

Minority Fellowship Program Webinar

Addressing Health Disparities through Culturally Informed Research and Evaluation Design

Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services

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• June 23, 2021 •



SAMHSA
Substance Abuse and Mental Health
Services Administration

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Disclaimer

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Learning Objectives

As a result of this webinar, participants will be able to:

- Identify at least two current models for collecting and coding race, ethnicity, and language data
- Recognize three challenges involved in obtaining data on race, ethnicity, and language in health care settings
- Explain the impact of cultural humility in conducting research and evaluation
- Discuss skills to manage adaptations necessary to conduct research/evaluation with culturally diverse groups

Minority Health and Health Disparities Defined

The National Institute for Minority Health and Health Disparities (NIMHD) is the lead federal agency for supporting research on both concepts, defined as follows:

– **Minority Health** -

- “...includes health characteristics and attributes of racial and/or ethnic minority groups (defined by Office of Management and Budget), who are socially disadvantaged due in part by being subject to potential discriminatory acts”
- “Research examines singularly and in combination the attributes, characteristics, behaviors, biology, and other factors that influence the health outcomes of minority racial and ethnic groups, including within-group or ethnic subpopulations”

– **Health Disparities**

- “—refers to health differences that adversely affect defined disadvantaged populations, based on one or more health outcomes”
- Research examines contributing factors and underlying causes to generate knowledge to mitigate their effects and improve population health outcomes.

The Issue (con't)

Implications for Research

- Minority health and health disparities are related but different concepts
- “Minority health” differences do not necessarily equate to “health disparities”
- Health disparities-populations are broader than racial and ethnic minorities, and include underserved rural residents, populations with less privileged socioeconomic status, and sexual and gender minorities
- Therefore, research and evaluation related to minority health and health disparities will have different foci.

Needed approaches

- “A fundamental step: bring the nature of the disparities and the groups at risk for those disparities to light by collecting health care quality information stratified by race, ethnicity and language data.” (IOM, 2009)
- Culturally competent researchers who can employ culturally-responsive and culturally-accountable approaches to collect and code data on race, ethnicity, and language for use in analyses and dissemination.

Models for Collecting and Coding Race, Ethnicity, and Language (REaL) data: National Sources/Federal Agencies

Federal Office of Management and Budget

- U.S. Census
- American Community Survey
- Behavioral Risk Factor Surveillance Systems (BRFSS)
- Youth Risk Behavior Survey (YRBS)
- National Health Interview Survey
- CDC Household Pulse Survey
- National Child Health Survey
- Pregnancy RAAMS
- ACES
- NHANES
- SAMHSA Datasets (example on later slide)
- National Survey on Drug Use and Health (NSDUH)

Guidance instructions for the 2020 U.S. Census were provided in 13 languages (out of 59 that a respondent could select on the survey)

REaL Data Models cont'd: National Sources/Federal Agencies

U.S. Census Bureau

Two-part race/ethnicity question

1. Must adhere to the 1997 Office of Management and Budget (OMB) standards, to include at least five categories:
 - White
 - Black or African American
 - American Indian or Alaska Native
 - Asian
 - Native Hawaiian or Other Pacific Islander
2. Also asks if respondent is of Hispanic or Latino origin (Yes/No); asked first, then select racial category
 - 1997 OMB standards permit the reporting of more than one race.
 - An individual's response to the race question is based upon self-identification.

Models: Asking Race in Census 2020 (2 Items)

1 2 3 4 5 6 7 8 9 10 11 12



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

For this census, Hispanic origins were not considered races. Hispanic origin can be viewed as the heritage, nationality, lineage, or country of birth of the person or the person's parents or ancestors before arriving in the United States. People who identify as Hispanic, Latino, or Spanish may be any race. See more about how this question should have been answered ...

Why we ask this question: These responses help create statistics about this ethnic group. This helps federal agencies monitor compliance with anti-discrimination provisions, such as those in the Voting Rights Act and the Civil Rights Act.

1 2 3 4 5 6 7 8 9 10 11 12



What is Person 1's race?

Here, you marked one or more boxes AND printed origins: White; Black or African American; American Indian or Alaska Native; Chinese; Filipino; Asian Indian; Vietnamese; Korean; Japanese; other Asian; Native Hawaiian; Samoan; Chamorro; other Pacific Islander; some other race. See more about how this question should have been answered

Why we ask this question: This enables us to create statistics about race and to analyze other statistics within racial groups. This data helps federal agencies monitor compliance with anti-discrimination provisions, such as those in the Voting Rights Act and the Civil Rights Act.

Models: Asking Race in Census 2020 (White)

White:

- The category “White” includes all individuals who identify with one or more nationalities or ethnic groups originating in Europe, the Middle East, or North Africa.
- Examples of these groups include, but are not limited to: German, Irish, English, Italian, Lebanese, Egyptian, Polish, French, Iranian, Slavic, Cajun, and Chaldean.

