Representation and Rules
2022 Retirement and Disability Research Consortium (RDRC) Keynote

Marcella Alsan
(Harvard and NBER)

August 5, 2022
Representation
Representation matters

- Representation (e.g., accurate description) in surveys and census data matters because these underlie
  - Forecasting (simulations) and retrospective (applied micro) work on policy impact
  - Allocation of resources (e.g., funds, congressional seats etc.)
  - Surveillance of health and other issues
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  - Forecasting (simulations) and retrospective (applied micro) work on policy impact
  - Allocation of resources (e.g., funds, congressional seats etc.)
  - Surveillance of health and other issues

- Representation (e.g., participation) matters because it can affect (perceptions of) legitimacy of the outcome of that process
  - Legitimacy - whether the procedure used was deemed appropriate
  - We apply to health
1.5 Million Missing Black Men

For every 100 black women not in jail, there are only 83 black men. The remaining men – 1.5 million of them – are, in a sense, missing.

Among cities with sizable black populations, the largest single gap is in Ferguson, Mo.

POLITICO

Cities risk losing out on trillions in federal aid as census deadline looms

Local leaders fear federal aid cuts as the pandemic, a shortened timeline and Trump's anti-immigration rhetoric complicate the national survey.

As coronavirus deaths surge, missing racial data worry L.A. County officials

Will Americans be able to trust the results of the 2020 Census?

Recent violence against Asian Americans highlights need for better tracking, reporting

Hate crime data don't capture the full scope of racist incidents against Asian Americans, experts say, so nonprofit groups have been filling the gaps.

2020 Census Undercounted Hispanic, Black and Native American Residents

The Census Bureau said that the overall population total was accurate but that counts of minorities were skewed. Advocacy groups threatened to go to court.
Historically, the Census has Disproportionately Undercounted the Black Population
Demographic analysis of net undercount, 1960-2010

Source: J. Gregory Robinson, Coverage of Population in Census 2000
Based on Demographic Analysis: The History Behind the Numbers
(Washington, DC: US Census Bureau, 2010).
Note: A negative percentage represents an overcount.
Where the Black population count was lower than the estimates

The share of the Black population in the 2020 count came in below the agency's own estimates for some states with the largest Black presence.

Percentage point difference between estimated and actual counts

Source: U.S. Census Bureau / Graphic: Mike Schneider
Percent Net Coverage Error for People by Tenure

*Net coverage error is statistically significantly different from zero
Net Coverage Error by Age for Children

*Net coverage error is statistically significantly different from zero*

## Percent net coverage error by race and Hispanic origin

<table>
<thead>
<tr>
<th>Race/Origin</th>
<th>2010 (1)</th>
<th>2020 (2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>0.01</td>
<td>-0.24</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>0.83*</td>
<td>1.64*</td>
</tr>
<tr>
<td>Black or African American</td>
<td>-2.06*</td>
<td>-3.30*</td>
</tr>
<tr>
<td>Asian</td>
<td>0</td>
<td>2.62*</td>
</tr>
<tr>
<td>American Indian or Alaska Native, Overall</td>
<td>-0.15*</td>
<td>-0.91*</td>
</tr>
<tr>
<td>American Indian or Alaska Native, on Reservation</td>
<td>-4.88*</td>
<td>-5.64*</td>
</tr>
<tr>
<td>Native Hawaiian or Other Pacific Islander</td>
<td>-1.02*</td>
<td>1.28*</td>
</tr>
<tr>
<td>Some Other Race</td>
<td>-1.63*</td>
<td>-4.34*</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>-1.54*</td>
<td>-4.99*</td>
</tr>
</tbody>
</table>

*Notes: *Net coverage error is statistically significantly different from zero.

