

UPDATED April 26, 2012

**RACE, ETHNICITY, LANGUAGE, DISABILITY, AND OTHER DEMOGRAPHIC DATA
COLLECTION IN CALIFORNIA HEALTH BENEFIT EXCHANGE**

**AB 1296 STAKEHOLDER MEETING
MAY 3, 2012**

**RACE, ETHNICITY, LANGUAGE, DISABILITY, GENDER, AND BIRTHPLACE
DATA COLLECTION IN CURRENT MEDI-CAL APPLICATION FORM**

<http://www.dhcs.ca.gov/services/medi-cal/pages/medicalapplications.aspx>

Q14A. What language/dialect do you speak best?

Q14B. What language do you read best?

Instructions for Q14A-B: Enter the language you speak and/or read best.

Q15. Gender Male Female

Q23. Has a physical, medical or emotional disability? Yes No

Disability expected to last 30 days or More 12 months or More

Q49. Place of birth

State or country:

Q56: Ethnicity (race) (optional):

Instructions for Q56: 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.

**RACE, ETHNICITY, LANGUAGE, DISABILITY, GENDER, AND BIRTHPLACE
DATA COLLECTION IN CURRENT HEALTHY FAMILIES APPLICATION FORM**

<http://www.healthyfamilies.ca.gov/downloads/applications.aspx>

Q6. What language do you want us to speak to you in?

Q7. What language should we write to you in?

Q15. Gender Boy Girl

Q16. Ethnicity - Optional:

Instructions for Q16: 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	

Q17. Birthplace

County:

State:

Or foreign country:

Q39. Does any child or other person in the home have a physical, mental, emotional or developmental disability and want Medi-Cal? Yes No

If yes, who? _____ (If you answer Yes, we will contact you to see if you qualify.)

Q51. Check all boxes that describe you:

Native American Indian
[for Special Population Plans]

**RACE, ETHNICITY, LANGUAGE, DISABILITY, AND GENDER
DATA COLLECTION IN CURRENT CALIFORNIA PRE-EXISTING CONDITION INSURANCE
PLAN/MAJOR RISK MEDICAL INSURANCE PROGRAM APPLICATION FORM**

<http://www.mrmib.ca.gov/MRMIB/MRMIP.html>

Section 1

Gender Female Male

Household information (optional)

What language do you want us to use when speaking with you?

What language should we use when we write to you?

Tell us about your ethnicity (optional)

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_____

Section 6

For PCIP: Have you received a letter from a licensed doctor, physician assistant, or nurse practitioner within the past 12 months, stating the individual has or had a medical condition, disability or illness? Yes No

If Yes, provide a copy of the provider letter.

**FEDERAL AND NATIONAL REQUIREMENTS AND STANDARDS FOR
COLLECTION OF RACE, ETHNICITY, LANGUAGE, DISABILITY, AND OTHER
DEMOGRAPHIC DATA**

U.S. Department of Health and Human Services

Centers for Medicare & Medicaid Services

Final Rule on Establishment of Exchanges and Qualified Health Plans

76 Fed. Reg. 18310-18475 (March 27, 2012)

<http://www.gpo.gov/fdsys/pkg/FR-2012-03-27/pdf/2012-6125.pdf>

45 CFR § 155.315 Verification process related to eligibility for enrollment in a QHP through the Exchange.

(i) Applicant information. The Exchange must not require an applicant to provide information beyond the minimum necessary to support the eligibility and enrollment processes of the Exchange, Medicaid, CHIP, and the BHP, if a BHP is operating in the service area of the Exchange, described in this subpart.

76 Fed. Reg. at 18341

Comment: Two commenters stated that HHS should be able to collect demographic information on a voluntary basis through the Exchange. Commenters believe that collection of demographic information would help to provide essential health information on vulnerable or underserved populations, facilitate tailored outreach and aid in enrollment activities, and provide input in the development of prevention and health care programming that address disparities.

Response: Section 1411(g) of the Affordable Care Act does not prohibit the collection of demographic data. We respond to this issue in greater depth in the preamble to § 155.405, which addresses the single, streamlined application.

76 Fed. Reg. at 18386

Comment: Numerous commenters urged HHS to add language to proposed § 155.405 stating that the standard single streamlined application should not include questions that are not pertinent to the eligibility and enrollment process. Other commenters wanted to ensure that the application will collect demographic information beyond what is established in the statute.

Response: The Exchange eligibility proposed rule and this final rule at § 155.315(g) [sic: should be § 155.315(i)] prohibit Exchanges from requiring information beyond the minimum necessary to support eligibility determinations for the Exchange and insurance affordability programs. This provision limits the application to information that is pertinent to the eligibility and enrollment process.

76 Fed. Reg. at 18314

Comment: Several commenters recommended we adopt the broad, U.S. Census data definition for “limited English proficient” which is “an individual whose primary language is not English and who speaks English less than very well.”

