

DRAFT

National Association of Insurance Commissioners (NAIC) Special Committee on Race and Insurance – Workstream 5 (Health) Principles for Data Collection

RECOMMENDS that state insurance departments and all insurance companies facilitating the business of health insurance promote, consider, and uphold the following principles according to their respective roles; and

THIS DOCUMENT is intended to establish consistent high-level guiding principles for the collection and treatment of data on race, ethnicity, and other demographic characteristics in the business of health insurance. These principles are guidance and do not carry the weight of law or impose any legal liability. This guidance can serve to inform state insurance departments and health insurance companies of recommendations aimed at addressing disparities in health insurance and health care. This guidance begins with the premise that in order to impact disparities in health care access and health outcomes, robust data collection must be a priority of state insurance regulators and the regulated health insurance companies. Data collection can help state leaders and industry alike both quantify existing disparities and evaluate the effectiveness of initiatives to address those disparities.

Data Collection

- a) Health insurance companies should be expected to systematically collect, maintain, protect, and report on, at minimum, enrollee data on race, ethnicity, preferred language, sex (including gender identity), sexual orientation, and disability.
- b) Health insurance companies should use data collection strategies and question language that has been consumer-tested and is widely recognized for increased accuracy and responsiveness. (The Appendix provides specific language for health insurance company consideration and also directs companies to other widely recognized sources for data collection integrity.)
- c) The disclosure of demographic data by prospective insureds and enrollees must always be voluntary and based on self-identification or disclosure. Submission of such information should always be optional.
- d) Health insurance companies should be encouraged to pursue the NCQA's Distinction in Multicultural Health Care (or an equivalent current NCQA product that addresses how organizations meet diversity, equity and inclusion goals for employees, members, and enrollees).
 - a. State-based exchanges should consider identifying insurers that have achieved the NCQA Distinction in Multicultural Health Care (or an equivalent current NCQA product) as part of the exchanges' public-facing websites.

Data Use and Regulation

- a) Insurance departments should confirm that neither state nor federal law prohibits an insurer from collecting race, ethnicity, language, sex (including gender identity), sexual orientation, and disability information. Such clarification should distinguish between the collection of demographic data and the prohibited use of demographic data in rating, underwriting practices, and benefit determinations.

- b) Health insurance companies should consider HIPAA protections to apply to demographic data and should consider the collection of demographic data as part of any plans that address protected health information. Health insurance companies should be prohibited from reporting demographic data that would permit the identification of individuals. In these limited circumstances—when privacy protections prevent reporting on disaggregated demographic data—health insurance companies and regulators should clearly state that this is the reason why the data was not reported.
- c) Insurance departments and health insurance companies should coordinate on acceptable uses of demographic data within company operations. Acceptable uses may include evaluating algorithms for bias; analyzing claims, enrollment, and complaint data to better understand health care disparities or to evaluate the efficacy of programs intended to reduce health care disparities; provider network development and coordination of care; reporting requirements; quality improvement of services; assessing or planning to meet the need for health-related social services and supports, including trauma-informed care; and targeted outreach to underserved populations, among other uses.
- d) Insurance departments, individually or collectively through the NAIC, should collect and review demographic data from health insurance companies to better understand the marketplace and efforts and opportunities for health insurance companies to advance and improve services and advance health equity.

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Appendix

Recommended Standards for Data Collection

This section provides specific recommendations for data collection standards for race and ethnicity. Though widely recognized for increased accuracy and responsiveness, these standards, examples, and sources are not the sole resources that health insurance companies may use to develop data collection systems and processes. As such, this section also provides a list of resources for data collection related to language, sexual orientation, gender identity, and disability. Health insurance companies should be familiar with long-standing guidance from the U.S. Department of Health and Human Services on [Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status](#).

a) On race and ethnicity

- a. In preparation for the 2020 Census, the U.S. Census Bureau conducted research to improve the collection of race/ethnicity data and found that providing a combined race/ethnicity question with detailed checkboxes decreased nonresponse and improved accuracy. In addition, as [summarized](#) by the State Health Access Data Assistance Center at the University of Minnesota, the research:
 - i. Reinforced the importance of allowing multiple responses;
 - ii. Suggested that “Mark all that apply” or “Select all that apply” is better than “Select one or more”;
 - iii. Suggested that using “race/ethnicity” terminology is less confusing than using terms like “category,” which can suggest a hierarchy; and
 - iv. Found that data collection is improved when there is a dedicated “Middle Eastern or North African” response category for race (currently classified as “White”).

Figure 2. U.S. Census Bureau Optimal Race/Ethnicity Question Forma

Source: [Collection of Race, Ethnicity, Language \(REL\) Data in Medicaid Applications](#), State Health Access Data Assistance Center at the University of Minnesota

WHAT IS THE PERSON'S RACE OR ORIGIN?

