



THE UCLA CENTER FOR HEALTH POLICY RESEARCH



# Hidden Identities, Hidden Lives: When Data Obscures Health Disparities

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# Agenda

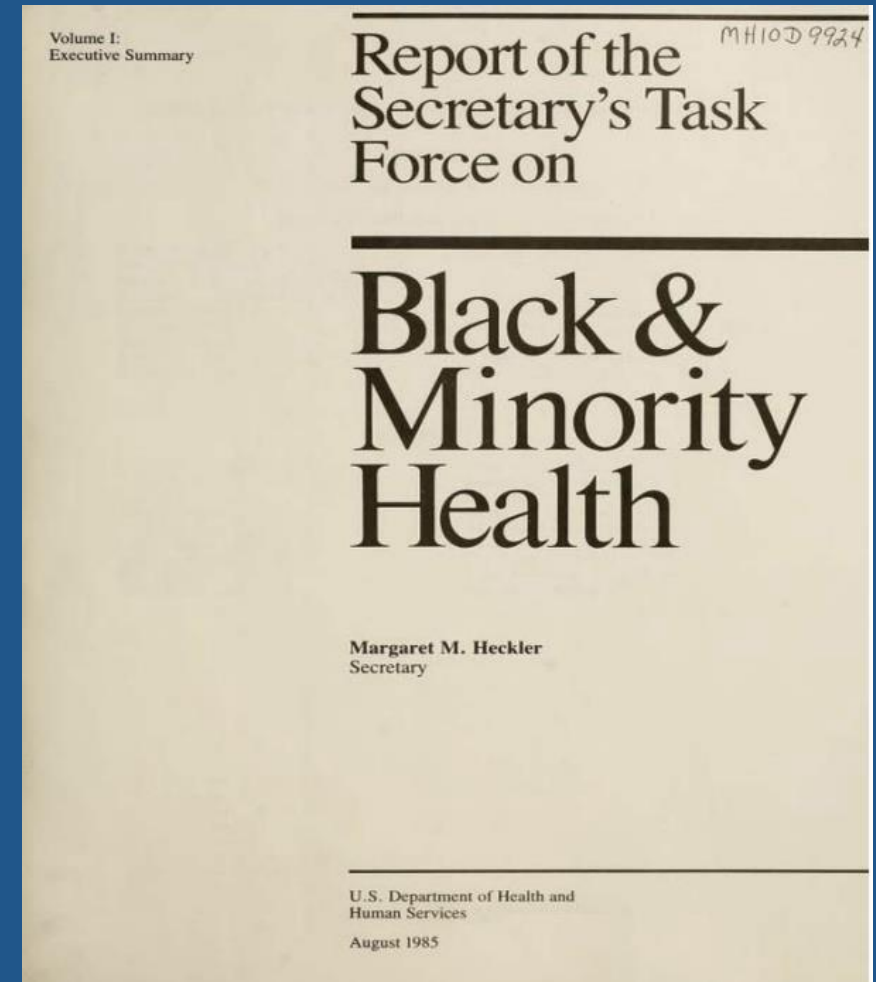
- Overview of data disaggregation
- Summary of PolicyLink report on data disaggregation
- How CHIS collects race/ethnicity data
- Analyses focused on Asian American Native Hawaiian Pacific Islander (AANHPI) and American Indian/Alaska Native (AIAN) groups

# 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”

–Margaret Heckler, 1985. Report of the Secretary's Task Force Report on Black and Minority Health. Washington D.C: US Department of Health and Human Services



# A Key Response: 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

# 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



## Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health

PolicyLink



“”

**Research that disaggregates the non-Hispanic White population is practically non-existent. A comprehensive review of the extant literature found no study that systematically disaggregates the health status of ethnic groups classified as non-Hispanic White.**

Jen'nan Read, Duke University, in the research review on the non-Hispanic White population done for this project<sup>21</sup>

“”

**It's hard to find the numbers on Arab Americans because they are included in the White population. We looked nationally and found only 34 reliable studies on Arab Americans, and 26 of them were conducted in Michigan.**

Hassan Jaber, Executive Director and Chief Executive Officer of ACCESS (Arab Community Center for Economic and Social Services), and member of the National Advisory Committee of the U.S. Census Bureau

