



THE UCLA CENTER FOR HEALTH POLICY RESEARCH



No Equity Without Data Equity

Convening Across Sectors for Colorado's Health Equity and Wellness (CASCHEW) Conference
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OVERVIEW



With examples /stories on what keeps me up at night:

1. The California Health Interview Survey
2. Native Hawaiian and Pacific Islander (NHPI) Data Policy Lab
3. Filipinx/a/o Community Health Association



The role of data and data equity

Data failures during COVID-19 and in general

The future of our public health data system

Q&A

Health Equity

Everyone has the opportunity to reach their full health potential without any disadvantage due to social circumstances



Social determinants of health are circumstances of people's lives that impact health, including access to care, schools and education, conditions of work and leisure, homes, communities, distribution of power, income, goods, and services

Measurement Is Key to Achieving Health Equity



U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

Health Disparities

- Measurement is comparative
 - Often the comparison of socially disadvantaged communities or populations with a most advantaged group
- Health disparities measurement by racialized race and ethnicity groups is limited by the quality of the data in its error of omissions and missingness, or lack of specificity of populations it purports to represent

A racialized group is individuals that have been grouped together by external entities, such as the U.S. Office and Management and Budget (OMB), based on observable and often phenotypical characteristics, e.g. skin color, country of origin, language

Data Equity

Data are collected, analyzed, interpreted, and distributed such that marginalized communities have access to and can use these data



Transformational change is needed to address:

- How datasets are created
- What data are collected
- Who is represented in data
- Who has access to data
- What actions are taken to address issues found in data

Data Equity to Uplift Communities



- Health disparities have been known for over 30 years, yet little progress has been made in health equity
- Data equity is now a recognized part of the equation and absolutely necessary for health equity
- There is notable momentum and cross-sectional and Federal interest in transformational change

No equity without data equity

The U.S. Office of Management and Budget (OMB) Directive 15, 1997

Ethnicity

- Hispanic or Latino
- Not Hispanic or Latino

The OMB standards explain that the specified race and ethnicity categories are socio-political constructs and should not be interpreted as being scientific or anthropological in nature.

“In no case shall the provisions of the standards be construed to limit the collection of data to the categories described above. The collection of greater detail is encouraged . . .”

source: <https://www.federalregister.gov/documents/2016/09/30/2016-23672/standards-for-maintaining-collecting-and-presenting-federal-data-on-race-and-ethnicity>

Race

- 5 minimum categories:
 - American Indian or Alaska Native (AIAN)
 - Asian
 - Black or African American
 - Native Hawaiian or Pacific Islander (NHPI)
 - White
- Can select one or more races



Story #1 the California Health Interview Survey

How my time as an advocate made me a better data producer. Pro-tip—you don't have to have advocacy creds, but listening to communities helps

What Is the California Health Interview Survey (CHIS)?

- Nation's largest state population-representative health survey
 - About 20,000 annual sample
 - Adults, Adolescents, Children
 - English, Spanish, Cantonese, Mandarin, Korean, Tagalog, Vietnamese
- Most comprehensive source of health information on Californians
- Researchers and community-based partners and advocates rely on population-based survey data to address specific health needs
- Population health surveys ask about living conditions, education, occupation, income, and trauma history—piecing together the “backstory” that may explain the racial/ethnic inequities in health access and health outcomes

California Health Interview Survey (CHIS)

Two main objectives:

- To provide substate/local estimates
- **To measure health disparities in the state**
 - Race/ethnicity/language
 - Sexual Orientation/Gender Identity
 - Citizenship/Immigration Status
 - Disability status
 - Educational Attainment, Occupation, Income

Centering Equity in Population Surveys

CHIS has explicit measurement objective to eliminate health inequities

The CHIS is coproduced by community-based partners through advisory committees, including one that is tasked with improving the value of the survey across multicultural populations

With organizational commitment and community accountability, population health surveys will have the equity objective front and center

