Race/ethnicity data disaggregation for advancing research and patient-centered practice

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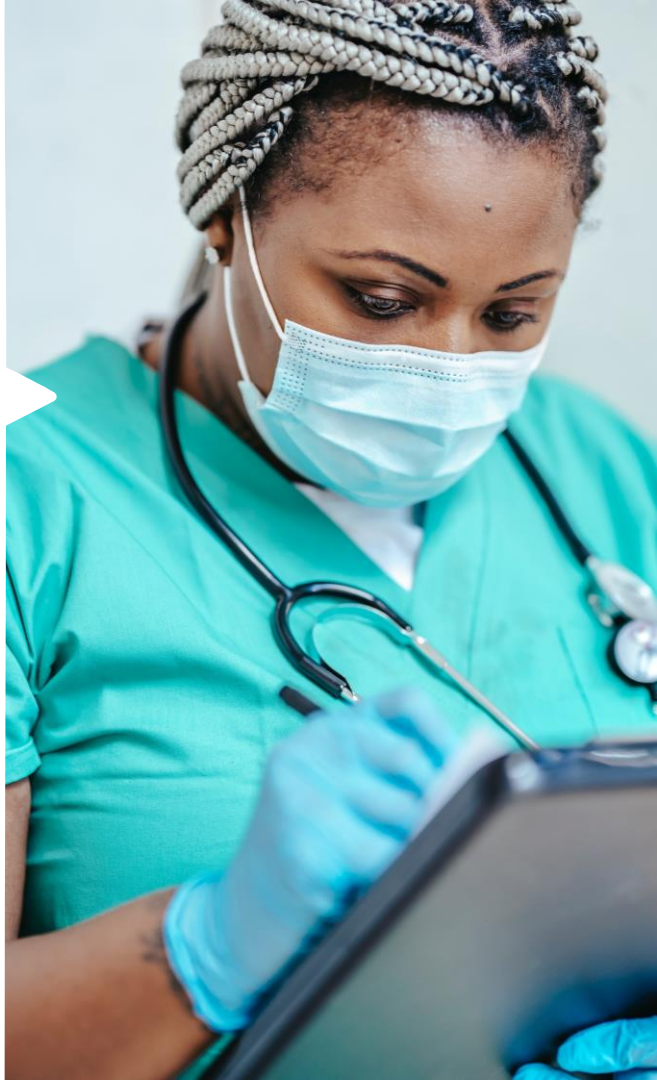

Learning objectives

- To describe the purpose of race/ethnicity data disaggregation and describe differences between disaggregated data and current federal standards
- To summarize research evidence currently motivating race/ethnicity disaggregation implementation in healthcare
- To identify the recommended methods currently used to analyze and interpret disaggregated race/ethnicity data with a health equity lens
- To understand the patient perspective on collecting and reporting granular race/ethnicity in healthcare settings

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1. Why disaggregate?

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OMB federal reporting: who is missing?

- Ethnic Categories
  - **Hispanic or Latino -** a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race
- Racial Categories
  - **White** – A person having origins in any of the original peoples of Europe, the Middle East, or North Africa
  - **Black or African American** – A person having origins in any of the Black racial groups of Africa
  - **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
  - **Native Hawaiian or Other Pacific Islander** – A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands

OMB federal reporting: what's wrong with the standard?

- **On race:**
  - Race is socially constructed and has no biological basis
  - Arbitrarily defined under OMB (geography, physical features, ethnocultural features?).
  - Disconnect between self-identity and the categories provided

  OMB standards result in:
  - Group homogenization
  - Systematic, nonrandom exclusion of people of color and English language-limited groups from 1) data collection and 2) data reporting (suppression)

- "Some Other Race" is the 3rd largest race group in the U.S.!