“”

**Some studies on immigrant health point to increased stress exposure the longer immigrants live in the U.S. which over time increases their likelihood to engage in health risk behaviors. There also may be specific cultural health factors prevalent in the beginning or changes that take place as a result of contact with culturally dissimilar people and groups related to integration that reduce or heighten their health risk.**

Carmela Alcántara, Associate Professor of Social Work, Columbia University

## Key Takeaways

- Increasing need for disaggregation, especially for American Indian/Alaska Native (AIAN), Middle East and North Africa (MENA)
- Ancestry, acculturation important, especially for Latin American immigrants
- For Blacks, skin color an important measure as it is associated with discrimination

# 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](http://www.chis.ucla.edu)

# Collection of Race/Ethnicity: CHIS

Source: [www.chis.ucla.edu](http://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

**'QA19\_A14' [AA5D] - Which tribe are you enrolled in?**

Apache

- ☐ 1 Mescalero Apache, NM
- ☐ 2 Apache (not specified)\_
- ☐ 3 Other Apache (SPECIFY: \_\_\_\_\_)

Blackfeet

- ☐ 4 Blackfoot/Blackfeet

Cherokee

- ☐ 5 Western Cherokee
- ☐ 6 Cherokee (not specified)
- ☐ 7 Other Cherokee (Specify: \_\_\_\_\_)

Choctaw

- ☐ 8 Choctaw Oklahoma
- ☐ 9 Choctaw (not specified)
- ☐ 10 Other Choctaw (Specify: \_\_\_\_\_)

Navajo

- ☐ 11 Navajo (not specified)

Pomo

- ☐ 12 Hopland Band, Hopland Rancheria
- ☐ 13 Sherwood Valley Rancheria
- ☐ 14 Pomo (not specified)
- ☐ 15 Other Pomo (SPECIFY: \_\_\_\_\_)

Pueblo

- ☐ 16 Hopi
- ☐ 17 Ysleta del Sur Pueblo of Texas
- ☐ 18 Pueblo (not specified)
- ☐ 19 Other Pueblo (Specify: \_\_\_\_\_)

Sioux

- ☐ 20 Oglala/ Pine Ridge Sioux
- ☐ 21 Sioux (not specified)
- ☐ 22 Other Sioux (Specify: \_\_\_\_\_)

Yaqui

- ☐ 23 Pascua Yaqui Tribe of Arizona
- ☐ 24 Yaqui (not specified)
- ☐ 25 Other Yaqui (Specify: \_\_\_\_\_)

Other

- ☐ 91 Other (Specify: \_\_\_\_\_)



# 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](http://www.chis.ucla.edu)

[www.healthpolicy.ucla.edu](http://www.healthpolicy.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
- ☐ 91 Other Pacific Islander (Specify:\_\_\_\_\_)

Source: [www.chis.ucla.edu](http://www.chis.ucla.edu)

[www.healthpolicy.ucla.edu](http://www.healthpolicy.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](http://www.chis.ucla.edu)

[www.healthpolicy.ucla.edu](http://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