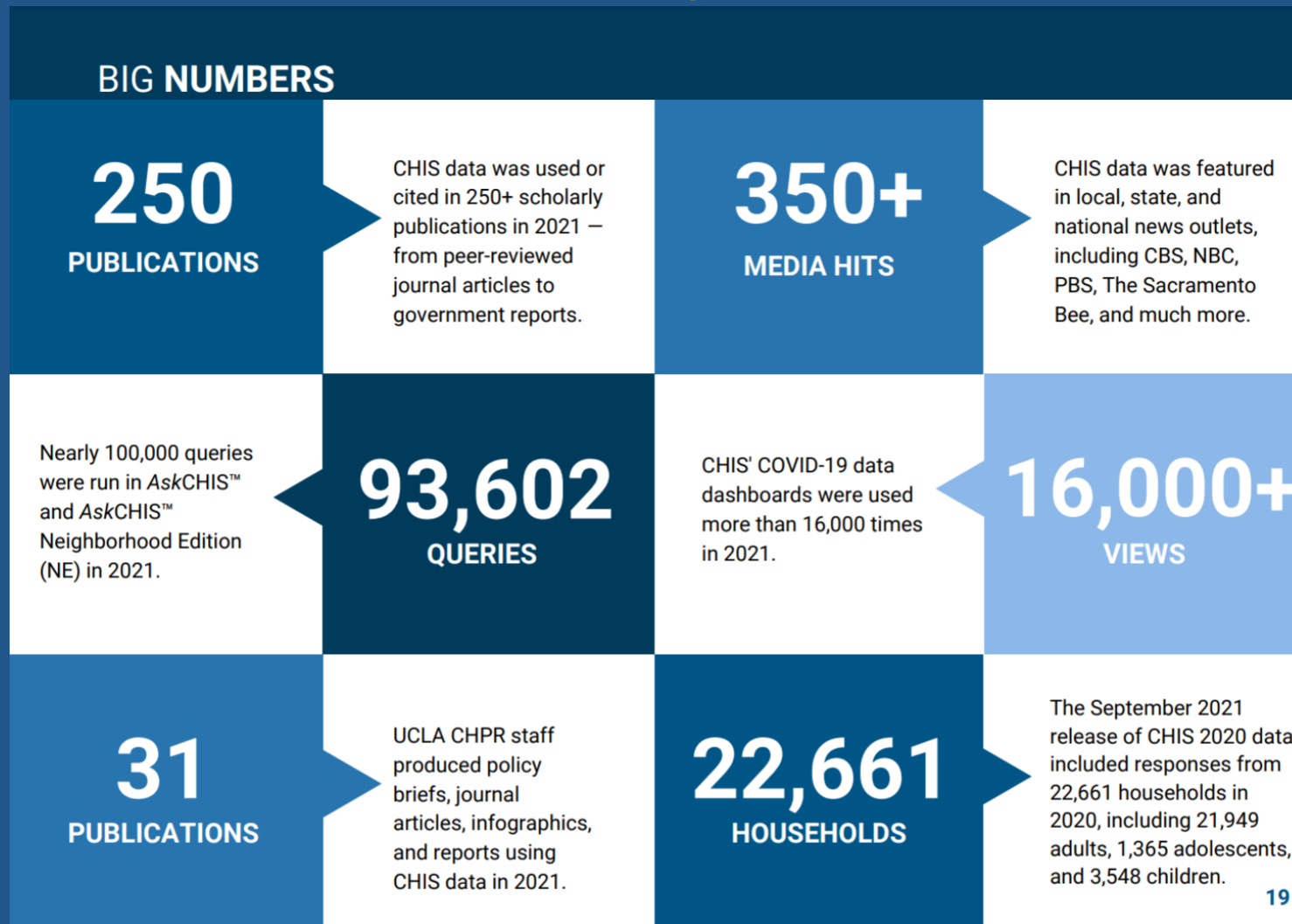
And, the quality of insights to formulate policies improving population health will improve

CHIS 2021 Making an Impact

A report of 2021 CHIS impact through:

- Access to data tools
- Legislation and advocacy
- Seminars, events, and presentations
- Journal articles and publications
- Media coverage

