November 15, 2021

Commissioner Jessica Altman, Co-Chair
Commissioner Ricardo Lara, Co-Chair
Special (EX) Committee on Race and Insurance—Workstream 5 (Health)
National Association of Insurance Commissioners (NAIC)

Attn: Jolie H. Matthews, Senior Health and Life Policy Counsel, NAIC

Re: Comments on the Revised Exposure Draft of Principles for Data Collection

Dear Commissioners Altman and Lara:

On behalf of the American Academy of Actuaries1 Health Equity Work Group (HEWG), I appreciate the opportunity to offer comments on the exposure draft of the Revised Principles for Data Collection (Principles) document released by the NAIC’s Special (EX) Committee on Race and Insurance—Workstream 5 (Health) on October 15, 2021. Our suggestions reflect the need for uniformity and consistency across all types of entities assuming health insurance risk.

We recognize the need for consistent, accurate, and comprehensive collection of data to understand and quantify health disparities and evaluate the effectiveness of initiatives to address health inequity. We believe the Principles document will go a long way toward achieving your goals and would serve as a framework not only for state departments of insurance, but also for other governmental agencies regulating entities bearing health insurance risk as they develop criteria for the collection and use of demographic and other related policy-level data. We also acknowledge the need to start addressing this type of data collection sooner rather than later, yet we suggest that the framework should allow flexibility to refine these processes as our collective understanding of the issues and opportunities related to the collection and analysis of this type of data become more apparent.

Finally, we note that insurers following consistent principles could decide to use valid yet different sets of data collection questions. Unless data are collected in a uniform way, the ability to analyze the data at a market level or geographic area level could be compromised. Therefore, you may wish to encourage in the data collection principles uniformity in addition to consistency of the collection of the data addressed in the Principles document.

1 The American Academy of Actuaries is a 19,500-member professional association whose mission is to serve the public and the U.S. actuarial profession. For more than 50 years, the Academy has assisted public policymakers on all levels by providing leadership, objective expertise, and actuarial advice on risk and financial security issues. The Academy also sets qualification, practice, and professionalism standards for actuaries in the United States.
Please find our redlined edits and comments in Attachment A.

We note that the Academy’s Health Equity Work Group is looking at health equity from a broader perspective, which includes race and ethnicity concerns across all types of health plans. The work group is also exploring issues related to algorithms and the use and collection of data as they relate to health equity. As we continue our work in these areas, we hope to have the opportunity to provide you with our findings and further recommendations and to learn from your experience as you work with states in launching these principles.

Thank you for the opportunity to provide input on the revised *Principles for Data Collection*. We welcome the opportunity to speak with you in more detail and answer any questions you have regarding these comments or on other topics related to health equity. If you do have any questions or would like to discuss further, please contact Matthew Williams, the Academy’s senior health policy analyst, at williams@actuary.org.

Sincerely,

Annette V. James, MAAA, FSA, FCA
Chairperson, Health Equity Work Group
American Academy of Actuaries

CC: Brian R. Webb, Assistant Director, Life and Health Policy and Legislation, NAIC
Comments are being requested on this draft document on or before Monday, Nov. 15, 2021. Comments should be sent by email only to Jolie Matthews at jmatthews@naic.org.

**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 health insurance companies 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. This guidance begins with the premise that robust data collection must be a priority of state insurance regulators and the regulated health insurance companies to both quantify existing disparities and evaluate the effectiveness of initiatives to address those disparities.

Throughout this document, “health insurance companies” is intended to include all entities bearing health insurance risk and for which the health products and services provided are regulated by state insurance departments. This will differ by state and includes applicable health maintenance organizations, life insurance, casualty insurance, or other types of entities that offer health insurance products, as well as provider organizations that are regulated by state insurance departments due to the nature of the risk borne.