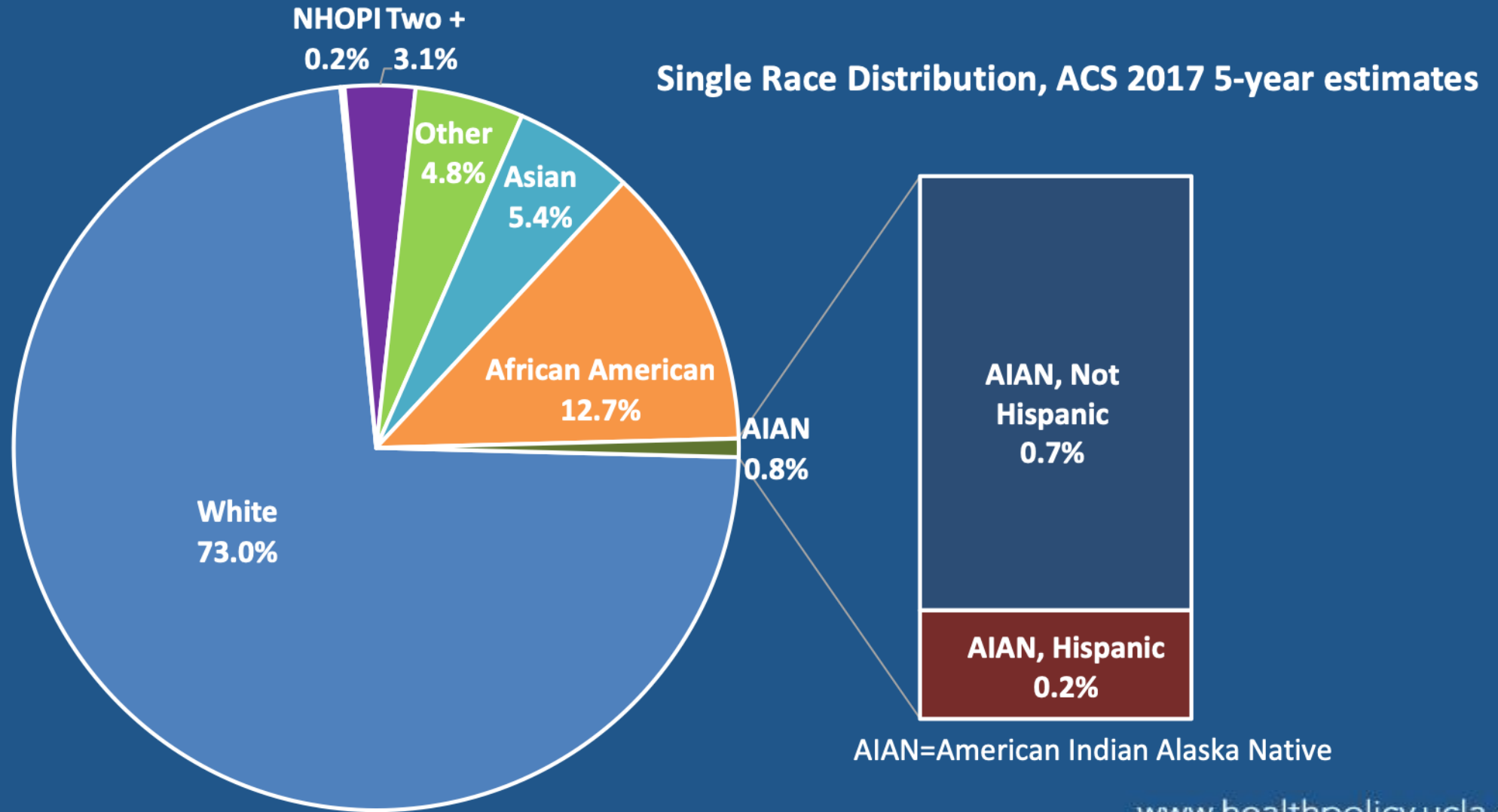


# Classification Challenge

- 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\*
  - ~6 million in 2009
  - ~9 million in 2018
- Measurement and classification of race has implications for health policy and healthy equity

\*Source: Kaiser Family Foundation, Population Distribution by Race/Ethnicity

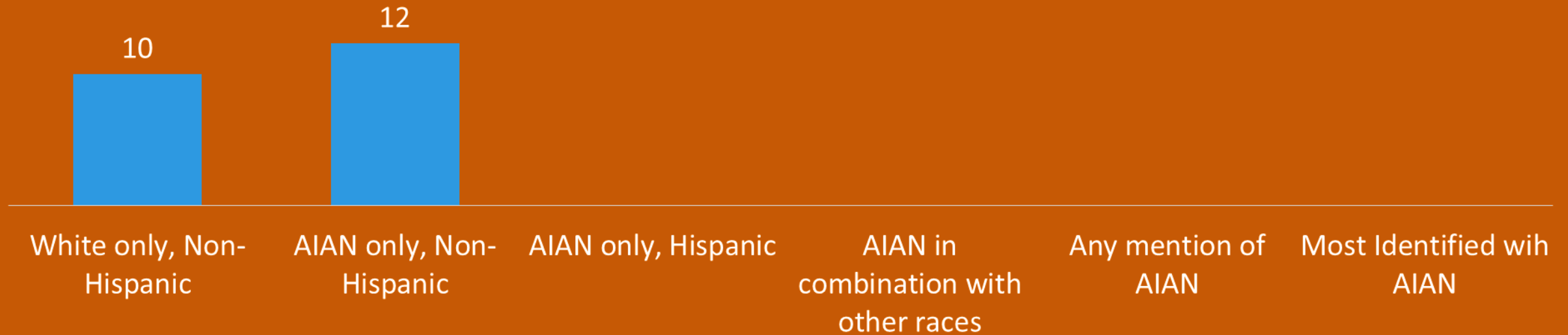
# Conventions in Racial Classification: AIAN