Mark all boxes that apply and print origins in the spaces below. Note, you may report more than one group.

White:
Print, for example, German, Irish, English, Italian, Polish, French, etc.

Middle Eastern or North African:
Print, for example, Lebanese, Iraqi, Egyptian, Syrian, Moroccan, Alger

Hispanic, Latino, or Spanish origin:
Print, for example, Mexican or Mexican American, Puerto Rican, Cuban, Salvadoran, Dominican, Colombian, etc.

Native Hawaiian or Pacific Islander:
Print, for example, Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, Marshallese, etc.

Black or African American:
Print, for example, African American, Jamaican, Haitian, Nigerian, Ethiopian, Somali, etc.

Asian:
Print, for example, Chinese, Filipino, Asian Indian, Vietnamese, Korean, Japanese, etc.

Don't Know

Unsure

Decline to State

American Indian or Alaska Native:
Print your tribal affiliation, for example, Navajo Nation, Blackfeet Tribe, Mi'kmaq, Native Village of Barrow, Inupiat Traditional Government, Nome Esquimaux Community, etc.

Some other Race or Origin:

Source: [Policy Recommendations: Health Equity Cannot Be Achieved Without Complete and Transparent Data Collection and the Disaggregation of Data](#) by Asian & Pacific Islander American Health Forum, UnidosUS, National Urban League, National Congress of American Indians, ACCESS

b) On preferred language

- a. The American Community Survey, consistent with recommendations from the Department of Health and Human Services, also captures data on English language proficiency and optional questions for the language spoken at home. These questions are recommended for anyone age 5 years or older.

HHS Recommendations – Language

In addition to race and ethnicity, HHS data collection standards include a question for capturing English language proficiency and optional questions for language spoken at home (modeled after questions on the U.S. Census). In all cases, HHS recommends this be asked of individuals five-years-old or older:

Data Standard for Primary Language	Language Spoken Standard (optional)
<p>How well do you speak English?</p> <ul style="list-style-type: none"> • Very well • Well • Not well • Not at all 	<p>Do you speak a language other than English at home?</p> <ul style="list-style-type: none"> • Yes • No <p>or persons speaking a language other than English (answering yes to the question above): What is this language?</p> <ul style="list-style-type: none"> • Spanish • Other language (Identify)

If a state wants to collect more detailed information on language other than Spanish, HHS recommends conducting analysis using U.S. Census Bureau American Community Survey (ACS) data to identify the ten most prevalent languages spoken (which can be rolled into "other" to comport with the minimum standards).

Source: [Collection of Race, Ethnicity, Language \(REL\) Data in Medicaid Applications](#), State Health Access

- c) On sex, sexual orientation, and gender identity
- a. The National Academies of Sciences, Engineering, and Medicine recently convened an expert panel entitled [Measuring Sex, Gender Identity, and Sexual Orientation](#) that will culminate in clear guidelines outlining the guiding principles and best practices for collecting sexual orientation and gender identity information. Recommendations will address collection and use of this information in research and non-research surveys, along with medical and other administrative records. These recommendations can help inform data collection by industry.
 - b. The Williams Institute at the UCLA School of Law has published several reports on best practices for asking questions about sex, sexual orientation, and gender identity. Key practices include:
 - i. Sexual orientation survey items should be culturally appropriate, relevant, acceptable, and compatible with the respondent’s understanding of the construct that the question is intended to measure. Sexuality can be understood differently in different racial/ethnic populations. It is recommended that surveys assess multiple dimensions of sexuality, such as measures of sexual behavior, sexual attraction, and self-identity. When measuring sexual diversity within racial/ethnic minority groups, researchers might also consider including additional response options for sexual orientation identity terms, such as two-spirit, same gender loving, homosexual, down low, or queer, that may turn out to be more relevant for non-white populations.
 - ii. Conceptually, sexual orientation has three major dimensions – self-identification (gay, lesbian, bisexual, heterosexual, queer, or asexual), sexual behavior or the sex of partners (same sex, different sex, both sexes, neither), and sexual attraction (the sex or gender of people that the respondent feels attracted to). Surveys should allow for a wide range of responses.
 - iii. When asking about sex, it is recommended to use a “two-step” approach. Respondents should be asked what sex they were assigned at birth or what sex is indicated on their birth certificate, and should also be asked how they describe their current gender identity. When describing current gender identity, respondents should be allowed to ‘check all that apply’ or fill in their own descriptor. If a respondent identifies as transgender, a follow-up question should be included to further identify whether male to female, female to male, or transgender gender nonconforming.
 - c. Sources:
 - i. The GenIUSS Group. (2014). *Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys*. J.L. Herman (ed.). Los Angeles, CA: The Williams Institute. <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Survey-Measures-Trans-GenIUSS-Sep-2014.pdf>
 - ii. [Cahill, S., Baker, K., Makadon, H. *Do Ask, Do Tell: A Toolkit for Collecting Sexual Orientation and Gender Identity Information in Clinical Settings*. Boston, MA: Fenway Institute. <https://doaskdotell.org/>](#)