Response: In the final rule, we do not adopt a definition for the phrase “limited English proficient.” We anticipate issuing future guidance that will interpret this term and will provide best practices and advice related to meaningful access standards for limited English proficient individuals.

**U.S. Department of Health and Human Services
Centers for Medicare & Medicaid Services**

Final Rule on Medicaid Program Eligibility Changes under the Affordable Care Act of 2010

76 Fed. Reg. 17144-17217 (March 23, 2012)

www.gpo.gov/fdsys/pkg/FR-2012-03-23/pdf/2012-6560.pdf

42 CFR § 435.907 Application.

(e) Limits on information.

(1) The agency may only require an applicant to provide the information necessary to make an eligibility determination or for a purpose directly connected to the administration of the State plan.

76 Fed. Reg. at 17165

Comment: A number of commenters requested that we codify in regulation that a State cannot require information that is not necessary to determine eligibility, including asking that we amend our regulations to preclude a State from “requesting” information from a non-applicant about his or her citizenship or immigration status. A number of commenters expressed concern that any inquiry about citizenship or immigration status will have a chilling effect on eligible applicants living with household members who are not applying for coverage.

Response: States may only require information that is necessary to make an eligibility determination or that is directly connected to administration of the State plan and we are codifying

this longstanding policy in regulation text in revised § 435.907(e)(1) of the final rule. In § 435.907(e)(2), we clarify that, in addition, a State may request information necessary to determine eligibility for another insurance affordability program or other benefit program. States may not request information regarding a non-applicant's citizenship or immigration status under this rule.

Office of Management and Budget

Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity
62 Fed. Reg. 58782-58790 (October 30, 1997)
<http://www.gpo.gov/fdsys/pkg/FR-1997-10-30/pdf/97-28653.pdf>

Standards for race and ethnicity data collection for all federally sponsored programs and services

Ethnicity:

- * Hispanic or Latino
- * Not Hispanic or Latino

Race:

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

Respondents shall be offered the option of selecting one or more racial designations. Recommended forms for the instruction accompanying the multiple response question are "Mark one or more" and "Select one or more."

Self-reporting or self-identification using two separate questions is the preferred method for collecting data on race and ethnicity.

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; however, any collection that uses more detail shall be organized in such a way that the additional categories can be aggregated into these minimum categories for data on race and ethnicity.

U.S. Department of Commerce

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.*
-

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

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.*

U.S. Department of Commerce

U.S. Census Bureau

American Community Survey (2012 Questionnaire)

http://www.census.gov/acs/www/methodology/questionnaire_archive/

[SAME ETHNICITY AND RACE QUESTIONS AS CENSUS 2010]

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.)

Q14a. Does this person speak a language other than English at home?

Yes

No

Q14b. What language

For example: Korean, Italian, Spanish, Vietnamese

Q14c. How well does this person speak English?

Very well

Well

Not well

Not at all

U.S. Department of Health and Human Services

Centers for Medicare & Medicaid Services

67 Fed. Reg. 40989-41116 (June 14, 2002)

<http://www.gpo.gov/fdsys/pkg/FR-2002-06-14/pdf/02-14747.pdf>

42 CFR section 438.204(b)(2)

States must provide Medicaid managed care organizations and health plans with the race, ethnicity, and primary language of Medicaid beneficiaries.

**U.S. Department of Health and Human Services
Centers for Medicare & Medicaid Services**

Final Rule for Medicare and Medicaid Program Electronic Health Record Incentive Program
75 Fed. Reg. 44314-44588 (July 28, 2010)
<http://www.gpo.gov/fdsys/pkg/FR-2010-07-28/pdf/2010-17207.pdf>

Requirements for hospitals and eligible providers for HITECH Act electronic health records
incentive payments under Medicaid and Medicare
42 CFR Sections 495.6(d)(7) and (f)(6)
Record patient demographics, including race, ethnicity, preferred language for >50% patients

Proposed Rule for Electronic Health Record Incentive Program Stage 2 Meaningful Use
Requirements
77 Fed. Reg. 13698-13829 (March 7, 2012)
<http://www.regulations.gov/#!documentDetail;D=CMS-2012-0022-0001>

Requirements for hospitals and eligible providers for HITECH Act electronic health records
incentive payments under Medicaid and Medicare
Proposed 42 CFR Section 495.6(j)(3) and 495.6(l)(2)
Record patient demographics, including race, ethnicity, preferred language for >80% patients

**U.S. Department of Health and Human Services
Office of National Coordinator for Health Information Technology**

Final Rule for Initial Set of Standards, Implementation Specifications, and Certification Criteria for
Electronic Health Record Technology
75 Fed. Reg. 44590-44654 (July 28, 2010)
<http://www.gpo.gov/fdsys/pkg/FR-2010-07-28/pdf/2010-17210.pdf>

Requirements for HITECH Act certified electronic health records
45 CFR Section 170.207 Vocabulary standards for representing electronic health information
The Secretary adopts the following code sets, terminology, and nomenclature as the vocabulary
standards for the purpose of representing electronic health information:
(f) Race and Ethnicity. Standard. The Office of Management and Budget Standards for
Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity, Statistical Policy
Directive No. 15, October 30, 1997.

