
- Greater global burden as indicated by population health measures
- Poorer health behaviors and clinical outcomes (related to above)
- Worse self-reported outcomes measures that reflect daily functioning or symptoms from specific conditions

HEALTH DETERMINANTS

Behavioral

Tobacco use
Diet and nutrition
Preventive health behaviors
Unprotected sexual intercourse
Domestic/Family violence
Physical activity
Substance use, abuse, misuse, and addiction
Compliance and adherence with prescribed therapy
Delays in seeking care after symptom awareness
Living responsibly with infectious disease
Hygiene/Oral hygiene
Cultural beliefs/Schemas
Religious beliefs/Schemas

Biological

Biochemical
Genome and epigenome
Proteome
Microbiome
In utero exposure
Metabolic factors
Pathogens
Physiologic responses to stress/Allostatic load
Organ systems
Nervous system
Telomere/Cellular aging/Senescence
Cellular functions & communication
Enzymes
Inflammation
Demographics
Endocrine system/Hormones

Clinical Events & Health Care Systems

Patient-clinician communication
Health insurance coverage/policies
Access to preventive services and/or quality health care
Disease management & functioning status
Symptom and pain management
Drug interactions and synergies
Use of alternative therapies
Appropriate diagnostics
Access to emerging technologies
Access to public health education, information, and health alerts
Precision medicine
Generalizability of research findings
Translation of research
Dissemination & diffusion of research results
Macro-structural stressors (e.g., policies & procedures)
Incorporation of spiritual and/or traditional healers
Institutional discrimination in health care
Health care system mistrust
Culturally competent care
Workforce diversity
Electronic medical records
Palliative and end-of-life care
Living with chronic illness and/or comorbid conditions
Long-term care
Access to health information/consent in primary language
Policies & political practices
Diversity of biomedical/health delivery workforce

Sociocultural Environment

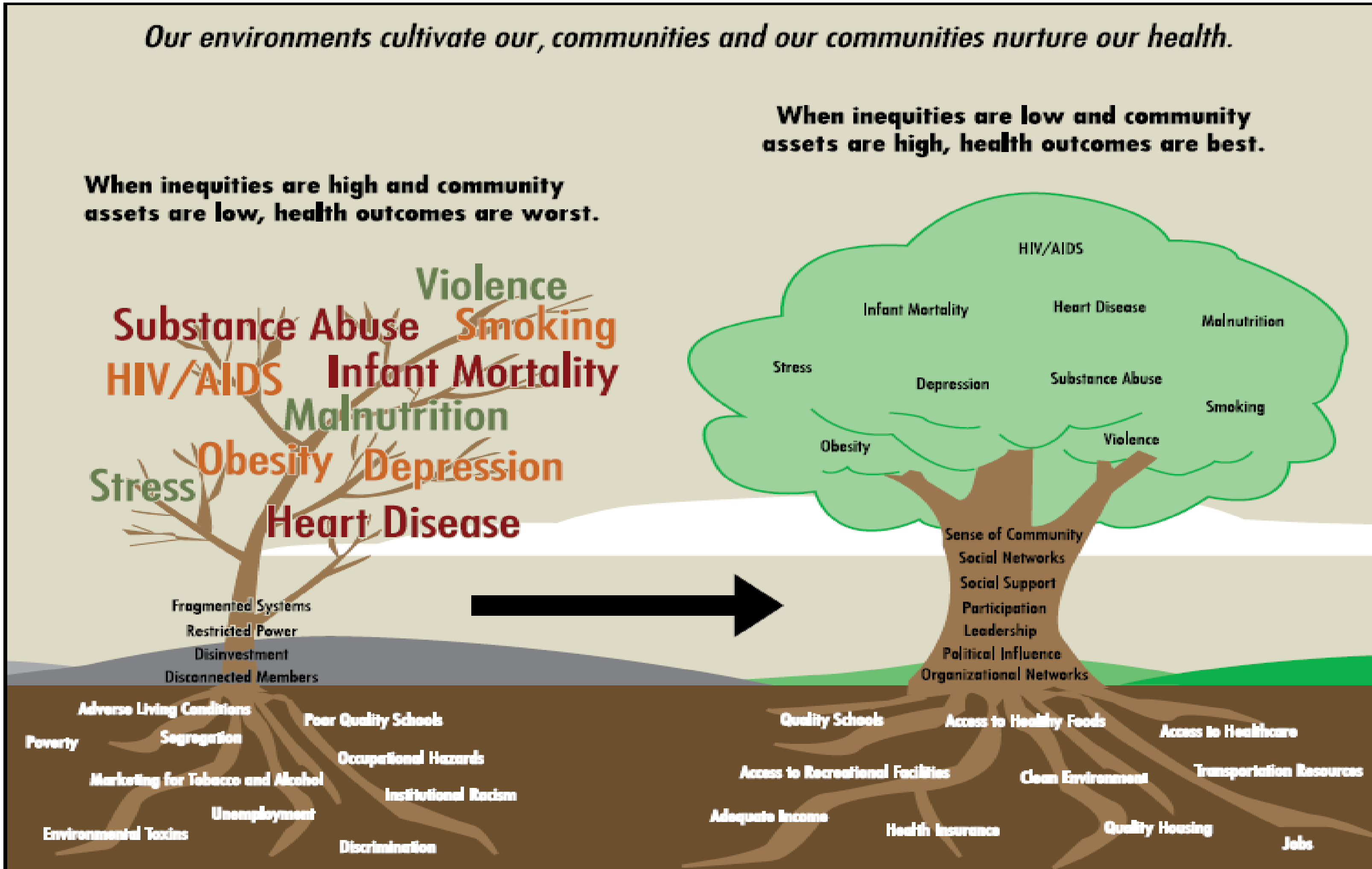
Employment status and security
Income
Housing and food security
Health insurance status (affordability/quality)
Social and economic adversity and/or inequality
Immigration and legal status
Geographic location
Residential segregation
Educational attainment
Access to quality education
Transportation options
Limited English Proficiency
Health literacy/numeracy
Discrimination, racism, and stigma
Health socialization and education
Psychosocial stressors
Historical trauma
Social safety net
Community reentry (e.g., prison, military service)

Physical Environment

Housing status
Neighborhood violence
Unhealthy housing units
Residence crowding
Exposure to toxic substances (e.g., pollution, radiation, lead, mold, dust mites)
Aesthetic elements (e.g., trees)
Access to safe recreational facilities
Quality of air and water
Concentration of fast-food outlets & access to full-service grocery stores
Public safety (e.g., fire dept., police)
Occupational conditions and/or hazards
Affordability of resources

Social Determinants of Health Shape Population Health

https://www.cdc.gov/nccdphp/dch/programs/healthycommunitiesprogram/tools/pdf/sdoh-workbook.pdf



From Brennan Ramirez et al, *Promoting Health Equity,* CDC, 2008 et al. Figure adapted from Anderson et all, 2003; Marmot et al, 1999; and Wilkinson et al, 2003

National Institute on Minority Health and Health Disparities

NIMHD INVESTED IN BIG DATA

- Need Data
  - Population representation that is adequate and accurate
  - Social determinants of health, the causes of health disparities

- Improve
  - Clinical care
  - Population health/Reduce health disparities

- Prevent additional health disparities generated by technological advances

Need for BIG DATA

TO IMPROVE MINORITY HEALTH
TO REDUCE HEALTH DISPARITIES

DEMOGRAPHICS – USA 2017 to 2019 Data

- Estimated population of 328,285,992 (~40% minorities/~50% HD populations)
- 82.3% of the population resides in cities and suburbs
- Hispanic and Latino Americans 18.1%
- African Americans 13.4%
- Asian Americans 5.8% / fast growing: 3% growth rate
- American Indian/Alaska Native 1.3%
- SGM/LGBT: 3-5% or 9 million Americans (adult population)
    - Estimated 19 million Americans (8.2%) report that they have engaged in same-sex sexual behavior
    - 25.6 million Americans (11%) acknowledge at least some same-sex sexual attraction.
- Poverty: 13.5% or 39.7 million Americans (2017 data)
- Rural: 19.3% or 60 million Americans (2017)

https://www.census.gov/quickfacts/fact/table/US/PST045218
https://williamsinstitute.law.ucla.edu/research/census-lgbt-demographics-studies/how-many-people-are-lesbian-gay-bisexual-and-transgender/
https://poverty.ucdavis.edu/faq/what-current-poverty-rate-united-states
https://www.census.gov/library/stories/2017/08/rural-america.html