- iii. Brown, T. N. T. and Herman, J. L. (2020). *Exploring International Priorities and Best Practices for the Collection of Data about Gender Minorities: A Focus on South America, Report of Meeting*. Los Angeles, CA: The Williams Institute. <https://williamsinstitute.law.ucla.edu/wp-content/uploads/WPATH-English-Mar-2020.pdf>
- iv. The Sexual Minority Assessment Research Team (SMART) (2009). *Best Practices for Asking Questions about Sexual Orientation on Surveys*. Los Angeles, CA: The Williams Institute. <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Best-Practices-SO-Surveys-Nov-2009.pdf>
- v. Centers for Disease Control and Prevention (2020). *Collecting Sexual Orientation and Gender Identity Information*. <https://www.cdc.gov/hiv/clinicians/transforming-health/health-care-providers/collecting-sexual-orientation.html>

Household Eligibility Results Summary

Additional Demographic Information

The following information is optional and confidential. It will not be used to determine eligibility.

What is your gender?
Check the box that best describes your current gender identity.

Female

Male

Transgender: male to female

Transgender: female to male

Non-Binary (neither male nor female)

Another gender identity

What sex was listed on your original birth certificate?

Female Male

Do you think of yourself as:

Straight or heterosexual

Gay or lesbian

Bisexual

Queer

Another sexual orientation

Unknown

Based on many years of experience collecting and using patient SOGI data in Electronic Health Records (EHRs), advocating for inclusion of SOGI in national health IT systems, and training health centers and other organizations in how to collect and use SOGI to improve quality of care, the Fenway Institute recommends the following SOGI questions:

Sexual orientation
Do you think of yourself as (Check one):

Straight or heterosexual

Lesbian, gay, or homosexual

Bisexual

Something else (e.g. queer, pansexual, asexual). Please specify _____

Don't know

Choose not to disclose

Gender identity
What is your current gender identity? (Check all that apply):

Female

Male

Transgender Woman/Transgender Female

Transgender Man/Transgender Male

Other* (e.g. non-binary, genderqueer, gender-diverse, or gender fluid).
Please specify _____

Choose not to disclose

What sex were you assigned at birth? (Check one):

Male

Female

*You may replace the term "other" on patient-facing forms with the term that is most affirming for the communities you serve (e.g. "something else" or "additional category").

These questions and response options were developed by the National LGBTQIA+ Health Education Center and approved by the Bureau of Primary Health Care at HRSA for use with the Health Center Program's Uniform Data System.¹⁸ These terms collect data that can be used to populate the Health Center Program's Uniform Data System.¹⁹ They are also only slightly different from the minimal standards adopted by the Office of the National Coordinator of Health Information Technology in 2015,^{20,21} based on research that the Fenway Institute and the Center for American Progress conducted with health center patients in South Carolina, Maryland, Chicago and Boston.²² For more information please see <https://www.lgbtoaheducation.org/>

Source: Letter to Dr. Rachel Levine, [LGBTQI Inclusion in COVID-19 Data Collection & Vaccination Planning](#)

d) On disability

- a. [Demographic questions](#) about disability have been asked in the American Community Survey since 1999, with modifications over time. The most recent revisions to these questions were adopted in 2008 and endorsed by the U.S. Department of Health and Human Services, in guidance issued in 2011 pursuant to the requirements of section 4302 the Affordable Care Act. These questions are:
 - i. Are you deaf or do you have serious difficulty hearing?

- ii. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
 - iii. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)
 - iv. Do you have serious difficulty walking or climbing stairs? (5 years old or older)
 - v. Do you have difficulty dressing or bathing? (5 years old or older)
 - vi. 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 old or older).
- b. Additional measures have been developed outside of the American Community Survey, such as the Washington Group Short Set of Questions on Disability. Those questions have been [analyzed](#) by the Centers for Disease Control and Prevention.

c. Sources:

- i. U.S. Department of Health & Human Services, Office of the Assistant Secretary for Planning and Evaluation. (2011) *U.S. Department of Health and Human Services Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status*. <https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status>
- ii. Centers for Disease Control and Prevention. (2020) *Disability Datasets: Population Surveys that Include the Standard Disability Questions*. <https://www.cdc.gov/ncbddd/disabilityandhealth/datasets.html>
- iii. Kuper, H, Polack, S. Mactaggart, I. *How to Measure Disability and Why It Is Important*. <https://www.futurelearn.com/info/courses/global-disability/0/steps/37579>