



THE UCLA CENTER FOR HEALTH POLICY RESEARCH 

# The Data Disaggregation Imperative to Achieve Health Equity

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# Agenda

Overview of a model of health equity and data disaggregation

- Brief history of Heckler Report, OMB Directive 15 (1997)
- Census, CHIS impact on AA NHPI health insights
- Data Collection and COVID-19
- The Way Forward

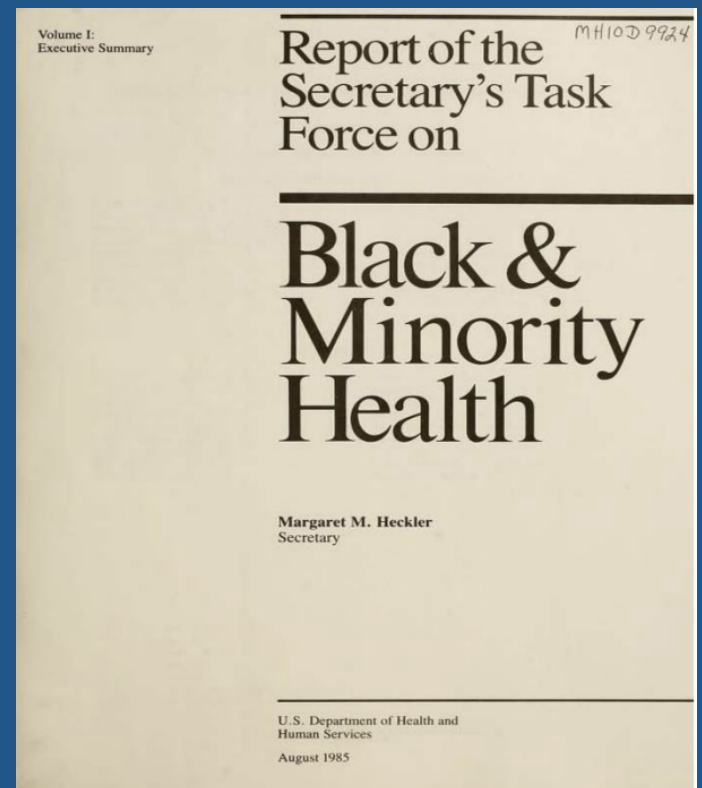


# What We've Known for 30+ Years

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”

—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



# 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!

# 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.

Age on April 1, 2020 *Print numbers in boxes.* 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.*



# 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

# How CHIS Has Impacted Data Equity Research

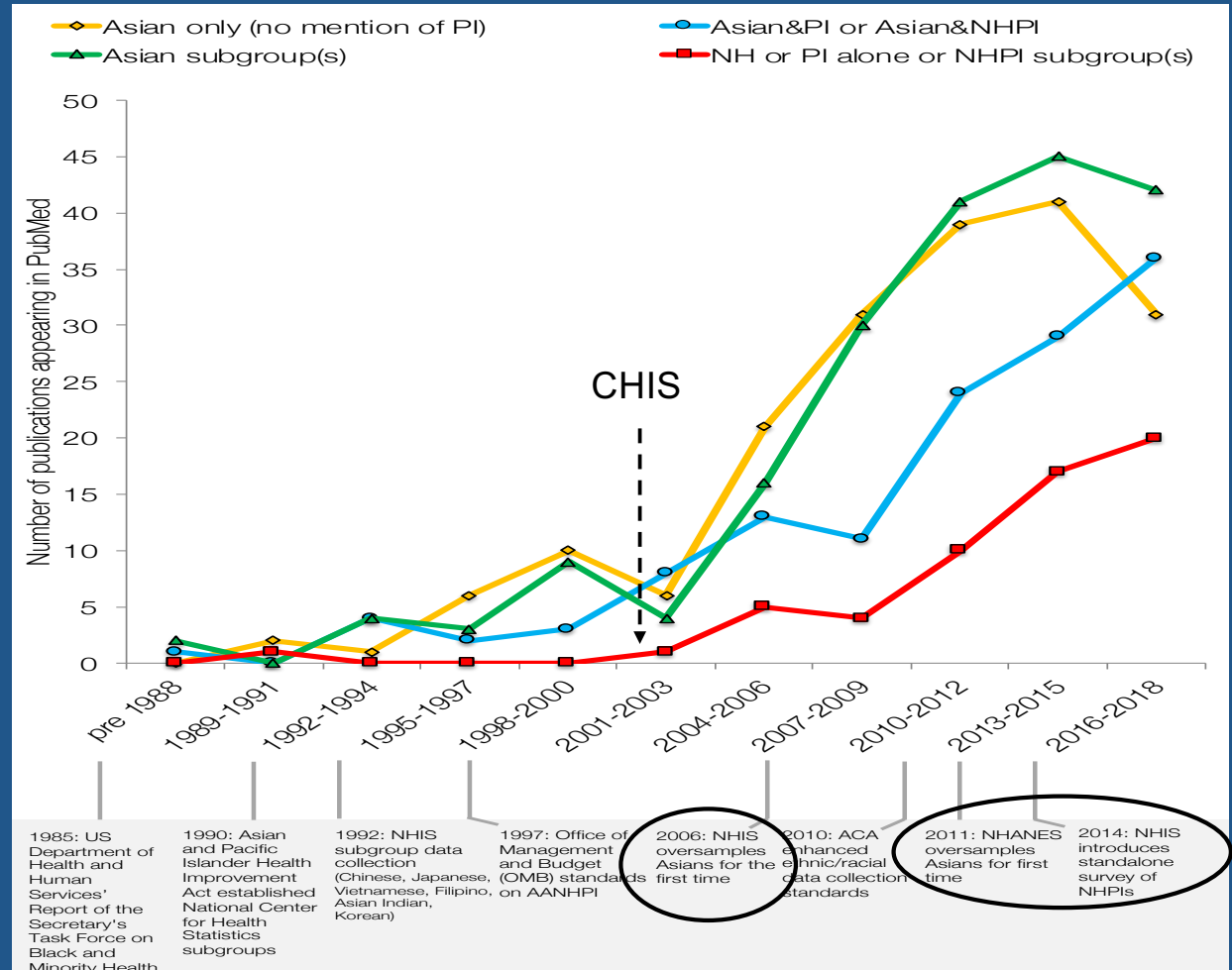
CHIS's impact on the body of research for AANHPI and other groups stems from these key factors:

- (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

Large Population Survey	No. of articles
CHIS	179
NHIS	81
BRFSS	78
Other population survey	54
Medicare data	51
NHANES	38
SIPP	26
Epidemiologic study survey	25
CDC surveillance survey	20
CPS	17
MEPS	17
ACS	12
CAHPS	11
HCUP	10
NAMCS	10
NIS	9

ECLS	8
HEDIS	6
NSCH	6
County health survey	5
NHDS	5
NSDUH	5
NTS	4
YRBSS	3
NSFG	2
NHSDA	2
MCBS	1
NLS	1
PATH	1
SAMHSA	1



# 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





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

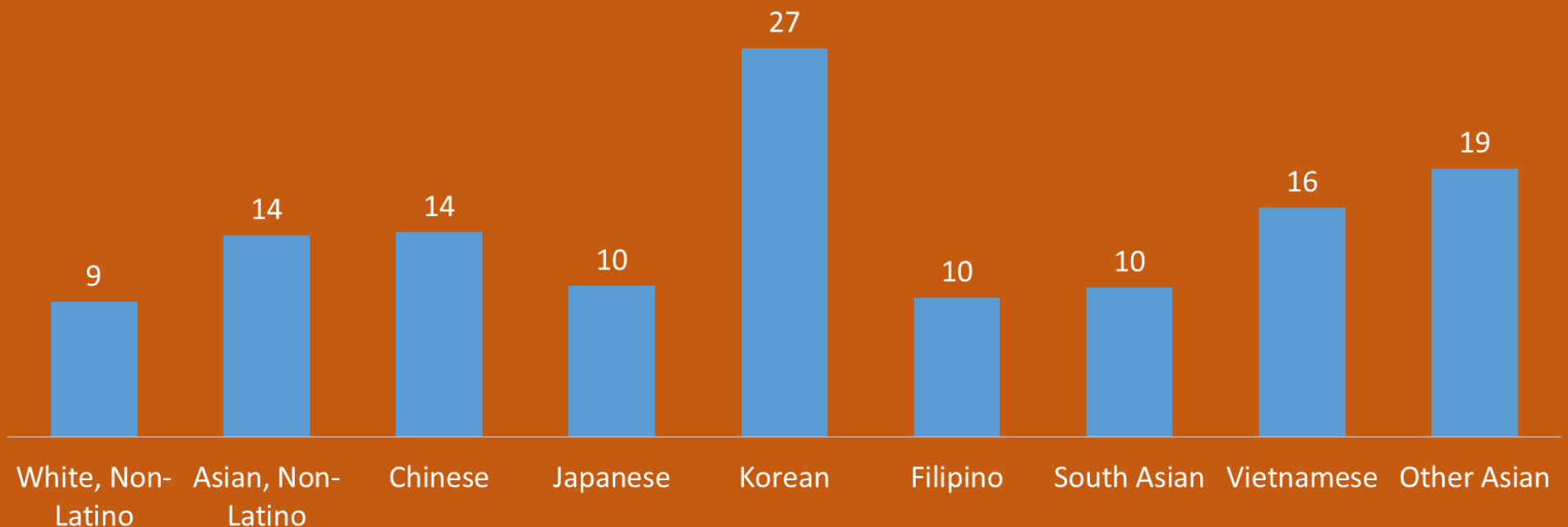
Uninsured (%), CHIS 2011-14





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

Uninsured (%), CHIS 2011-14





# 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](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

Race/Ethnicity	Cases	%Cases		Deaths	%Deaths	% CA pop		%Cases/ %CA pop	%Deaths/ %CA pop
Latino	341,600	61.1		7,389	48.4	38.9		1.57	1.24
White	95,499	17.1		4,567	29.9	36.6		0.47	0.82
Asian	30,841	5.5		1,794	11.7	15.4		0.36	0.76
