



California Pan-Ethnic Health Network

Eliminating Health Disparities Standardizing data collection on race, ethnicity, and primary language

Background

Numerous studies have documented the need for better collection of race, ethnicity, and primary language data in order to better understand disparities in health care coverage and services.¹ What data there is on health disparities has helped to illustrate some alarming disparities in our state. For example in California, communities of color comprise over three-quarters of the uninsured.² Black, Latino, and American Indian/Alaskan Native (AI/AN) populations have higher rates of high blood pressure and obesity compared to Whites and Asian/Pacific Islander populations.³ While this data is useful, it doesn't tell the entire story. The ability to disaggregate data by subpopulations and language needs will help California better target health interventions to the communities that need them the most and begin to address the persistent disparities communities of color experience.

New Requirements under the Affordable Care Act

The Affordable Care Act (ACA)⁴ requires states to adopt new federal data collection standards for collecting race, ethnicity, and primary language data. The new HHS standards, published in 2011, apply to "any federally conducted or supported health care or public health program," including Medi-Cal, Healthy Families, and the new Health Benefit Exchange. The standards provide additional granularity for Hispanic (four additional categories) and Asian subpopulations (seven additional categories) beyond the Office of Management and Budget (OMB) minimum standard categories (see Table 1). Additionally the standards now require a question aimed at measuring language proficiency.

California should take the lead in promoting health equity

California has an important opportunity under the ACA to take the lead in eliminating health disparities by both implementing and building upon the new federal data standards. The federal standards are a good first step; however, the tremendous diversity of our state necessitates adopting additional data categories (as recommended by the Institute of Medicine (IOM)) that better reflect the demographics of our state.⁵ This more robust approach to data collection is encouraged by OMB as long as the detailed information can be aggregated back to the minimum

¹ *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, Institute of Medicine (IOM) issued in 2002

² *California Healthcare Almanac: California's Uninsured*, California Healthcare Foundation, December 2010.

³ *Health of California's Adults, Adolescents and Children: Findings from CHIS 2005 and CHIS 2003*, UCLA Center for Health Policy Research, September 2008.

⁴ Section 4302.

⁵ "Race, Ethnicity and Language Data: Standardization for Health Care Quality Improvement," Institute of Medicine (IOM), August 31, 2009, <http://iom.edu/Reports/2009/RaceEthnicityData.aspx>

standard set of race and ethnicity categories.⁶ Currently there is no standardized format or practice for collecting data on race, ethnicity, and primary language in California (see Table 2). With the state developing a new, simplified enrollment form for online, mail, phone, and in-person enrollment, now is the ideal time to adopt new standards with minimal added expense.

Recommendations

Race/Ethnicity

- In addition to adopting the required federal standard questions for the collection of race, ethnicity, and primary language (see Table 1), California should include additional race/ethnicity categories as recommended by the IOM to more accurately reflect the diversity of our state. These categories could be based on the most current U.S. Census data categories (see Table 3).
- Accessible drop-down menus with all of the race/ethnicity categories should be included on all forms. Applicants should be allowed to check-off more than one race if relevant.⁷
- An additional drop-down menu for ancestry should be included on all forms (see Table 4).

Language

- In addition to adopting the required federal standard question measuring English proficiency, California should continue to include additional questions measuring language spoken as recommended by HHS and currently collected on California forms (see Tables 1 & 2).
- An accessible drop-down menu with a list of common languages spoken in California, accompanied by an open-ended response option for those whose language does not appear on the list should be adopted. These categories could be based on the most current U.S. Census data categories (see Table 5).

Encouraging responses

Studies have shown that applicants are more likely to respond and complete self-reported data on race, ethnicity and primary language with an explanation on how the data will be used.⁸ The state should inform consumers on the application form that the data is being collected to monitor and improve the quality of care for everyone. The state could adapt the following suggested wording as part of the Health Research and Education Trust (HRET) Disparities Toolkit for this purpose:

⁶ “*Explanation of Data Standards for Race, Ethnicity, Sex, Primary Language and Disability*,” Department of Health and Human Services, Office of Minority Health, Oct. 31, 2011, <http://minorityhealth.hhs.gov/templates/content.aspx?ID=9228&lvl=2&lvlID=208>

⁷ The state can choose various options for ensuring accessibility including breaking the form up into steps and displaying the entire list on a new page. This may be more accessible than a drop-down menu, particularly for those with visual impairments or manual impairments who have difficulty using a mouse. If the state chooses to use drop-down menus they must be navigable using the keyboard only and the menu selections must also be labeled in a logical manner. WebAim.org: (<http://webaim.org/techniques/forms/>) has some helpful information on ensuring accessibility. The state may also be able to use a DHTML menu like this one (<http://www.udm4.com/menu/>).