Proposed Rule for ONC Certification of Electronic Health Records
77 Fed. Reg. 13832-13885 (March 7, 2012)
<http://www.regulations.gov/#!documentDetail;D=HHS-OS-2012-0004-0001>

Proposed 45 CFR Section 170.207(f)
Continues use of OMB standards for race and ethnicity

Proposed 45 CFR Section 170.207(j) Preferred language. Standard.
ISO 639-1:2002 (incorporated by reference in section 170.299).

International Standards Organization (ISO) 639-1
But see ISO 639-2 (uses three alpha characters vs. the two alpha characters in ISO 639-1)
http://www.loc.gov/standards/iso639-2/php/code_list.php

**U.S. Department of Health and Human Services
Office of Minority Health**

National Standards for Culturally and Linguistically Appropriate Services (2000)
<http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15>

Standard 10: Health care organizations should ensure that data on the individual
patient's/consumer's race, ethnicity, and spoken and written language are collected in health

records, integrated into the organization's management information systems, and periodically updated.

U.S. Department of Health and Human Services

Office of Minority Health

Data Standards for Federal Health Surveys (ACA section 4302)

<http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=208>

These standards only apply to federal and federally-funded health surveys (such as the National Health Interview Survey); they are not yet applicable to health care organizations or patient data collection

Ethnicity

Are you Hispanic, Latino/a, or Spanish origin

(one or more categories may be selected)

- a. No, not of Hispanic, Latino/a, or Spanish origin
- b. Yes, Mexican, Mexican American, Chicano/a
- c. Yes, Puerto Rican
- d. Yes, Cuban
- e. Yes another Hispanic, Latino, or Spanish origin

Race

What is your race?

(one or more categories may be selected)

- a. White
- b. Black or African American
- c. American Indian or Alaska Native

- d. Asian Indian
- e. Chinese
- f. Filipino
- g. Japanese
- h. Korean
- i. Vietnamese
- j. Other Asian

- k. Native Hawaiian
- l. Guamanian or Chamorro
- m. Samoan
- n. Other Pacific Islander

Preferred Language

How well do you speak English? (5 years old or older)

- Very well
- Well
- Not well
- Not at all

Do you speak a language other than English at home? (5 years old or older)

- Yes
- No

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

What is this language? (5 years old or older)

- Spanish
- Other Language (Identify)

Sex

What is your sex?

- a. Male
- b. Female

Disability Status

1. Are you deaf or do you have serious difficulty hearing?
 - a. Yes
 - b. No
2. Are you blind or do you have serious difficulty seeing even when wearing glasses?
 - a. Yes
 - b. No
3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years or older)
 - a. Yes
 - b. No
4. Do you have serious difficulty walking or climbing stairs? (5 years or older)
 - a. Yes
 - b. No
5. Do you have difficulty dressing or bathing? (5 years or older)
 - a. Yes
 - b. No
6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years or older)
 - a. Yes
 - b. No

Sexual Orientation and Gender Identity

<http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=209>

As part of its implementation of section 4302, HHS is developing data collection standards based on sexual orientation and gender identity

Institute of Medicine

Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement (2009)

<http://iom.edu/Reports/2009/RaceEthnicityData.aspx>

OMB Hispanic Ethnicity

- Hispanic or Latino
- Not Hispanic or Latino

OMB Race

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

Granular ethnicity

- Locally relevant choices from a national standard list with CDC/HL7 codes
- Other, please specify: _____
- Roll-up to OMB categories

Recommendation 3-1: An entity collecting data from individuals for purposes related to health and health care should:

- Collect data on granular ethnicity using categories that are applicable to the populations it serves or studies. Categories should be selected from a national standard list on the basis of health and health care quality issues, evidence or likelihood or disparities, or size of subgroups within the population. The selection of categories should also be informed by analysis of relevant data (e.g. Census data) on the service or study population. In addition, an open-ended option of “Other, please specify: _____” should be provided for persons whose granular ethnicity is not listed as a response option
- Elicit categorical responses consistent with the current OMB standard race and Hispanic ethnicity categories, with the addition of a response option of “Some other race” for persons who do not identify with the OMB race categories.

Recommendation 3-2: Any entity collecting data from individuals for purposes related to health and health care should collect granular ethnicity data in addition to data in the OMB race and Hispanic ethnicity categories and should select the granular ethnicity categories to be used from a national standard set. When respondents do not self-identify as one of the OMB race categories or do not respond to the Hispanic ethnicity question, a national scheme should be used to roll up the granular ethnicity categories to the applicable broad OMB race and Hispanic ethnicity categories to the extent feasible.

