AB 1296 Stakeholder Meeting – May 3, 2012

Recommendations on Data Collection for
Race, Ethnicity, Primary Language, Disability Status, Gender and Sexual Orientation

Introduction: California has an important opportunity to take the lead in increasing access to quality health care services and eliminating health disparities by both implementing and building upon the new federal data standards set forth under the ACA. 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.[1][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. The tables below reflect recommendations of the California Pan-Ethnic Health Network (CPEHN), Disability Rights and Education Defense Fund (DREDF) and Equality California (EQCA) for state standards for collecting data on race, ethnicity, primary language, disability status, gender and sexual orientation.

Collecting Optional Demographic Information: Questions that deal with eligibility determinations and accessibility issues (e.g. disability status, oral interpretation, translation assistance, sex) should be considered mandatory questions asked at the front end of the application. Optional questions pertaining to demographic information (e.g. race, ethnicity, gender identity and sexual orientation) should be asked at the end of the application so as not to discourage anyone from filling out the rest of the form. A statement clarifying that the question is voluntary and will only be used to ensure equal access to quality care for everyone should be included as part of the instructions to recipients. We recommend the following statement:

> ***Demographic Information (optional):*** *Please tell us about yourself. This information is confidential and will only be used to make sure that everyone has the same access to health care. It will not be used to decide what health program you are eligible for.*

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[1] "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
[2] "The Health of Lesbian, Gay, Bisexual and Transgender People; Building a Foundation for Better Understanding," Institute of Medicine (IOM), March 21, 2011, http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx. For further information go to: http://books.nap.edu/openbook.php?record_id=13128&page=95

TABLE 1: Race/Ethnicity/Primary Language Data Recommendations

Race/Ethnicity/Primary Language	Recommendation(s)	Suggested Question(s)
Hispanic Ethnicity	***OMH guidance recommends separate questions on race and ethnicity which California should adopt:*** "To provide flexibility and ensure data quality, separate questions for race and ethnicity should be used wherever feasible. Specifically, when self-reporting or other self-identification approaches are used, ethnicity is asked first, and then race."[3] ***CPEHN recommends:*** Use the U.S. Census 2010 Q5. to ask about Hispanic Ethnicity followed by an accessible drop-down menu of other Hispanic Ethnicity categories not included in Q5. These should be based on U.S. Census/ACS generated data on Race/Ethnicity categories for California as shown.	**U.S. Census Bureau** Census 2010 Form http://2010.census.gov/2010census/about/interactive-form.php **Q5 Is this person 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 origin, for example, Argentinean, Colombian, Dominican, Nicaraguan, Salvadoran, Spaniard, and so on.* _____ **Drop-Down Menu (from Table 3. CPEHN Brief)** **Hispanic or Latino** — **CA Population** 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

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[3] *"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

		Paraguayan 1,228 Other Central American 14,719 Other South American 5,826 All other Hispanic or Latino 151,614
Race	***HHS expands the categories of race and ethnicity:*** The new HHS data standards for race and ethnicity include additional granularity, but all categories roll-up to the OMB standards. These new categories which are based on the ACS and U.S. Census categories provide additional granularity for Hispanic (four additional categories) and Asian subpopulations (7 additional categories) beyond the OMB minimum standard categories. ***CPEHN recommends:*** Use the U.S. Census 2010 Question 6. on race which includes the new HHS categories. To reflect California's demographics under Asian add three additional checkboxes for Hmong, Cambodian and Laotian. Insert drop-down menus for "Asian Other" and "Pacific Islander Other" categories.	**U.S. Census Bureau** Census 2010 Form http://2010.census.gov/2010census/about/interactive-form.php **Q6 What is this person's race? *Mark one or more boxes.*** ☐ White ☐ Black, African Am., or Negro ☐ American Indian or Alaska Native - *Print name of enrolled or principal tribe.* _____ ☐ Asian Indian ☐ Japanese ☐ Native Hawaiian ☐ Chinese ☐ Korean ☐ Guamanian or Chamorro ☐ Filipino ☐ Vietnamese ☐ Samoan ☐ ***Hmong*** ☐ ***Cambodian*** ☐ ***Laotian*** ☐ Other Asian - *Print race, for example, Hmong, Laotian, Thai, Pakistani, Cambodian, and so on.* ☐ Other Pacific Islander – *Print race, for example, Fijian, Tongan, and so on.* _____ _____ ☐ Some other race - *Print race.* _____ **Drop-Down Menu (from Table 3. CPEHN Brief)** **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	
Granular Ethnicity (Ancestry)	***OMH guidance encourages the collection of additional granular ethnicity data*** as long as the additional detail can be aggregated back to the minimum standard set of race and ethnicity categories. ***CPEHN recommends:*** Use U.S. Census data Q 13. Include a drop-down menu of Granular Ethnicity (Ancestry) questions based on 2000 American Community Survey Ancestry	**U.S. Census Bureau** Census 2010 Form http://2010.census.gov/2010census/about/interactive-form.php **Q13. What is this person's ancestry or ethnic origin?** _____ (For example: Italian, Jamaican, African Am., Cambodian, Cape Verdean, Norwegian, Dominican, French Canadian, Haitian, Korean, Lebanese, Polish, Nigerian, Mexican, Taiwanese, Ukrainian, and so on.) **Drop-Down Menu (from Table 4. CPEHN Brief)**		