⁸ “Race, Ethnicity and Language Data: Standardization for Health Care Quality Improvement,” Institute of Medicine (IOM), August 31, 2009, <http://iom.edu/Reports/2009/RaceEthnicityData.aspx>

“We want to make sure that all our patients get the best care possible. We would like you to tell us your racial/ethnic background so that we can review the treatment that all patients receive and make sure that everyone gets the highest quality of care.”

Table 1.

New 2011 HHS Data Standards for Race, Ethnicity and Primary Language

Ethnicity Data Standard	Categories
<p><i>Are you Hispanic, Latino/a, or Spanish origin (One or more categories may be selected)</i></p> <p>a. <input type="checkbox"/> <i>No, not of Hispanic, Latino/a, or Spanish origin</i></p> <p>b. <input type="checkbox"/> <i>Yes, Mexican, Mexican American, Chicano/a</i></p> <p>c. <input type="checkbox"/> <i>Yes, Puerto Rican</i></p> <p>d. <input type="checkbox"/> <i>Yes, Cuban</i></p> <p>e. <input type="checkbox"/> <i>Yes, Another Hispanic, Latino, or Spanish origin</i></p>	<p>These categories roll-up to the Hispanic or Latino category of the OMB standard</p>
Race Data Standard	Categories
<p><i>What is your race? (One or more categories may be selected)</i></p> <p>a. <input type="checkbox"/> <i>White</i></p> <p>b. <input type="checkbox"/> <i>Black or African American</i></p> <p>c. <input type="checkbox"/> <i>American Indian or Alaska Native</i></p>	<p>These categories are part of the current OMB standard</p>
<p>d. <input type="checkbox"/> <i>Asian Indian</i></p> <p>e. <input type="checkbox"/> <i>Chinese</i></p> <p>f. <input type="checkbox"/> <i>Filipino</i></p> <p>g. <input type="checkbox"/> <i>Japanese</i></p> <p>h. <input type="checkbox"/> <i>Korean</i></p> <p>i. <input type="checkbox"/> <i>Vietnamese</i></p> <p>j. <input type="checkbox"/> <i>Other Asian</i></p>	<p>These categories roll-up to the Asian category of the OMB standard</p>
<p>k. <input type="checkbox"/> <i>Native Hawaiian</i></p> <p>l. <input type="checkbox"/> <i>Guamanian or Chamorro</i></p> <p>m. <input type="checkbox"/> <i>Samoan</i></p> <p>n. <input type="checkbox"/> <i>Other Pacific Islander</i></p>	<p>These categories roll-up to the Native Hawaiian or Other Pacific Islander category of the OMB standard</p>

C. Primary Language

The standard for primary language is a measure of English proficiency. The recommended question is based on that used on the U.S. Census Bureau's, American Community Survey (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

For agencies that wish to collect data on the specific language spoken, the Data Council recommends collecting data on language spoken at home. The recommended survey items are used in the ACS (see below). Collecting this additional information would be optional and at the discretion of the agency, if information on specific language was desired.

Data Collection for Spoken Language

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)*

For agencies that desire to collect information on specific languages beyond Spanish, and have sufficient sample sizes to support such estimates, HHS would publish on the HHS website a list of the ten most prevalent languages spoken in the U.S., as reported by ACS. These would roll up to the "Other Language" category, and provide technical notes to assist in coding. Spanish as a category is reported about 60 percent of the time in the ACS.^{[vi](#)}

Table 2. Current practices regarding data collection on race, ethnicity and primary language on California health forms

	Medi-Cal	Healthy Families	PCIP/MRMIP
Language on the form	What language/dialect do you speak best? What language do you read best?	What language do you want us to speak to you in? What language should we write to you in?	What language do you want us to use when speaking with you? What language should we use when writing to you?
Race, Ethnicity questions	Ethnicity (race) (optional) for each member of the family	Ethnicity(optional): see page 6	
Race, Ethnicity instructions for answering questions	You can choose to enter the Ethnicity (race) for each person. This information is used for statistics only and has no effect on your eligibility for Medi-Cal.	What do I write for ethnicity? Write the ethnic group that the child or pregnant woman belongs to. Here is a list that may help: Alaska Native Hispanic Amerasian Japanese Asian Indian Korean Black/African-American Laotian Cambodian Native American Indian Chinese Other Asian Filipino Samoan Guamanian Vietnamese Hawaiian White Other	Tell us about your ethnicity: White Black, African American Hispanic: Cuban Mexican Mexican American Puerto Rican Other Hispanic_____ Asian: Asian Indian Cambodian Chinese Japanese Amerasian Korean Laotian Vietnamese Filipino Other Asian_____ Pacific Islander: Hawaiian Guamanian Samoan Other Pacific Islander_____ Aleut /Alaska Native American Indian Native American Eskimo Other, not listed above_____