<https://healthpolicy.ucla.edu/chis/Pages/impact.aspx>



CHIS 2021 Data Collection Results: OMB Minimum Guidelines

CHIS 2021 RACIAL/ETHNIC GROUP SAMPLES BY AGE

	ADULT (Age 18+)	ADOLESCENT (Ages 12-17)	CHILD (Ages 0-11)
Total Sample Size	24,453	1,169	4,067
RACE*			
White	15,787	689	2,257
Asian	4,026	176	663
Native Hawaiian/Pacific Islander	55	7	9
African American	1,099	33	175
American Indian/Alaska Native	529	20	71
Other single race	1,680	108	398
Two or More Races	1,277	136	494
LATINO ETHNICITY			
Latino	6,027	431	1,670
Non-Latino	18,426	738	2,397

<http://chis.ucla.edu/methodology>

CHIS 2021 Race and Ethnicity

Data Collection

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: _____)

You said, American Indian or Alaska Native, and what is your tribal heritage?

Check all that apply

- 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: _____)

Are you an enrolled member in a federally or state recognized tribe?

- 1 Yes
- 2 No

CHIS 2021 Race and Ethnicity Data Collection

You said you are Pacific Islander. What specific ethnic group are you? *Check all that apply*

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

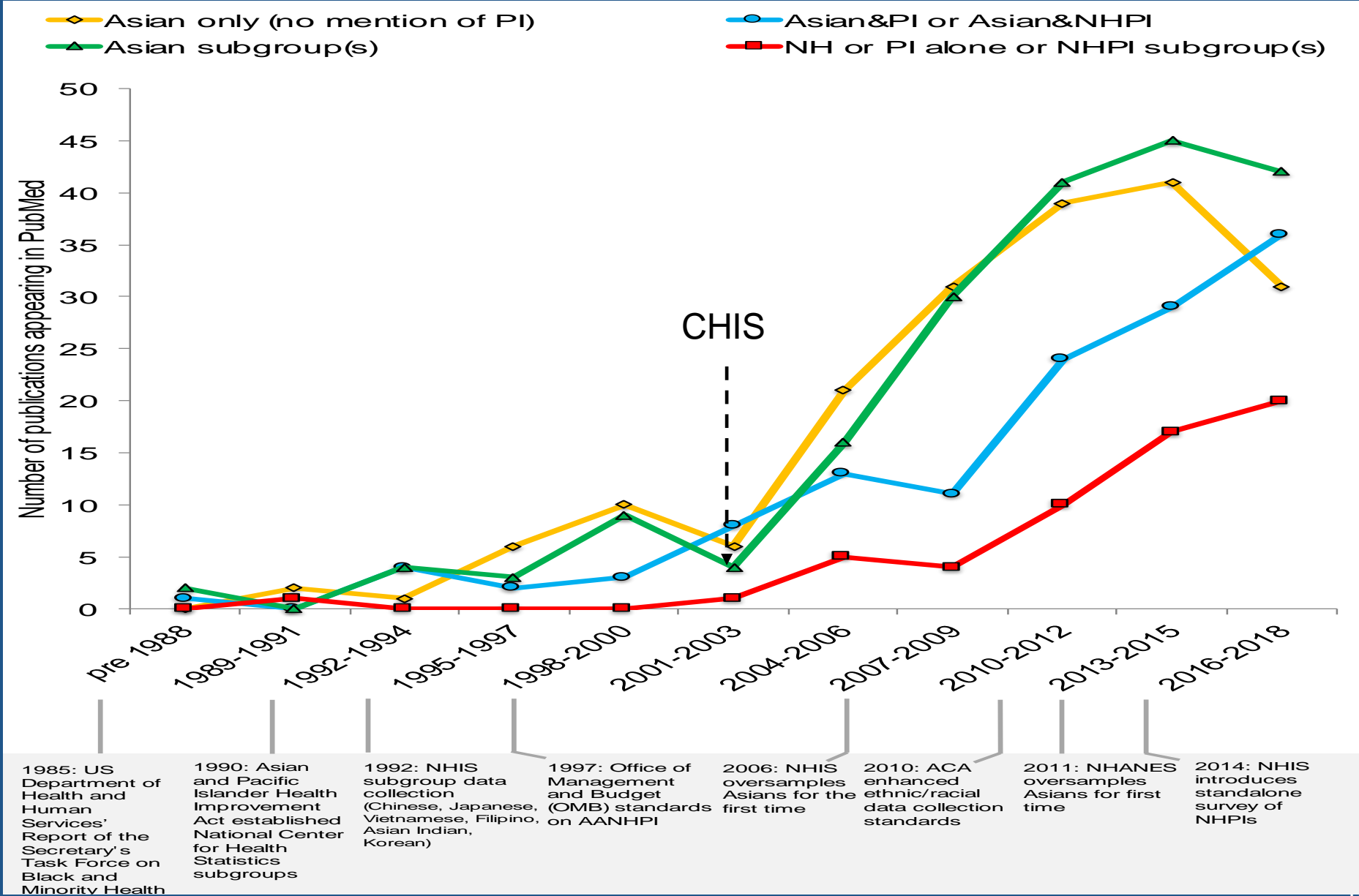
You said that you are: {INSERT MULTIPLE RESPONSES FROM AA5, AA5A, AA5E AND AA5E1}. Do you identify with any one race in particular?