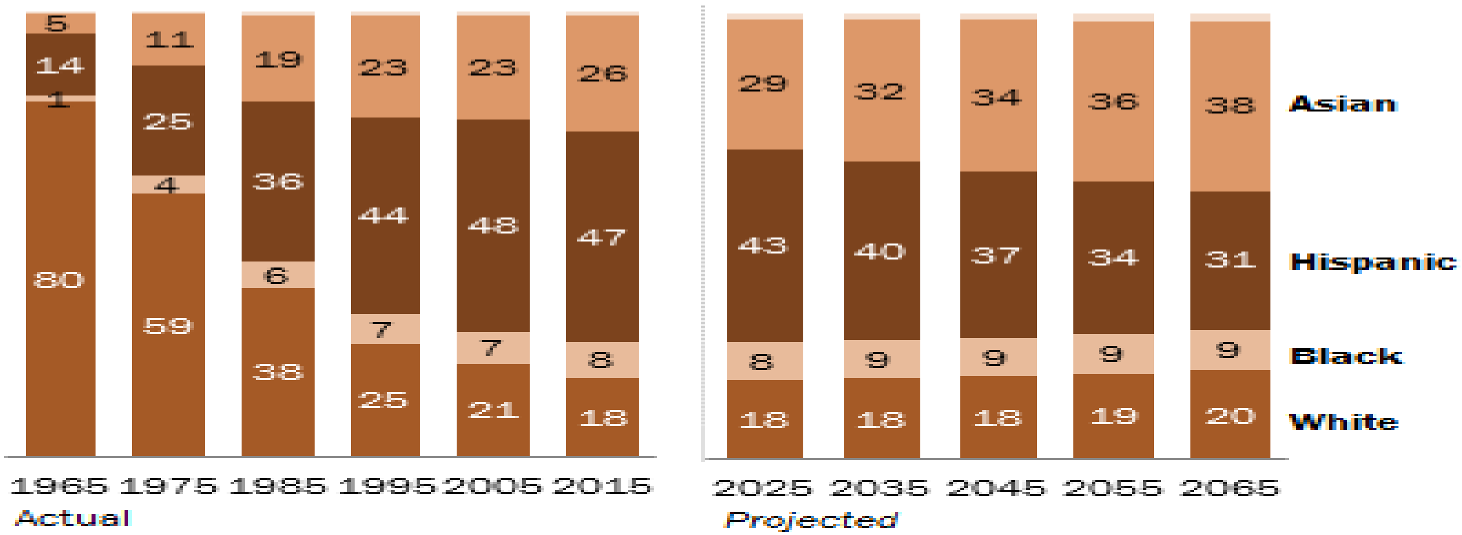
NIH National Institute on Minority Health and Health Disparities

Asians Projected to Become the Largest Immigrant Group, Surpassing Hispanics

FIGURE 5

Asians Projected to Become the Largest Immigrant Group, Surpassing Hispanics

% of immigrant population



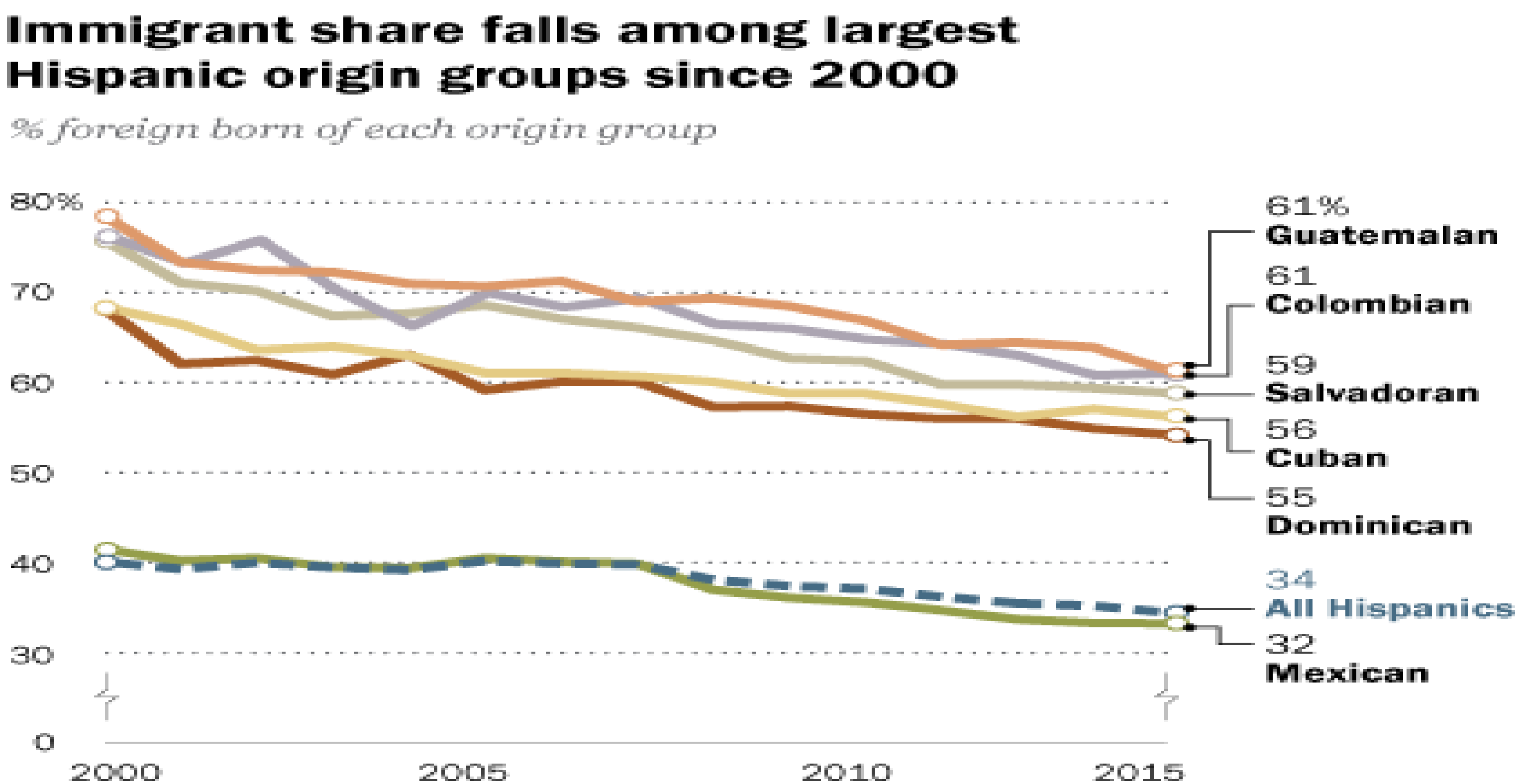
Note: Whites, blacks and Asians include only single-race non-Hispanics. Asians include Pacific Islanders. Hispanics are of any race. Other races shown but not labeled.

Source: Pew Research Center estimates for 1965-2015 based on adjusted census data; Pew Research Center projections for 2025-2065

PEW RESEARCH CENTER

National Institute on Minority Health and Health Disparities

Hispanic Immigration Declining



Note: "Immigrants" includes those born outside the U.S. or its territories (including Puerto Rico) to non-U.S. citizen parents. People in group quarters such as college dormitories or institutions are not included in figures for 2001 to 2005. Due to changes in the wording of the Hispanic origin question in the 2000 census some Hispanic origin groups may have led to many not indicating their Hispanic origin, resulting in low population estimates. For more see http://www.pewhispanic.org/2002/05/09/counting-the-other-hispanics/