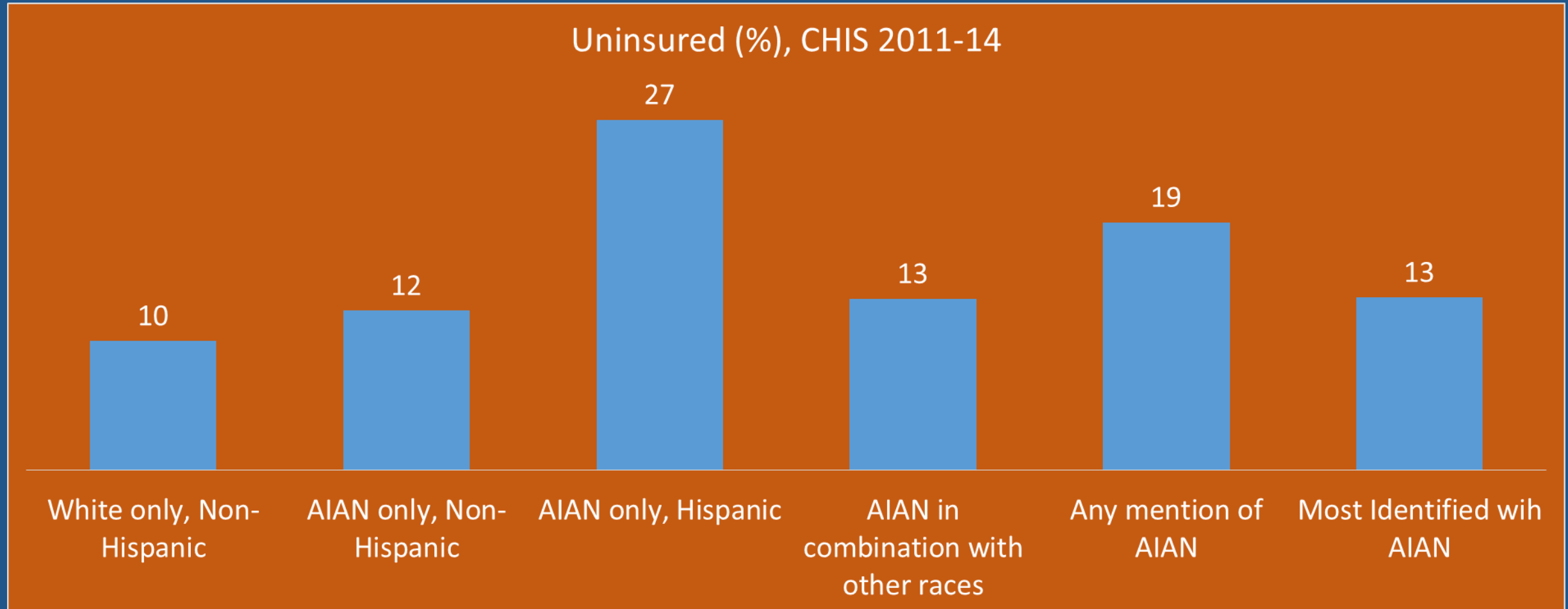


# Impact of Classification on Health Disparities: Conventional Classification of AIAN

Uninsured (%), CHIS 2011-14

