THE UCLA CENTER FOR HEALTH POLICY RESEARCH

Reflecting Your Population: Considerations for Data Collection and Processing

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Addressing Health Equity through Data Disaggregation
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Agenda – Overview

- Overview: What are the current strategies to ensure data represents the diversity of your population

  - Data collection

  - Racial/ethnic grouping

  - Classification & reporting

Agenda – Case Studies

1. How to choose?
   - Community engagement
   - Granularity
   - Survey languages
2. How to pay?
   - Funding/financing disaggregation efforts

Poll

- Census Regions and elsewhere?

Poll

- Predominantly Data Producer or Data Consumer?

Poll

- Type of organization

The 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.

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

There is no "multi-racial" category.

OMB Definitions for Race/Ethnicity Categories

- **American Indian or Alaska Native** - A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

- **Asian** - A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

- **Black or African American** - A person having origins in any of the black racial groups of Africa. Terms such as ''Haitian'' or ''Negro'' can be used in addition to ''Black or African American.''

- **Hispanic or Latino** - A person of Cuban, Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race. The term, ''Spanish origin,'' can be used in addition to ''Hispanic or Latino.'' ⬚ Native Hawaiian or Other Pacific Islander - A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

- **White** - A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

The OMB Directive 15, 1997

2-Question MINIMUM Format

Ethnicity

1. Hispanic or Latino
2. Not Hispanic or Latino

Race

1. American Indian or Alaska Native
2. Asian
3. Black or African American
4. Native Hawaiian or Other Pacific Islander
5. White

Can select one or more races

1-Question MINIMUM Combined Format ("When self-identification is not feasible or appropriate")

1. American Indian or Alaska Native
2. Asian
3. Black or African American
4. Hispanic or Latino
5. Native Hawaiian or Other Pacific Islander
6. White

Can select one or more races

The OMB Directive 15, 1997

Reporting

"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://racism.org/articles/race/what-is-race/274-race0601

"The categories should set forth a minimum standard; additional categories should be permitted provided they can be aggregated to the standard categories. The number of standard categories should be kept to a manageable size, as determined by statistical concerns and data needs."

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

Poll

- Of the OMB categories, which one is most important to your work to increase disaggregation?

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

- How to collect granular ethnicity?
- How to to collect language at home and level of English proficiency?
- How to collect country of birth, parent's country of birth if known?
- How to democratize the data!

Census 2020

→ **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

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

'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 specfied)
- ○ 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

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

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

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

Resources for Collection and Processing

- OMB Directive 15: https://www.govinfo.gov/content/pkg/FR-1997-10-30/pdf/97-28653.pdf
- IOM. Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement Report, 2009: underused, but guidebook on collection of race/ethnicity, and language AND includes guide on rollup: https://www.nap.edu/read/12696/

- ACA Section 4302: https://minorityhealth.hhs.gov/assets/pdf/checked/1/Fact_Sheet_Section_4302.pdf
- National Network of Health Surveys: https://healthsurveynetwork.org

IOM 2009 Report on Rollup

https://www.nap.edu/read/12696/chapter/13#185. Page 185

- The CDC/HL7 Code Set, Massachusetts Superset, Census Ancestry Code List, and Kaiser Permanente Granular Ethnicity Code Set interchangeably use country or place names to indicate ethnicities (i.e., Singapore to represent Singaporean). The subcommittee revised the list to represent categories with ethnicities as opposed to places, whenever possible; this is reflected in the subcommittee's template (Table E-1).

- The CDC/HL7 Code Set includes an extensive list of American Indian or Alaska Native categories and codes. Thus, the CDC/HL7 Code Set may serve as the template from which entities can choose locally relevant tribal categories and codes. The Census Ancestry Code list does not include American Indian or Alaska Native tribes. The Massachusetts Superset and the Kaiser Permanente Granular Ethnicity Code Set both include limited lists of locally relevant tribes.

ACA Section 4302

http://aspe.hhs.gov/datacncl/standards/ACA/4302

- Section 4302 requires the Secretary of DHHS to establish data collection standards for race, ethnicity, sex, primary language, and disability status. The law requires that, once established, these data collection standards be used, to the extent practicable, in all national population health surveys. In response to this statutory requirement, this implementation guidance outlines the new minimum data collection standards for race, ethnicity, sex, primary language and disability status for implementation in HHS, along with a description of the data standards development process, the rationale for each data standard, and instructions for their implementation.