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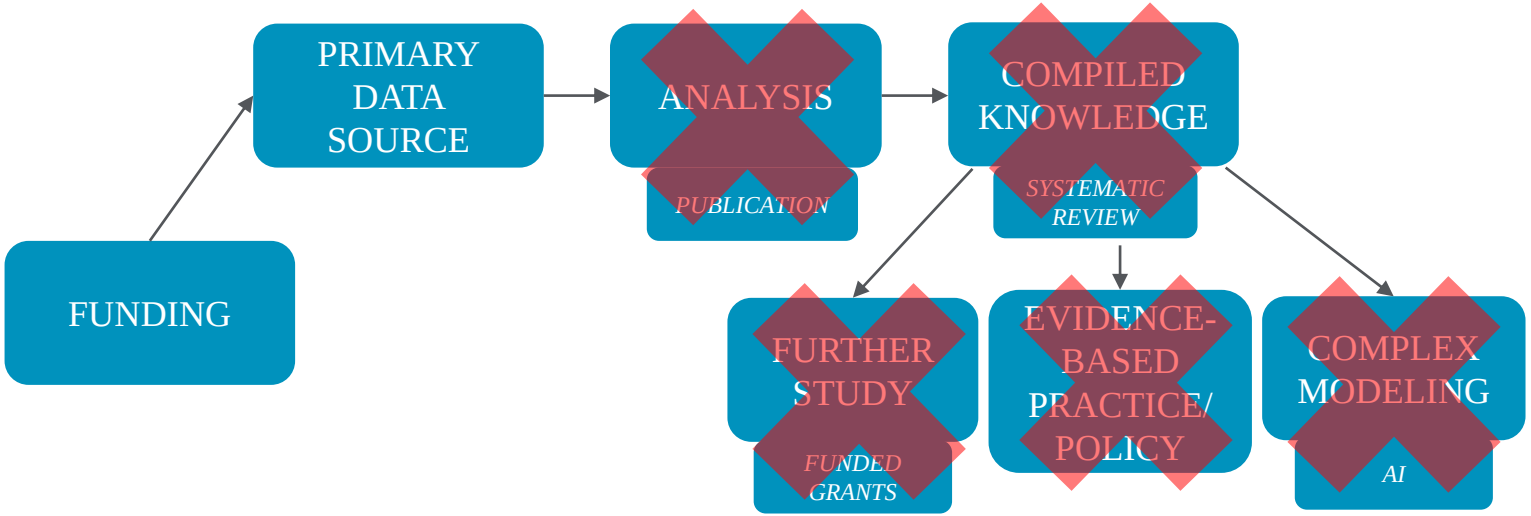
OMB federal reporting: what is the effect?

Data collection is an important starting point to planning, resource allocation, and policymaking



Race/ethnicity misunderstandings lead to medical bias

- A large study of medical education finds that health professionals often discuss race as a biological category rather than a social construct
- Impact: race-based diagnostic bias, race-based clinical guidelines, pathologizing race rather than the true cause of disease

The NEW ENGLAND JOURNAL of MEDICINE

Source: https://www.nejm.org/doi/full/10.1056/NEJMms2025768?query=featured_home

MEDICINE AND SOCIETY

Misrepresenting Race — The Role of Medical Schools in Propagating Physician Bias

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Race/ethnicity data disaggregation

- Definition (from Minnesota Compass)
  - *"Data disaggregation" means splitting large, general categories into more specific groups*
  - *When we are talking about race data disaggregation, for example, Asian Americans can be divided into cultural groups such as Hmong, Vietnamese, Lao, Chinese, Korean, etc.*
- Why disaggregate?
  - Uncover within-group health disparities
    - Patient-centered care
    - Equitable resource allocation
  - Provide more inclusive, locally-relevant response options to choose from
    - Self-identification = gold standard
    - Reduce non-response