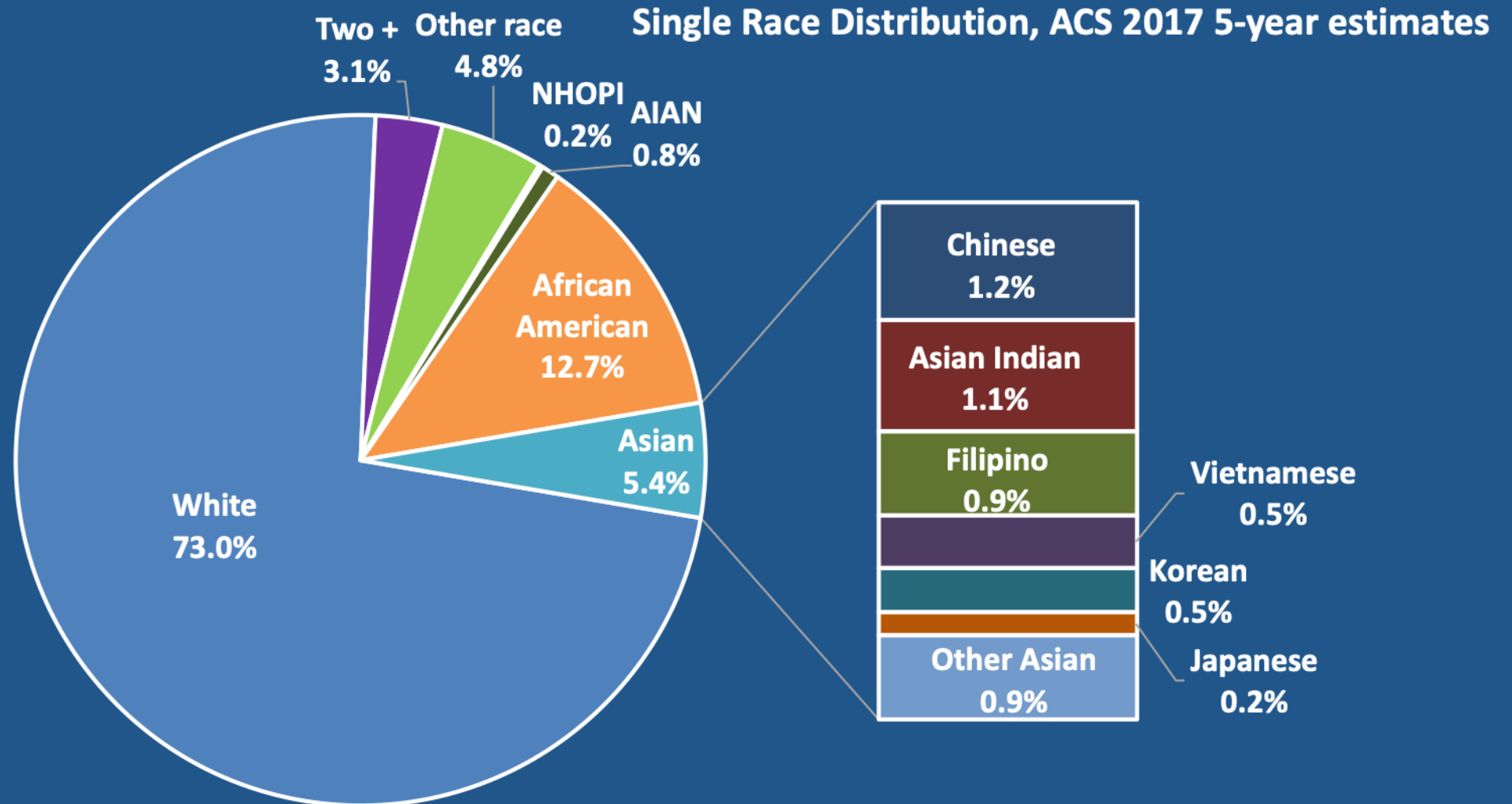


# Impact of Classification on Health Disparities: Conventional Classification of