Models: Asking Race in Census 2020 (Black or African American)

Black or African American:

- The category “Black or African American” includes all individuals who identify with one or more nationalities or ethnic groups originating in any of the black racial groups of Africa.
- Examples of these groups include, but are not limited to, African American, Jamaican, Haitian, Nigerian, Ethiopian, and Somali. The category also includes groups such as Ghanaian, South African, Barbadian, Kenyan, Liberian, and Bahamian.

American Indian or Alaska Native:

- The category “American Indian or Alaska Native” includes all individuals who identify with any of the original peoples of North and South America (including Central America) and who maintain tribal affiliation or community attachment.
- It includes people who identify as “American Indian” or “Alaska Native” and includes groups such as Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Traditional Government, and Nome Eskimo Community.

Models: Asking Race in Census 2020 (Asian)

Asian:

The category “Asian” includes all individuals who identify with one or more nationalities or ethnic groups originating in the Far East, Southeast Asia, or the Indian subcontinent (see box at right).

The category also includes groups such as Pakistani, Cambodian, Hmong, Thai, Bengali, Mien, etc.

There are individual Asian checkboxes for people who identify as one or more of the following:

- Chinese
- Filipino
- Asian Indian
- Vietnamese
- Korean
- Japanese
- Other Asian (for example, Pakistani, Cambodian, and Hmong)

Models: Asking Race in Census 2020 (Native Hawaiian and Pacific Islander)

Native Hawaiian and Pacific Islander:

The category “Native Hawaiian or Other Pacific Islander” includes all individuals who identify with one or more nationalities or ethnic groups originating in Hawaii, Guam, Samoa, or other Pacific Islands.

Examples of these groups include, but are not limited to, Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, and Marshallese. The category also includes groups such as Palauan, Tahitian, Chuukese, Pohnpeian, Saipanese, Yapese, etc.

- There are individual Pacific Islander checkboxes for people who identify as one or more of the following:
 - Native Hawaiian
 - Samoan
 - Chamorro
 - Other Pacific Islander (for example, Tongan, Fijian, and Marshallese)

REaL Data Models: OMB - SAMHSA Data Set

Excerpt from SAMHSA Report: Treatment Episodes Data Set (TEDS)

United States TEDS admissions aged 12 years and older, by primary substance use and gender, age at admission, race, and ethnicity: Percent, 2018 (N = 2.06M)

Race	All Substances	Alcohol Only	Alcohol with secondary drug	Heroin	Other opiates	Cocaine (smoked)
White	64.4	67.2	59.4	69.9	79.3	39.1
Black or African-American	19.0	15.8	24.8	16.4	9.0	51.1
American Indian or Alaska Native	2.7	4.3	3.5	1.1	1.5	0.7
Asian or Native Hawaiian or Other Pacific Islander	1.0	1.1	0.7	0.7	0.6	0.6
Other	7.2	6.9	7.3	8.2	3.3	4.7
Unknown	5.8	4.7	4.3	3.7	6.2	3.1
Total	100.0	100.0	100.0	100.0	100.0	100.0
Ethnicity	All Substances	Alcohol Only	Alcohol with secondary drug	Heroin	Other opiates	Cocaine (smoked)
Hispanic or Latino	13.5	13.8	13.3	13.6	8.4	8.7
Not Hispanic or Latino	82.2	83.1	84.0	84.0	85.7	89.1
Unknown	4.2	3.1	2.7	2.4	5.9	2.2
Total	100.0	100.0	100.0	100.0	100.0	100.0

REaL Data Models: OMB - Census Household Pulse Survey

Q3 Are you of Hispanic, Latino, or Spanish origin?

- No, not of Hispanic, Latino, or Spanish origin (1)
- Yes, Mexican, Mexican American, Chicano (2)
- Yes, Puerto Rican (3)
- Yes, Cuban (4)
- Yes, another Hispanic, Latino, or Spanish origin (5)

Q4 What is your race? Please select all that apply.

- White (1)
- Black or African American (2)
- American Indian or Alaska Native (specify) (3)
- Asian Indian (4)
- Chinese (5)
- Filipino (6)
- Japanese (7)
- Korean (8)
- Vietnamese (9)
- Other Asian (specify) (10) _____
- Native Hawaiian (11)
- Chamorro (12)
- Samoan (13)
- Other Pacific Islander (specify) (14) _____

REaL Data Models: OMB Minimum Recommendations and CDC WONDER's Use of Census Data

Data query from CDC WONDER (wonder.cdc.gov)

Recommended minimum from OMB (in order on their site):

- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander

AND WHETHER

- Hispanic/Latino

ift + Click for a range.

Race

- All Races
- American Indian or Alaska Native
- Asian or Pacific Islander
- Black or African American
- White

Ethnicity

- All Ethnicities
- Hispanic or Latino
- Not Hispanic or Latino

CHAT: What do you see as a takeaway here?

