November 15, 2021

Commissioner Jessica Altman, Co-Chair
Commissioner Ricardo Lara, Co-Chair
Workstream Five, Special Committee on Race and Insurance
National Association of Insurance Commissioners
444 North Capitol Street NW, Suite 700
Washington, D.C. 20001-1512

Submitted electronically to: Jolie Matthews (jmatthews@naic.org)

RE: Comments on Revised Draft Principles for Data Collection

Dear Commissioners Altman and Lara:

The Blue Cross Blue Shield Association (BCBSA) appreciates the opportunity to provide comments on the revised draft Principles for Data Collection distributed by the Special (EX) Committee on Race and Insurance (Special Committee – Workstream 5). BCBSA supports the continued efforts to advance diversity and inclusion and address racial disparities that disadvantage people of color and historically underrepresented communities.

BCBSA is a national federation of 35 independent, community-based and locally operated Blue Cross and Blue Shield (BCBS) companies (Plans) that collectively provide health care coverage for one in three Americans. For more than 90 years, Blue Cross and Blue Shield companies have offered quality health care coverage in all markets across America — serving those who purchase coverage on their own, as well as those who obtain coverage through an employer, Medicare and Medicaid.

As we have previously shared, BCBSA believes everyone should have access to high-quality health coverage and care regardless of race, ethnicity, national origin, sex, gender identity, sexual orientation, religion, education level, age, geography or disability. We agree we must recognize the negative impact of long-standing structures of racism and discrimination, underlying bias and social factors on the health and well-being of many Americans. To that end, every BCBS company across the country, and in Puerto Rico, has launched at least one local initiative to address health disparities.

BCBSA’s commitment to health equity is illustrated in the policy recommendations outlined in our Issue Brief, Addressing Health Disparities and Inequities in Communities of Color, which also aligns with the Special Committee’s efforts to promote improved access to quality, affordable coverage and culturally competent care. To successfully achieve these shared objectives, we believe it is foundational for the Special Committee to take a collaborative approach to data collection practices across the health care system, recognizing that several different organizations and government agencies are already engaged in considering the parameters and appropriate practices on collection and use of health equity data. We encourage the National Association of Insurance Commissioners (NAIC) to provide a collaborative forum for broad stakeholder engagement and recommend that NAIC convene all stakeholders to: 1) identify current barriers, 2) identify best practices for data collection; and 3) foster ideas to reduce disparate or duplicative requirements and practices at both the federal
and state levels. BCBSA is currently doing our part by working to build a multi-stakeholder coalition to drive the development and adoption of uniform standards for the collection and use of REL data, which are critical before government mandates are placed on insurers or other entities. We are happy to keep the NAIC apprised of further developments on the industry standards development work of the multi-industry coalition.

As encouraged during the last Workstream 5 call, BCBSA has provided an attached redline reflecting our suggested edits to the revised principles. We recognize the significant work by the NAIC on the development of these principles and share your overall goals. However, for meaningful progress to be achieved on data collection and appropriate use principles, more work is required to reach consensus among all the stakeholders. We respectfully ask that Workstream 5 continue to work toward meaningful consensus among all stakeholders on these important principles and not rush to finalization.

Below is an overview and explanation of our proposed changes:

**Data Collection:**

- BCBSA believes health insurance companies should enable processes to facilitate the systematic collection of REL and SOGI data where industry standards exist and have been adopted by the health care ecosystem, including providers, payers and others. We suggest adding the above language to subsection a) to recognize the current lack of industry standards and the need to establish such practices.

- We encourage the development and identification of best practices regarding data collection strategies and recommend specifying utilization of “industry-wide best practices” in the revised principles document.

- BCBSA supports the inclusion of a “prefer to not answer” option in the revised principles. In addition, we recommend adding an “other” option to help identify additional future data collection categories.

- BCBSA supports health insurance companies having the opportunity to pursue programs and distinctions to demonstrate how companies are meeting diversity, equity and inclusion goals for employees, members and enrollees, including but not exclusive to NCQA’s Distinction in Multicultural Health Care. We suggest broadening the language in subsection e) to reflect support for the overall goal without limiting insurers to a single credentialing source.

- BCBSA suggests the addition of subsection d) health insurers have existing requirements regarding training and compliance on maintaining privacy of sensitive information requires further clarification. We suggest adding reference to “sensitive information” at the end of the subsection.