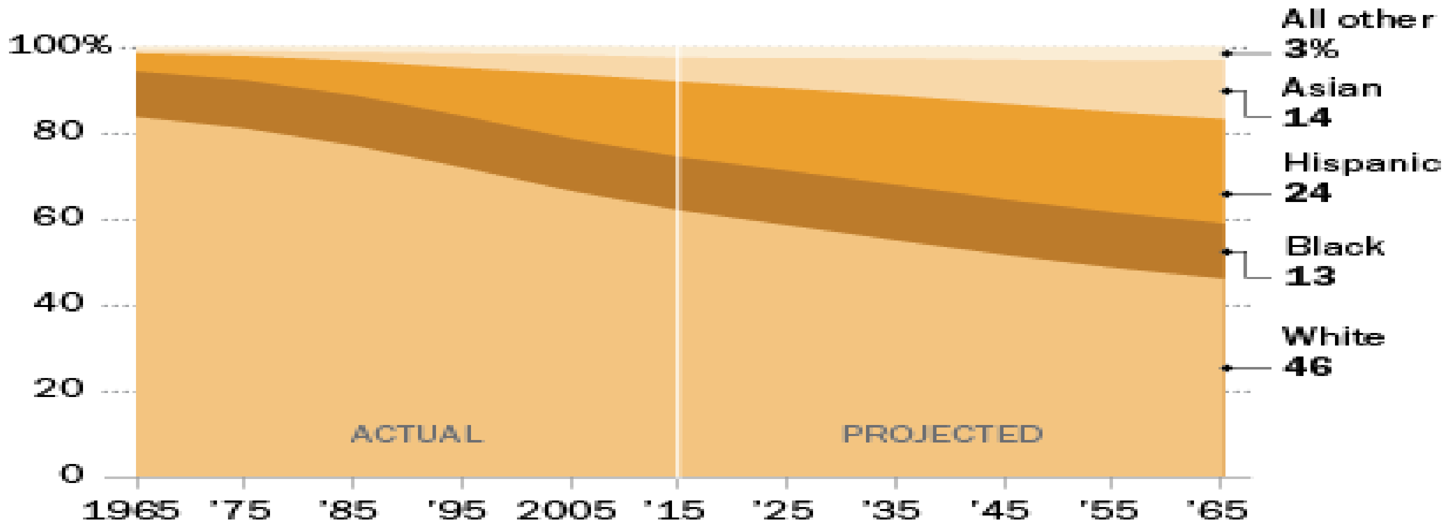
Source: Pew Research Center tabulations of 2000 census (5% IPUMS) and 2001-2015 American Community Surveys (1% IPUMS).

PEW RESEARCH CENTER

Americans are more Racially and Ethnically Diverse than in the past, and the U.S. is projected to be even more diverse by 2055

The changing face of America, 1965–2065

% of the total population



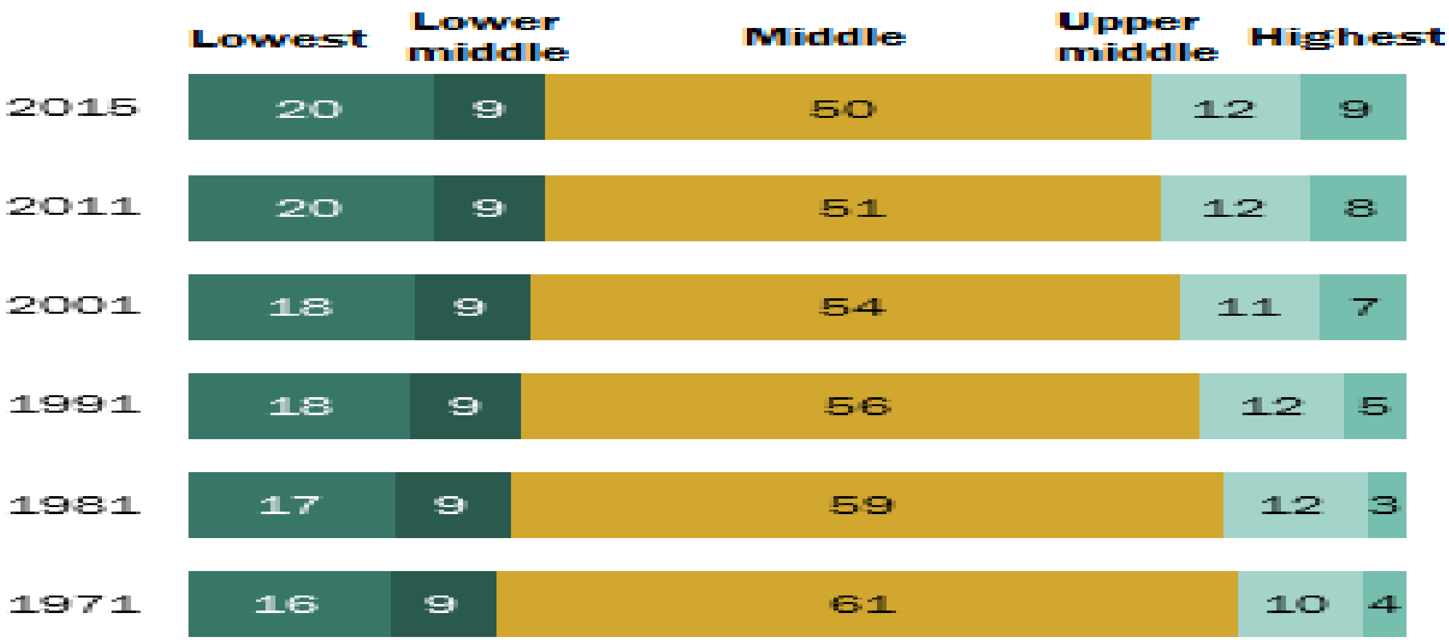
Note: Whites, blacks and Asians include only single-race non-Hispanics; Asians include Pacific Islanders. Hispanics can be of any race.
Source: Pew Research Center 2015 report, "Modern Immigration Wave Brings 59 Million to US, Driving Population Growth and Change Through 2065"

PEW RESEARCH CENTER

INCREASING LOWER CLASS

Share of adults living in middle-income households is falling

% of adults in each income tier



Note: Adults are assigned to income tiers based on their size-adjusted household income in the calendar year prior to the survey year. Figures may not add to 100% due to rounding.

Source: Pew Research Center analysis of the Current Population Survey, Annual Social and Economic Supplements

PEW RESEARCH CENTER

USA EDUCATION

- US Overall High School Education 89%
- College Degree
  - Whites 37%
  - Blacks 23%
  - Hispanics 16.4%
  - Asian American 55.9%

- Students from low and moderate income households could afford to pay for just 1% to 5% of college tuition in USA
- Adults with HS education earned - $35,615 ave
- Adults with BS degree earned - $65,482 ave

Census Data 2016

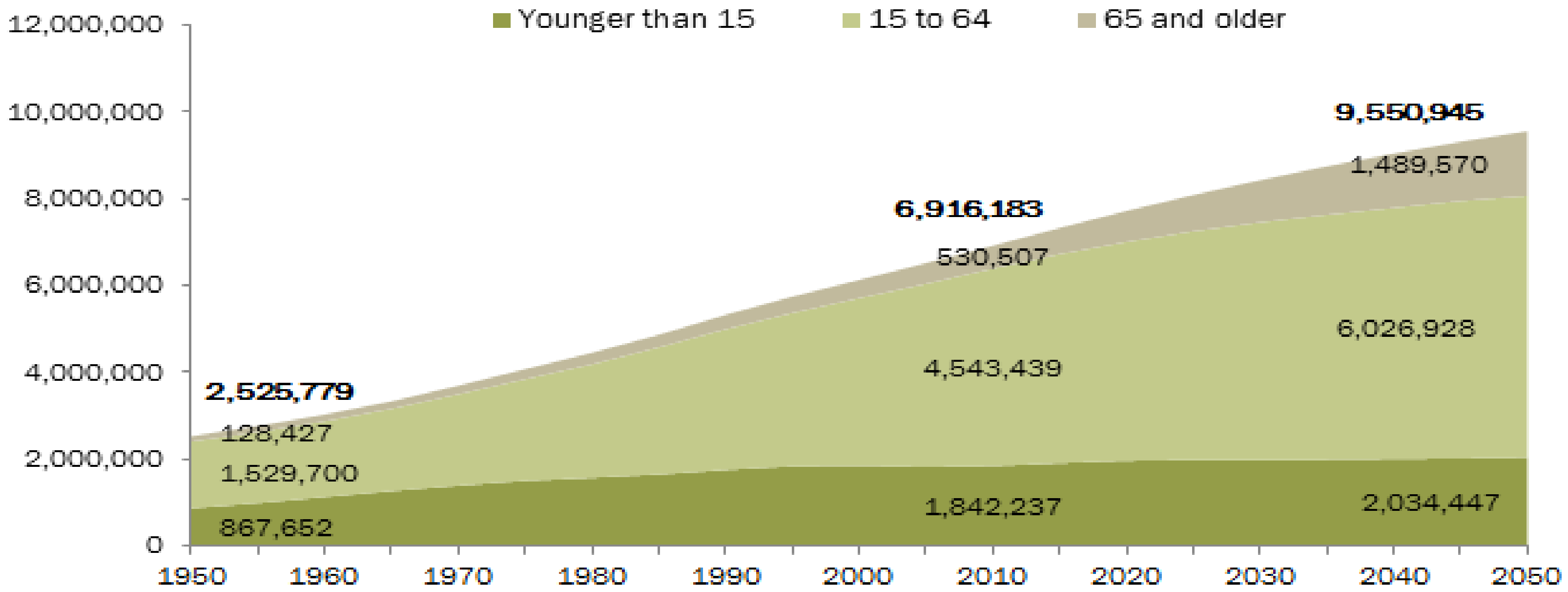
1950-2010 POPULATION: AGING

USA DOUBLED

GLOBAL TRIPLED

Estimates of the Global Population, by Age, 1950 to 2050

Thousands



Source: United Nations, Department of Economic and Social Affairs, *World Population Prospects: 2012 Revision*, June 2013, http://esa.un.org/unpd/wpp/index.htm

