The Data Disaggregation Imperative to Achieve Health Equity

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Presentation to APPEAL/ADEPT Conference September 28, 2020
Agenda

Overview of a model of health equity and data disaggregation
- Census, CHIS impact on AA NHPI health insights
- Data Collection and COVID-19
- The Way Forward
What We’ve Known for 30+ Years

The 1985 annual US health report card:

“That report--like its predecessors--documented significant progress: Americans were living longer, infant mortality had continued to decline--the overall American health picture showed almost uniform improvement. But, and that "but" signaled a sad and significant fact; there was a continuing disparity in the burden of death and illness experienced by Blacks and other minority Americans as compared with our nation's population as a whole”

The Office of Management and Budget (OMB) Directive, 1997

**Ethnicity**
- Hispanic or Latino
- Not Hispanic or Latino

**Race**
- 5 minimum categories:
  - American Indian or Alaska Native (AIAN)
  - Asian
  - Black or African American
  - Native Hawaiian or Other Pacific Islander (NHOPI)
  - White
- Can select one or more races
Unmasking Heterogeneity of Groups

Most population-based surveys present minimum racial/ethnic categories required by OMB, but OMB categories may mask the heterogeneity of groups constituting these broad categories.

- Need to collect granular ethnicity
- Need for other race option for those who do not identify with OMB categories
- In addition to ethnicity, need to collect language at home and level of English proficiency
- Country of birth, parent’s country of birth if known
- Democratize the data!
Collecting Race/Ethnicity:
California Health Interview Survey (CHIS)

‘QA19_A9’ [AA4] - Are you Latino or Hispanic?
☐ 1 Yes
☐ 2 No

*If = 2, -3, goto ‘PN_QA19_A11’*

‘QA19_A10’ [AA5] - And what is your Latino or Hispanic ancestry or origin?
Check all that apply

☐ 01 Mexican/Mexican American/Chicano
☐ 04 Salvadoran
☐ 05 Guatemalan
☐ 06 Costa Rican
☐ 07 Honduran
☐ 08 Nicaraguan
☐ 09 Panamanian
☐ 10 Puerto Rican
☐ 11 Cuban
☐ 12 Spanish-American (from Spain)
☐ 91 Other Latino (Specify: __________)

‘QA19_A11’ [AA5A] - {You said you are Latino or Hispanic. Also,} please tell me which one or more of the following you would use to describe yourself. Would you describe yourself as

☐ 01 White
☐ 02 Black or African American
☐ 03 Asian
☐ 04 American Indian or Alaska Native
☐ 05 Other Pacific Islander
☐ 06 Native Hawaiian
☐ 91 Other (Specify: __________)

Source: www.chis.ucla.edu
Collection of Race/Ethnicity: CHIS

Source: www.chis.ucla.edu

‘QA19_A12’ [AA5B] - You said, American Indian or Alaska Native, and what is your tribal heritage?

Check all that apply

(11 maximum responses)

- 1 Apache
- 2 Blackfoot/Blackfeet
- 3 Cherokee
- 4 Choctaw
- 5 Mexican American Indian
- 6 Navajo
- 7 Pomo
- 8 Pueblo
- 9 Sioux
- 10 Yaqui
- 91 Other tribe (Specify: ________________)

‘QA19_A13’ [AA5C] - Are you an enrolled member in a federally or state recognized tribe?

- 1 Yes
- 2 No
Collecting Race/Ethnicity: CHIS

'QA19_A15' [AA5E] - You said Asian, and what specific ethnic group are you?

Check all that apply

(18 maximum responses)

- 1 Bangladeshi
- 2 Burmese
- 3 Cambodian
- 4 Chinese
- 5 Filipino
- 6 Hmong
- 7 Indian (India)
- 8 Indonesian
- 9 Japanese
- 10 Korean
- 11 Laotian
- 12 Malaysian
- 13 Pakistani
- 14 Sri Lankan
- 15 Taiwanese
- 16 Thai
- 17 Vietnamese
- 91 Other Asian (Specify: ________)

Source: www.chis.ucla.edu
Collecting Race/Ethnicity: CHIS

‘QA19_A16’ [AA5E1] - You said you are Pacific Islander. What specific ethnic group are you?

Check all that apply

(5 maximum responses)

- 1 Samoan/American Samoan
- 2 Guamanian
- 3 Tongan
- 4 Fijian
- 9 Other Pacific Islander (Specify:_______)

Source: www.chis.ucla.edu
Collecting Race/Ethnicity: CHIS

‘QA19_A17’ [AA5G] - You said that you are: (INSERT MULTIPLE RESPONSES FROM AA5, AA5A, AA5E AND AA5E1).

Do you identify with any one race in particular?

☐ 1 Yes
☐ 2 No

‘QA19_A18’ [AA5F] - Which do you most identify with?

Source: www.chis.ucla.edu
www.healthpolicy.ucla.edu
Country of Birth & Ancestry: CHIS

‘QA18_G1’ [AH33] -
Now a few more questions about your background.
In what country were you born?

‘QA18_G2’ [AH34] -
In what country was your mother born?