- 1 Yes
- 2 No

Which do you most identify with?

You said Asian, and what specific ethnic group are you? *Check all that apply*

- 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: _____)



White and Black Origin Write-Ins and MENA

- In response to changes made to the 2020 U.S. Census form, the CHIS 2021 questionnaire added two questions to collect detailed origins for those who respond white or Black/African American to the race question
- The first 6 responses to each have been coded
- The adult Public Use File for CHIS 2021 contains new variables for **Middle Eastern or North African (MENA)**, **Black: Caribbean**, and **Black: Sub-Saharan African**, per Census definitions
- Research using the detailed origin data is possible using the Data Access Center

“What are your white origin or origins? For example, German, Irish, English, Italian, Armenian, Iranian, etc.

Specify: _____”

“What are your Black origin or origins? For example, African American, Nigerian, Ethiopian, Jamaican, Haitian, Ghanaian, etc.

Specify: _____”

Noteworthy Additions to CHIS 2021-2022: Adults

- Climate change, and related impacts on physical health, mental health, and finance^{1,2}
- Presence and storage of firearms in the home, concerns about firearm victimization^{1,2,3}
- CBD (cannabidiol) use^{1,2}
- Housing security/stability^{1,2}
- Encounters with police or court system^{1,2,3}
- Adverse childhood experiences (ACEs), positive childhood experiences^{1,2,3}
- Paid family leave^{1,2}
- Notice of action from Medi-Cal¹
- COVID-19 risk reduction practices^{1,2}

Reinstated content:

- Alcohol use, binge drinking^{1,2}
- Intimate partner violence^{2,3}
- Pre-diabetes/borderline diabetes^{1,2}
- Discrimination in a healthcare setting^{1,2}
- Length of residency^{1,2}

1. Available in Public Use Files (PUFs)
2. Available through AskCHIS™ (ask.chis.ucla.edu)
3. Confidential data only available through the Data Access Center (DAC).

Surveying Hate and its Impacts During the COVID-19 Pandemic Among Asian Americans and Native Hawaiians and Pacific Islanders

- Analysis of the 2020 California Health Interview Survey (CHIS) AANHPI COVID-19 Module
 - Association between experiencing and/or witnessing a hate incident and its association with serious psychological distress, forgone care and perceived neighborhood safety