PEW RESEARCH CENTER

BIG DATA

Structured
Unstructured

Use with Caution

National Institute
on Minority Health
and Health Disparities

Platforms

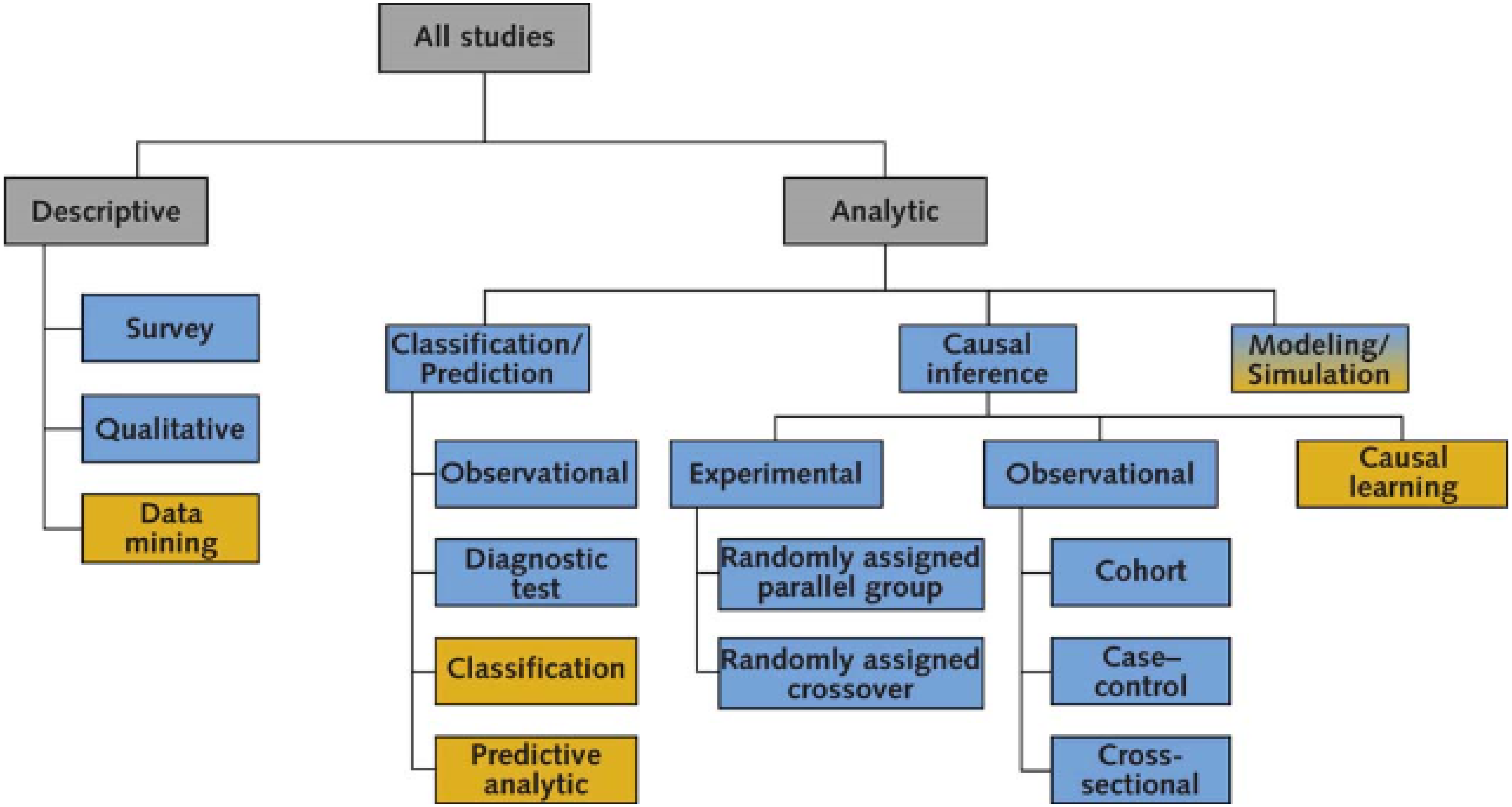
- **Structured** - organized such that data can be described and analyzed in conventional ways, including hypothesis testing. The unit is an individual with well-defined characteristics.

  Examples: **Medicare, SEER-Medicare, National Health Interview Survey, American Community Survey**

- **Unstructured** – analyzed using a new discipline, data science that looks for patterns. The unit of analysis is usually a location without well-defined personal characteristics. Artificial intelligence algorithms.

  Examples: **Genome data, Google searches, Facebook, mobile sensors, and data collected for marketing purposes**

Two Ways of Knowing: Structured and Unstructured Data



Source: Sim I., Two Ways of Knowing: Big Data and Evidence-Based Medicine
Annals of Internal Medicine 2016

Race/Ethnicity in Structured Data

- Census data has evolved
  - o Beginning in 1960, Americans reported their own race
  - o Beginning in 1980, ancestry/ethnic origin was asked
  - o Since 2000, respondents could report more than one race
  - o Missing racial categories
  - o Hispanic/Latino (ethnicity)

- Census data are used to:
  - o Make policy and allocate funding ($800 billion)
  - o Test hypotheses

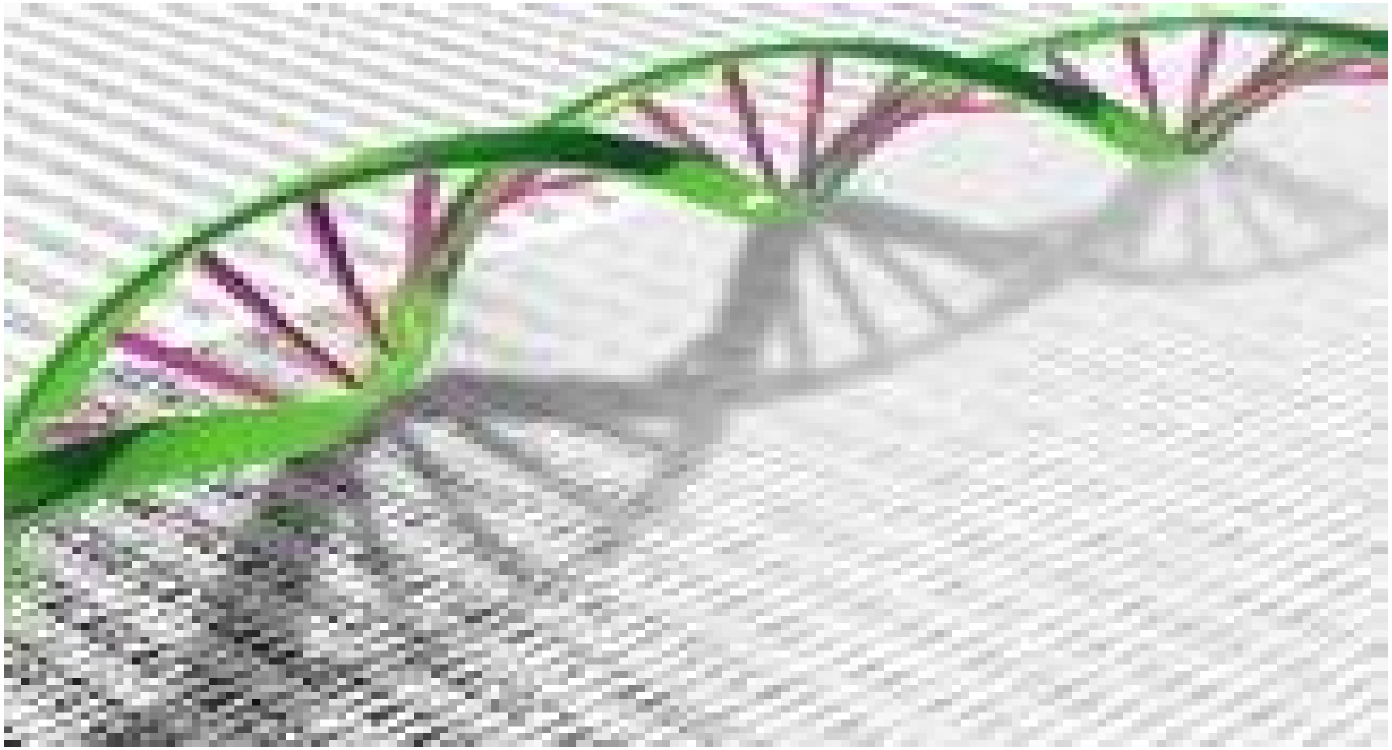
- Gold Standard: Self Reported Race/Ethnicity

- Ancestry biomarkers

- Movement to collect Social Determinants of Health

Unstructured Data: Adequate and Accurate Racial/Ethnic Data?