‘QA18_G3’ [AH35] -
In what country was your father born?

- 01 UNITED STATES
- 02 AMERICAN SAMOA
- 03 CANADA
- 04 CHINA
- 05 EL SALVADOR
- 06 ENGLAND
- 07 FRANCE
- 08 GERMANY
- 09 GUAM
- 10 GUATEMALA
- 11 HUNGARY
- 12 INDIA
- 13 IRAN
- 14 IRELAND
- 15 ITALY
- 16 JAPAN
- 17 KOREA
- 18 MEXICO
- 19 PHILIPPINES
- 20 POLAND
- 21 PORTUGAL
- 22 PUERTO RICO
- 23 RUSSIA
- 24 TAIWAN
- 25 VIETNAM
- 26 VIRGIN ISLANDS
- 91 OTHER (SPECIFY: ____________)
- -7 REFUSED
- -8 DON'T KNOW
How CHIS Has Impacted Data Equity Research

CHIS’s impact on the body of research for AANHPI and other groups stems from these key factors:

1. CHIS collects health and socio-demographic information for Asian and NHPI subgroups per the OMB recommendations; AANHPI and Latinx subgroups, AIAN tribal affiliation, SOGI
2. CHIS uses oversampling for AANHPI data collection, AIAN oversamples, Black and Latinx oversamples in some areas
3. CHIS conducts interviews in a variety of Asian languages: Cantonese, Mandarin, Korean, Vietnamese, and Tagalog
4. Currently conducting CTCP Tobacco using Respondent Driven Design—target sample of 800 adults each for two groups with inadequate samples in probability-based surveys: NHPIs and LGBTQ
Importance of Policy and Guidance on Disaggregation Practices

- Guidelines are necessary but not sufficient
- Federal or state mandates on uniform reporting across agencies needed
- Research community resources and better datasets spur studies
### CHIS in Peer-Reviewed Literature

Examined all studies using population-based surveys (N=688 studies from 1967-2018, PubMed) that measured health outcomes for AANHPI children and adults.

Studies using CHIS represent 26% of all of these studies.

<table>
<thead>
<tr>
<th>Large Population Survey</th>
<th>No. of articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHIS</td>
<td><strong>179</strong></td>
</tr>
<tr>
<td>NHIS</td>
<td>81</td>
</tr>
<tr>
<td>BRFSS</td>
<td>78</td>
</tr>
<tr>
<td>Other population survey</td>
<td>54</td>
</tr>
<tr>
<td>Medicare data</td>
<td>51</td>
</tr>
<tr>
<td>NHANES</td>
<td>38</td>
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<tr>
<td>SIPP</td>
<td>26</td>
</tr>
<tr>
<td>Epidemiologic study survey</td>
<td>25</td>
</tr>
<tr>
<td>CDC surveillance survey</td>
<td>20</td>
</tr>
<tr>
<td>CPS</td>
<td>17</td>
</tr>
<tr>
<td>MEPS</td>
<td>17</td>
</tr>
<tr>
<td>ACS</td>
<td>12</td>
</tr>
<tr>
<td>CAHPS</td>
<td>11</td>
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<tr>
<td>HCUP</td>
<td>10</td>
</tr>
<tr>
<td>NAMCS</td>
<td>10</td>
</tr>
<tr>
<td>NIS</td>
<td>9</td>
</tr>
<tr>
<td>ECLS</td>
<td>8</td>
</tr>
<tr>
<td>HEDIS</td>
<td>6</td>
</tr>
<tr>
<td>NSCH</td>
<td>6</td>
</tr>
<tr>
<td>County health survey</td>
<td>5</td>
</tr>
<tr>
<td>NHDS</td>
<td>5</td>
</tr>
<tr>
<td>NSDUH</td>
<td>5</td>
</tr>
<tr>
<td>NTS</td>
<td>4</td>
</tr>
<tr>
<td>YRBSS</td>
<td>3</td>
</tr>
<tr>
<td>NSFG</td>
<td>2</td>
</tr>
<tr>
<td>NHSDA</td>
<td>2</td>
</tr>
<tr>
<td>MCBS</td>
<td>1</td>
</tr>
<tr>
<td>NLS</td>
<td>1</td>
</tr>
<tr>
<td>PATH</td>
<td>1</td>
</tr>
<tr>
<td>SAMHSA</td>
<td>1</td>
</tr>
</tbody>
</table>

www.healthpolicy.ucla.edu
Classification Challenge

- Collection of data on race/ethnicity
  - Latino/Hispanic ancestry collected separately from race
  - Which race groups are included as response options to race Q’s
- Increasing number of people who select more than one race
  - ~8.4 million in 2010 (2.7% of the US population)*
  - ~11.3 million in 2019 (3.6% of the US population)
- 56% of NHPIs are multiracial; 50% of AIANs are multiracial
- 21.5% of single race AIANs are Hispanic; in CA: 53.6%
- Measurement and classification of race has implications for health policy and healthy equity

Sources: ACS 2019 1-yr files, *ACS 2010 1-yr files
Impact of Classification on Health Disparities: Conventional Classification for Asian Americans