REaL Data Models: Local Sources and Uses

- **State and local health departments:** use the OMB 2-item model—e.g., <https://www.iowadatacenter.org/aboutdata/raceclassification>
 - Vital statistics
 - Disease burden and health risk surveillance
 - Issue: Some states and localities do not report by race/ethnicity

- **Health care settings**

SOURCES

- Electronic health records
- Other informational management systems
- Administrative data
- Intake forms
- Client satisfaction/feedback surveys

USES

- Annual Reports
- Grant or contract progress reports
- Needs Assessments
- Evaluation activities
- Community Benefit reports (required by ACA)
- Board Reports
- Diversity, Equity, and Inclusion (DEI) audits
- Workforce Diversity tracking reports

CHAT:

- ***What other sources of REaL data are in your settings?***

- ***What other uses do you have or will you have for REaL data in your setting?***

OBSERVATIONAL MEDICAL OUTCOMES PARTNERSHIP (OMOP)

COMMON DATA MODEL (CDM)

- OMOP CDM is maintained by a collaborative, the Observational Health Data Sciences and Informatics (OHDSI) program.
- *All of Us Program (NIH)* Data and Research Center leverages the OMOP CDM to empower researchers by using existing, standardized vocabularies and a harmonized data representation. T
- These factors enable connection to other ontologies, datasets, and tools that use the same codes or data model. [Learn more about OHDSI's OMOP CDM initiative.](#)

AS A RESEARCHER, HERE'S WHAT YOU SHOULD KNOW ABOUT OMOP:

- **OMOP is a relational database** - a set of formally described tables with defined relationships allowing data to be accessed in many different ways (the curated dataset has [OMOP Tables](#))
- **OMOP is standardized.** Standard vocabularies (despite differences in how each data element may be captured--e.g., variation among the many electronic health records), all of the data are represented consistently in the data model. For each broad category of data, or "domain," OMOP incorporates important existing vocabularies so that everyone using the data can speak the same language.
- **OMOP is where metadata rules.** Data are represented in a standardized way, are common across many institutions, and are easily retrievable using standardized search methodologies
- **Resources can help.** [Athena](#), a platform that maps OMOP standardized vocabularies to other nonstandard vocabularies. Discover more on the [Github Wiki](#).

REaL Data Models: Local Level Sources

HD*Pulse* (NIMHD)

Source: HD*Pulse*: An Ecosystem of Minority Health and Health Disparities Resource. National Institute on Minority Healthy and Health Disparities (NIMHD). Created 6/7/2021. Available from <https://hdpulse.nimhd.nih.gov>

PHENX Toolkit (2020)

- NIMHD launched the PhenX Social Determinants of Health (SDOH) Assessments Collection, within the PhenX Toolkit
- Expands upon the previous SDOH collection to help measure upstream factors that shape behaviors and health outcomes
- Collection provides a common currency for studying social determinants of health across public health research studies. <https://www.nimhd.nih.gov/programs/collab/phenx/index.html>.
- Allows for researchers across studies to compare data on race, ethnicity or preferred languages
- Includes a Race/Ethnicity Protocol based on OMOP model that provides for additional collection of data on countries of origin/nativity

CHAT: Are there other sources of REaL data you use? Are there other uses you have or will have for REaL data in your healthcare setting?

REaL Data Models: NIMHD HDPulse Data Portal

The screenshot displays the NIMHD HDPulse Data Portal interface. At the top left is the NIH logo and the text "National Institute on Minority Health and Health Disparities". To the right, there is a link to "Subscribe to our Email Newsletter" with icons for Twitter, email, and Facebook. A navigation bar contains links for "HDPulse Home", "Data Portal", "Intervention Portal", "About", and "Contact Us". Below this is a yellow banner with the "HDPulse" logo and the tagline "An Ecosystem of Health Disparities and Minority Health Resources". The breadcrumb trail reads "HDPulse » Data Portal » Data Topics » Interactive Maps". The main content area is titled "Interactive Maps" and features a "Data Options" section. A dropdown menu is open, showing a list of race/ethnicity categories. The categories are: "All Races (incl. Hisp)", "White (incl. Hisp)", "White Hispanic/Latino", "White (Non-Hispanic/Latino)", "Black (incl. Hisp/Latino)", "Black (Non-Hispanic/Latino)", "Hispanic/Latino (any race)", "American Indian / Alaskan Native (incl. Hisp/Latino)", "American Indian / Alaskan Native (Non-Hispanic/Latino)", "Asian / Pacific Islander (incl. Hisp/Latino)", "Asian / Pacific Islander (Non-Hispanic/Latino)", and "Native Hawaiian or Other Pacific Islander". The "Data Group" label is next to "Hispanic/Latino (any race)", the "Topic" label is next to "Asian / Pacific Islander (incl. Hisp/Latino)", and the "Variable" label is next to "Asian only". A red circle highlights the entire dropdown menu, a purple circle highlights "Hispanic/Latino (any race)", a green circle highlights "Asian only", and a blue circle highlights the dropdown header "--- choose race/ethnicity ---".

Source: HD Pulse NIMHD - HDPulse: An Ecosystem of Minority Health and Health Disparities Resource. National Institute on Minority Health and Health Disparities. Created 6/7/2021. Available from <https://hdpulse.nimhd.nih.gov>

REaL Data Models: NIH's PHENX Toolkit-Race protocol

Allows for researchers across studies to compare data on race and ethnicity

MEASURE

- The first item asks if the person considers himself or herself to be Hispanic, Latino or Spanish and, if so, asks an additional question about his or her specific Hispanic origin is asked. One or more Hispanic origin categories may be selected.
- The second item asks about race, with multiple close-ended answer choices and optional write-in to provide more country of origin. These items are self-reported.