Genome / Omic Data Bases



Misclassified Ancestry in AA Cancer Cell Lines (inadequate and inaccurate)

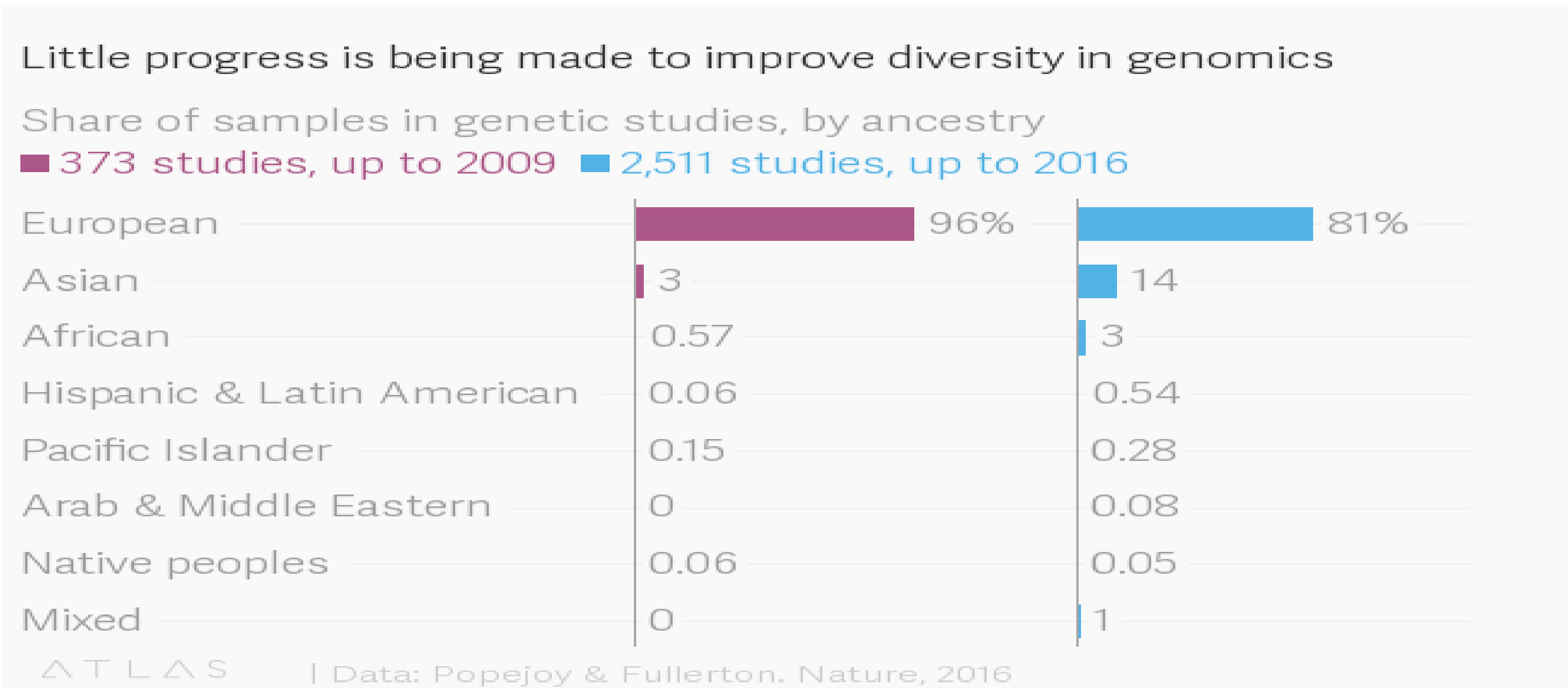
- Cell lines are used by cancer researchers to probe molecular mechanisms. Few cell lines are non-European
- Observed differences in how certain cancers behave at the biological level in various ethnic groups, highlighting the need for ethnically diverse cell lines to probe the molecular basis for these differences.
- A team of researchers analyzed genetic ancestry of 15 prostate, breast, and cervical cancer cell lines and found that several lines labeled as mixed or black/African-American were misclassified
  - A common prostate cancer cell line classified as African-American actually carries more than 90% European ancestry (22Rv1 had 99% European ancestry)
  - E006AA-hT, (prostate) labeled as African-American actually carries 91% European ancestry.
  - HeLa (Heneritta Lacks) cells contain 66% West African ancestry, which is slightly lower than the average of about 80% West African ancestry for US born African-Americans.

- Published studies using misclassified cell lines may be inadequate to understand the disease within a population group and inaccurate for the development of personalized medicines

Source: Hooker SE, Woods-Burnham L, Lloyd SM et al, CEBP, 2019 / (Cancer Epidemiol. Biomarkers Prev. 2019, DOI: 10.1158/1055-9965.EPI-18-1132).

Human Genomics–Homogenous
Don’t know what we don’t know

2016 meta-analysis: 2,511 studies from around the world found that 81% of participants in genome-mapping studies were of European descent. (2009, 96% of European descent)



National Institute on Minority Health and Health Disparities

https://qz.com/1367177/if-ai-is-going-to-be-the-worlds-doctor-it-needs-better-textbooks/

‘Omic Limited Data Sources

- International Cancer Genome Consortium (ICGC)-20 countries 32 projects in USA, 1 in India and 0 in Africa
- Some inherent bias in genomic data stems from non-scientific roots
    - Over-represent people who get sick more
    - Demographics around hospital
    - Clinical trial enrollment
    - Costs
- 2015 study found that 2% of the more than 10,000 NIH-funded cancer studies include adequate sample of minority groups to measure statistically significant change.
- Too frequently, rely on observation classification for race/ethnicity

https://qz.com/1367177/if-ai-is-going-to-be-the-worlds-doctor-it-needs-better-textbooks/

Artificial Intelligence

Artificial Intelligence (AI) Plays Integral Role in Medical Diagnostics

- AI will sift through the vast amounts of health information produced by our society
  - Find patterns that will help us be more efficient, wealthier and happier
  - Assist clinical decision making
  - Reduce diagnostic and therapeutic errors
  - Inferences for health risks

- To address diagnostic error, researchers and companies are leveraging artificial intelligence
  - **Chatbots**: Speech recognition capability to identify patterns in patient symptoms to form a potential diagnosis, prevent disease and/or recommend an appropriate course of action.
  - **Oncology**: Train algorithms to recognize cancerous tissue at a level comparable to trained physicians.
  - **Pathology:** Pathology is the medical specialty that is concerned with the diagnosis of disease based on the laboratory analysis of bodily fluids such as blood and urine, as well as tissues. Machine vision and other machine learning technologies can enhance the efforts traditionally left only to pathologists with microscopes.
  - **Rare Diseases**: Facial recognition software is being combined with machine learning to help clinicians diagnose rare diseases. Patient photos are analyzed using facial analysis and deep learning to detect phenotypes that correlate with rare genetic diseases.

https://emerj.com/ai-sector-overviews/machine-learning-medical-diagnostics-4-current-applications/

Correctional Offender Management Profiling for Alternative Sanctions (COMPAS)

- US justice system, reviled for its racial bias, turned to technology for help- algorithms had a racial bias too.

- More prone to mistakenly label black defendants as likely to reoffend – wrongly flagging them at almost twice the rate as white people (45% to 24%)

- Black defendants were 77 percent more likely to be assigned higher risk scores than white defendants.

- White defendants who re-offended within the next two years were mistakenly labeled low risk almost twice as often as black re-offenders (48 percent vs. 28 percent)

- PedPol Crime Hot Spots: Suggested majority black neighborhoods at about twice the rate of white ones / when the statisticians modelled the city's likely overall drug use, based on national statistics, it was much more evenly distributed.