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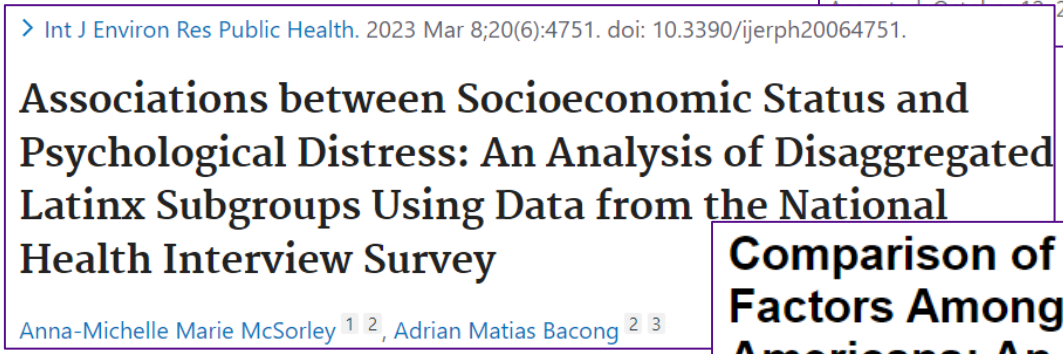
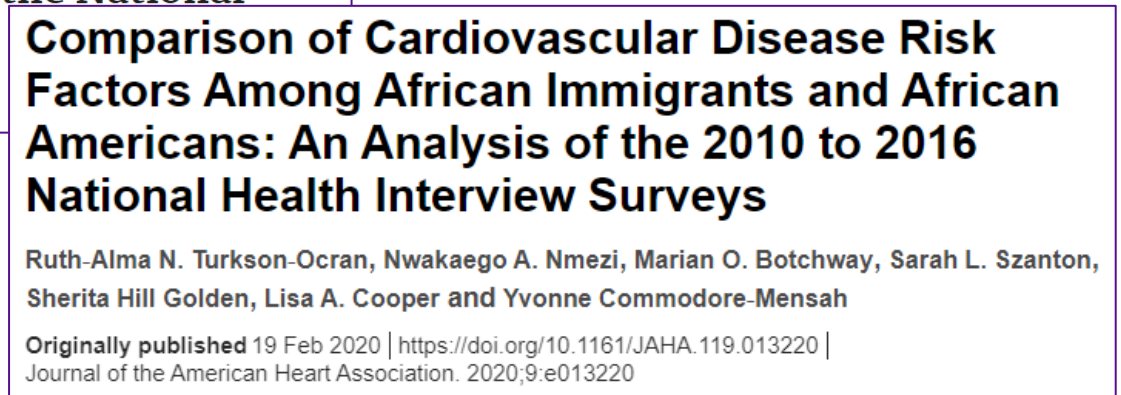

Int J Environ Res Public Health. 2023 Mar 8;20(6):4751. doi: 10.3390/ijerph20064751.
Associations between Socioeconomic Status and Psychological Distress: An Analysis of Disaggregated Latinx Subgroups Using Data from the National Health Interview Survey
Anna-Michelle Marie McSorley [1] [2], Adrian Matias Bacong [2] [3]


Comparison of Cardiovascular Disease Risk Factors Among African Immigrants and African Americans: An Analysis of the 2010 to 2016 National Health Interview Surveys
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Originally published 19 Feb 2020 | https://doi.org/10.1161/JAHA.119.013220 | Journal of the American Heart Association. 2020;9:e013220

2. Implementation barriers

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Logistics of collecting disaggregated race

- Potential costs associated with granular data collection in EMR
- Determining response categories
- Added administrative burden on staff performing data entry & staff training needs
- Data comparability across reporting facilities & over time
- Best practices → more complex data
  - Free text response options
  - Multiracial reporting, especially for those with 2+ identities

Terminological consensus? - MENA case example

Michigan

- Detroit Metro Area contains largest concentration of Arab Americans in U.S.
- Arab Community Center for Economic and Social Services leads local and national advocacy for inclusive data collection
- Michigan Department of Health:
  - 'Arab' ethnicity category added for select health data (e.g. COVID-19 testing)
  - Allows Arabs to select both race and ethnicity, like Hispanic/Latino group

Illinois

- Arab American Family Center of Chicago noticed COVID-19 disparities among city's Arab community
- Joined forces with local media outlets to place political pressure
- 'MENA' category in Illinois DPH
  - Considered 'race' not ethnicity
  - Limited to COVID-19 vaccination data

What is the MENA region? Who are MENA Americans?