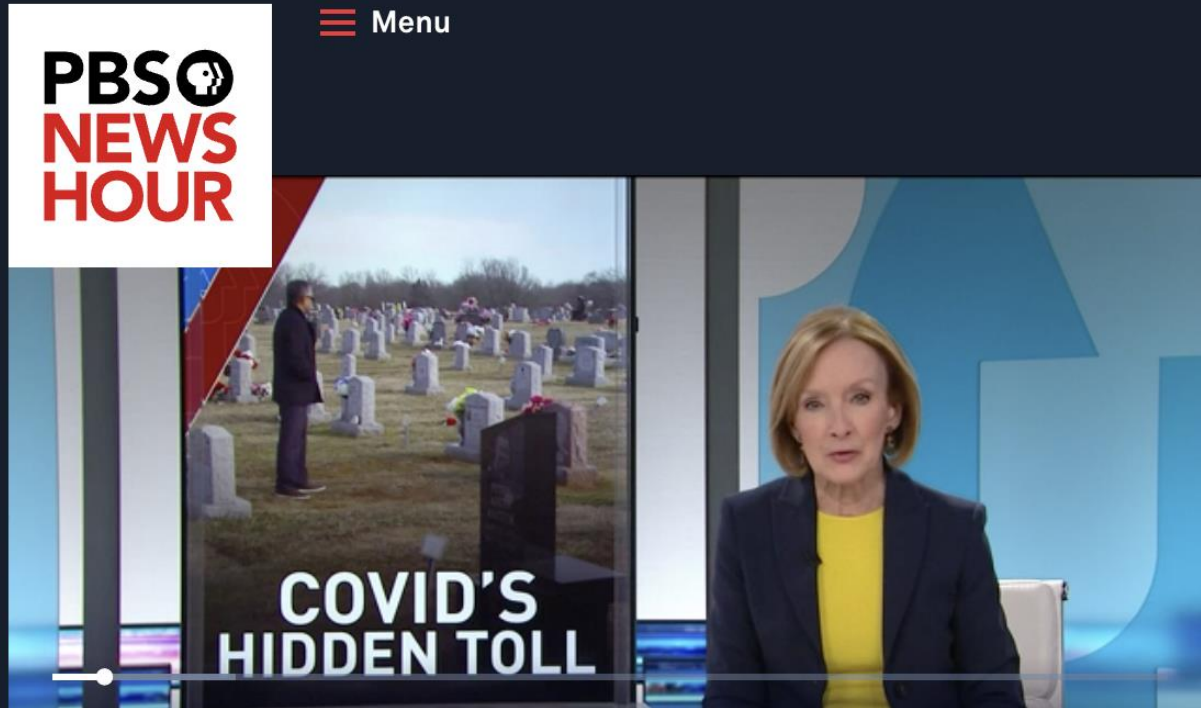


Source: Shimkhada R, Ponce NA. Surveying Hate and its Impacts During the COVID-19 Pandemic Among Asian Americans and Native Hawaiians and Pacific Islanders. AJPH, 2022

- Estimates of being a victim of a hate incident ranged from 6% to 30% among all surveys examined
- In CHIS, 28% experienced and/or witnessed a hate incident
- **Experiencing/witnessing a hate incident was significantly associated with serious psychological distress (AOR 5.33), forgoing care (AOR 2.27), and not feeling safe in one's neighborhood (AOR 2.70)**



Story #2 the NHPI Data Policy Lab @ UCLA CHPR



▶ Full Episodes || Podcasts ✉ Subscribe

Live

Inconsistent data masks the pandemic's toll on Native Hawaiians and Pacific Islanders