Acadian/Cajun	Guyanese	African
Afghan	Hungarian	Other
Albanian	Icelander	Subsaharan
Alsatian	Iranian	African
	Irish	

	data. Note: The Institute of Medicine (IOM) has recommendations for how to code Granular Ethnicity so the categories can be aggregated back to the minimum standard set of race and ethnicity categories (see IOM Report Table E-1 based on CDC codes).	Arab: Egyptian Iraqi Jordanian Lebanese Moroccan Palestinian Syrian Arab/Arabic Other Arab Armenian Assyrian/Chaldean/Syriac Australian Austrian Basque Belgian Brazilian British Bulgarian Canadian Carpatho Rusyn Celtic Croatian Cypriot Czech Czechoslovakian Danish Dutch Eastern European English Estonian European Finnish French (except Basque) French Canadian German German Russian Greek	Israeli Italian Latvian Lithuanian Luxemburger Macedonian Maltese New Zealander Northern European Norwegian Pennsylvania German Polish Portuguese Romanian Russian Scandinavian Scotch-Irish Scottish Serbian Slavic Slovak Slovene Soviet Union Subsaharan African: Cape Verdean Ethiopian Ghanian Kenyan Liberian Nigerian Senegalese Sierra Leonean Somalian South African Sudanese Ugandan Zairian Zimbabwean	Swedish Swiss Turkish Ukrainian United States or American Welsh West Indian (excluding Hispanic origin groups): Bahamian Barbadian Belizean Bermudan British West Indian Dutch West Indian Haitian Jamaican Trinidadian and Tobagonian U.S. Virgin Islander West Indian Other West Indian Yugoslavian Other groups	

Language	**OMH guidance mandates a standard question on primary language and encourages additional granularity to record language spoken.** The standard is based on the ACS, which assesses both English proficiency and language spoken other than English, and has been collected by the Census Bureau since 1980. The questions are necessary for research and clinical purposes. This recommendation is consistent with language recommendations from the Institute of Medicine report *Race, Ethnicity, and Language Data Collection: Standardization for Health Care Quality Improvement*. **CPEHN recommends:** CA should continue asking about spoken and written language preferred. Add another question on language proficiency. All three questions should be mandatory as they assess accessibility and communication needs of applicants and enrollees.	**Medi-Cal/HFP/PCIP question(s):** What language do you want us to speak to you in? What language should we write to you in? **Additional OMH Question:** *How well do you speak English? (5 years old or older)* a. ____*Very well* b. ____*Well* c. ____*Not well* d. ____*Not at all*

TABLE 2. Disability Status Recommendations

Disability Status	Suggested Questions

Accessibility/Communication Assessment – Mandatory Questions	**Accessibility/Communication Assessment – Mandatory questions**
	• *Incorporate the following questions into information requested of the person applying on their own and/or a family member/child's behalf to enable eligibility workers to provide reasonable accommodations or modifications needed during the application process.*
	  - If you have difficulty hearing spoken language or speaking, what translation assistance do you need for effective communication?
	  - If you have difficulty (even with glasses) seeing, reading, or understanding written language, what alternative format do you need for effective communication?
	  - Do you have difficulty concentrating, remembering, or making decisions due to a physical, mental, emotional, or developmental condition?
	