PURPOSE

- Ethnicity is used to stratify study populations and to associate those populations with physical, geographic, biological, social, and cultural characteristics (e.g., Dominican).
- Ethnicity is a social and epidemiological factor, and individuals of some ethnicity are at greater risk for disease.
- By capturing the ethnicity of respondents, the researcher will be able to identify those who are or are not of Hispanic origin and will be able to stratify the study population accordingly.
- Race is also used to stratify study populations and to associate those populations with physical, geographic, biological, social, and cultural characteristics (e.g., African Americans). Race is also a social and epidemiological construct, and individuals of some races are at greater risk for certain diseases.

Source: <https://www.phenxtoolkit.org/protocols/view/11901>

REaL Data Models: NIH's PHENX Toolkit-Culturally-accountable approach

- The OMOP's “**ethnicity** concept” is the same as that of the OMB: Hispanic/Latino/Spanish origin or not
- However, the model expands codes for the “**race concept**” and includes four pages of terms (next slide):

REaL Data Models: OMOP Common Data Codes for Race

Culturally-accountable approach

TS				
	African	Bhutanese	Hmong	Micronesian
	African American	Black	Indonesian	Middle Eastern or North African
	Alaska Native	Black or African American	Iwo Jiman	Native Hawaiian or Other Pacific Islander
	American Indian	Burmese	Jamaican	Nepalese
	American Indian or Alaska Native	Cambodian	Japanese	Okinawan
	Arab	Chinese	Korean	Other Pacific Islander
	Asian	Dominica Islander	Laotian	Pakistani
	Asian Indian	Dominican	Madagascar	Polynesian
	Bahamian	European	Malaysian	Singaporean
	Banqladeshi	Filipino	Maldivian	Sri Lankan
		Haitian	Melanesian	Taiwanese
		Umgng		Thai
				Utner Pacific Islander
				Pakistani
				Polynesian
				Singaporean
				Sri Lankan
				Taiwanese
				Thai
				Tobagoan
				Trinidadian
				Vietnamese
				West Indian
				White

REaL Data Models: NIH's PHENX Toolkit-All of Us'

Culturally-accountable approach *OMOP Race Protocol*

↳ Black, African American, or African (For example: African American, Ethiopian, Haitian, Jamaican, Nigerian, Somali, etc.)

Answer	Concept Code	Participant Count	% Answered out of 67080
Black Specific: African American	1585621	64,380	95.97%
Black Specific: Black None Of These Describe Me	1585627	1,840	2.74%
Black Specific: Caribbean	1585617	1,720	2.56%
Black Specific: Jamaican	1585622	1,400	2.09%
Skip	903096	1,040	1.55%
Black Specific: Haitian	1585623	960	1.43%
Black Specific: Nigerian	1585624	740	1.10%
Black Specific: Barbadian	1585616	300	0.45%
Black Specific: Ghanaian	1585626	260	0.39%
Black Specific: Ethiopian	1585625	180	0.27%
Black Specific: South African	1585620	160	0.24%
Black Specific: Liberian	1585618	140	0.21%
Black Specific: Somali	1585619	80	0.12%
Did not answer	0	≤ 20	0.03%

Takeaway:
By asking for more specificity such as country of origin, researchers can make more informed policy and practice recommendations

Source: PHENX Toolkit: Race Protocol, <http://www.phenxtoolkit.org/protocols/view/11901#tabsource>

Challenges in Obtaining REaL Data in Health Care Settings

- 1) **Minimizing inconsistencies across data sources in terms of how data are:**
 - Captured (in-person, from records/documents, online, paper-pencil, voice only)
 - Recorded (self-written, other's written notes, audio, A/V, individual/group)
 - Coded (what is included and what is excluded, categories, codes)
 - Managed (recoded, collapsed)
 - Analyzed (comparative, non-comparative, disaggregated, aggregated)
 - Reported (comparative, non-comparative, no distinctions, language)

Exercise: Inconsistencies in Labeling Race/Ethnicity in Data Reports

6/7/2021 **A** Quick Profiles - HD Pulse

Premature deaths: Average number of years of potential life lost prior to age 75 per 100,000 population (2016-2017)	Louisiana Years	USA Years	Table
White (includes Hispanic/Latino)	8,210	6,841	
Black (includes Hispanic/Latino)	12,506	10,321	
American Indian / Alaskan Native (includes Hispanic/Latino)	4,404	11,467	
Asian / Pacific Islander (includes Hispanic/Latino)	3,262	3,091	
Hispanic/Latino (any race)	4,690	4,846	

B

Average Number of Days During the Past 30 Days When an Adult's Physical Health Was Not Good by Race (2017)	Louisiana Days	USA Days	Map	Comparison Table	Comparison Graph
White (includes Hispanic/Latino)	4.7	4.1			
Black (includes Hispanic/Latino)	5.0	4.1			
Hispanic/Latino (any race)	6.4	3.7			