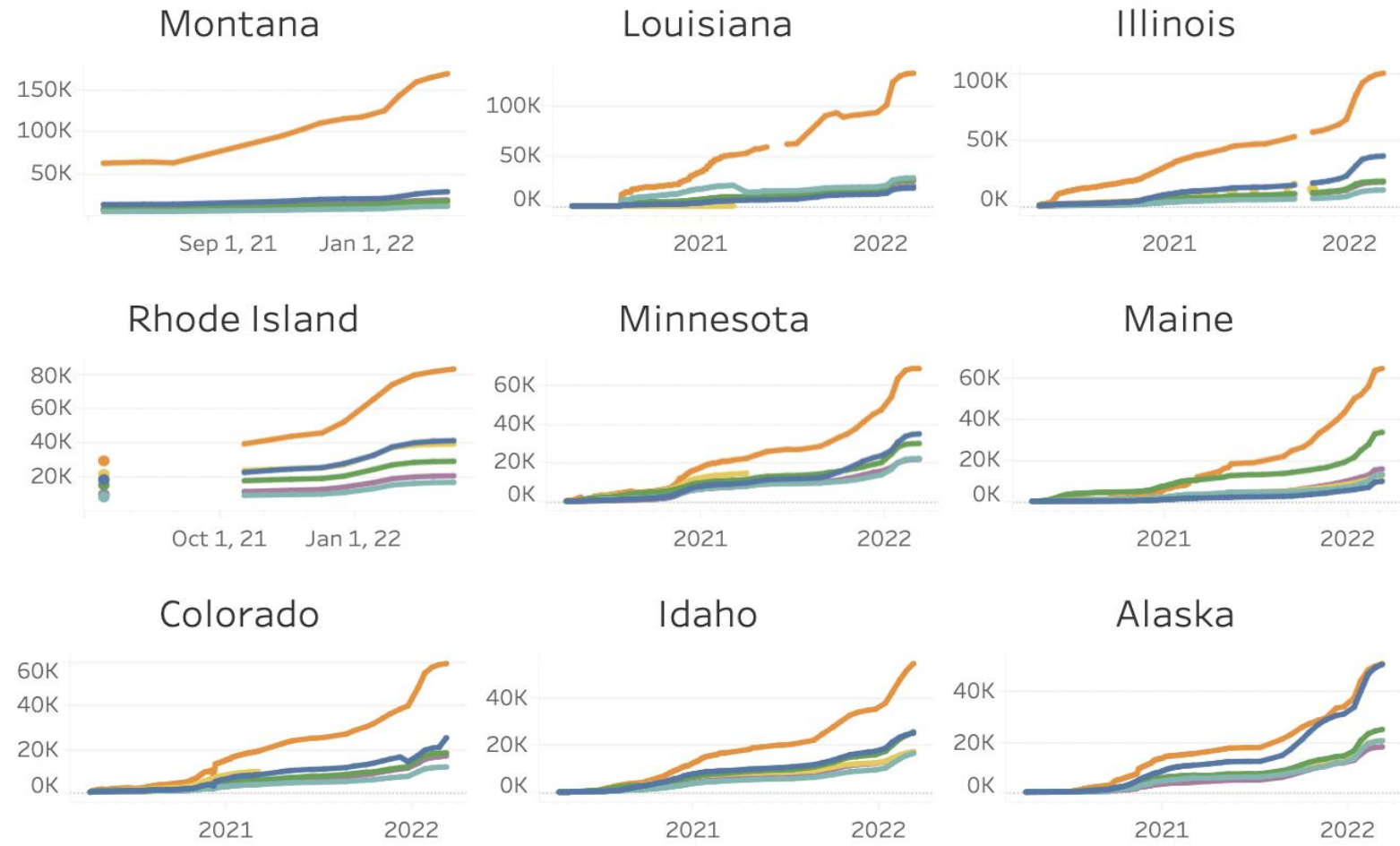
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Melisa Laelan could see the pain COVID was causing in her {Marshallese} community, but until they worked with Ponce's team at UCLA, they didn't have the data to prove the need.

U.S. NHPI COVID-19 Cases	U.S. NHPI COVID-19 Deaths	State NHPI COVID-19 Data	Top 9 States by NHPI Case Rate	Data Sources & Methodology
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Top 9 States Ranked by Case Rate per 100,000 by Race and Ethnicity



NHPI COVID-19 Dashboard

<https://healthpolicy.ucla.edu/health-profiles/Pages/NHPI-COVID-19-Dashboard.aspx>