African American	23,848	4.3		1,177	7.7	6		0.72	1.28
Multi-Race	5,883	1.1		99	0.6	2.2		0.50	0.27
AIAN	1,480	0.3		49	0.3	0.5		0.60	0.60
NHPI	3,034	0.5		69	0.5	0.3		1.67	1.67
Other	56,629	10.1		125	0.8	0			
Total with data	558,814	100.0		15,269	100.0	100.0		1.00	1.00
AANHPI	33,875	6.0		1,863	12	16		0.38	0.78

## NHPI COVID-19 Data Policy Lab Dashboard

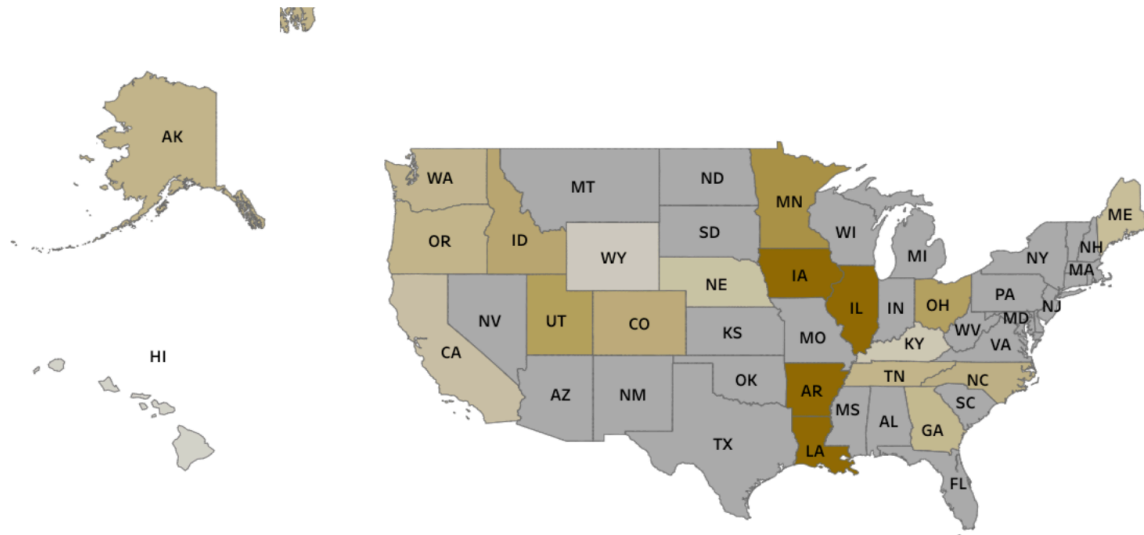
U.S. NHPI COVID-19  
Cases


U.S. NHPI COVID-19  
Deaths

State NHPI COVID-19  
Data

Data Sources &  
Methodology

As of: **September 9, 2020**  
Total NHPI COVID-19 Cases:  
**15,181**



NHPI Case Rate per 100,000  
0  30,363

## HEALTH AFFAIRS BLOG

RELATED TOPICS:  
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## Count Native Hawaiian And Pacific Islanders In COVID-19 Data—It's An OMB Mandate

Richard Calvin Chang, Corina Penaia, Karla Thomas

AUGUST 27, 2020 DOI: 10.1377/hblog20200825.671245



<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*



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Thank  
you!