Why *census* representation matters

- Census data undercounting affects accuracy of other survey datasets
  - Other surveys often rely on census sampling or weight respondents based on census counts (Survey of Income and Program participation, General Social Survey, Current Population Survey)
**Why census representation matters**

- Census data undercounting affects accuracy of other survey datasets
  - Other surveys often rely on census sampling or weight respondents based on census counts (Survey of Income and Program participation, General Social Survey, Current Population Survey)

- Researchers depend on survey-based datasets to understand equity implications of policies and programs
  - After SSA discontinued publication of race and ethnicity, researchers interested in Social Security disparities link to surveys to obtain these variables
A view from Minnesota food shelves

The State of Minnesota wants to know how COVID-19 is affecting you.

The State of Minnesota is conducting a survey to better understand how the COVID-19 pandemic is affecting the Twin Cities area and what the barriers to care are in your community.

You May Qualify if You
- Are 18 years or older
- Speak English or Spanish
- Have access to a phone or computer to take the survey
- You have not previously taken the survey

Participation Involves
- Completing an online survey that will take approximately 15 minutes

Potential Benefits
- Participation in this survey may help improve access to COVID-19 testing in your community
- Participants will be compensated with a $10 online gift card for their time
- Compensation will be sent through text message to the participants cell phone

Take the Survey:
To take the survey, please visit the following link and enter the password below:
- Link: minnesota.msd.mssr.org
- Password: [password]

We hope you will hear from members of your community. You can pass this flyer along to family and friends.

Source: Alsan, Ayers, Banerjee, Breza, Chandrasekhar, Duflo, Goldsmith-Pinkham, Kim, Merrick, Olken, Shankar

Panel A: Government Low-Incentive Flyer

Panel B: Researcher High-Incentive Flyer
Response rates to intervention

Source: Alsan, Ayers, Banerjee, Breza, Chandrasekhar, Duflo, Goldsmith-Pinkham, Kim, Merrick, Olken, Shankar
Response rates to intervention

Figure 1: Treatment effects of Unit Non-Response Intervention

Source: Alsan, Ayers, Banerjee, Breza, Chandrasekhar, Duflo, Goldsmith-Pinkham, Kim, Merrick, Olken, Shankar
Census participation rates in field and online surveys

Census self-response by state

<table>
<thead>
<tr>
<th></th>
<th>MN Field Survey</th>
<th></th>
<th>Online Qualtrics Panel</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Overall (1)</td>
<td>Black (2)</td>
<td>White (3)</td>
</tr>
<tr>
<td>Never Filled out Census</td>
<td>41.8%</td>
<td>50.0%</td>
<td>31.8%</td>
</tr>
<tr>
<td>Δ Black and White Respondents</td>
<td>18.2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never Filled out Major Survey</td>
<td>39.5%</td>
<td>48.0%</td>
<td>31.1%</td>
</tr>
<tr>
<td>Δ Black and White Respondents</td>
<td>16.9%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Data: Alsan, Ayers, Banerjee, Breza, Chandrasekhar, Duflo, Goldsmith-Pinkham, Kim, Merrick, Olken, Shankar; Alsan & Eichmeyer
Proprietary health data
Public health data

- Medicare
  - Older patient population
  - Medicare Advantage insurers enter and exit, change products

- Veterans Affairs or Tricare
  - Predominately male
  - VA: selected on vet status (and seeking care at VA)

- National Vital Statistics System
  - Death reporting, also decentralized
    - Coroners (elected) vs. medical examiner system – differential reporting
    - Varying lag times in reporting rates (stop payments related to death records)

Death certificates
Data: CDC, (2022). 1 Data reported by state and territorial jurisdictions (accessed July 20, 2022). Numbers are ratios of age-adjusted rates standardized to the 2019 U.S. intercensal population estimate. Calculations use only the 66% of case reports that have race and ethnicity; this can result in inaccurate estimates... 2 Data source: COVID-NET (March 1, 2020 through July 9, 2022). Numbers are ratios of age-adjusted rates standardized to the 2020 US standard COVID-NET catchment population. Starting the week ending 12/4/2021, Maryland temporarily halted data transmission of COVID-19 associated hospitalizations...Hospitalization rates are likely underestimated. 3 Data Source: National Center for Health Statistics provisional death counts. Numbers are ratios of age-adjusted rates standardized to the 2019 U.S. intercensal population estimate.
Representation and legitimacy: evidence from clinical trials

