



**BlueCross BlueShield  
Association**

An Association of Independent  
Blue Cross and Blue Shield Plans

1310 G Street, N.W.  
Washington, DC 20005

August 19, 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: Kay Noonan ([knoonan@naic.org](mailto:knoonan@naic.org))

**RE: Comments on 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 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 stated, 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 to surface existing best practices and to develop guidance around existing legal and regulatory barriers to the collection and appropriate use of race, ethnicity and language (REL) and sexual orientation and gender identity (SOGI) data to meet the health equity needs of our communities.

With these shared objectives and goals in mind, we highlight the current challenges facing the industry and offer considerations for the Workstream 5 dialogue around the draft principles on data collection and use. In light of these challenges, we propose that the industry guide and identify best practices around REL and SOGI data collection and use.

## **1. Data Collection**

**Issue:** The Special Committee proposes that health insurers “systematically collect, maintain, protect, and report on, at minimum, enrollee data on race, ethnicity, preferred language, sex (including gender identity), sexual orientation, and disability.”

### **Recommendation:**

The NAIC should continue to serve as a forum for all stakeholders to identify current barriers and best practices in data gathering and fostering ideas to reduce disparate or duplicative requirements and practices at federal and state levels.

Today, collection of REL and SOGI data varies greatly based on available data sets and line(s) of business. While some lines of business, such as Medicaid, enable collection of such data, the provision of the data is voluntary. At the same time, collection of REL and SOGI data sets are often inconsistent, derived from different sources (i.e., provider records, employer records, member-provided information, imputation algorithms), and collected under varying standards. Based on these factors, it is challenging to accurately, consistently and completely gather the data.

For instance, it has been BCBS Plans' experience that there are multiple factors that hamper the ability to gather accurate and complete REL and SOGI data:

- Voluntary reporting mandated by federal and often state law
- Lack of national industry standards
- Patient mistrust regarding the importance of providing and the use of the data
- Evolution and fluidity of self-identification in some cases

- Accuracy of data collection given voluntarily vs. mandatory requirements (e.g., leveraging imputation methods) and data sources

Even Medicare plans, which are generally permitted to gather much of this data, struggle. For example, in 2015, a study showed that while approximately 75 percent of Medicare plans reported “complete and partially complete data on race,” data on ethnicity and language needs were limited. The same study demonstrated that Medicaid and commercial plans have substantially less REL data than Medicare plans.<sup>1</sup>

For private markets, the most accurate and uniform way to collect data may be at the time of application. However, some states specifically prohibit the collection of race and ethnicity data in insurance applications.<sup>2</sup> Additionally, due to the voluntary nature of self-reported data, often the data are not complete. As a result, we are concerned that inaccurate conclusions will be drawn on the basis of such data and insurers may waste time and resources predicated upon faulty data. State departments of insurance and other regulatory bodies may similarly face limited information about the successes or failures of health equity initiatives because of incomplete reporting. Additionally, collecting REL data may place insurers at elevated risk of litigation or enforcement. Insurers are subject to numerous anti-discrimination statutes on the state and federal level. Collecting REL information, without specific protection from liability or clarity in terms of national industry practices, may expose insurers to meritless and costly litigation.

Similar issues arise with the collection of SOGI data. In addition to methodological challenges (i.e., absence of universal standards, sample size, individual willingness, reliable metrics and evolving classifications, to name a few), there are several technical challenges to collecting SOGI data that must also be addressed before successful systematic collection can be achieved. These technical challenges include: the conversion to previously unused SOGI codes, storage of such codes, operationalizing additional or new codes and the ability to share such data with a variety of stakeholders and vendors. The challenges associated with sharing such data highlights the limited definition of SOGI values today and infrastructure limitations that persist across a variety of stakeholders, slowing enhancements to data collection efforts.

In addition to time required to align with additional value sets for SOGI data, each vendor must also consider the impact on clients who will, in turn, require enhancements to their supporting systems. It will take extensive time and broad-based coordination and planning among all affected stakeholders to be effective.

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<sup>1</sup> Ng, Ye, Ward, et. al., Data on Race, Ethnicity and Language Largely Incomplete for Managed Care Plan Members, Health Affairs, Vol. 36. No. 2, March 2017, available at <https://www.healthaffairs.org/doi/10.1377/hlthaff.2016.1044>.

<sup>2</sup> Pennsylvania law prohibits “[q]uestions as to race or color ... on the application.” 31 Pa. Code § 89.12. California’s prohibition is broader, stating that “[n]o 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.” Cal. Ins. Code § 10141. The application period is an excellent opportunity to collect this type of information, and gathering the information at the beginning of the relationship would help to ensure that new members receive applicable supports.