Exercise: Ignore headers and data reported, just look at the racial/ethnic categories and answer: *What inconsistencies in categories of race/ethnicity labeling do you see here in comparing:*

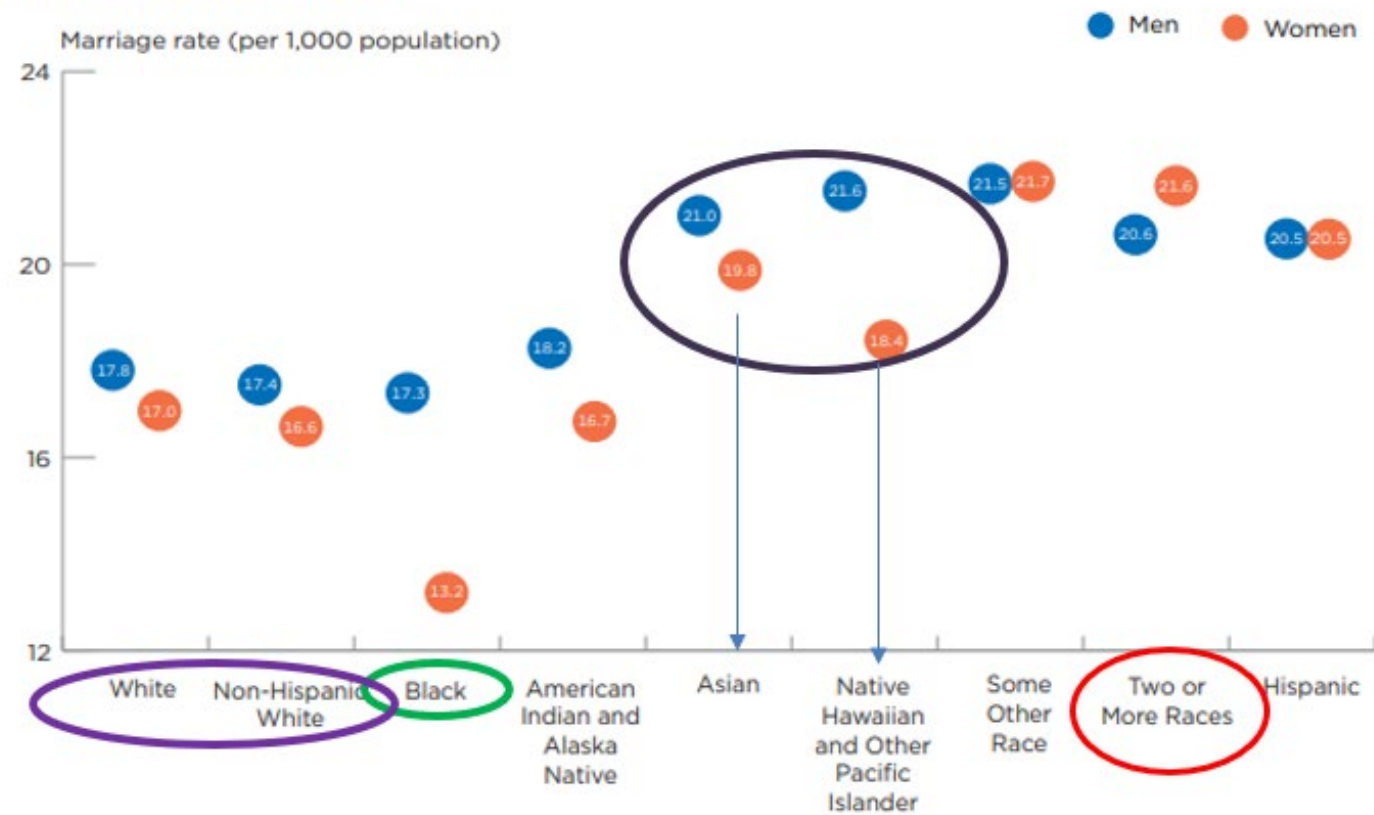
- 1) A vs. B?
- 2) A vs. C?
- 3) B vs. C?

C

Demographics: Population - Race/Ethnicity	Louisiana Percent	USA Percent	Map	Table
Foreign born, 2013-2017	4.2	13.4		
Black, 2013-2017	32.2	12.7		
American Indian/Alaska Native, 2013-2017	0.6	0.8		
Asian / Pacific Islander, 2013-2017	1.8	5.5		
Hispanic, 2013-2017	5.0	17.6		
White, 2013-2017	62.4	73.0		

Minimizing Inconsistencies: American Community Survey

Figure 3.
Marriage Rate per 1,000 Men and Women 15 Years and Over by Race and Hispanic Origin: 2016



Source: U.S. Census Bureau, 2016 American Community Survey, 1-year estimates.