**Data Collection**

a) Health insurance companies should be expected to systematically collect, maintain, protect, and report on, at minimum, enrollee data on race, ethnicity, income, occupation, geographic location, highest level of education, 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. Therefore, a “prefer to not answer” option should be included if insureds and enrollees are asked to answer demographic questions.

d) To the extent that insurers use staff to collect and/or analyze demographic data, insurers should develop and implement trainings on how to ask questions about race, ethnicity, and language (REL), and sexual orientation and gender identity (SOGI), including training on how to maintain privacy.

e) 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, insureds, 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.

f) Insurers should collect demographic data about participating providers in their networks to ensure network adequacy requirements are being met and to ensure that the provider network addresses the needs of the service area.

Data Use and Regulation

a) Insurance departments should confirm that neither state nor federal law prohibits an insurer from collecting race, ethnicity, income, occupation, geographic location, highest level of education, preferred 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 apply HIPAA protections to demographic data and should consider the collection of demographic data in measures 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. State insurance departments and health insurance companies should coordinate on appropriate guidelines for defining the circumstances that would prevent reporting on disaggregated data due to privacy concerns.

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; service quality improvement; 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 and health insurance companies should coordinate on criteria for validating the data collected to ensure a uniform minimum level of quality.

d) Insurance departments and health insurance companies should coordinate on guidelines for ensuring that data collected for this purpose are not inadvertently comingled with data used for purposes for which the use of demographic data is prohibited.

Insurance departments, individually or collectively through the NAIC, or designated third parties, 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.

Commented [AAA6]: It may be helpful to suggest that companies validate the data collected based on minimum standards set by the state department of insurance.

Commented [AAA7]: We also suggest including suggestions to ensure that the data collected in accordance with these principles are not inadvertently comingled with data used for purposes for which the use of demographic data is prohibited.

Commented [AAA8]: Consider revising this section to allow for the use of a third party/parties to collect and/or review this data in accordance with these principles.
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. All questions should allow for the option to self-identify, including a “choose not to answer” option or a blank, fillable option.

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. Data should be collected at a granular level to allow for disaggregation, particularly for Asian Americans, Native Hawaiians and Pacific Islanders (AANHPI), Hispanics, and Middle Eastern and Northern African (MENA) populations.
**Figure 2. U.S. Census Bureau Optimal Race/Ethnicity Question Form.**

<table>
<thead>
<tr>
<th>Race/Ethnicity Options</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>Print, for example, German, Irish, Italian, Polish, Portuguese, etc.</td>
</tr>
<tr>
<td>Hispanic, Latino, or Spanish origin</td>
<td>Print, for example, Mexican, Cuban, Puerto Rican, Salvadoran, Dominican, Colombian, etc.</td>
</tr>
<tr>
<td>Black or African American</td>
<td>Print, for example, African American, Jamaican, Haitian, Nigerian, Ethiopian, Somali, etc.</td>
</tr>
<tr>
<td>Middle Eastern or North African</td>
<td>Print, for example, Lebanese, Palestinian, Egyptian, Syrian, Moroccan, Algerian, etc.</td>
</tr>
<tr>
<td>Native Hawaiian or Pacific Islander</td>
<td>Print, for example, Hawaiian, Samoan, Chamorro, Tongan, Fijian, Marshall Islander, etc.</td>
</tr>
<tr>
<td>Asian</td>
<td>Print, for example, Chinese, Filipino, Asian Indian, Vietnamese, Korean, Japanese, etc.</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>Print, for example, Navajo Nation, Blackfeet Tribe, Haudenosaunee, Azttec, Native Village of Barrow, Traditional Government, Navajo, etc.</td>
</tr>
<tr>
<td>Don’t Know</td>
<td></td>
</tr>
<tr>
<td>Unsure</td>
<td></td>
</tr>
<tr>
<td>Decline to State</td>
<td></td>
</tr>
<tr>
<td>Some Other Race or Origin</td>
<td></td>
</tr>
</tbody>
</table>

Source: Collection of Race, Ethnicity, Language (REL) Data in Medicaid Applications, State Health Access Data Assistance Center at the University of Minnesota.
c. Sources


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.

![Image of HHS Recommendations - Language](image)

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

b. 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.

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. 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

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

e) In the event data collection remains low after best practices are implemented, regulators and insurers should engage consumers and consumer advocates, engage navigators/enrollment assistants, develop communications and trainings focused on the importance of demographic data collection, and modify enrollment and renewal interfaces.