AIAN

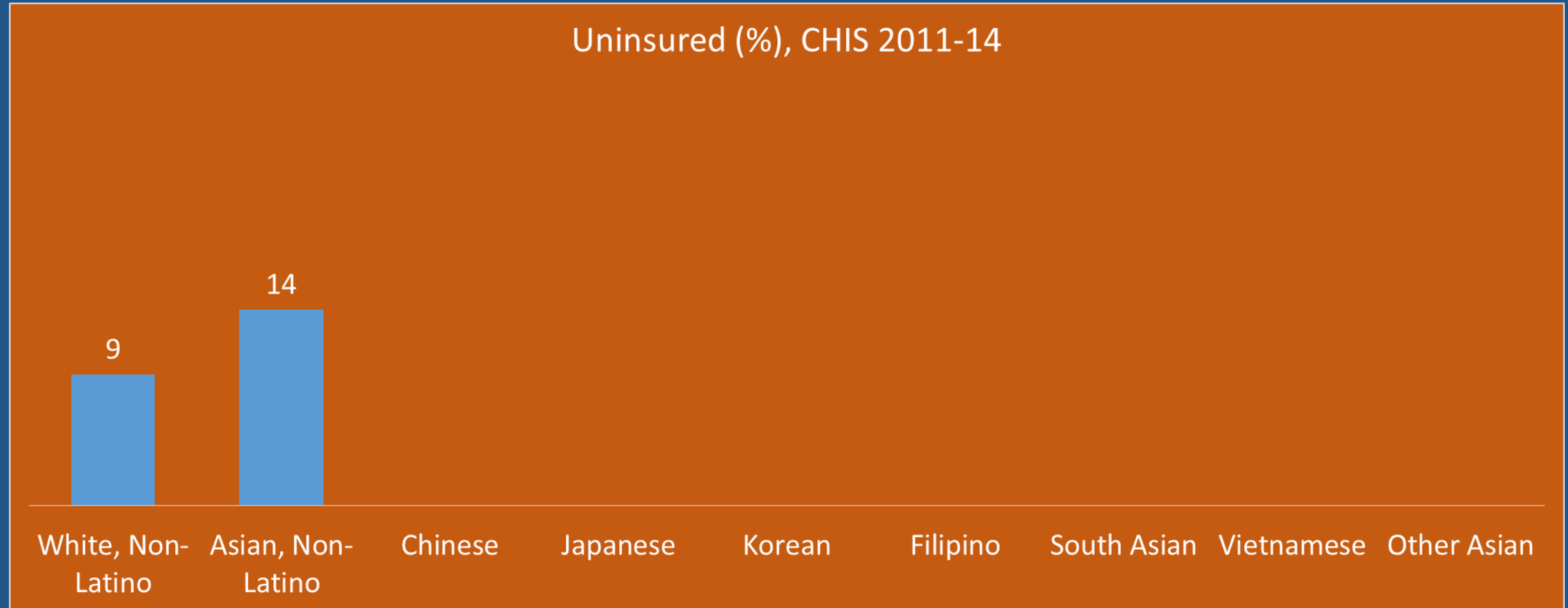




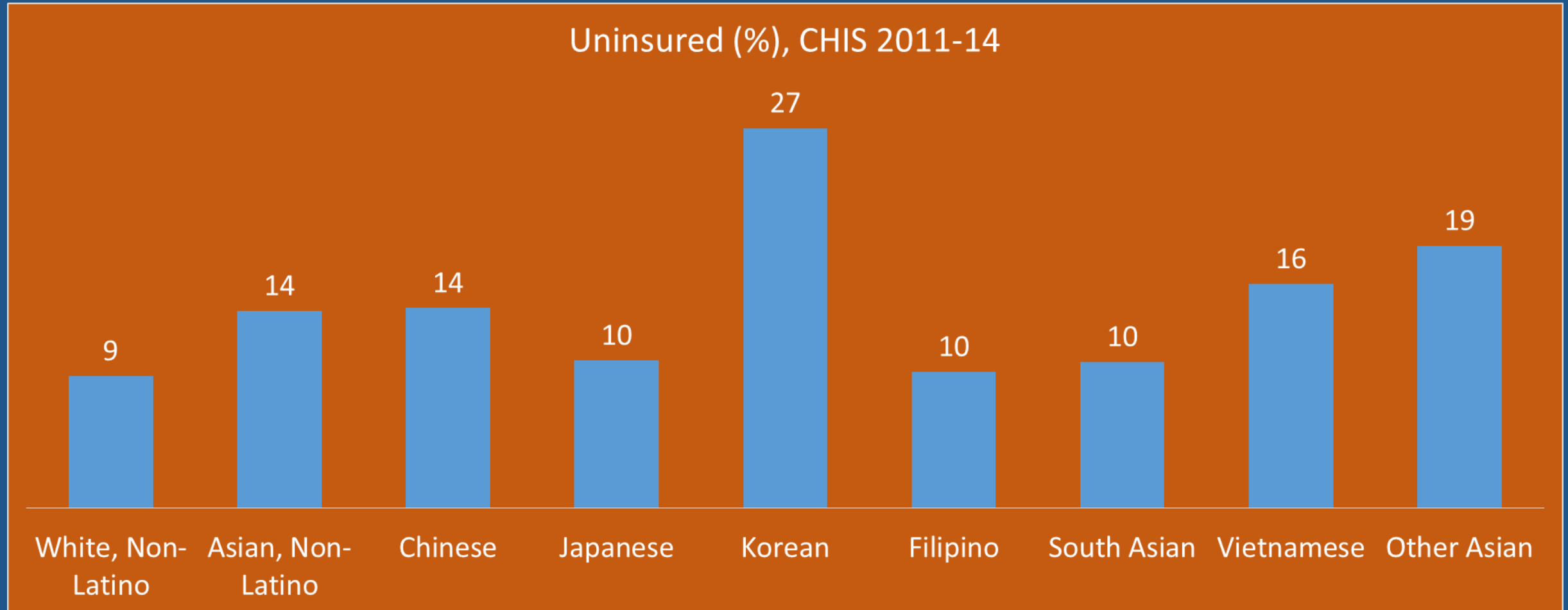
# Conventions in Racial Classification: Asian