Medical innovation and prescription inequality

Source: Alsan, Durvasula, Gupta, Schwartzstein, Williams
Physician Experiment

Top Decile % Black ZIPs
Top Decile % White ZIPs
All Other ZIPs

Screening Questions
(IM/FP, Practicing PCP, Has MD/DO, Office-Based, <50% Children)

Characteristics of Patient Panel and Practice

Randomize Diversity and Efficacy (Numeraire) in 8 Drug Profiles

1 2 3 4 5 6 7 8

Elicit Primary Outcomes (Relevance and Prescribing Intent)

Mechanism, Decision-Making, and Open-Text Questions

Follow-Up Question on Donation (1-3 Weeks Later)

Patient Experiment

Black Patients
White Patients

Screening Questions
(Age 35+, U.S.-Born, Passes Attention Check, Has Hypertension)

Introduction and Prior Elicitation

Randomize Racial Diversity Across Same Drug

Diverse Trial
Non-Diverse Trial

Elicit Primary Outcomes (Relevance, Efficacy Updating, Ask Doctor)

Mechanism, Health Information, and Open-Text Questions

Download Personalized Report

Alsain, Durvasula, Gupta, Schwartzstein & Williams
Physician prescribing intent by patient panel and trial representation

Source: Alsan, Durvasula, Gupta, Schwartzstein, Williams
Physician prescribing intent by patient panel and trial representation

Source: Alsan, Durvasula, Gupta, Schwartzstein, Williams
Physician prescribing intent by patient panel and trial representation

Source: Alsan, Durvasula, Gupta, Schwartzstein, Williams
Patient updating on efficacy by trial representation

Prior and posterior beliefs

Share of Patients Loading on Signal

Low (<1%) Black Representation

Higher (15%) Black Representation

White Patients

Black Patients

Source: Alsan, Durvasula, Gupta, Schwartzstein, Williams
Prescribing gaps and representation gaps

Source: Alsan, Durvasula, Gupta, Schwartzstein, Williams
Rules
## Rules - OASDI (Old Age, Survivors, and Disability Insurance)

<table>
<thead>
<tr>
<th>Insurance Program</th>
<th>Eligibility Criteria (Rules)</th>
<th>Potential Equity Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>OASDI</td>
<td>Historically excluded agri-cultural and domestic workers</td>
<td>Excluded 1/2 of Black Americans in the labor force and 3/5 of Black southern workers</td>
</tr>
<tr>
<td></td>
<td>Minimum age of 62</td>
<td>Disadvantages retirement benefits for Black Americans and low-income individuals, as well as others who have lower life expectancies</td>
</tr>
<tr>
<td></td>
<td>Benefits tied to earnings</td>
<td>Higher-earners may gain more in benefits. Progressive formula may redistribute</td>
</tr>
<tr>
<td></td>
<td>Work credit requirement</td>
<td>Excludes people who are primarily in uncompensated care-taking roles or leave the workforce for care-taking roles</td>
</tr>
<tr>
<td></td>
<td>10-year min for marriage-based benefits</td>
<td>May disqualify individuals with marriage instability, late entry into marriage, or historical exclusion from legal marriage</td>
</tr>
<tr>
<td></td>
<td>Not incarcerated</td>
<td>Disqualifies people in prisons, jails, halfway houses</td>
</tr>
</tbody>
</table>

**Female/Male earnings ratios**
## Rules – SSDI (Social Security Disability Insurance) and SSI (Supplemental Security Income)