Appendix E: Developing a National Standard Set of Granular Ethnicity Categories and Rollup Scheme

http://www.nap.edu/catalog.php?record_id=12696

Spoken English proficiency

- Very well
- Well
- Not well
- Not at all

(Limited English proficiency is defined as less than “very well”)

Spoken language preferred for health care

- Locally relevant choices from a national standard list
- Other, please specify: _____
- Inclusion of sign language in spoken language need list and Braille when written language is elicited

Recommendation 4-1: To assess patient/consumer language and communication needs, all entities collecting data from individuals for purposes related to health and health care should:

- At a minimum, collect data on an individual’s assessment of his/her level of English proficiency and on the preferred spoken language needed for effective communication with health care providers. For health care purposes, a rating of spoken English-language proficiency of less than very well is considered limited English proficiency.
- Where possible and applicable, additionally collect data on the language spoken by the individual at home and the language in which he/she prefers to receive written materials.

Recommendation 4-2: The choice of response categories for spoken and written language questions should be informed by analysis of relevant data on the service area (e.g. Census data) or service population, and any response list should include an option of “Other, please specify: _____” for persons whose language is not listed.

Recommendation 4-3: When any health care entity collects language data, the languages used as response options or categories should be selected from a national standard set of languages in use in the United States. The national standard set should include sign language(s) for spoken language and Braille for written language.

National Quality Forum

Comprehensive Framework and Preferred Practices for Measuring and Reporting Cultural Competency (2009)

http://www.qualityforum.org/projects/cultural_competency.aspx

Preferred Practice 36: Utilize the Health Research & Educational Trust Disparities Toolkit to collect patient race/ethnicity data and primary written and spoken language data from patients in a systematic, uniform manner.

Preferred Practice 37: Ensure that, at minimum, data on an individual patient's race and ethnicity (using the Office of Management and Budget categories as modified by HRET) and primary written and spoken language are collected in health records and integrated into the organization's management information system. Periodically update the language information.

Health Research & Educational Trust Disparities Toolkit

<http://www.hretdisparities.org/>

Endorsed by National Quality Forum to collect race and ethnicity data

Ethnicity

(OMB recommends asking ethnicity before race)

Are you Hispanic, Latino, or Spanish origin?

*No, not of Hispanic, Latino, or Spanish origin

- Yes, Mexican, Mexican American, Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latino, or Spanish origin

*Declined

*Unavailable/Unknown

Race

Which category best describes your race? (One or more categories may be marked)

- American Indian/Alaska Native
- Asian
- Black or African American
- Native Hawaiian/Other Pacific Islander
- White
- Some other race
- Declined
- Unavailable/Unknown

Suggested granular ethnicity categories:

<http://www.hretdisparities.org/Howt-4176.php#4274>

Language

1. How well do speak English?

- Very Well
- Well
- Not Well
- Not at all
- Declined
- Unavailable

2. Would you like an interpreter?

- Yes
- No
- Don't know
- Declined
- Unavailable

3. Do you speak a language other than English (5 years old or older)

- Yes
- No
- Declined
- Unavailable

4. What is this language? (5 years old or older)

- Spanish
- Other language (identify)
- Declined
- Unavailable

5. What language do you feel most comfortable speaking with your doctor or nurse?

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

6. In which language would you feel most comfortable reading medical or health care instructions?

African languages	Hungarian	Russian
American Sign Language	Italian	Scandinavian languages
Arabic	Japanese	Serbo-Croatian
Armenian	Korean	Spanish
Chinese	Laotian	Tagalog
English	Miao Hmong Mon-Khmer	Thai
French	Cambodian	Urdu
French Creole	Navajo	Vietnamese
German	Other Native North American languages	Yiddish
Greek	Persian	Availability of Sign Language or other auxiliary aids or services

Gujarathi Hebrew Hindi	Polish Portuguese Portuguese Creole	Other, please specify: ____ Do not know Unavailable Declined
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7. How satisfied are you with your ability to read English?

- Very satisfied
- Somewhat satisfied
- Satisfied
- Somewhat dissatisfied
- Very dissatisfied
- Declined
- Unavailable

**CALIFORNIA REQUIREMENTS AND STANDARDS FOR
COLLECTION OF DATA ON RACE, ETHNICITY, AND LANGUAGE**

Assembly Bill 1296

California Welfare and Institutions Code Section 15925(b)(3)

The planning and development process shall consider issues, including, but not limited to, all of the following:

(D) What data collection standards to utilize for the collection of race, ethnicity, primary language, and disability status.

California Welfare and Institutions Code Section 15926(c)(1)

A single, accessible, standardized paper, electronic, and telephone application for state health subsidy programs shall be developed by the department in consultation with MRMIB and the board governing the Exchange as part of the stakeholder process described in subdivision (b) of Section 15925. The application shall be used by all entities authorized to make an eligibility determination for any state health subsidy programs and by their agents.

(c)(3)

The application form shall, to the extent not inconsistent with federal statutes, regulations, and guidance, satisfy all of the following criteria:

(F) Include questions that are voluntary for applicants to answer regarding demographic data categories, including race, ethnicity, primary language, disability status, and other categories recognized by the federal Secretary of Health and Human Services under Section 4302 of the PPACA

California Insurance Code Section 10141

No application for insurance or insurance investigation report furnished by such an insurer to its agents or employees for use in determining the insurability of the applicant shall carry any identification, or any requirement therefor, of the applicant's race, color, religion, ancestry, national origin, or sexual orientation.