# Impact of Classification on Health Disparities: Conventional Classification for Asian

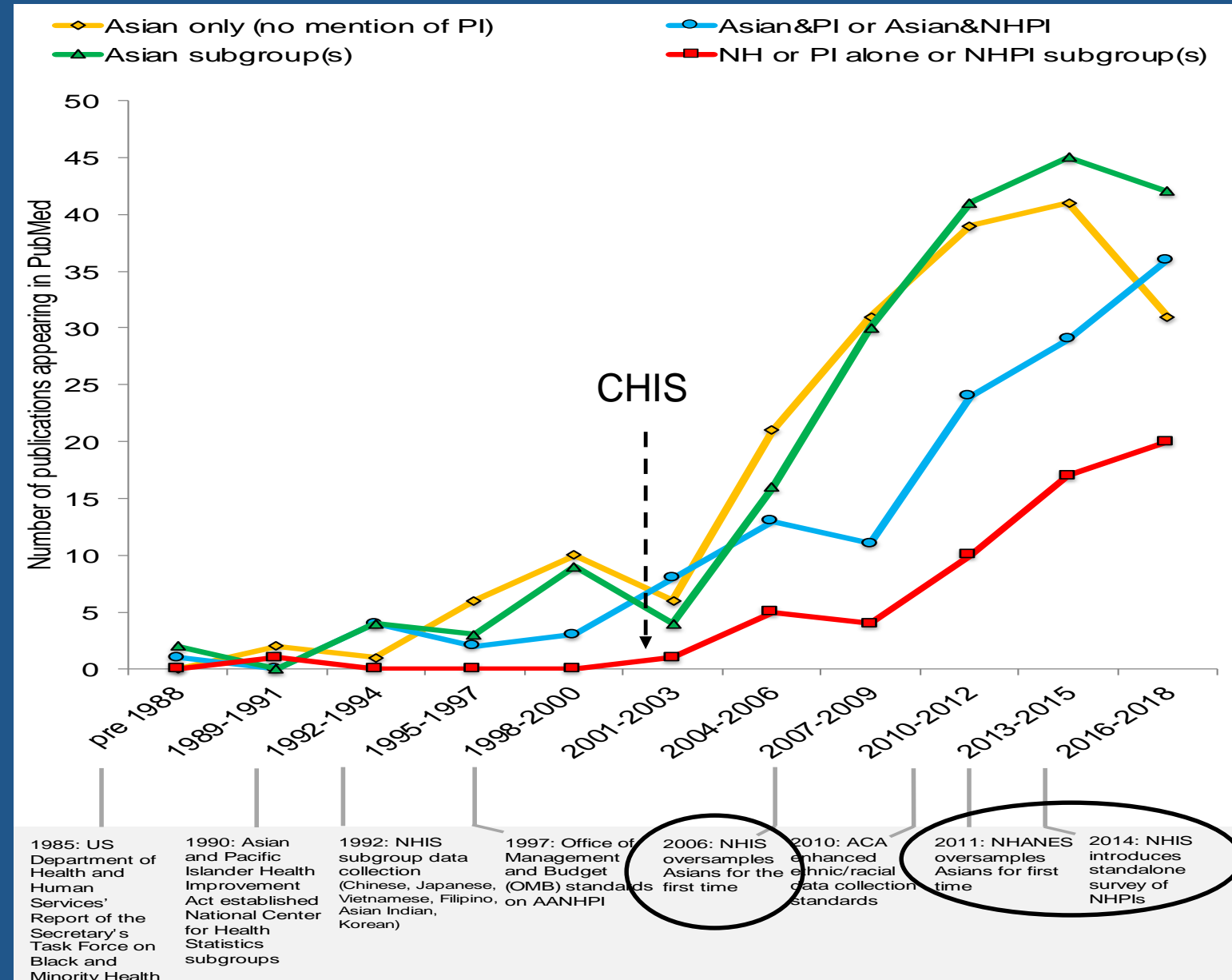


# Impact of Classification on Health Disparities: Conventional Classification for Asian



# 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





# 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

# 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?

Presentation on some of these answers at AcademyHealth HealthDataPalooza 2020 Conference—links to video presentation per request

RWJ-funded grant RFP program forthcoming

# 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. 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](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 also tends to have largest multiracial segments. For example, in Arkansas, which has a concentration of Marshallese, the Pacific Islander COVID-rates will vary from 300 cases /100,000 to over 400 cases/100,000 depending on whether the denominator is single race or “any mention”. And, community leaders there think that if the PI group is disaggregated, the Marshallese may have higher rates, but we can’t see this in aggregated data.

# Census 2020

5. Please provide information for each person living here. If there is someone living here who pays the rent or owns this residence, start by listing him or her as Person 1. If the owner or the person who pays the rent does not live here, start by listing any adult living here as Person 1.

What is Person 1's name? *Print name below.*

First Name

MI

Last Name(s)

6. What is Person 1's sex? Mark ☒ ONE box.

☐ Male ☐ Female