<table>
<thead>
<tr>
<th>Insurance Program</th>
<th>Eligibility Criteria (Rules)</th>
<th>Potential Equity Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>SSDI</td>
<td>Definition of disability</td>
<td>Requires health literacy and access to medical care and examiner; standards of disability may be gendered</td>
</tr>
<tr>
<td></td>
<td>Work credit requirement</td>
<td>Excludes people in care-taking roles</td>
</tr>
<tr>
<td></td>
<td>Marriage</td>
<td>Disabled Adult Children (DAC) lose benefits once married</td>
</tr>
<tr>
<td></td>
<td>Not incarcerated</td>
<td>Disqualifies people in prisons, jails, halfway houses</td>
</tr>
<tr>
<td>SSI</td>
<td>Definition of disability</td>
<td>Requires health literacy and access to medical care and examiner; standards of disability may be gendered</td>
</tr>
<tr>
<td></td>
<td>Limited income / resources</td>
<td>Limits income and resources to $2000 for individuals and $3000 for couples, which reduces or eliminates benefits for married couples</td>
</tr>
<tr>
<td></td>
<td>Not incarcerated</td>
<td>Disqualifies people in prisons, jails, halfway houses</td>
</tr>
</tbody>
</table>
Concluding thoughts

Better representation can change the rules. Rules can change who gets represented.

- **Data:** Where do data come from? How were the data collected? Who is missing?

- **Rules:** When were rules created? How do they impact inequality (specifically, are they making things worse)?
Concluding thoughts

- Better representation can change the rules. Rules can change who gets represented.

- **Data:** *Where* do data come from? *How* were the data collected? *Who* is missing?

- **Rules:** *When* were rules created? *How* do they impact inequality (specifically, are they making things worse)?
Evidence paid family leave mitigates family health shocks
Benefit of Federalist system – lessons from states making rules that may not worsen inequality.

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Source: Coile, Rossin-Slater, Su
Thank you!
Appendix
2020 Census Self-Response by State

This map features self-response rates from households that responded to the 2020 Census online, by mail, or by phone.

National Self-Response: 67.0%

Minnesota Self-Response: 75.1%

Source: U.S. Census Bureau, (2020).
Death certificates

- **Coroners**: usually elected laypersons, can be partisan
- **Medical Examiners**: appointed physicians with specialized training in death investigation

Source: CDC, (2022).

ACS coverage rates by race and ethnicity over time

Population Coverage rate for group A (state x, year y) is defined by:

\[
\text{uncontrolled ACS estimate of total persons for group A for state x in year y} \quad \div \quad \text{official estimate of total persons for group A for state x in year y}
\]

ACS response rates and reasons for noninterviews (in percent) — housing units

Notes: Response rates for year 2020 (71.2%) not included.

Notes: Reasons listed as “Other” not included.

Data: U.S. Census Bureau, (2020).
Change in life expectancy by race

Figure 4. Change in life expectancy at birth, by Hispanic origin and race and sex: United States, 2019–2020

<table>
<thead>
<tr>
<th></th>
<th>Hispanic Male</th>
<th>Non-Hispanic black Male</th>
<th>Non-Hispanic black Female</th>
<th>Hispanic Female</th>
<th>Non-Hispanic white Male</th>
<th>Non-Hispanic white Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change (years)</td>
<td>-3.7</td>
<td>-3.3</td>
<td>-2.4</td>
<td>-2.0</td>
<td>-1.3</td>
<td>-1.1</td>
</tr>
</tbody>
</table>

NOTES: Life expectancies for 2019 by Hispanic origin and race are not final estimates; see Technical Notes. Estimates are based on provisional data for 2020. Provisional data are subject to change as additional data are received.
FIGURE 3.

2010 Census White Overcount and Black Undercount by Selected Categories

Source: Census Bureau Releases Estimates of Undercount and Overcount in the 2010 Census [Press Release], U.S. Census Bureau (May 22, 2012); Marc H. Morial, Testimony to House Committee on Oversight and Reform Subcommittee on Civil Rights and Civil Liberties, 2020 Census Field Hearing (NYC) (May 28, 2019)

### Overcounts and undercounts for racial and Hispanic groups generally grew in 2020

*Net overcount or undercount, in thousands*

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>&lt;50</td>
<td>-800</td>
</tr>
<tr>
<td><strong>White alone, non-Hispanic</strong></td>
<td>+1,600*</td>
<td>+3,100*</td>
</tr>
<tr>
<td><strong>Black</strong></td>
<td>-900*</td>
<td>-1,600*</td>
</tr>
<tr>
<td><strong>Asian</strong></td>
<td>0</td>
<td>+600*</td>
</tr>
<tr>
<td><strong>Hispanic</strong></td>
<td>-800*</td>
<td>-3,300*</td>
</tr>
<tr>
<td><strong>American Indian or Alaska Native on reservation</strong></td>
<td>-60*</td>
<td>-80*</td>
</tr>
</tbody>
</table>

* Error is statistically significant.