- BCBSA believes it is premature to include the provider REL data requirements in the principles at this time. We recommend instead further evaluation and consideration through the NAIC’s Provider Network white paper process. As currently drafted, the revised principles suggest insurers should be requiring demographic information from providers in order to meet network adequacy standards.
Data Use and Regulation:

- As noted above and in our previous comments, BCBSA continues to believe efforts to collect and report REL and SOGI data should take existing federal and state laws into consideration. We recommend revising the language in subsection a) to reflect that, and adding language suggesting health insurers and regulators make clear when certain demographic data was not reported specifically due to prohibition by existing law. BCBSA also recommends adding language that suggests insurance departments distinguish between the collection of demographic data to be used for specific purposes, such as analysis of health disparities and care management, from the prohibited use of demographic data in rating, underwriting practices or benefit determinations.

- BCBSA recommends adding a subsection clarifying that existing federal and state privacy laws serve as the standard for any information sharing or analysis. Insurers and insurance departments should ensure that information shared publicly is aggregated and does not identify any single individual.

- BCBSA supports the evaluation of algorithms for bias and recommends expanding the language to capture evaluation for purposes of identifying and mitigating bias (or disparate impact).

- In subsection e), BCBSA recommends the language be revised in a way that requires insurance department collection of demographic data from public databases, federal and state, to seek opportunities for the departments to better understand and address issues around health equity.

Appendix:

- BCBSA supports the inclusion of language in the appendix that data be collected at a granular level to allow for disaggregation, particularly for certain demographics.

- In subsection e) where the revised principles reference modifying enrollment and renewal interfaces in the event of low data collection, BCBSA recommends adding “where legally permissible” to the end of the sentence.

We appreciate the opportunity to share our views with the Special Committee and welcome the opportunity to further discuss our comments. If you have questions, please contact Randi Chapman, managing director, state relations, at Randi.Chapman@bcbsa.com or Lauren Choi, managing director for health data and technology policy, at Lauren.Choi@bcbsa.com.

Sincerely,

Justine Handelman
Senior Vice President
Office of Policy and Representation
Below please find the BCBSA suggested redlines (11/15/2021)

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 and health care. This guidance begins with the premise that robust and accurate 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.

Data Collection

a) Health insurance companies should be where national industry standards exist and have been adopted across the healthcare ecosystem (providers, payers, and others) expected to enable processes 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 utilize industry-wide best practice in terms of data collection strategies and survey language 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, and an “other” option should be considered to help identify additional future data collection categories.

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 of this sensitive information.

e) Health insurance companies should be encouraged to pursue demonstrate how they are
meeting diversity, equity and inclusion goals for employees, insureds, and enrollees. (For instance, the NCQA’s Distinction in Multicultural Health Care (or an equivalent program/distinction) current NCQA product that addresses how organizations meet diversity, equity and inclusion goals for employees, insureds, and enrollees). 

a. For instance, State-based exchanges should may consider identifying insurers that have achieved demonstrated equality goals such as 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 must take into consideration any should confirm that neither state nor federal law that would prohibits or restrict the collection and/or reporting of an insurer from collecting race, ethnicity, language preference, sex (including gender identity), sexual orientation, and disability information. Such clarification Departments should distinguish between the collection of demographic data to be used for specific purposes, such as analysis of health disparities and inequities, from and the prohibited use of demographic data in rating, underwriting practices, and or benefit determinations. If existing laws prohibits collection of certain demographic data, health insurance companies and regulators should clearly state that this is the reason why the data was not reported.

b) Health insurance companies should apply HIPAA protections to demographic data, which should be considered HIPAA protected health information (PHI), 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.

b) All existing federal and state privacy laws and statutes shall continue to serve as the standard for any information sharing or analysis. When sharing publicly, both insurers and the Departments should ensure that any demographic information is aggregated and does not identify any single individual.

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 to identify and mitigate disparate impact or 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, individually or collectively through the NAIC, should collect and review demographic data from public sources including state and federal demographic databases health insurance companies to better understand the marketplace and efforts and opportunities for health insurance companies to advance and improve services and advance the departments to
address issues around 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. 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.
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.

![HHS Recommendations – Language](image)

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. Additionally, when providing identification approaches for Transgendered individuals, consider classifications also identified through the Gender Harmony project and the existing HL7 categories.

c. Sources:


   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/


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 of 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](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 assisters, develop communications and trainings focused on the importance of demographic data collection, and modify enrollment and renewal interfaces where legally permissible under state and federal laws.