Recommended minimum from OMB:

- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander

AND WHETHER

- Hispanic/Latino

CHAT: What do you see as takeaways here? (refer to the circled data and previous slide from CDC Wonder—race groupings)

Exercise: Collapsed Labeling of Race/Ethnicity in Published Reports

A

6/7/2021 Quick Profiles - HDPutse

Premature deaths: Average number of years of potential life lost prior to age 75 per 100,000 population (2016-2017)	Louisiana Years	USA Years	Table
White (includes Hispanic/Latino)	8,210	6,841	
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Hispanic/Latino (any race)	4,690	4,846	

B

National Vital Statistics Reports

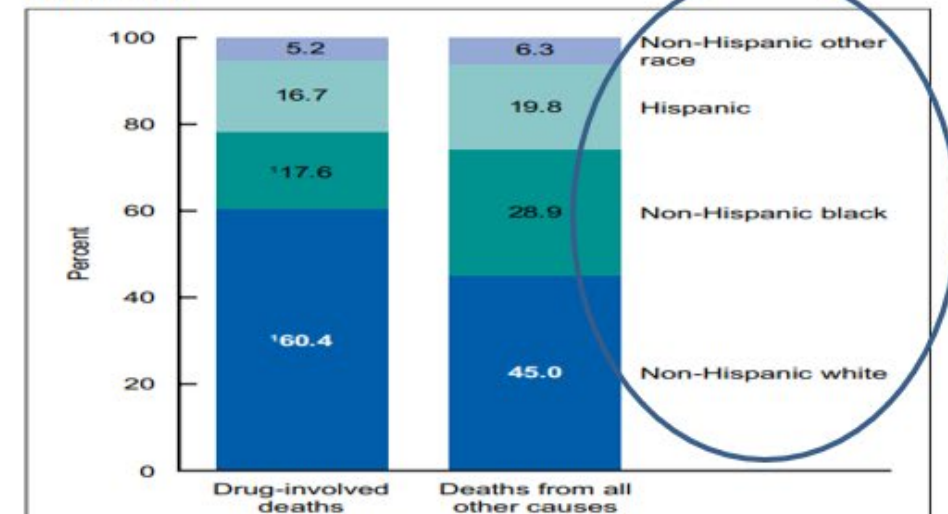
Volume 70, Number 7



June 3, 2021

Drug-involved Infant Deaths in the United States, 2015–2017

Figure 1. Percent distribution of drug-involved infant deaths and infant deaths from all other causes, by maternal race and Hispanic origin: United States, 2015–2017



¹Significant difference from deaths from all other causes ($p < 0.05$).
 NOTES: Race and Hispanic origin are reported separately on birth certificates; persons of Hispanic origin may be of any race. Race categories are consistent with the 1977 Office of Management and Budget standards. Percentages may not add to 100% due to rounding.
 SOURCES: National Center for Health Statistics, National Vital Statistics System, drug-involved mortality file and linked birth/infant death file.

*Exercise: Ignore headers and data reported, just look at the racial/ethnic categories and answer: **What inconsistencies in categories of race/ethnicity labeling do you see here in comparing: Table in A vs. Chart/Graphs in B?***

Challenges in Obtaining REaL Data in Health Care Settings

2) Addressing racial, ethnic, linguistic, and cultural nuances

- More than one race – capturing can have utility for strategic planning and evaluation
- Nativity/Country of origin – can unmask differences for sub-groups within an OMB category
- Ethnicity – region of country, heritage, tribal, religious belief (subdivisions—sects, etc.)
- Intergenerational ethnicity – parents’ countries of origin, grandparents’ countries of origins
- Immigration status – citizen, non-citizen, green card, visa, years in U.S., age at which immigrated
- Preferred language – situational and place-based --(situational and place-based)—e.g., for speaking reading, writing; in home, social settings, healthcare settings
- More than one language – *“What language does your patient hurt in?”*

Source: Salimbene, S. (2005)

REaL Data Models: The Federal Government

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. ↴

<input type="checkbox"/> Chinese	<input type="checkbox"/> Vietnamese	<input type="checkbox"/> Native Hawaiian
<input type="checkbox"/> Filipino	<input type="checkbox"/> Korean	<input type="checkbox"/> Samoan
<input type="checkbox"/> Asian Indian	<input type="checkbox"/> Japanese	<input type="checkbox"/> Chamorro
<input type="checkbox"/> Other Asian – Print, for example, Pakistani, Cambodian, Hmong, etc. ↴		<input type="checkbox"/> Other Pacific Islander – Print, for example, Tongan, Fijian, Marshallese, etc. ↴

Some other race – Print race or origin. ↴

Source: [census.gov](https://www.census.gov)

REaL Data Models: Other Guidance

Source: The Alliance for National Psychological Associations for Racial and Health Equity COVID-19 Needs Assessment Project – Phase I Survey - *Developed with input from the Indigenous Wellness Research Institute*

You selected "American Indian or Alaska Native". Please answer the question below:

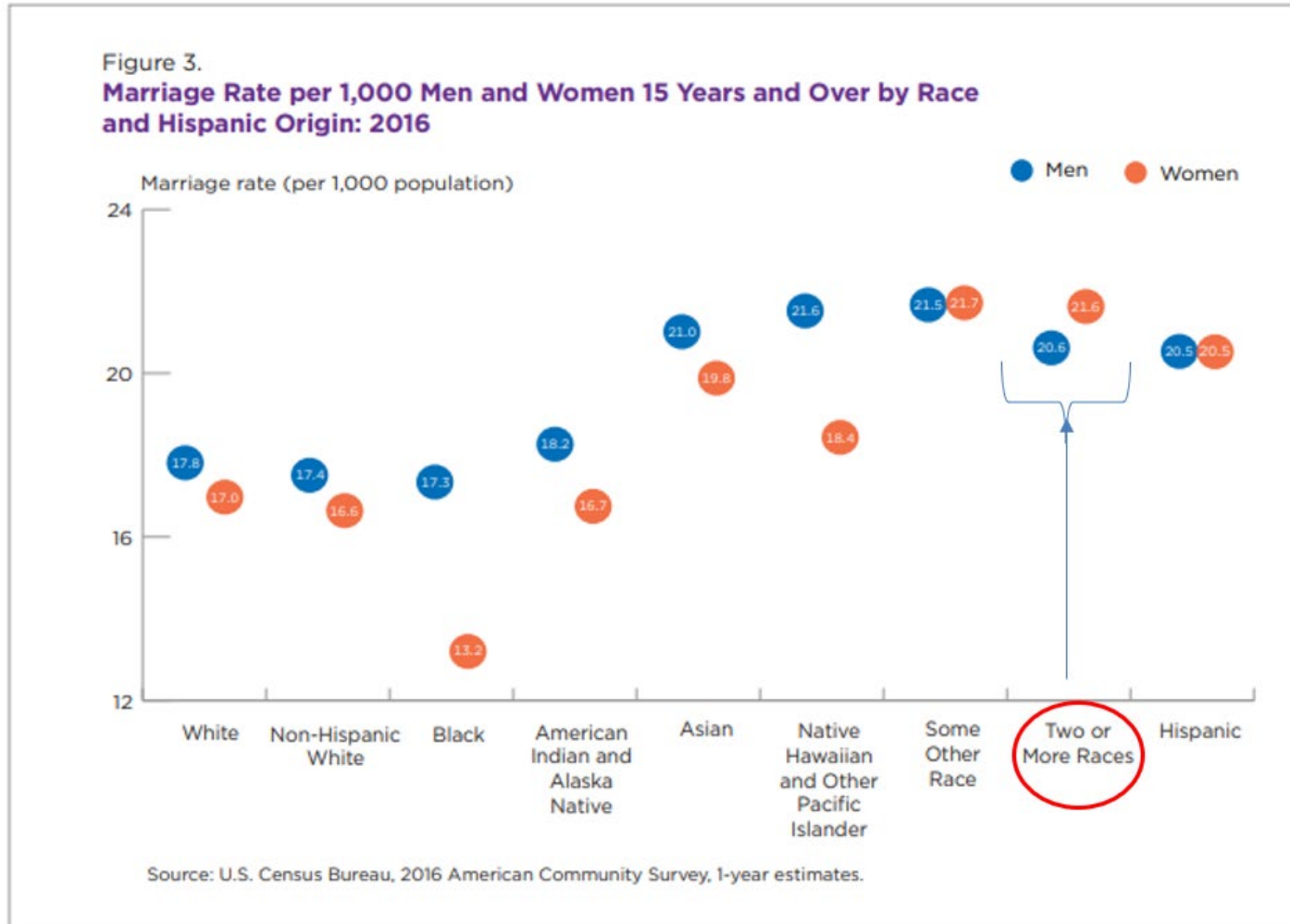
Tribal affiliation (Please specify):

Indigenous from Mexico (Please specify):

Indigenous from Central America (Please specify):

Indigenous from South American (Please specify):

Capturing More Than One Race: Example of Utility in American Community Survey



CHAT: What do you see as a takeaway here? (refer to data for the circled item)

3) Language barriers

- Use interpreters and/or translators
- Know the difference and when to use
- Methods – e.g., for translations – from English to 2nd language and back to English
- Original source from which coded: paper-pencil, audio, virtual (A/V), sign language
- Purpose and setting for intake over the phone, by Zoom, in the clinic or health care setting, in a home, etc.

Challenges in Obtaining Language Data: Strategies to Address

How do you collect the data on which language to use, if English is not one's first language?

- 2020 Census included instructions in 13 of 59 languages; determine which of these relate to your setting; ask other researchers for guidance on how they approach the language issues with their projects
- Develop a glossary of terms used in your healthcare settings for research purposes and translate these, as needed from English into the primary language read or spoken in your setting; augment this list with the terms from the other language that may be colloquialisms used as alternatives to the English versions
- Develop a language template or guidebook for how/which languages are captured for your setting
- Consult the Culturally and Linguistically Appropriate Services (CLAS) Standards

Infusing Cultural Competency Into Research and Evaluation

The National Standards for Culturally Linguistically Appropriate Services (CLAS)

- Developed by the U.S. Department of Health and Human Services, Office of Minority Health in 2001 and updated in 2013.
- Intended to advance health equity, improve quality of health services, and help eliminate health care disparities
- Focus on 1) Governance, Leadership, and Workforce; 2) **Communication and Language Assistance (standards 5-8)**; and 3) **Engagement, Continuous Improvement and Accountability**

Source: <https://thinkculturalhealth.hhs.gov/clas/standards>

National CLAS Standards 5-8

Communication and Language Assistance:

Standard 5: Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to all health care and services.