Table 3. Sample list of 2010 U.S. Census/American Community Survey generated Race/Ethnicity categories for California

Hispanic or Latino

Mexican	11,423,146
Salvadoran	573,956
Guatemalan	332,737
Puerto Rican	189,945
Nicaraguan	100,790
Peruvian	91,511
Cuban	88,607
Honduran	72,795
Colombian	64,416
Argentinean	44,410
Ecuadorian	35,750
Chilean	24,006
Costa Rican	22,469
Panamanian	17,768
Bolivian	13,351
Dominican (Dominican Republic)	11,455
Venezuelan	11,100
Uruguayan	4,110
Paraguayan	1,228
Other Central American	14,719
Other South American	5,826
All other Hispanic or Latino	151,614

African American alone or in combination

Black or African American	2,683,914
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American Indian/Alaska Native alone or in combination

American Indian/Alaska Native	723,225
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Asian

Filipino	1,195,580
Chinese (except Taiwanese)	1,150,206
Vietnamese	581,946
Asian Indian	528,176
Korean	451,892
Japanese	272,528
Taiwanese	96,009
Hmong	86,989
Cambodian	86,244
Laotian	58,424
Thai	51,509
Pakistani	46,780
Indonesian	25,398
Burmese	15,035
Sri Lankan	10,240
Bangladeshi	9,268
Nepalese	5,618
Malaysian	2,979
Bhutanese	694

Pacific Islander

Samoan	40,900
Guamanian or Chamorro	24,299
Native Hawaiian	21,423
Fijian	19,355
Tongan	18,329
Marshallese	1,559

Table 4. Ancestry, 2000 American Community Survey

Acadian/Cajun	Guyanese	African
Afghan	Hungarian	Other Subsaharan African
Albanian	Icelander	
Alsatian	Iranian	Swedish
	Irish	Swiss
Arab:	Israeli	Turkish
Egyptian	Italian	Ukrainian
Iraqi	Latvian	United States or American
Jordanian	Lithuanian	Welsh
Lebanese	Luxemburger	
Moroccan	Macedonian	West Indian (excluding
Palestinian	Maltese	Hispanic origin groups):
Syrian	New Zealander	Bahamian
Arab/Arabic	Northern European	Barbadian
Other Arab	Norwegian	Belizean
	Pennsylvania German	Bermudan
Armenian	Polish	British West Indian
Assyrian/Chaldean/Syriac	Portuguese	Dutch West Indian
Australian	Romanian	Haitian
Austrian	Russian	Jamaican
Basque	Scandinavian	Trinidadian and
Belgian	Scotch-Irish	Tobagonian
Brazilian	Scottish	U.S. Virgin Islander
British	Serbian	West Indian
Bulgarian	Slavic	Other West Indian
Canadian	Slovak	
Carpatho Rusyn	Slovene	Yugoslavian
Celtic	Soviet Union	Other groups
Croatian		
Cypriot	Subsaharan African:	
Czech	Cape Verdean	
Czechoslovakian	Ethiopian	
Danish	Ghanian	
Dutch	Kenyan	
Eastern European	Liberian	
English	Nigerian	
Estonian	Senegalese	
European	Sierra Leonean	
Finnish	Somalian	
French (except Basque)	South African	
French Canadian	Sudanese	
German	Ugandan	
German Russian	Zairian	
Greek	Zimbabwean	

Table 5. Institute of Medicine (IOM) Sample list of Languages Spoken taken from National U.S. Census

- African languages
- American Sign Language
- Arabic
- Armenian
- Chinese
- French
- French Creole
- German
- Greek
- Gujarathi
- Hebrew
- Hindi
- Hungarian
- Italian
- Japanese
- Korean
- Laotian
- Hmong
- Mon-Khmer Cambodian
- Other native North American languages
- Persian
- Polish
- Portuguese
- Portuguese Creole
- Russian
- Scandinavian languages
- Serbo-Croatian
- Spanish
- Tagalog
- Thai
- Urdu
- Vietnamese
- Yiddish
- Availability of Sign Language or other auxiliary aids or services
- Other, please specify: ____
- Do not know
- Unavailable/Unknown
- Declined