Health Policy Fact Sheet

May 2021

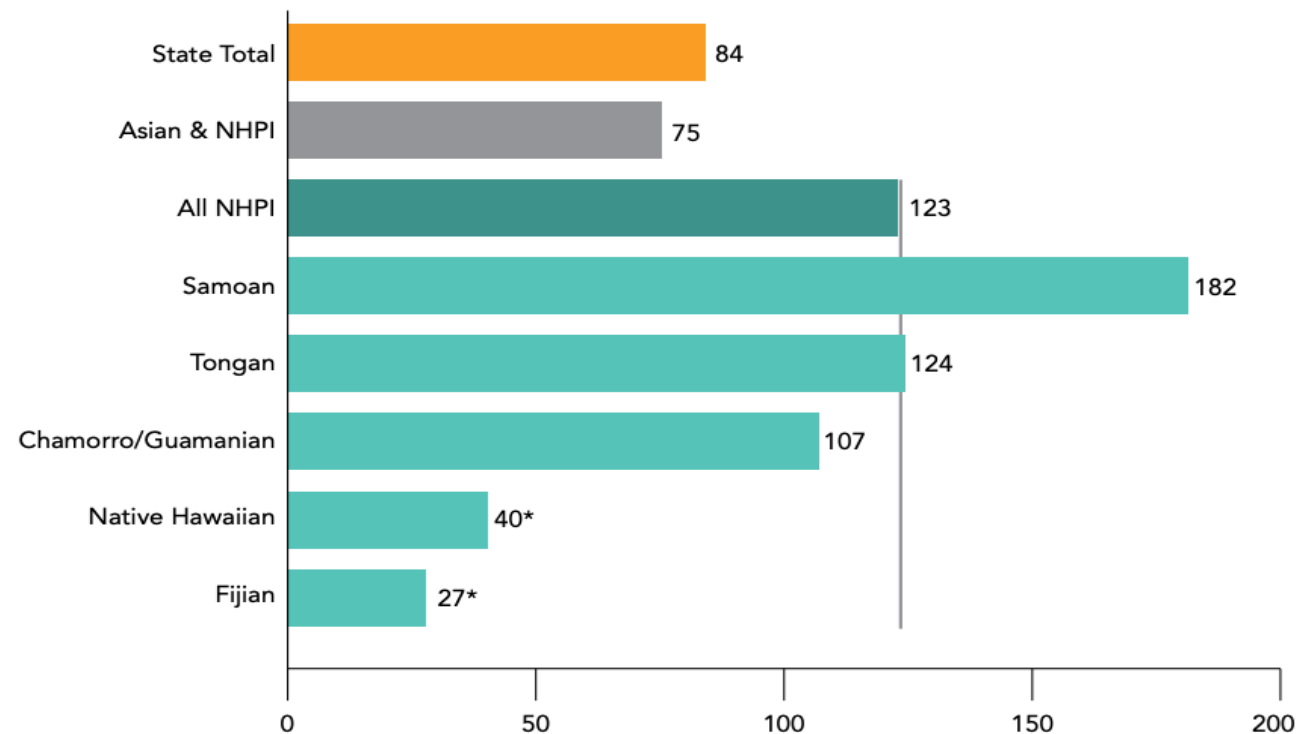
Disaggregating California's COVID-19 Data for Native Hawaiians and Pacific Islanders and Asians

Ninez A. Ponce, Riti Shimkhada, and 'Alisi Tulua

Exhibit 1

California COVID-19 Crude Mortality Rate (Deaths per 100,000) for Non-Latino Single-Race NHPIs, All Ages, Jan. 1, 2020–Dec. 31, 2020

“Death rates per 100,000 are higher for the Samoan subgroup compared to the aggregated NHPI category.”



* <11 deaths



Story #3 Filipinx/a/o Community Health Association

Is Surveillance Left to Memorials and Elegies?



HONOR, VISIBILITY & RECOGNITION

KANLUNGAN is intended to be a memorial to the transnational people of Philippine ancestry who make up a huge sector of the global healthcare system.