MENA? SWANA? Arab?

- Terminology is contested, not always accurate
- Middle East & North Africa / Southwest Asia & North Africa is multilingual, multiracial, multiethnic, multicultural, multireligious, etc.

To disaggregate or not to disaggregate?

- Consider population sizes for representativeness and disclosure avoidance

Afghan	Algerian	Armenian	Assyrian/ Chaldean	Amazigh/ Imazigh	Azerbaijani	Bahraini
Circassian	Coptic	Djiboutian	Egyptian	Emirati	Georgian	Iranian/ Persian
Iraqi	Jordanian	Kurdish	Kuwaiti	Lebanese	Libyan	Mauritanian
Mizrahi/ Sephardic Jewish	Moroccan	Nubian	Omani	Palestinian	Syrian	Tunisian
Turkish	Yemeni	Qatari	Saudi	Somali	Sudanese	Another SWANA group

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(non-random) nonresponse & disclosure avoidance

- Privacy and surveillance concerns, more likely to affect historically oppressed and surveilled groups
- Small groups may need to be suppressed or re-aggregated in data reports
- Collection of specific race/ethnicity also requires tightening of privacy/confidentially procedures → increased risk of disclosure when combined with other identifiers

“Pathologization” of race is still a concern

Stratification of detailed race/ethnicity without context can lead to misinterpretations:

- Downplay the role of structural inequities in favor of individual behavior
- Perpetuate theories of biological inferiority
- Vilify cultural norms

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3. Overcoming barriers

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Shared decision-making

- Community/patient consultation at all steps of the data pathway:
  - Collection (e.g. deciding race/ethnicity categories)
  - Analysis (e.g. guidance on free text responses or re-coding)
  - Reporting (e.g. provide drafts of reports to make sure data interpretations are sound)
- Models of community collaboration
  - Patient advisory boards, community focus groups, surveys public forums, etc.
- Methods require cross-sector capacity building
- Frequent engagement as public perceptions and policies change

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Addressing patient concerns

- Healthcare personnel training
  - Dialogue-based learning maximizes buy-in from staff
  - Set clear procedures for staff collecting race/ethnicity; do not select based on observation & ensure self reporting
  - Scripts & patient response matrices available from American Hospital Association to help staff address patient questions, concerns, and unclear answers → see Resources

Patient Response Matrix - Routine

Patient Response	Suggested Response	Hints	Code
"I'm American."	Would you like to use an additional term, or would you like me to just put American?		American or others if specified
"Can't you tell by looking at me?"	Well, usually I can. But sometimes I'm wrong, so we think it is better to let people tell us. I don't want to put in the wrong answer. I'm trained not to make any assumptions.		
If using open-ended option: "I don't know. What are the responses?	You can say White, Black or African American, Latino or Hispanic, Asian, American Indian or Alaska Native, Pacific Islander or Native Hawaiian, some other race, or any combination of these. You can also use more specific terms like Irish, Jamaican, Mexican		
"I was born in Nigeria, but I've really lived here all my life. What should I say?"	That is really up to you. You can use any term you like. It is fine to say that you are Nigerian.	*It's best not to ask for this information again.*	

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Analytical support

- Small sample sizes
  - Restrict access to data to certain researchers
  - Suppress and aggregate data from small population as standard practice
  - Release only limited data
- Free text responses
  - Open-ended responses recommended by RWJF, IOM, UCLA, others
  - Use automated coding procedures for large volumes of free text (e.g. matching strings, NLP)
  - Manual coding for smaller samples
- Multiple selection
  - Multiracial populations the most rapidly growing group in the U.S.
  - Consider survey format (check box vs. radio dial) and write-in options
  - Tabulation and statistical guidelines exist; can model after U.S. Census Bureau

Data reporting: asset vs. deficit framing

- Avoid harmful statistical comparisons
  - Ex: "Teen pregnancy in White populations is X times lower than in Hispanic/Latino populations"
- Highlight positive health outcomes and suggest solutions that place onus on healthcare system
- Contextualize results – foreground structural inequities that lead to disparities over time
- Make feedback requests from orgs with cultural expertise a standard practice

