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.
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”).
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.
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:


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:


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