Assembly Bill 1088

California Government Code Section 8310.5(a)

All state agencies must use separate collection categories for at least Chinese, Japanese, Filipino, Korean, Vietnamese, Asian Indian, Laotian, and Cambodian for Asians

State agencies must use separate collection categories for at least Hawaiian, Guamanian, and Samoan for Pacific Islanders

California Government Code Section 8310.7

Department of Industrial Relations and Department of Fair Employment and Housing must use additional categories for Bangladeshi, Hmong, Indonesian, Malaysian, Pakistani, Sri Lankan, Taiwanese, and Thai for Asians

Department of Industrial Relations and Department of Fair Employment and Housing must use additional categories for Fijian and Tongan for Pacific Islanders

Senate Bill 853

California Health and Safety Code Sections 1367.07(a) and 1367.04(b)

Managed care plans must report on data collection as part of language assistance needs assessment

California Insurance Code Sections 10133.9(a) and 10133.8(b)(2)

Health insurance plans must report on data collection as part of language assistance needs assessment

California Office of Statewide Health Planning and Data

California Health and Safety Code Sections 1287735, 128736 and 128737 require hospitals, emergency departments, and ambulatory surgery centers to report the race and ethnicity of their patients:

<http://www.leginfo.ca.gov/cgi-bin/displaycode?section=hsc&group=128001-129000&file=128675-128810>

Unfortunately, the categories used are not standardized:

http://www.oshpd.ca.gov/hid/mirca/Text_pdfs/Bulletins/QuickNotesV2.pdf

For hospital inpatient/discharge data, hospitals use the following codes:

Ethnicity

- 1 = Hispanic
- 2 = Non-Hispanic
- 3 = Unknown

Race

- 1 = White
- 2 = Black
- 3 = Native American/Eskimo/Aleutian
- 4 = Asian/Pacific Islander
- 5 = Other
- 6 = Unknown

Emergency departments and ambulatory surgery centers use the following codes:

Ethnicity

- E1 = Hispanic or Latino
- E2 = Non-Hispanic or Non-Latino
- 99 = Unknown

Race

- R1 = American Indian
- R2 = Asian
- R3 = Black or African American
- R4 = Native Hawaiian or Pacific Islander
- R5 = White
- R9 = Other Race
- 99 = Unknown

California Health Interview Survey

University of California Los Angeles Center for Health Policy Research
2009 Adult Questionnaire v.3.4 (March 2011)

<http://www.chis.ucla.edu/questionnaires.html>

QA09_A6 Are you Latino or Hispanic?

YES

NO

REFUSED

DON'T KNOW

QA09_A7 And what is your Latino or Hispanic ancestry or origin? Such as Mexican, Salvadoran, Cuban, Honduran-- and if you have more than one, tell me all of them.

MEXICAN/MEXICAN AMERICAN/CHICANO

SALVADORAN

GUATEMALAN

COSTA RICAN.

HONDURAN

NICARAGUAN

PANAMANIAN

PUERTO RICAN

CUBAN

SPANISH-AMERICAN (FROM SPAIN)

OTHER LATINO (SPECIFY: _____)

REFUSED

DON'T KNOW

QA09_A8 {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 Native Hawaiian, Other Pacific Islander, American Indian, Alaska Native, Asian, Black, African American, or White?

WHITE

BLACK OR AFRICAN AMERICAN

ASIAN

AMERICAN INDIAN OR ALASKA NATIVE

OTHER PACIFIC ISLANDER

NATIVE HAWAIIAN

OTHER (SPECIFY: _____)

REFUSED

DON'T KNOW

QA09_A9 You said, American Indian or Alaska Native, and what is your tribal heritage? If you have more than one tribe, tell me all of them.

APACHE

BLACKFOOT/BLACKFEET

CHEROKEE

CHOCTAW

MEXICAN AMERICAN INDIAN

NAVAJO

POMO

PUEBLO

SIOUX

YAQUI

OTHER TRIBE (SPECIFY: _____)

REFUSED

DON'T KNOW

QA09_A10 Are you an enrolled member in a federally or state recognized tribe?

YES
NO
REFUSED
DON'T KNOW

QA09_A11 Which tribe are you enrolled in?