National Institute on Minority Health and Health Disparities

https://www.newscientist.com/article/2166207-discriminating-algorithms-5-times-ai-showed-prejudice/

Dark-Skinned People & Females

- AI-Driven Dermatology: potential to save thousands of people from skin cancer each year—while putting others at greater risk
  - African-Americans have the highest mortality rate for skin cancer so AI trainers are missing skin cancer in African-Americans
  - Particularly bad at identifying women of color: 34% less accurate at recognizing darker-skinned females compared to lighter-skinned males
- Three of the latest gender-recognition AIs (Megvii)
  - Id person's gender 99% of time for white men
  - Id person's gender 35% of time for dark-skinned women
- Google search for CEO
  - 11% resulted in women (27% female CEOs in US)
  - Online advertising showed high-income jobs to men more than women

https://www.newscientist.com/article/2166207-discriminating-algorithms-5-times-ai-showed-prejudice/

National Institute on Minority Health and Health Disparities

Discriminating Algorithms Amplified Racist Sexist Age Biases

- If you don’t teach the algorithm with a diverse set of images, then that algorithm won’t work out in the public that is diverse. Algorithms have:
  - mistaken images of black people for gorillas
  - misunderstood Asians to be blinking when they weren’t
  - “judged” only white people to be attractive
  - Linkedin showed a preference for male name searches
  - Chatbot-Tay learned from twitter and began spouting anti-sematic messages

- AI systems are calibrated for younger, more urban bodies because poorer and older members of society don’t have access to the digital technologies and therefore do not end up in trainer data

- The highly selective nature of randomized control trials (RCT) systemically disfavors women, racial/ethnic minorities, the elderly, and those with co-morbidities

https://www.newscientist.com/article/2166207-discriminating-algorithms-5-times-ai-showed-prejudice/

National Institute on Minority Health and Health Disparities

Weapons of Math Destruction

- Public/Patient perception might be that the algorithms are impartial.
- Garbage In-Garbage Out / Racism In-Racism Out (Khan 2017)
- Danger of outsourcing decisions to computers with biases
- Most vulnerable in society who are exposed to evaluation by automated systems
- Prevent AI from amplifying the inequalities of our past and affecting the most vulnerable members of our society. Data fed the machines reflects the history of our own unequal society--in effect, asking the program to learn our own biases.
- Bryson describes the way that machine learning can expose the prejudices embedded in our use of language. It encodes both the wisdom and the folly of all those who have used language.

Guardian Inequality Project: Rise of the racist robots – how AI is learning all our worst impulses by Stephen Buranyi Aug 2017

Do Not Automate Biases Computers Learn from Us

- The formula for AI-powered systems is almost the same across all medical disciplines
    - Gather data on patients
    - Use it to predict what will happen when a new patient come in

- AI Training data are crucial to accuracy.
    - If data don’t accurately represent a population of patients then any algorithm relying on the data is at a higher risk of making a mistake
    - Patients not in the training data set will not get an accurate diagnosis

- Deep learning – finding patterns in the data it is trained on– is especially susceptible to bias

The Food and Drug Administration (FDA) is now paying close attention to subject demographics in AI software.

AI Algorithms Need to Include Groups at Risk of Health Disparities

- Applications of AI in medical diagnostics are in the early adoption phase with limited data on patient outcomes
- AI applications have the potential to impact
  - How clinicians and health care systems approach diagnostics
  - How individuals understand changes to their health in real-time.
- Rigorous testing of applications will be needed to validate utility

Unless AI algorithms represent all racial/ethnic and other groups at risk of health disparities, undetected disease will result in **undetected disparities**

Think of Problem from Beginning
Biased Outcomes from a Biased Algorithm
(easier to spot than the biased data fed into the machine)

Consider what could happen when doctors begin relying on AI to diagnose diseases like skin cancer, or determine which drug treatment is best for a serious illness based on biological markers. In products like Google Photos, these biases reaffirm false stereotypes and have detrimental impacts on users, but **in the field of medicine, they can be the difference between life and death.**

Bias at any point in data handling for precision medicine **can lead to the recapitulation of longstanding health disparities**," wrote Ferryman and Pitcan in a February report for Data & Society. That means a world where black Americans die more often than white Americans will, at best, remain unchanged; worse, that demographic gap could widen.

In health care, these biased outcomes **tend to mean one group of people gets better medical treatment than another.** Groups are often characterized by gender or race, or other traits, like language, skin type, genealogy, or lifestyle.

National Institute on Minority Health and Health Disparities

HEAL THYSELF, ALGORITHM If AI is going to be the world's doctor, it needs better textbooks
By Dave GershgornSeptember 6, 2018

Successful AI Kidney Matching

- AI can identify potential donors and recipients who are biologically suited for one another; but not who gets one
- The algorithms evaluate all the transplants possible among the patient-donor pool at once. Matches are made primarily on biological suitability, with the hardest-to-match patients getting first priority. The technology weighs criteria including the time the recipient has been on the waiting list, his or her age (children get priority), and whether the person who needs a kidney has been a living organ donor in the past (with the reasoning that people who have stepped up to give before should get priority if they one day find themselves in need).
- Machine making a decision based on what it has learned about human values.

Fumo, D. E., Kapoor, V., Reece, L. J., Stepkowski, S. M., Kopke, J. E., Rees, S. E., Smith, C., Roth, A. E., Leichtman, A. B., … Rees, M. A. (2015). Historical Matching Strategies in Kidney Paired Donation: The 7-Year Evolution of a Web-Based Virtual Matching System. *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons*, *15*(10), 2646-54.

AI Kidney Matching – Systematic Racial and Gender Discrimination

- In the kidney question, fair-minded principle that kidneys should be given to the people who will likely have the most years of productive life after receiving one. Before a computer can calculate the longevity of potential recipients, scientists have to feed the algorithm data on life expectancy for various populations.
- But this leads to some problems. Men tend to die before women do. Black Americans die younger than Americans of any other ethnicity. A 65-year-old white woman in the US could expect to live another 20.5 years in 2015, four years longer than a black man of the same age.
- What started with good intentions ends in systematic racial and gender discrimination.
- Back to the drawing board – deal with it in beginning

Importance of Big Data for Health Disparities Research and Clinical Care for Minorities

FUSING

National Institute
on Minority Health
and Health Disparities

Fusing Data Platforms

- Structured big data (surveys, health/medical records, and administrative data) have the advantage of including demographic information about individuals included, and a defined population with known representation
  - Disadvantage is lack of granularity.
    - National Health Interview Survey is designed to measure outcomes at the national level
    - Behavioral Risk Factor Surveillance system is designed to measure outcomes at the state level
- Unstructured big data (Google, Facebook) has the advantage of millions of observations, hence plenty of granularity
  - Disadvantage is lack of knowledge about the representativeness of the data.
    - Who is included?
    - Who is missed?
- Limitations suggest that unstructured data needs to be fused with structured data for maximum utility in health disparities research

Source: Sim I., Two Ways of Knowing: Big Data and Evidence-Based Medicine, *Annals of Internal Medicine* 2016

Fusing Data: Mining for Racism

- The study calculated an Internet-based geographic measure of "racism" from Google searches of 196 market areas.

More N-word hits = More racism

- Used geographic area racism measure to test for an association with higher African American mortality (structured data) in those same areas

- Found a one standard deviation increase in area racism was associated with a 6% increase in the all-cause Black mortality rate, after adjusting for covariates