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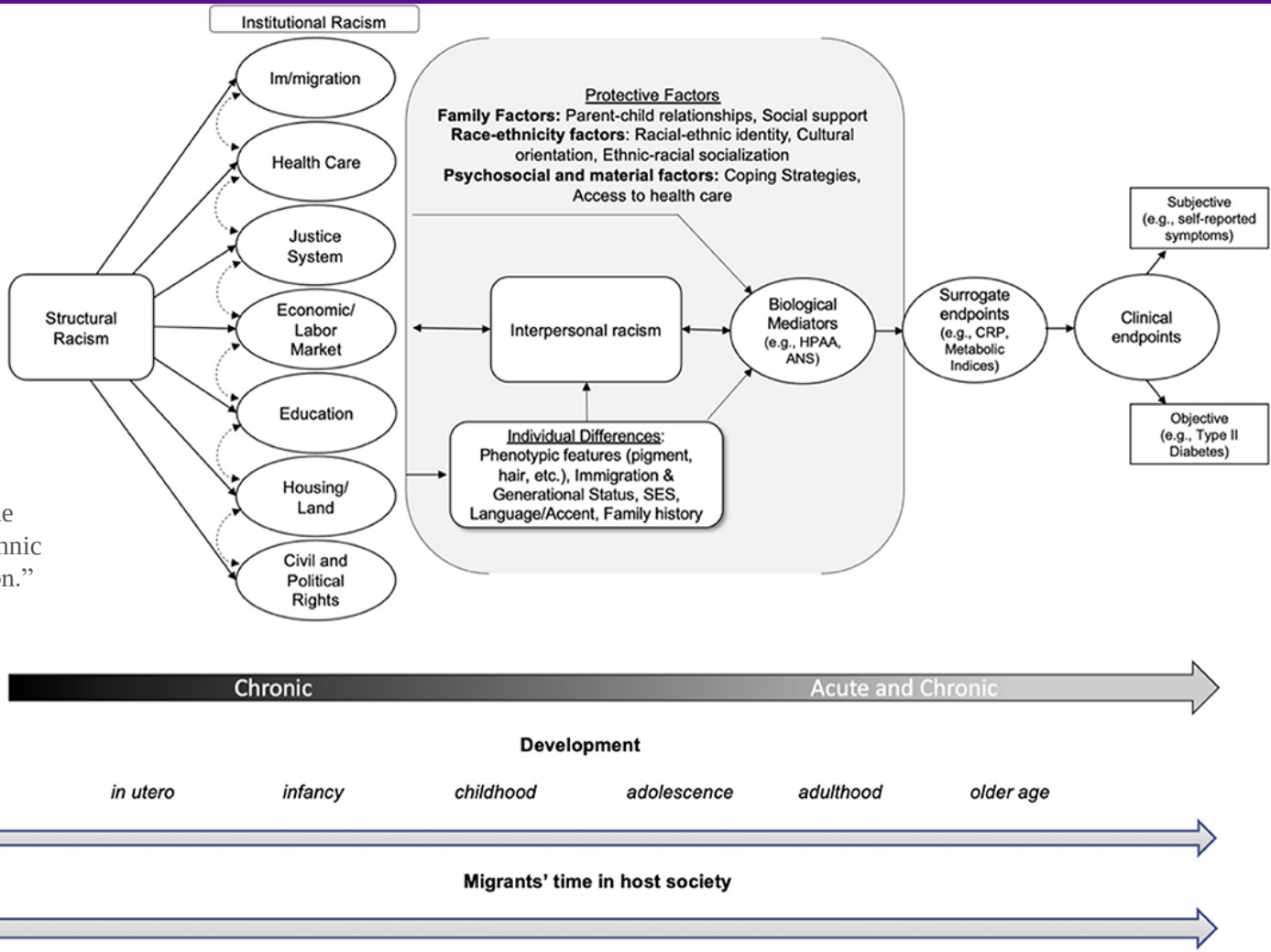
Contextualizing disparities



Martinez et al. "The Importance of Biobehavioral Research to Examine the Physiological Effects of Racial and Ethnic Discrimination in the Latinx Population." Front. Public Health, 2021.