APACHE

MESCALERO APACHE, NM
APACHE (NOT SPECIFIED)
OTHER APACHE [Ask for spelling]
(SPECIFY:_____)

BLACKFEET

BLACKFOOT/BLACKFEET

CHEROKEE

WESTERN CHEROKEE
CHEROKEE (NOT SPECIFIED)
OTHER CHEROKEE [Ask for spelling]
(SPECIFY:_____)

CHOCTAW

CHOCTAW OKLAHOMA
CHOCTAW (NOT SPECIFIED)
OTHER CHOCTAW [Ask for spelling]
(SPECIFY:_____)

NAVAJO

NAVAJO (NOT SPECIFIED)

POMO

HOPLAND BAND, HOPLAND RANCHERIA
SHERWOOD VALLEY RANCHERIA
POMO (NOT SPECIFIED)
OTHER POMO [Ask for spelling]
(SPECIFY:_____)

PUEBLO

HOPI
YSLETA DEL SUR PUEBLO OF TEXAS
PUEBLO (NOT SPECIFIED)
OTHER PUEBLO [Ask for spelling]
(SPECIFY:_____)

SIOUX

OGLALA/PINE RIDGE SIOUX
SIOUX (NOT SPECIFIED)
OTHER SIOUX [Ask for spelling]
(SPECIFY:_____)

YAQUI

PASCUA YAQUI TRIBE OF ARIZONA
YAQUI (NOT SPECIFIED)
OTHER YAQUI [Ask for spelling] (SPECIFY:_____)

OTHER

OTHER [Ask for spelling] (SPECIFY: _____)
REFUSED
DON'T KNOW.

QA09_A12 You said Asian, and what specific ethnic group are you, such as Chinese, Filipino, or Vietnamese? If you are more than one, tell me all of them.

BANGLADESHI
BURMESE
CAMBODIAN
CHINESE

FILIPINO
HMONG
INDIAN (INDIA)
INDONESIAN
JAPANESE
KOREAN
LAOTIAN
MALAYSIAN
PAKISTANI
SRI LANKAN
TAIWANESE
THAI
VIETNAMESE
OTHER ASIAN (SPECIFY: _____)
REFUSED
DON'T KNOW

QA09_A13 You said you are Pacific Islander. What specific ethnic group are you, such as Samoan, Tongan, or Guamanian? If you are more than one, tell me all of them.

SAMOAN/AMERICAN SAMOAN
GUAMANIAN
TONGAN
FIJIAN
OTHER PACIFIC ISLANDER (SPECIFY: _____)
REFUSED
DON'T KNOW

QA09_A14 You said that you are: {INSERT MULTIPLE RESPONSES FROM QA09_A7, QA09_A8, QA09_A12 AND QA09_A13}.

Do you identify with any one race in particular?

YES
NO
REFUSED
DON'T KNOW

QA09_A15 Which do you most identify with?

MEXICAN/MEXICAN AMERICAN/CHICANO
SALVADORAN
GUATEMALAN
COSTA RICAN
HONDURAN
NICARAGUAN
PANAMANIAN
PUERTO RICAN
CUBAN
SPANISH-AMERICAN (FROM SPAIN)
LATINO, OTHER SPECIFY
LATINO
NATIVE HAWAIIAN
OTHER PACIFIC ISLANDER
AMERICAN INDIAN OR ALASKA NATIVE
ASIAN
BLACK OR AFRICAN AMERICAN
WHITE
RACE, OTHER SPECIFY
BANGLADESHI
BURMESE

CAMBODIAN
CHINESE
FILIPINO
HMONG
INDIAN (INDIA)
INDONESIAN
JAPANESE
KOREAN.
LAOTIAN
MALAYSIAN
PAKISTANI
SRI LANKAN
TAIWANESE
THAI
VIETNAMESE
ASIAN, OTHER SPECIFY
SAMOAN/AMERICAN SAMOAN
GUAMANIAN
TONGAN
FIJIAN
PACIFIC ISLANDER, OTHER SPECIFY
BOTH/ALL/MULTIRACIAL
NONE OF THESE
REFUSED
DON'T KNOW

QA09_G4 What languages do you speak at home?

ENGLISH
SPANISH
CANTONESE
VIETNAMESE
TAGALOG
MANDARIN
KOREAN
ASIAN INDIAN LANGUAGES
RUSSIAN
OTHER 1 (SPECIFY: _____)
OTHER 2 (SPECIFY: _____)
REFUSED
DON'T KNOW

QA09_G5 {Since you speak a language other than English at home, we are interested in the languages you use in other situations.} What language do you speak with your friends?

ONLY ENGLISH
BOTH ENGLISH AND OTHER LANGUAGE(S)
ONLY OTHER LANGUAGE(S)
REFUSED
DON'T KNOW

QA09_G6 In what languages are the TV shows, radio stations, or newspapers that you usually watch, listen or read?

ONLY ENGLISH
BOTH ENGLISH AND OTHER LANGUAGE(S)
ONLY OTHER LANGUAGE(S)
REFUSED
DON'T KNOW

QA09_G7 {Since you speak a language other than English at home, we are interested in your opinion of how well you speak English.} Would you say you speak English...

VERY WELL

WELL

NOT WELL, OR

NOT AT ALL

REFUSED

DON'T KNOW

DISABILITY STATUS QUESTIONS

QA09_D4 Are you blind or deaf, or do you have a severe vision or hearing problem?

YES

NO

REFUSED

DON'T KNOW

QA09_D5 Are you legally blind?