Notes: Positive numbers indicate overcounts; negative numbers indicate undercounts. **Bold** numbers indicate a statistically significant change from 2010. Black, Asian and American Indian or Alaska Native include those groups alone or in combination (including Hispanics and non-Hispanics).

Source: Pew Research Center estimates based on U.S. Census Bureau Post-Enumeration Surveys and P.L. 94-171 census counts by race and Hispanic origin.

**Pew Research Center**

Exhibit 1: CDC collects racial and ethnic data for COVID-19 testing, cases, hospitalizations, and deaths from providers and public health departments.

**Testing**
- **Providers**: Collect race and ethnicity data from patients
- **Labs**: Confirm or disconfirm COVID-19
- **Public health departments**: May conduct followup for missing race and ethnicity data
- **Dataset of positive and negative test results**

**Cases**
- **Providers**: Collect race and ethnicity data from patients
- **Labs**: Confirm COVID-19
- **Public health departments**: May conduct followup for missing race and ethnicity data
- **National Notifiable Diseases Surveillance System (NNDSS)**

**Hospitalizations**
- **Hospitals**: Collect race and ethnicity data from patients
- **Surveillance officers**: In the 14 States participating in infectious disease surveillance programs prior to COVID-19
- **COVID-NET**

**Deaths**
- **Funeral directors**: Record race and ethnicity data with assistance from friends or relatives of deceased
- **State vital records offices**
- **National Vital Statistics System (NVSS)**

*Note: This exhibit represents racial and ethnic data on COVID-19 hospitalizations that CDC obtains through COVID-NET reporting. CDC’s additional sources of COVID-19 hospitalizations data, such as the National Syndromic Surveillance Program and the Premier healthcare database, may also contain racial and ethnic data.*


Screening Some Sooner May Reduce Racial and Ethnic Disparities in Diabetes Diagnosis, Researchers Show

Written by: Jacqueline Mitchell  |  Connor Chloe Jack, emch@bwh.org
May 10, 2022

Asian, Hispanic and Black Americans are at increased risk for diabetes at lower weights and younger ages than white Americans.

BOSTON – Diabetes is a leading cause of death and disability in the United States, affecting more than 34 million adults and generating $330 billion in annual healthcare expenditures. Excess body weight is one risk factor that increases one’s odds of developing diabetes, and federal guidelines recommend starting screening at age 35 for all overweight adults – defined as those who have a body mass index (BMI) of 25 or higher.

However, Asian, Hispanic, and Black Americans are at increased risk for diabetes at lower weights and younger ages than white Americans. In a new study published in the *Annals of Internal Medicine*, a team of physician-scientists at the Smith Center for Outcomes Research in Cardiology at Beth Israel Deaconess Medical Center (BIDMC) sought to reduce racial and ethnic disparities in diabetes diagnosis. The team used statistical modeling to determine the BMI levels and age at which the prevalence of diabetes in racial and ethnic minority populations in the United States is equivalent to the prevalence of diabetes in white Americans considered at risk of diabetes. The team’s findings suggest that screening Asian, Hispanic, and Black Americans for diabetes at lower BMI and younger ages than white Americans has the potential to reduce the rate of undiagnosed diabetes in these groups and as a result, improve health equity in diabetes care.