ACA Section 4302: Race

http://aspe.hhs.gov/datacncl/standards/ACA/4302

Ethnicity Data StandardAre you Hispanic, Latino/a,or Spanish Origin?(One or more categories may be selected)	
Categories	Notes
a. _____ No, not of Hispanic, Latino/a, or Spanish origin	These categories roll-up to the Hispanic or Latino category of the OMB standard
b. _____ Yes, Mexican, Mexican American, Chicano/a	
c. _____ Yes, Puerto Rican	
d. _____ Yes, Cuban	
e. _____ Yes, Another Hispanic, Latino/a or Spanish origin	

Race Data StandardWhat is your race?(One or more categories may be selected)	
Categories	Notes
a. _____ White	These are part of the current OMB standard
b. _____ Black or African American	
c. _____ American Indian or Alaska Native	
d. _____ Asian Indian	These categories roll-up to the Asian category of the OMB standard
e. _____ Chinese	
f. _____ Filipino	
g. _____ Japanese	
h. _____ Korean	
i. _____ Vietnamese	
j. _____ Other Asian	
k. _____ Native Hawaiian	These categories roll-up to the Native Hawaiian or Other Pacific Islander category of the OMB standard
l. _____ Guamanian or Chamorro	
m. _____ Samoan	
n. _____ Other Pacific Islander	

ACA Section 4302: Language

http://aspe.hhs.gov/datacncl/standards/ACA/4302

▪ PRIMARY LANGUAGE

The standard for primary language is a measure of English proficiency. The recommended question is based on that used on the ACS. The question applies to survey participants aged five years and above.

DATA STANDARD FOR PRIMARY LANGUAGE

How well do you speak English? (5 years old or older) a. ____Very well b. ____Well c. ____Not well d. ____Not at all

Optional Granularity

1. Do you speak a language other than English at home? (5 years old or older) a. ____ Yes b. ____ No

For persons speaking a language other than English (answering yes to the question above):

2. What is this language? (5 years old or older) a. ____Spanish b. ____Other Language (Identify)

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

Challenges to Data Disaggregation

- <u>How do we pay for this?</u>

- 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?

- <u>Why is it important? Role of advocates, data equity champions</u>

Case Study: Community Engagement

Learning Objectives:

-What and who should help lead decision-making?

-Example of NHPI & COVID-19

Example - 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"

Why Race matters for COVID-19

Susceptibility

- *Race/Ethnicity/Language/Literacy*
  - *Age*
  - *Employment, Income, and Food Insecurity*
  - *Gender*
  - *Immigration status*
  - *Sexual Orientation and Gender Identity*
  - *Urban Space/Density*

Infectious

- *Race/Ethnicity/Language/Literacy*
  - *Housing and household composition—density, multigenerational households*
  - *Essential work occupations*
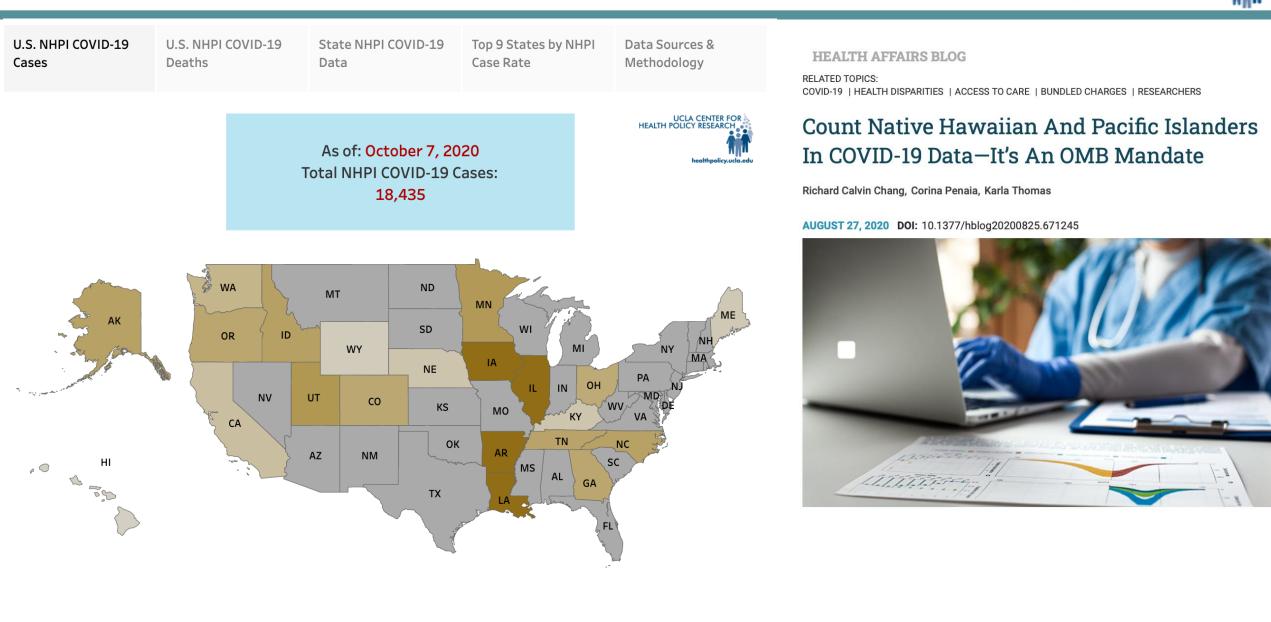 - *Cultural gatherings*