Standard 6: Inform all individuals of the availability of language assistance services clearly and in their preferred language, verbally and in writing.

Standard 7: Ensure the competence of individuals providing language assistance, recognizing that the use of untrained individuals and/or minors as interpreters should be avoided.

Standard 8: Provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area.

Cultural Humility in Conducting Research and Evaluation

Definition

- *Ongoing process of reflection to gain a deeper understanding of cultural differences in order to improve the way vulnerable groups are treated and researched (Yaeger & Bauer-Wu, 2013. {[PDF](#)})*

Significance of humility in conducting research/evaluation

- Relates to ethical principles in human subjects' research protections—beneficence, justice

Requires

- Self reflection and self-assessment (an essential element of cultural competency) to be aware of one's own values and biases (setting aside ethnocentrism, racism, stereotyping) as well as the values, history (e.g., historical trauma), and beliefs of research participants (cultural trust/mistrust)
- Recognizing the power dynamics between researcher and participants and addressing imbalances
- Ongoing monitoring of oneself and research team to ensure respect for integrity (strengths/assets) of participants' culture/history and use of this information to improve collection of data on race, ethnicity, language, and other variables

Skills To Manage Adaptations To Conduct Research/Evaluation With Culturally Diverse Groups

- Facilitation (focus groups, meetings with partners/stakeholders)
- Reflexivity – to reflect on personal biases and values before engaging
- Conflict resolution and problem-solving
- Establishing and maintaining trusting, collaborative relationships
- Resourcefulness to identify common data that might apply in your setting
- Technology awareness to work with technical staff to integrate needed race, ethnicity, and language data into EHR or pull existing data to create a new racial/ethnic/language variable
- Internet searching to use existing common data models/tools (OMOP, PHEN-X) to identify candidate measures and adapt them for specific groups/subgroups
- Analytic skills to select appropriate techniques to analyze disaggregated data and small samples; and produce charts/graphic displays
- Writing to produce protocols reflecting the culturally-responsive procedures

National CLAS Standards 9-12

Engagement, Continuous Improvement, and Accountability:

Standard 9: *Establish culturally/linguistically appropriate goals/policies and management accountability and infuse them throughout the organization's planning and operations.*

Standard 10: *Conduct ongoing assessments of the organization's CLAS-related activities and integrate CLAS-related measures into measurement and CQI activities.*

Standard 11: *Collect and maintain accurate/reliable demographic data to monitor and evaluate the impact of CLAS on health equity and outcomes and to inform service delivery.*

Standard 12: *Conduct regular assessments of community health assets and needs and use the results to plan and implement services that respond to the cultural and linguistic diversity of populations in the service area.*

National CLAS Standards 13-15

Engagement, Continuous Improvement, and Accountability

Standard 13: *Partner with the community to design/implement/evaluate policies, practices, and services to ensure cultural and linguistic appropriateness.*

Standard 14: *Create conflict and grievance resolution processes that are culturally and linguistically appropriate to identify, prevent, and resolve conflicts or complaints.*

Standard 15: *Communicate the organization's progress in implementing and sustaining CLAS to all stakeholders, constituents, and the general public.*

Resources

- Duran D, Perez-Stable E. Overview: novel approaches to advance minority health and health disparities research. *Am J Public Health*. 2019;109(suppl1):S8–S10. [[PMC free article](#)] [[PubMed](#)] [[Google Scholar](#)]
- USA Facts, [Race in America](#)
- Cultural humility and promise for health disparities researchers. Yeager, Katherine A., PhD, RN, & Bauer-Wu, Susan, PhD, RN, FAAN. (2013). Cultural humility: Essential foundation for clinical researchers. *Appl Nurs Res*. 2013 November ; 26(4): Retrieved 6-3-2021 at Retrdoi:10.1016/j.apnr.2013.06.008. {[PDF](#)}
- About Languages. JAN. 13, 2020 – The U.S. Census Bureau [2020census.gov](#) included content in [59 languages](#), including language assistance guides and videos that explained how to complete the 2020 Census questionnaire online, by phone or by mail. People could respond to the census online and by phone in 13 languages
- 1997 Office of Management and Budget Guidelines (1997). {[PDF](#)}
- The All of Us Research Program Investigators. Special Report: The “All of Us” Research Program. *N Engl J Med* 2019; 381: 668-676. <https://www.nejm.org/doi/full/10.1056/NEJMSr1809937>
- **OBSERVATIONAL MEDICAL OUTCOMES PARTNERSHIP (OMOP) COMMON DATA MODEL.** The *All of Us* Data and Research Center leverages the OMOP CDM to empower researchers by using existing, standardized vocabularies and a harmonized data representation to other ontologies, datasets, and tools that use the same codes or data model. Learn more about OHDSI’s [OMOP CDM initiative](#).
- Salimbene, S. (2005). What language does your patient hurt in?: A practical guide to culturally competent patient care. Amherst, MA: Diversity Resources, Inc.

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