7. What is Person 1's age and what is Person 1's date of birth? *For babies less than 1 year old, do not write the age in months. Write 0 as the age.*

*Print numbers in boxes.*

Age on April 1, 2020

Month

Day

Year of birth

years

→ NOTE: Please answer BOTH Question 8 about Hispanic origin and Question 9 about race. For this census, Hispanic origins are not races.

8. Is Person 1 of Hispanic, Latino, or Spanish origin?

- ☐ No, not of Hispanic, Latino, or Spanish origin
- ☐ Yes, Mexican, Mexican Am., Chicano
- ☐ Yes, Puerto Rican
- ☐ Yes, Cuban
- ☐ Yes, another Hispanic, Latino, or Spanish origin – *Print, for example, Salvadoran, Dominican, Colombian, Guatemalan, Spaniard, Ecuadorian, etc.*

9. What is Person 1's race?

Mark ☒ one or more boxes **AND** print origins.

- ☐ White – *Print, for example, German, Irish, English, Italian, Lebanese, Egyptian, etc.*

- ☐ Black or African Am. – *Print, for example, African American, Jamaican, Haitian, Nigerian, Ethiopian, Somali, etc.*

- ☐ American Indian or Alaska Native – *Print name of enrolled or principal tribe(s), for example, Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, etc.*

- ☐ Chinese ☒ Vietnamese ☐ Native Hawaiian

- ☒ Filipino ☐ Korean ☐ Samoan

- ☒ Asian Indian ☐ Japanese ☐ Chamorro

- ☒ Other Asian – *Print, for example, Pakistani, Cambodian, Hmong, etc.*

- ☐ Other Pacific Islander *Print, for example, Tongan, Fijian, Marshallese, etc.*

- ☐ Some other race – *Print race or origin.*





HEALTH DISPARITIES UNDETECTED  
WITH AGGREGATED DATA



DATA DISAGGREGATION IMPORTANT  
NOT JUST IN SURVEYS BUT IN ALL  
PUBLIC HEALTH SURVEILLANCE  
SYSTEMS

Thank you!

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