“The simplicity of a single screening threshold for all Americans is alluring, but it is deeply inequitable,” said senior author Dhruv Kazi, MD, MSc, MS, associate director of the Smith Center and associate professor of medicine at Harvard Medical School. “Our findings suggest that Asian, Hispanic, and Black Americans may need to be screened at lower BMI or younger ages than white Americans. If the current thresholds are universally applied, without accounting for differential risk in racial/ethnic groups, clinicians may underdiagnose diabetes in Asian, Hispanic, and Black Americans. On the other hand, applying a more tailored approach may allow reduce rates of
Age Profiles of Female/Male Earnings Ratios across Five-Year Birth Cohorts, Born 1936–1985

Source: Juhn et al. (2017)
Figure 2. Life expectancy at birth, by Hispanic origin and race: United States, 2018 and 2019

<table>
<thead>
<tr>
<th>Race</th>
<th>2018</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Hispanic Asian</td>
<td>85.6</td>
<td>81.8</td>
</tr>
<tr>
<td>Hispanic</td>
<td>81.8</td>
<td>81.9</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>78.6</td>
<td>78.8</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>74.7</td>
<td>74.8</td>
</tr>
<tr>
<td>Non-Hispanic American Indian or Alaska Native</td>
<td>---</td>
<td>71.8</td>
</tr>
</tbody>
</table>

Life expectancy estimates are not available for 2018.

Panel A. Prior Beliefs

Panel B. Posterior Beliefs

Source: Alsan, Durvasula, Gupta, Schwartzstein, Williams
Gender differences in disability benefits

- Low and Pistaferri show that women with a severe, work-related, permanent impairment about 25pp more likely to have their application rejected
  - About 5ppt is due to the medical evaluation — step assessing whether the health condition is severe and long lasting
  - About 19ppt is due to the vocational stage – step whether condition prevents the applicant from doing alternative work
- Cabral and Dillender, studying the Texas workers’ comp system, show that women are more likely to be denied by male evaluator and the gap closes with a female evaluator
- Low and Pistaferri note:
  - It is also possible that the screening system evolves (with lags) to fit the gender composition of applicants, who were initially mostly men. However, this is rapidly changing, with women representing in 2016 almost half of the stock and half of the flow of new entrants into DI.
Rule example: workers’ comp evaluation training materials

Upper Extremity Case 5 MMI/IR CTS

Treatment History:
- The patient has been a meatpacking worker for 30 years.
- His most recent job is with a whizzzard knife cutting shoulder flanks of pork product. This involves a line speed of 780 per hour.
- He is right handed, using the whizzzard knife with the right hand and a hook with the left hand.

Upper Extremity Case 5 MMI/IR CTS

Designated Doctor Medical History:
- He presents to the DD exam with c/o bilateral numbness and tingling worse at night.
- He has been able to return to playing frisbee golf. (For ADLs to use for Grade see T. 11, P. 48)
- He is not working.
- His surgeon recommended surgery, but he does not want to do this.

Table 3. Relationship of Impairment of the Upper Limb to Impairment of the Whole Person

<table>
<thead>
<tr>
<th>% Impairment of Upper Extremity</th>
<th>% Impairment of Upper Extremity</th>
<th>% Impairment of Upper Extremity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Upper Extremity</td>
<td>Whole Person</td>
<td>Upper Extremity</td>
</tr>
<tr>
<td>Upper Extremity</td>
<td>Upper Extremity</td>
<td>Whole Person</td>
</tr>
<tr>
<td>Upper Extremity</td>
<td></td>
<td>Upper Extremity</td>
</tr>
<tr>
<td>Upper Extremity</td>
<td></td>
<td>Upper Extremity</td>
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<td>Upper Extremity</td>
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<tr>
<td>Upper Extremity</td>
<td></td>
<td>Upper Extremity</td>
</tr>
<tr>
<td>Upper Extremity</td>
<td></td>
<td>Upper Extremity</td>
</tr>
</tbody>
</table>

- Convert:
  - 22% UE = 13% Whole Person

Upper Extremity Case 5 MMI/IR CTS

Designated Doctor Physical Examination:
- He is a pleasant male 5’8” tall and 300 pounds.
- Examination of both hands indicated no thenar atrophy.
- He has full ROM of both wrists.