	• *A non-exhaustive list of examples of "translation assistance" and "alternative formats" should accompany the above questions, as a page link or accessible "drop down menu" from the online application, and in the accompanying instructions in paper applications. Representatives taking applications by phone should also be trained to provide the examples when assisting individuals with making a phone application. Examples of "translation assistance" include* Qualified sign language interpreters, qualified notetakers, computer-aided transcription services, written materials, telephone handset amplifiers, assistive listening devices or systems, telephones compatible with hearing aids, closed caption decoders, telecommunications devices for deaf persons (TDD's), videotext displays, speech-to-speech relay services, or other means of making oral interactions available to individuals with hearing or speech impairments. Examples of "alternative formats" include Qualified readers, taped texts, audio recordings, Brailled materials, large print materials, electronic formats, or other effective methods of making visually delivered materials available to individuals with visual or print comprehension impairments.
	
	• *The instructions should also explain the kinds of accommodations that can be provided for someone who indicates cognitive processing difficulties due to a physical, mental, emotional, or developmental condition* (e.g., appointments for in-person consultation, extended timelines for, or assistance with, gathering needed reference materials or documents, etc.)

Eligibility Determination – Mandatory Question	**Eligibility Determination – Mandatory Question** • *Replace wording in the current Medi-Cal, Healthy Families, and other California health subsidy program applications relating to the applicant and/or a family member/child having a "physical, mental, emotional or developmental disability" as follows:* Does the person have " difficulty hearing or seeing, or difficulty performing the following functions at an age appropriate level: concentrating, remembering, making decisions, engaging in common social interactions and conversation, walking or climbing stairs, maintaining motor control or holding still, dressing or

bathing, or doing errands alone.

- ***Replace the "Disability expected to last" component of the disability question with*** "Impairment expected to last?"

The above questions are derived from the six 2011 American Community Survey (ACS) questions relating to disability that have also been proposed in the federal Department of Health and Human Service (HHS) Notice of Proposed Rulemaking concerning the data collection requirements in Section 4302 of the Affordable Care Act (ACA). The "ACS six" describe the functional limitations that accompany disabilities rather than use the unexplained term "disability," which has untoward connotations and stigma for many individuals. The ACS questions have been federally tested as a means of data collection on disability status, and are written out in the disability status section of the April 28, 2011 data collection letter prepared by the Leadership Conference on Civil and Human Rights, at pp. 12-13. At the same time, the ACS questions have some recognized limitations for capturing certain groups of people with speech, developmental, learning, neurological, and mental health disabilities (*see* August 1, 2011 letter from DREDF to HHS Secretary Kathleen Sebelius concerning data collection standards under Section 4302 of the ACA for additional information). The above questions recommended here are modified in recognition of these limitations in the ACS questions, as well as the fact that application forms require brevity.

Other Issues:
- ***Use of Drop-Down Menus:*** The state can choose various options for ensuring accessibility including breaking the form up into steps and displaying additional optional or related lists 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/).

TABLE 3. Gender Identity and Sexual Orientation Recommendations

Gender and Sexual Orientation	Suggested Question(s)
Sexual Orientation	Adopt the question in development by the federal Department of Health and Human Service (HHS) Data Council, and the National Center for Health Statistics, for standardization of LGBT data collection. http://minorityhealth.hhs.gov/templates/content.aspx?lvl=2&lvlid=209&id=9004#A
Gender Identity	Some people describe themselves as transgender when they experience a different gender identity from their sex at birth. For example, a person born into a male body, but who feels female or lives as a woman. Do you consider yourself to be transgender? [ ] Yes [ ] No [ ] Don't know/not sure (from the Massachusetts Executive Office of Health and Human Services, Health Behavioral Risk Factor Surveillance System, http://www.mass.gov/eohhs/docs/dph/behavioral-risk/survey-11.pdf)