Uninsured (%), CHIS 2011-14

- White, Non-Latino: 9
- Asian, Non-Latino: 14
- Chinese
- Japanese
- Korean
- Filipino
- South Asian
- Vietnamese
- Other Asian
Impact of Classification on Health Disparities: Conventional Classification for Asian

Uninsured (%), CHIS 2011-14

- White, Non-Latino: 9
- Asian, Non-Latino: 14
- Chinese: 14
- Japanese: 10
- Korean: 27
- Filipino: 10
- South Asian: 10
- Vietnamese: 16
- Other Asian: 19
AANHPI Data Disaggregation and COVID-19

- Race/ethnic disparities – disproportionate impact among communities of color reflects long-standing inequities in health care and economic systems
- Data disaggregation is lacking – e.g. earlier this year, mortality data for NHPI merged with Asians in National Death statistics

https://data.cdc.gov/d/pj7m-y5uh/visualization
https://www.cdc.gov/nchs/nvss/vsrr/covid_weekly/index.htm#Race_Hispanic

- Each state collecting, and tabulating R/E data differently---most impacts smaller populations, which are sometimes not reported, or aggregated with other groups of “Other” or “Multirace”
### CA COVID-19 Race and Ethnicity Data

**September 26, 2020**

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Cases</th>
<th>%Cases</th>
<th>Deaths</th>
<th>%Deaths</th>
<th>% CA pop</th>
<th>%Cases/ %CA pop</th>
<th>%Deaths/ %CA pop</th>
</tr>
</thead>
<tbody>
<tr>
<td>Latino</td>
<td>341,600</td>
<td>61.1</td>
<td>7,389</td>
<td>48.4</td>
<td>38.9</td>
<td>1.57</td>
<td>1.24</td>
</tr>
<tr>
<td>White</td>
<td>95,499</td>
<td>17.1</td>
<td>4,567</td>
<td>29.9</td>
<td>36.6</td>
<td>0.47</td>
<td>0.82</td>
</tr>
<tr>
<td>Asian</td>
<td>30,841</td>
<td>5.5</td>
<td>1,794</td>
<td>11.7</td>
<td>15.4</td>
<td>0.36</td>
<td>0.76</td>
</tr>
<tr>
<td>African American</td>
<td>23,848</td>
<td>4.3</td>
<td>1,177</td>
<td>7.7</td>
<td>6.0</td>
<td>0.72</td>
<td>1.28</td>
</tr>
<tr>
<td>Multi-Race</td>
<td>5,883</td>
<td>1.1</td>
<td>99</td>
<td>0.6</td>
<td>2.2</td>
<td>0.50</td>
<td>0.27</td>
</tr>
<tr>
<td>AIAN</td>
<td>1,480</td>
<td>0.3</td>
<td>49</td>
<td>0.3</td>
<td>0.5</td>
<td>0.60</td>
<td>0.60</td>
</tr>
<tr>
<td>NHPI</td>
<td>3,034</td>
<td>0.5</td>
<td>69</td>
<td>0.5</td>
<td>0.3</td>
<td>1.67</td>
<td>1.67</td>
</tr>
<tr>
<td>Other</td>
<td>56,629</td>
<td>10.1</td>
<td>125</td>
<td>0.8</td>
<td>0.0</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Total with data</td>
<td>558,814</td>
<td>100.0</td>
<td>15,269</td>
<td>100.0</td>
<td>100.0</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>AANHPI</td>
<td>33,875</td>
<td>6.0</td>
<td>1,863</td>
<td>12.0</td>
<td>16.0</td>
<td>0.38</td>
<td>0.78</td>
</tr>
</tbody>
</table>
As of: September 9, 2020
Total NHPI COVID-19 Cases: 15,181

https://healthpolicy.ucla.edu/health-profiles/Pages/NHPI-COVID-19-Dashboard.aspx
More than 200,000 LGBT adults in California at high risk for COVID-19 illness

- COVID-19 data systems nationally and in the state does not currently collect by Sexual Orientation, Gender Identity
- Williams Institute report uses CHIS data
  - They measure the health and economic characteristics that may increase vulnerability to COVID-19 for the nearly 1.7 million LGBT adults in California
- A bill introduced in the California Legislature, SB 932, would require monitoring systems to include questions to identify LGBT people. Signed by Governor 9/26/2020. California the first state in the country to collect LGBTQ COVID-19 data.
Challenges to Data Disaggregation

- How do we pay for this?
- Will there be user interest?
- Will users be able to access because of disclosure risk?
- How do we protect respondents with more granular identification?
- Why collect if not enough sample?

UCLA CHPR /RWJ-funded Technical Assistance grant RFP program forthcoming

- Why is it important? Role of advocates, data equity champions
Challenges to Progress

- The movement to eliminate racial and ethnic disparities in health continues to be impeded by the quality of population health data on race/ethnicity
- Growing racial/ethnic diversity of the US, including the increasing numbers of America’s population reporting multiple races
- *More data producers need to lead, design, disseminate, apply, formulate with health equity at every step of the knowledge generation process—not just an afterthought*
Thank you!

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