More racism = Excessive AA Mortality Rates

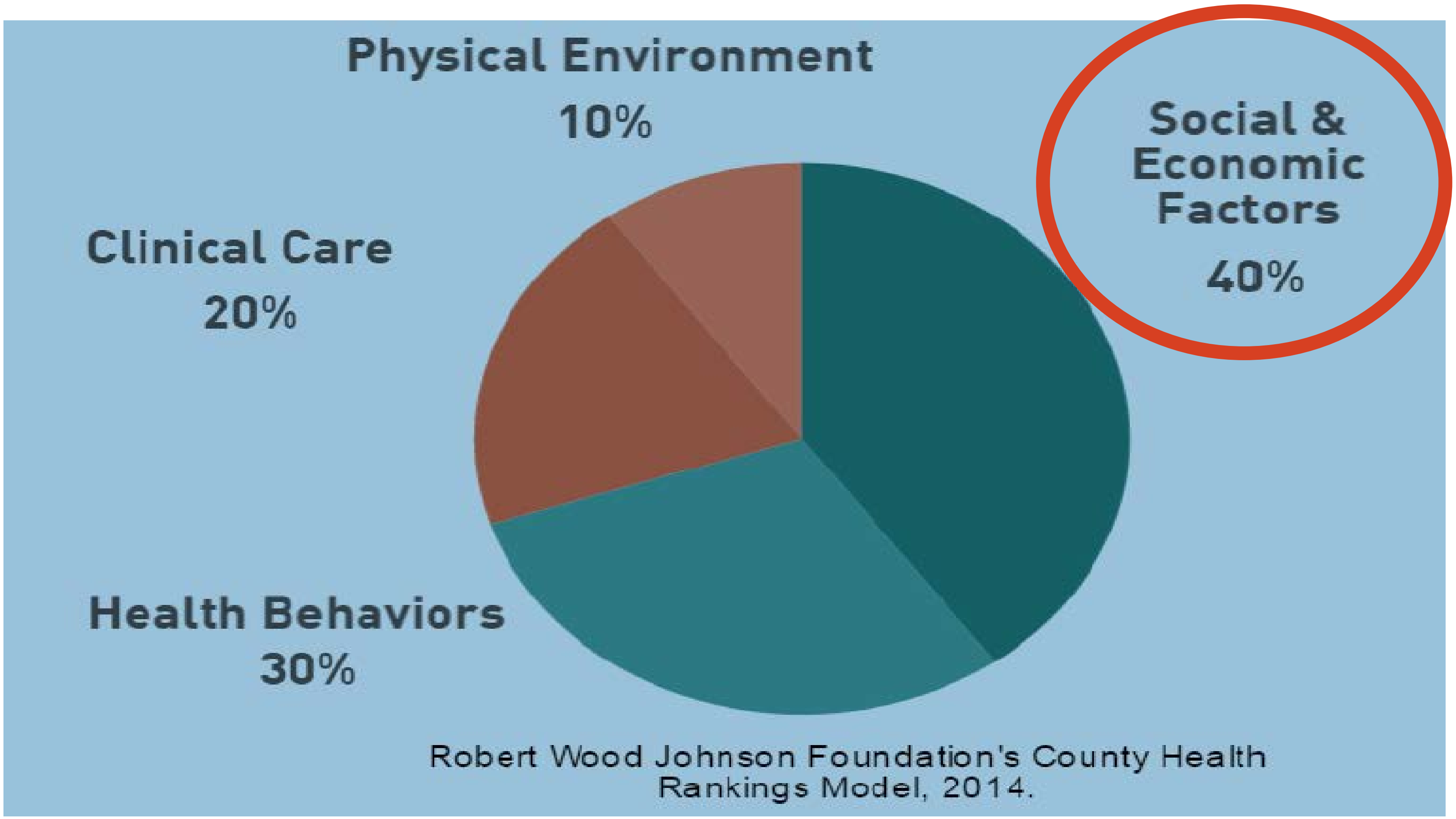
Source: Chae DH, Clouston, Hatzenbuehler, et al, *PloS One* 2015

Fusing Data: Environmental Health Disparities

Massachusetts study found that two air pollutants decreased significantly between 2003–2010, but racial and ethnic disparities in exposure remained

Fused Environmental Data with Census Data and Mortality Data

Relative Impact of Determinants on Health – Need Social Economic Data



Clinicians Need to Know about their Patients’ Social Determinants

The Spirit Level by Wilkinson and Pickett -provided evidence that decreasing income, education, social status, and social support is correlated with increased morbidity and premature mortality.

A survey conducted by the Robert Wood Johnson Foundation found that 4 out of 5 physicians do not feel confident in their capacity to meet their patients’ social needs, and they believe this impedes their ability to provide quality care.

Examples of social determinants role in clinical care:

- Treatment options – social risk
- Adherence
- Better care for underserved marginalized individuals (reduce health disparities)
- Impact on DNA (other biological changes)

Public Health Rev. 2018; 39: 19. Published online 2018 Jun 22. doi: 10.1186/s40985-018-0094-7
PMCID: PMC6014006 PMID: 29977645 Screening for social determinants of health in clinical care: moving from the margins to the mainstream Anne Andermann

Who you are as a person is not just defined by your DNA, but by which parts of it your epigenome permits to be expressed- Fusing Poverty Stressors & DNA

- Stresses of being poor have a biological effect that can last a lifetime. Lower socioeconomic status during adolescence is associated with an increase in methylation of the proximal promoter of the serotonin transporter gene," which primes the amygdala—the brain's center for emotion and fear—for "threat-related amygdala reactivity."[5] While there may be some advantages to being primed to experience high levels of stress (learning under stress, for example, may be accelerated[6]), the basic message of these studies: Chronic stress and uncertainty during childhood makes stress more difficult to deal with as an adult.

- Evidence suggesting that these effects may be inheritable, whether it is through impact on the fetus, epigenetic effects, cell subtype effects, or something else. The science of the biological effects of the stresses of poverty, although in is its early stages, has presented us with multiple mechanisms through which such effects could happen, and many of these admit an inheritable component. If a pregnant woman, for example, is exposed to the stresses of poverty, her fetus and that fetus' gametes can both be affected, extending the effects of poverty to at least her grandchildren. And it could go further.

- Scientific understanding of the experience of poverty can also inform medical treatments later in life. Hippocampus samples from suicide victims with a history of childhood abuse and tested for DNA methylation controlling the expression of the gene *NR3C1*.[4] They discovered an increased methylation around the *NR3C1* promoter, which, in other studies, has been directly linked to a reduced expression of a protein called brain-derived neurotropic factor (BDNF). BDNF is among the most active neurotrophic factors, which drive the growth and development of new neurons even in adulthood. And the degree to which it is expressed may be inheritable. A 2015 study linked *NR3C1* and reduced expression of BDNF in infants born to mothers who reported prenatal depressive symptoms.[13]

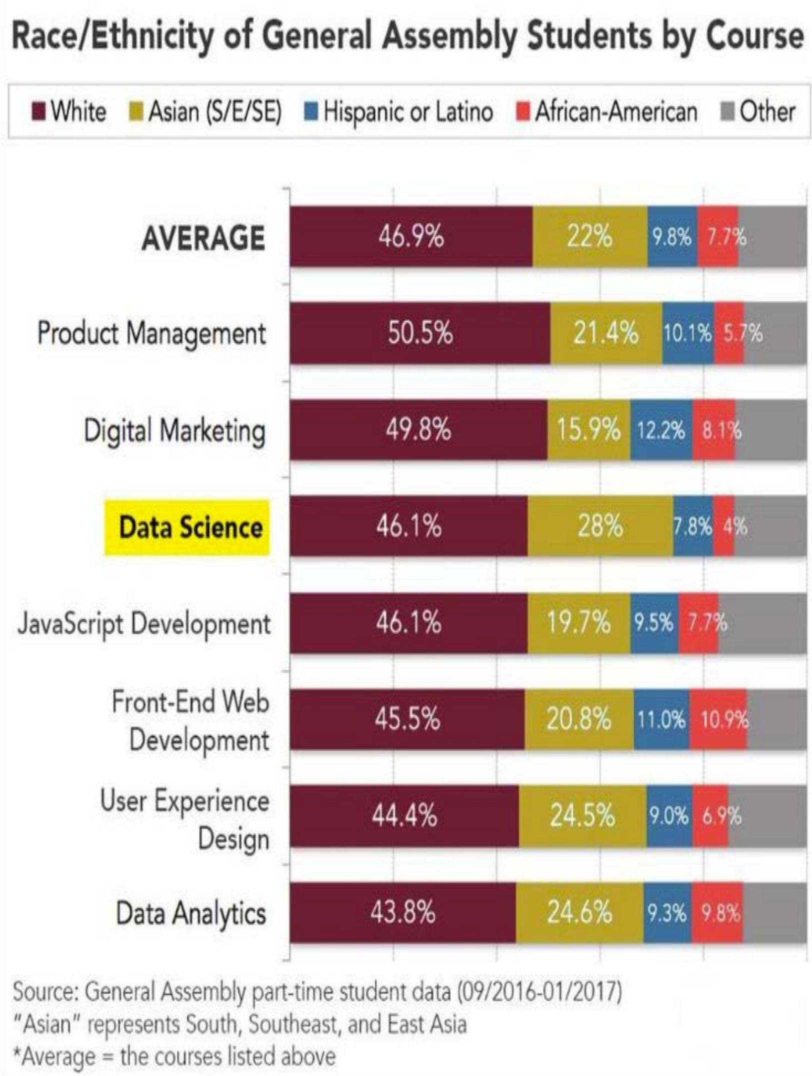
National Institute on Minority Health and Health Disparities

Blair, C., & Raver, C. C. (2016). Poverty, Stress, and Brain Development: New Directions for Prevention and Intervention. *Academic pediatrics*, *16*(3 Suppl), S30-6.