Given the current challenges associated with the availability of quality data, the lack of national industry practices around REL and SOGI data collection, and the practical, regulatory and statutory impediments to appropriate collection and use of REL and SOGI data, mandating data collection will not address health equity objectives without the removal of legal and regulatory barriers and development of consistent national health care industry practices.

Therefore, we ask that prior to finalizing any draft principles on data collection, NAIC continue to serve as a forum for all stakeholders to identify current barriers and best practices in data gathering and fostering ideas to reduce disparate or duplicative requirements and practices at federal and state levels. It may be advantageous for NAIC and all stakeholders to consider recent information gathering efforts, including for example, the Centers for Medicare & Medicaid Services' (CMS) efforts on collecting health equity data. (See e.g., CMS' proposed 2022 Physician Fee Schedule Rule and CMS' 2022 Proposed Outpatient Prospective Payment System Rule.) NAIC could engage with the stakeholders to identify "what works" and state and federal regulators could consider and harmonize any data gathering initiatives based on stakeholder experience and feedback.

## **2. Data Use**

**Issue:** The draft principles propose that state insurance departments confirm that neither state nor federal law prohibits an insurer from collecting REL and SOGI data; that the insurers collaborate with state insurance departments to determine the acceptable uses of demographic data distinguishing between the collection of demographic data and the prohibited uses of demographic data in rating, underwriting practices and benefit determinations; and that state insurance departments should collect and review demographic data to understand the market and identify opportunities for insurers in the aggregate to improve services and advance health equity.

### **Recommendations:**

First, we want to thank the Special Committee for recognizing the existence of current legal and regulatory barriers to REL and SOGI data collection for insurers at the state levels by their inquiry above. As discussed previously, many state and federal legal and regulatory barriers currently exist that limit the industry's ability to collect this data in a consistent and accurate way.

This challenge is compounded by the fact that even assuming data were available, it will take time and resources to implement appropriate systems and processes to use the information effectively and appropriately. Additionally, in order to overcome patient mistrust and concern regarding such personal data collection, there must be robust and nationally recognized industry practices, as well as consumer communication initiatives, around collection and use of REL and SOGI data for health equity purposes, which currently do not exist. Absent such nationally acceptable practices, further voluntary collection of such data will also be challenging. In addition, it will be critical that there be a multi-industry effort around industry data use practices to ensure that this sensitive information is assessed and used appropriately. Any mandates around data collection and use would be premature in building and maintaining consumer trust. Instead, a multi-industry collaboration around the development of national industry data

collection practices, along with acceptable use guidance, would be more effective in addressing the current health equity needs.

As discussed above, health insurers are already constrained by multitude of federal and state laws governing their use and disclosure of protected health information (PHI), which would include demographic data on members. Enforcement of these laws is already robust, and NAIC oversight of insurer uses of demographic data are also defined by the limits and parameters of these laws. Additionally, there are no national industry standards or practices in terms of appropriate use of REL/SOGI data and multiple efforts are underway at the national level to design appropriate practices grounded in specific equity driven use cases, and which NAIC's efforts to engage stakeholders could be important in providing state guidance around nationally acceptable practices and guidelines.

Therefore, we ask that prior to finalizing any draft principles around equity data uses, NAIC engage with broad groups of health care stakeholders including health care providers, health plans and consumer organizations to surface ideas around national best practice guidelines on the appropriate use of REL and SOGI data with a focus on the health equity needs of our communities.

### **3. NCQA Distinction**

**Issue:** The draft principles propose that health insurance companies 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; and that 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.

#### **Recommendations:**

BCBSA has been engaging with NCQA to refine and develop their quality measures on advancing health equity and addressing social determinants of health. We recently submitted comments on NCQA's proposed changes to the Distinction in Multicultural Health Care which will become the new Health Equity Accreditation program. Since this program is currently being updated, we think it is premature for NAIC to include this recommendation at this time. We would also caution NAIC from singling out one specific entity's designation. It would be prudent for the committee to examine other designation programs with similar criteria or encourage other entities to create them in the future.

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](mailto:Randi.Chapman@bcbsa.com) or Lauren Choi, managing director for health data and technology policy, at [Lauren.Choi@bcbsa.com](mailto:Lauren.Choi@bcbsa.com).

Sincerely,

A handwritten signature in black ink that reads "Justine Handelman". The signature is written in a cursive style with a long, sweeping tail on the final letter.

Justine Handelman  
Senior Vice President  
Office of Policy and Representation