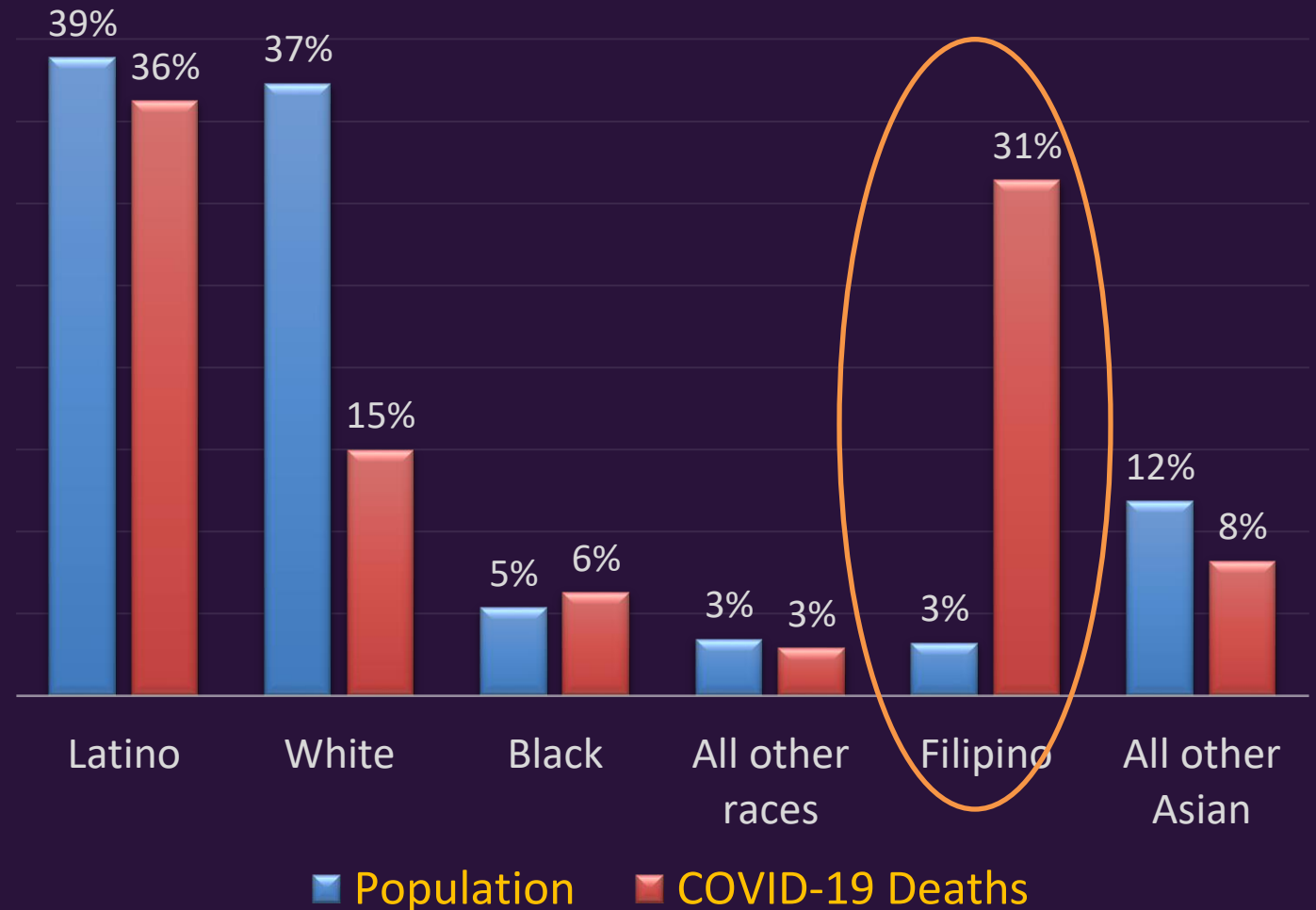
Visibility in Restricted Access Data

Filipinx Healthcare Workers are Disproportionately Affected by COVID-19

Filipinx make up 3% of population and 31% of COVID-19 Healthcare Workers Deaths

November 5, 2020 restricted data presented by Division of Communicable Disease Control, CDPH

Proportions of Population and COVID-19 Healthcare Worker Deaths, California 11.5.20



Community Engagement, Information Sharing-- Podcast



What keeps me going (and my topline Rx to do better)



Knowledge Production to Produce Data Equity for Health Equity

- Data infrastructure—CHIS
- Community-Academic Partnerships-NHPI Lab and Filipinx/a/o Community Health Association
- Technical Assistance and Pipeline Building

Recommendations from RWJF National Commission to Transform Public Health Data

- Changing how we tell stories about the health of people and communities so equity informs meaningful narrative change
- Prioritizing governance of our data infrastructure to put equity at the center
- Ensuring that public health measurement captures and addresses structural racism and other inequities



HONOR, VISIBILITY & RECOGNITION

KANLUNGAN is intended to be a memorial to the transnational people of Philippine ancestry who make up a huge sector of the global healthcare system.

Biden Administration's Equitable Data Working Group

- January 2021 executive order on advancing racial equity
- Formation of the Equitable Data Working Group
 - Co-chaired by representatives from Office of Science and Technology Policy and OMB
 - Key recommendations fall into large buckets in figure
- April 2022--Identified tasks in FY 2023 budget



The Future of Our Public Health Data System



Meaningful, Trustworthy and Accessible

- Democratize data
- Be community-driven

Intentionally include the communities you extract data from in the processes of collection, interpretation, and dissemination

Thank you and Q & A

CHPR Resources from today's slides:
healthpolicy@ucla.edu

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healthpolicy.ucla.edu/seminars

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