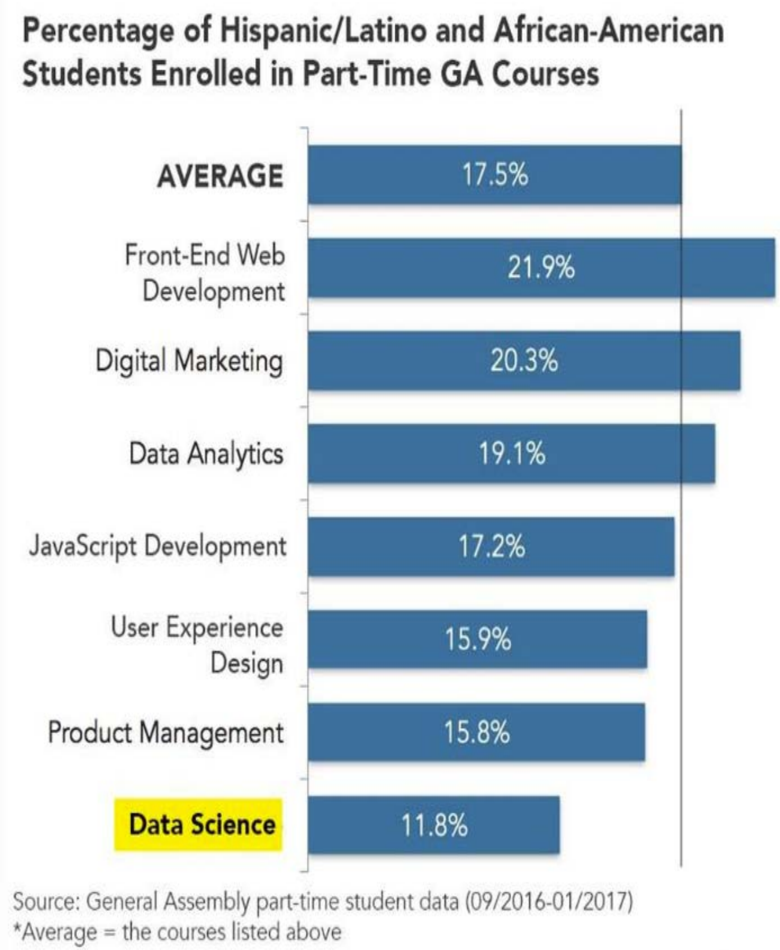
NIMHD: Big Data into Health Disparities Research

National Institute
on Minority Health
and Health Disparities

Data Science Diversity Gap-Students



Course enrollment by demographic. GENERAL ASSEMBLY



Course enrollment by demographic. GENERAL ASSEMBLY

National Institute on Minority Health and Health Disparities

Incorporating Big Data into Health Disparities Research

Approach	Example	Exemplary Challenge	Resources
Linking structured data	SEER-Medicare	Limited to ages 65 y and older	https://healthcaredelivery.cancer.gov/seermedicare
Harmonizing data elements	Cancer Research Network	Limited to insured	https://crn.cancer.gov
Fostering citizen science	Our Voice project	Scaling up existing small projects	http://med.stanford.edu/ourvoice.html
Developing big longitudinal cohorts	NIH All of Us cohort	Sustaining engagement	https://allofus.nih.gov
Mining Internet and social media data to improve disparities surveillance	Google searches for disease and disparity keywords	Validation, big data hubris, algorithm dynamics and stability	https://gking.harvard.edu/files/gking/files/0314policyforumff.pdf https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0122963

Note. NIH = National Institutes of Health; SEER = Surveillance, Epidemiology, and End Results program.

Source: Breen N, Jackson JS, Wood F, Wong DWS, Zhang X, Translational Health Disparities Research in a Data-Rich World, *AJPH* Supplement 1, 2019

HDPulse combines data sources to offer quick access to state and county data

https://hdpulse.nimhd.nih.gov/

Publications to Encourage Use of Big Data in Health Disparities Research

Publications:

- Zhang X, Perez-Stable EJ, Bourne PE et al, Big Data Science: Opportunities and Challenges to Address Minority Health and Health Disparities in the 21st Century, *Ethnicity and Disease*, 2017
- Breen N, Jackson JS, Wood F, Wong DWS, Zhang X, Translational Health Disparities Research in a Data-Rich World, AJPH Supplement 1, 2019
- Bagby SP, Martin D, Chung ST, Rajapakse N, From the Outside In: Biological Mechanisms Linking Social and Environmental Exposures to Chronic disease and to Health Disparities, *AJPH*, 2019
- Kasman M, Breen N, Hammon RA, Complex Systems Science in *The Science of Health Disparities Research and Applications*, Wiley, forthcoming

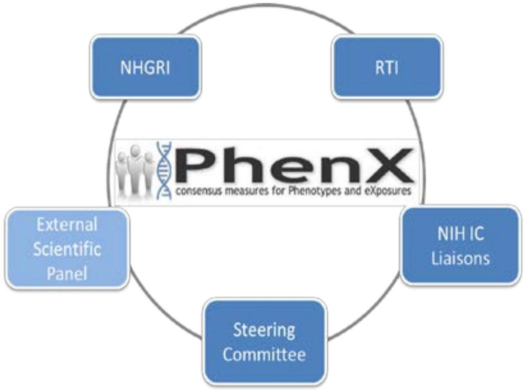
Forthcoming: Common Data Elements-Social Determinants of Health

Common Data Element - standard measure for a variable

- precisely specified question
- fixed set of permissible answers (discrete or continuous)
- Core/key variables – not all variables
- Used across multiple sites, projects, initiatives, etc.

PhenX Toolkit – web-based catalog of high-priority measures for genome-wide studies

- CDEs for SDOH can facilitate cross-study analyses
- Validate studies or combine to increase statistical power



Funding Announcements

Title	BRAIN Initiative: Theories, Models and Methods for Analysis of Complex Data from the Brain (R01 Clinical Trial Not Allowed)
Notice Number	RFA-EB-17-005
Organization	NIBIB
Application Due Date	9/4/2019

Title	Secondary Data Analysis to Examine Long-Term and/or Potential Cross-Over Effects of Prevention Interventions: What are the Benefits for Preventing Mental Health Disorders? (R01 Clinical Trial Not Allowed)
Notice Number	RFA-MH-20-110
Organization	NIMH
Application Due Date	1/3/2020

Title	Mechanism for Time-Sensitive Opportunity in Environmental Health Sciences (R21)
Notice Number	RFA-ES-16-005
Organization	NIEHS
Application Due Date	9/4/2019

Title	BRAIN Initiative: Integration and Analysis of BRAIN Initiative Data (R01 Clinical Trial Not Allowed)
Notice Number	RFA-MH-19-147
Organization	NIMH
Application Due Date	3/5/2021

Title	BRAIN Initiative: Theories, Models and Methods for Analysis of Complex Data from the Brain (R01 Clinical Trial Not Allowed)
Notice Number	RFA-EB-17-005
Organization	NIBIB
Application Due Date	9/4/2019

Title	Disparities Elimination through Coordinated Interventions to Prevent and Control Heart and Lung Disease Risk (DECIPHeR) - Research Coordinating Center (RCC) (U24 Clinical Trial Not Allowed)
Notice Number	RFA-HL-20-004
Organization	NHLBI
Application Due Date	10/2/2019

Title	Post-Stroke Vascular Contributions to Cognitive Impairment and Dementia (VCID) in the United States Including in Health Disparities Populations (U19 Clinical Trial not Allowed)
Notice Number	RFA-NS-19-012
Organization	NINDS
Application Due Date	4/18/2019

Title	HEAL Initiative: Back Pain Consortium (BACPAC) Research Program Data Integration, Algorithm Development and Operations Management Center (U24 Clinical Trial Not Allowed)
Notice Number	RFA-AR-19-027
Organization	NIAMS
Application Due Date	3/21/2019

Title	Natural Products NMR Open Data Exchange (NP-NODE) (U24 Clinical Trial Not Allowed)
Notice Number	RFA-AT-19-002
Organization	NCCIH
Application Due Date	4/18/2019

Title	NIDCR Small Research Grants for Oral Health Data Analysis and Statistical Methodology Development (R03 Clinical Trial Not Allowed)
Notice Number	PAR-19-145
Organization	NIDCR
Application Due Date	1/8/2022

Title	NLM Research Grants in Biomedical Informatics and Data Science (R01 Clinical Trial Optional)
Notice Number	PAR-18-896
Organization	NLM
Application Due Date	9/8/ 2021

Title	Data Science Research: Personal Health Libraries for Consumers and Patients (R01 Clinical Trial Optional)
Notice Number	PAR-19-072
Organization	NLM
Application Due Date	7/31/2021

Title	NLM Career Development Award in Biomedical Informatics and Dat Science (K01)
Notice Number	PAR-16-204
Organization	NLM
Application Due Date	5/18/2019

Title	Predoctoral Training in Advanced Data Analytics for Behavioral and Social Sciences Research (BSSR) - Institutional Research Training Program [T32]
Notice Number	RFA-OD-19-011
Organization	NIH
Application Due Date	5/26/2019

Connect With NIMHD

Visit us online **www.nimhd.nih.gov**

Connect with us on Facebook
www.facebook.com/NIMHD

Follow us on Twitter
@NIMHD

durande@mail.nih.gov