YES

NO

REFUSED

DON'T KNOW

QA09_D6 Do you have a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?

YES

NO

REFUSED

DON'T KNOW

QA09_D7 Because of a physical, mental, or emotional condition lasting 6 months or more, do you have any of the following:

Any difficulty learning, remembering, or concentrating?

YES

NO

REFUSED

DON'T KNOW

QA09_D8 Any difficulty dressing, bathing, or getting around inside the home?

YES

NO

REFUSED

DON'T KNOW

QA09_D9 Any difficulty going outside the home alone to shop or visit a doctor's office?

YES

NO

REFUSED

DON'T KNOW

QA09_D10 Any difficulty working at a job or business?

YES

NO

REFUSED

DON'T KNOW

QA09_D11 Do you have a physical or mental condition that has kept you from working for at least a year?

YES

NO

REFUSED

DON'T KNOW

SEXUAL ORIENTATION QUESTIONS

QA09_D15 Do you think of yourself as straight or heterosexual, as {gay/gay,lesbian} or homosexual, or bisexual?

[IF NEEDED, SAY: "Straight or Heterosexual people have sex with, or are primarily attracted to people of the opposite sex. {Gay/Gay and Lesbian} people have sex with, or are primarily attracted to people of the same sex, and Bisexuals have sex with or are attracted to people of both sexes."]

STRAIGHT OR HETEROSEXUAL

GAY, LESBIAN, OR HOMOSEXUAL

BISEXUAL

NOT SEXUAL/CELIBATE

OTHER (SPECIFY: _____)

REFUSED

DON'T KNOW

ADDITIONAL QUESTIONS ON COUNTRY OF BIRTH

QA09_G1 In what country were you born?

UNITED STATES

AMERICAN SAMOA

CANADA

CHINA

EL SALVADOR

ENGLAND

FRANCE

GERMANY

GUAM

GUATEMALA

HUNGARY

INDIA

IRAN

IRELAND

ITALY

JAPAN

KOREA

MEXICO

PHILIPPINES

POLAND

PORTUGAL

PUERTO RICO

RUSSIA

TAIWAN

VIETNAM

VIRGIN ISLANDS

OTHER (SPECIFY: _____)

REFUSED

DON'T KNOW

QA09_G2 In what country was your mother born?

[SAME RESPONSE OPTIONS]

QA09_G3 In what country was your father born?
[SAME RESPONSE OPTIONS]

ADDITIONAL REFERENCES AND RESOURCES ON RACE, ETHNICITY, LANGUAGE, DISABILITY STATUS, AND OTHER DEMOGRAPHIC DATA COLLECTION

Escarce JJ, Carreon R, Veselovskiy G, Lawson EH. Collection of race and ethnicity data by health plans has grown substantially, but opportunities remain to expand efforts. *Health Aff* (2011);30(10):1984-1991

National Health Plan Collaborative to Reduce Disparities

<http://www.nationalhealthplancollaborative.org>

Toolkit to Reduce Racial & Ethnic Disparities in Health Care

<http://www.rwjf.org/qualityequality/product.jsp?id=33960>

Kaiser Permanente Evolution of Data Collection on Race, Ethnicity, Language Preference Information

Appendix G, Institute of Medicine, *Race, Ethnicity, Language Data: Standardization for Health Care Quality Improvement* (2009)

http://www.nap.edu/catalog.php?record_id=12696

Contra Costa Health Plan Language Assistance Database and Ethnicity Categories

Appendix H, Institute of Medicine, *Race, Ethnicity, Language Data: Standardization for Health Care Quality Improvement* (2009)

http://www.nap.edu/catalog.php?record_id=12696

National Committee for Quality Assurance

Health Plan Accreditation

<http://www.ncqa.org/tabid/689/Default.aspx>

Element Quality Improvement 4A

The organization assesses the cultural, ethnic, racial and linguistic needs of its members and adjusts the availability of practitioners within its network, if necessary

National Committee for Quality Assurance

Accountable Care Organization Accreditation

<http://www.ncqa.org/tabid/1312/default.aspx>

Element CM1A Patient information

The organization uses an electronic system that records the following as structured (searchable) data for more than 50% of its patients:

Factor CM1A3 Race

Factor CM1A4 Ethnicity

Element AA1H Access to culturally competent care

Factor AA1H2 Analyzes the capacity of its practitioners to meet the needs of its patients for culturally appropriate care

Factor AA1H3 Develops a plan to address any gaps identified as a result of analysis, if applicable

Factor AA1H4 Addresses gaps based on its plan, if applicable

Element PR2D Use of data to assess disparities

Factor PR2D1 Analyze one or more valid measures of clinical performance, such as HEDIS, by race/ethnicity

Factor PR2D3 Analyze one or more valid measures of eligible individual experience, such as CAHPS, by race/ethnicity or language

Factor PR2E Addressing health care disparities

Factor PR2E1 Identifies and prioritizes opportunities to reduce health care disparities