Hospitalized/Recovered/Death

- *Race/Ethnicity/Language/Literacy*
  - *All of the above → access to care, navigation, communication, unfair treatment, stigma*

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

As of: October 7, 2020
Total NHPI COVID-19 Cases:
18,435

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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

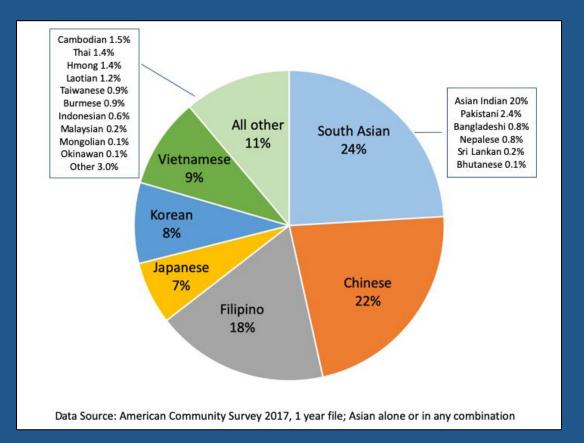**COVID-19 Testing site Race/Ethnicity Reporting**

Poll

- Does your organization explicitly put health equity as a health data objective?

Case Study: Granularity of Categories

Learning Objectives:

-How to decide which groups to disaggregate?

-Example of AI/AN Tribal Affiliation

How Small Can You Report and Represent?

- Population survey relies heavily on the size of population
- Special race/ethnic group surveys may focus on specific groups
  - E.g. South Asian community needs assessment in NYC, special look at taxi drivers
- Community engagement & advocacy

Cambodian 1.5%
Thai 1.4%
Hmong 1.4%
Laotian 1.2%
Taiwanese 0.9%
Burmese 0.9%
Indonesian 0.6%
Malaysian 0.2%
Mongolian 0.1%
Okinawan 0.1%
Other 3.0%

All other 11%

South Asian 24%

Asian Indian 20%
Pakistani 2.4%
Bangladeshi 0.8%
Nepalese 0.8%
Sri Lankan 0.2%
Bhutanese 0.1%

Vietnamese 9%

Korean 8%

Japanese 7%

Filipino 18%

Chinese 22%

Data Source: American Community Survey 2017, 1 year file; Asian alone or in any combination

Example - Collection of Tribal Affiliation AI/AN in CHIS

- If respondent reports American Indian/Alaska Native race
- Tribal affiliation:
  - What is your tribal heritage? If you have more than one, tell me all of them.
    - Apache
    - Blackfoot/Blackfeet
    - Cherokee
    - Choctaw
    - Mexican American Indian
    - Navajo
    - Pomo
    - Pueblo
    - Sioux
    - Yaqui
    - Other tribe

Case Study: Survey Languages

Learning Objectives:

-How to decide what languages to use for survey administration?

-Example of language selection in CHIS

Poll

- Which languages do you currently conduct your surveys in (other than English)?

Survey Language Choice

- Size of population

- Linguistic isolation

- Community engagement & advocacy

Source: USC, Neighborhood Data for Social Change. "In Los Angeles, Linguistic Isolation is Still a Challenge" February 26, 2019.