Breakout activity: personal identity and experience

- How easy or hard is it for you to choose a response to closed-ended questions about your race and ethnicity? For example, when a form has a set of check boxes for you to pick from, do you feel the responses match your self-identity?
- What do you do if you see race and ethnicity options listed and none of them match your identity (e.g., check a box that doesn't fully represent you, write in your answer, skip the question altogether)?
- Do you feel more, less, or the same amount of comfort disclosing your race/ethnicity in a healthcare context?

Do not feel obligated to share more than you are comfortable with!

4. Focus group findings

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Methods

Race/ethnic category	Number of focus groups
Asian	2
African American/Black	2
Latine	2
Middle Eastern/North African (MENA)	2
Multiracial/Multiethnic	2
Native Hawaiian/Pacific Islander (NH/PI)	1
White	2
Total	**13**
Race/Ethnic Category	**Number of key informant interviews**
American Indian/Alaska Native (AI/AN)	1

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Methods continued

- Questions focused on:
  - perceptions of racial/ethnic categories
  - preferences for reporting race and ethnicity across settings
  - recommendations for improving racial/ethnic categories
  - recommendations about health information communication

Set 1: OMB Standard Question

Question 1: Are you of Hispanic, Latino or Spanish origin?

- ☐ Yes
- ☐ No
- ☐ Prefer not to answer

Question 2: What is your race? Select one or more.

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White
- ☐ Some other race, please specify: _____
- ☐ Prefer not to answer

Set 2: Updated Race and Ethnicity Question

Question 1: What is your race or ethnic origin (check all that apply)?

- ☐ White
- ☐ Hispanic, Latino, or Spanish origin
- ☐ Black
- ☐ Middle Eastern or North African
- ☐ Native Hawaiian or Pacific Islander
- ☐ Asian
- ☐ American Indian, Native, First Nations, Indigenous Peoples of the Americas, or Alaska Native
- ☐ Some other Race or Origin: _____
- ☐ Don't know
- ☐ Prefer not to answer

Follow up questions for each race and ethnicity listed in set 2 question 1:

Question 2: Since "American Indian, Native, First Nations, Indigenous Peoples of the Americas, or Alaska Native" was selected, which group best represents your origin or ancestry (check all that apply)?

- ☐ Blackfeet
- ☐ Cherokee
- ☐ Choctaw
- ☐ Iroquois or Haudenosaunee
- ☐ Sioux
- ☐ Central American Indian (For example, Mayan-K'iche', Mam, Yucatan, Garifunas, among others)
- ☐ Mexican American Indian (For example, Mixteco, Nahua, Otomi, Tlapaneco, among others)
- ☐ Southern American Indian (For example, Quechua, Kichwa, Shuar, Aymara, among others)
- ☐ Other: _____
- ☐ Don't know
- ☐ Prefer not to answer

Question 2: Since "Asian" was selected, which group best represents your origin or ancestry (check all that apply)?

- ☐ Asian Indian
- ☐ Chinese
- ☐ Filipino
- ☐ Guyanese
- ☐ Japanese
- ☐ Korean
- ☐ Nepali
- ☐ Taiwanese
- ☐ Thai
- ☐ Vietnamese
- ☐ Other: _____
- ☐ Don't know
- ☐ Prefer not to answer

Findings: How people identify

- Participants described themselves in many different ways

When I'm speaking to someone of the same race and ethnicity, I try to diversify and tell you details of my origin; where I come from, if I'm from the Caribbean, if I'm from Africa, what country I was from in Africa, where my roots are from, where my dad was from, and how I got to the United States. (Focus group 2, Black)

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Findings: Identifying in health-related contexts

- Participants expressed positive views on the collection of race and ethnicity information in health-related contexts

If I'm at a doctor's clinic or in a hospital, I'm really comfortable with expressing my identity because this is actually gonna help them treat me. Because certain ethnicities have tendencies to develop diabetes, hypertension, or so on. So, expressing your ethnicity or nationality might even get you a better treatment. (Focus group 11, MENA)