Factor PR2E2 Implements at least one intervention to address a disparity

Factor PR2E3 Evaluates the effectiveness of the intervention

National Committee for Quality Assurance

Multicultural Health Care Distinction

<http://www.ncqa.org/tabid/1195/Default.aspx>

Element MHC 1 Race/ethnicity and language data

Factor MHC 1A Collection of data on race and ethnicity

Factor MHC 1C Privacy protections for race/ethnicity/language data

Factor MHC 1D Notification of privacy protections

Element MHC 4 Culturally and linguistically appropriate services program

Factor MHC 4A Program description

Factor MHC 4B Annual evaluation

Element MHC 5 Reducing health care disparities

Factor MHC 5A Use of data to assess disparities

Factor MHC 5B Use of data to monitor and assess services

Factor MHC 5C Use of data to measure culturally and linguistically appropriate services and disparities

U.S. Department of Labor

Current Population Survey

http://www.bls.gov/cps/cpsdisability_faq.htm

The CPS uses a set of six questions to identify persons with disabilities. A response of “yes” to any one of the questions indicates that the person in question has a disability. The disability questions appear in the CPS in the following format:

This month we want to learn about people who have physical, mental, or emotional conditions that cause serious difficulty with their daily activities. Please answer for household members who are 15 years old or over.

1. Is anyone deaf or does anyone have serious difficulty hearing?
2. Is anyone blind or does anyone have serious difficulty seeing even when wearing glasses?
3. Because of a physical, mental, or emotional condition, does anyone have serious difficulty concentrating, remembering, or making decisions?
4. Does anyone have serious difficulty walking or climbing stairs?
5. Does anyone have difficulty dressing or bathing?
6. Because of a physical, mental, or emotional condition, does anyone have difficulty doing errands alone such as visiting a doctor’s office or shopping?

International Classification of Functioning, Disability, and Health

<http://www.who.int/classifications/icf/en/>

<http://apps.who.int/classifications/icfbrowser/>

http://perspectives.ahima.org/index.php?option=com_content&view=article&id=86:icf-representing-the-patient-beyond-a-medical-classification-of-diagnoses&catid=39:clinical-terms-a-vocabularies&Itemid=85

National Committee on Vital and Health Statistics

Classifying and Reporting Functional Status (2001)

www.ncvhs.hhs.gov/010617rp.pdf

The Committee believes that the International Classification of Functioning, Disability and Health should be evaluated for use in coding functional status information in both electronic patient records and administrative data. This research should begin as soon as possible, under the leadership of HHS, with the intention of readying a code set for use when broader agreement has been reached that it is needed.

National Committee on Vital and Health Statistics

Shaping a Vision for Health Statistics in the 21st Century (2002)

<http://www.ncvhs.hhs.gov/21st%20final%20report.pdf>

Recommended:

+Assure that appropriate measures of functional status and well-being are included in ongoing systems that are part of the health statistics enterprise

+The International Classification of Functioning, Disability and Health presents a framework for assessing function that takes into account the social aspects of functional status and provides a mechanism to document the impact of the social and physical environment on a person's functioning.

National Committee on Vital and Health Statistics

Federal Consolidated Health Informatics (CHI) Initiative (2006)

<http://www.ncvhs.hhs.gov/031209p6.pdf>

Endorsed both International Classification of Functioning, Disability and Health and Systematized Nomenclature of Medicine Clinical Terms (SNOMED-CT) as standards for vocabulary content in the functioning and disability domains

http://www.nlm.nih.gov/research/umls/Snomed/snomed_main.html

National Committee on Vital and Health Statistics

Conference on the International Classification of Functioning, Disability and Health (2010)

<http://ncvhs.hhs.gov/101202t1.pdf>

Institute of Medicine

Future of Disability in America (2007)

<http://iom.edu/Reports/2007/The-Future-of-Disability-in-America.aspx>

Recommended adoption and refinement of International Classification of Functioning, Disability and Health as the conceptual framework for disability monitoring and research

[Under ACA section 3023 (payment bundling) and section 2013 (quality measure development), HHS is examining measures of functional status]

Centers for Medicare & Medicaid Services

Post Acute Care Payment Reform Demonstration Continuity Assessment Record and Evaluation (CARE) Tool

<http://www.pacdemo.rti.org/meetingInfo.cfm?cid=caretool>

Centers for Medicare & Medicaid Services

Minimum Data Set (Active Resident Information Report)

Must be used for all residents at CMS-certified Medicare or Medicaid nursing homes

<http://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MDSPubQlandResRep/activeresreport.html>

<http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/MDS30RAIManual.html>

Institute of Medicine

The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding (2011)

<http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx>

Recommends that data on patient sexual orientation and gender identity be collected in electronic health records

Joint Commission

Advancing Effective Communication, Cultural Competency, and Patient- and Family-Centered Care for Lesbian, Gay, Bisexual, and Transgender Communities – A Field Guide (2011)

<http://www.jointcommission.org/lgbt/>

Recommends that hospitals and other accredited health care organizations collect data on sexual orientation and gender identity

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