Example – Survey Language Selection in CHIS

- To capture the diversity of the California population, interviews conducted in 6 languages: English, Spanish, Chinese (Mandarin and Cantonese dialects), Vietnamese, Korean, and Tagalog

- Flexibility and decision-making considerations made before each survey cycle

- What if so few people take the survey in a language—when do you "retire" a language to make room for another language?

Poll

- If you are a data producer, which types of funders are your investors?

Case Study: Who Pays?

Learning Objectives:

-Where you might find funding for disaggregation

-Example of various funding streams used in CHIS

Paying for Disaggregation Efforts

- Foundation Grants

- Survey Stakeholders

- Departments of Public Health

- Medicaid Program Match

Example – Funding for Disaggregation in CHIS

- Counties have asked to oversample groups
  - SF Dept of Public Health – focus on Latinx, Chinese, and Black communities in SF
- AIAN oversamples - funded by CRIHB/CDC, Indian Health Services
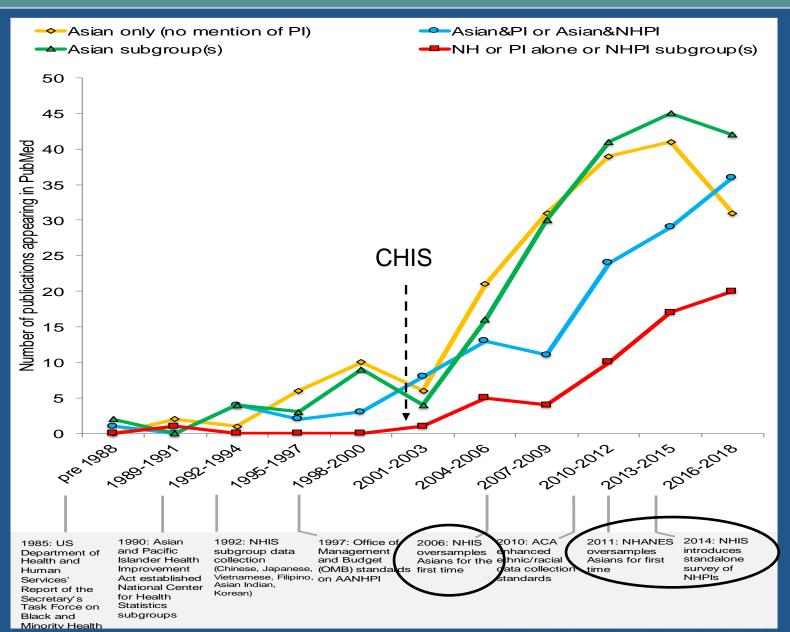- Korean and Vietnamese language and oversamples – CHIS funded

Poll

- Do you live in a state (or county) that mandates racial/ethnic data disaggregation for some or all of the 5 OMB major race categories and the Hispanic/Latinx ethnicity category?

Importance of Policy and Guidance on Disaggregation Practices

- Guidelines are necessary <u>but not sufficient</u>
- Federal or state mandates on uniform reporting across agencies needed—AB1726—the AHEAD ACT
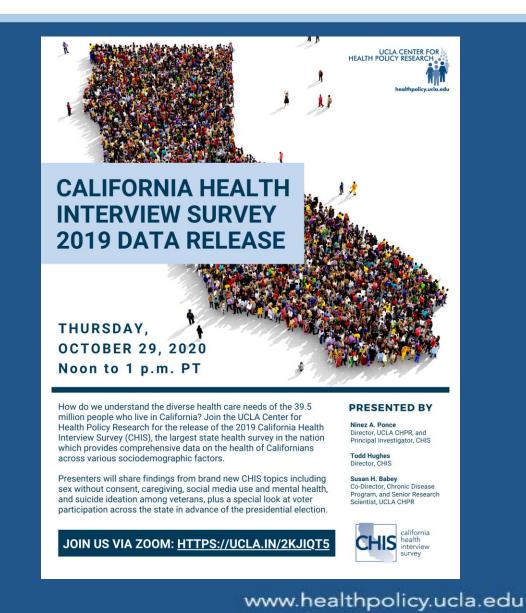- Research community resources and better <u>datasets</u> spur studies

The Data Disaggregation Imperative

- 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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(dashboards and data)

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