Findings: Survey question recommendations

- Simple question stems
- Limited number of answer categories that do not appear arbitrary

The list of countries do seem a little random to me. I can't tell if it's based on population size – it's definitely not based on population size if it's excluding Pakistan. So, it just seems strange to me that these were the countries represented here. (Focus group 7, Asian)

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Findings: Survey question recommendations

- Race and ethnicity should be combined into one question
  - Latine identity should not be the focus of a separate question

I don't really get why that's everywhere, that, "Are you Hispanic or Latino?" How is that so different from being Black, Middle Eastern, or Asian? I've never quite understood that. I don't think that it is. (Focus group 1, Black)

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Findings: Survey question recommendations

- Provide an opportunity to choose more than one answer category and write in additional details

On a lot of forms, it's annoying that it doesn't have biracial or multiracial options. But it'll say Hispanic, not Black. So, it forces me to choose between Hispanic or Black…. A lot of the options, "African American" or it might say "Black," and then the other options are "White" and "Hispanic" with "not Black" in parenthesis. So, I have to choose from "Hispanic" or "Hispanic" with "not Black" in parenthesis. (Focus group 9, Multiracial/Multiethnic)

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Findings: Survey question recommendations

- Provide information about why race and ethnicity is collected and how it will be used

I think that if you're telling us why you need that information, we're going to be a little bit more understanding as to why you need it and why we should provide it to you. So, convince me, pretty much, why you need my info. (Focus group 8, Latine)

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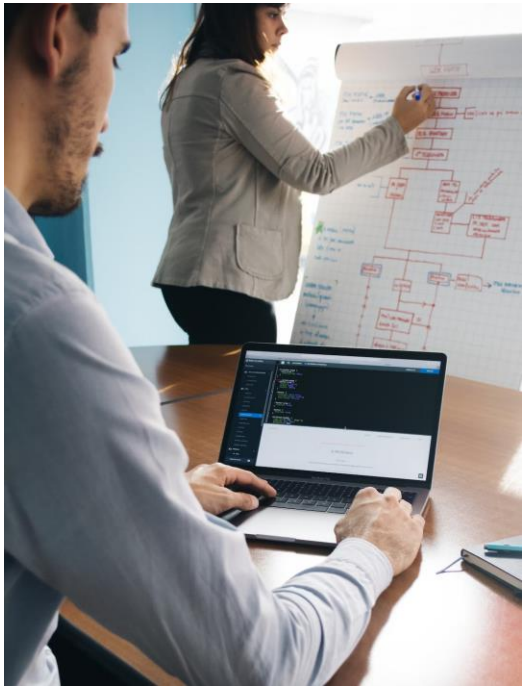
Key takeaways: focus group findings

- People described themselves in different ways across and within race and ethnic groups
- Opinions regarding how questions about race and ethnicity should be asked varied; however, there were consistent recommendations across groups
- Largely positive views about collecting race and ethnicity information in a health-related context!

Key takeaways: disaggregation implementation

- There is no one-size-fits all approach
- Many best practices have been tested and evaluated already – however, practice case examples are limited and constantly under development
- Health departments and healthcare organizations must consider local:
  - population demographics
  - data system specifications
  - self-described community needs and concerns
- Racial formation is socially constructed and constantly change; therefore, updated data practices should find the balance between comparability and adaptability



Recommended resources

Kader et al. Disaggregating Race/Ethnicity Data Categories: Criticisms, Dangers, And Opposing Viewpoints. Health Affairs, 2022.

NYAM: Findings from community focus groups.

NYU Center for the Study of Asian American Health and Coalition for Asian American Children and Families Data Disaggregation Toolkits

PolicyLink: "Counting a Diverse Nation" report

APIAHF: Policy recommendations + sample questionnaire

UCLA: Data disaggregation webinar series

The Leadership Conference Education Fund's FAQ on the combined question format

American Hospital Association's Disparities Toolkit

Questions?

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