

**To:** The Special (EX) Committee on Race & Insurance Workstream Five (Health Insurance)  
The National Association of Insurance Commissioners (NAIC)  
444 North Capitol Street NW, Suite 700  
Washington, DC 20001

**Re:** *Principles for Data Collection*

August, 19,2021

Dear Committee Members,

On behalf of 29 national LGBTQ and healthcare advocacy organizations, we are writing to strongly support the document, *Principles for Data Collection*, issued by NAIC Special Committee on Race and Insurance – Workstream 5. State insurance departments and insurance companies are vital stakeholders in advancing health equity. Therefore, we believe that insurance companies should be systematically collecting, maintaining, protecting and reporting enrollee data based on race, ethnicity, preferred language, disability, and sex (including sexual orientation, gender identity and variations in sex characteristics). We urge NAIC to adopt these guidelines and encourage regulators and insurers to expand and improve data collection. We are grateful for the NAIC’s leadership in establishing the Special (EX) Committee on Race and Insurance and for Commissioner Ricardo Lara and Commissioner Jessica Altman in leading the efforts of Workstream 5, including the development of these critical guiding principles for data collection.

Comprehensive data collection is critical to advancing health equity and improving the healthcare delivery system for all patients, including patients from historically marginalized communities. A lack of data stymies policymakers’ ability to identify systemic issues in access to coverage, claims denials, appeals, and other measures. Limited or inaccurate data also makes it difficult to implement serious investments in improving quality of care for patients and reducing racial and ethnic health disparities. Comprehensive data is especially important to addressing disparities that are made worse when compounded with marginalized identities based on disability, gender identity, sexual orientation, and variations in sex characteristics (also known as intersex traits).

As LGBTQI+ advocacy and research organizations, we have long understood the importance of LGBTQI+ people being counted in insurance- and health-related data and having their gender identities and sexual orientations recognized. During Pride Month in June 2021, over 180 organizations published an [open letter](#) urging health leaders to routinely collect and report on sexual orientation, gender identity, and variations in sex characteristics (SOGISC) whenever demographic health data are collected. The letter also highlighted the disproportionate impact of

COVID-19 on LGBTQI+ communities that remained invisible because of a lack of SOGISC data collection.

We believe that *Principles for Data Collection*'s guidelines for data collection are a fundamental step towards advancing health equity by the health insurance industry and to addressing the needs of patients with historically marginalized identities. We strongly support the inclusion of SOGISC data alongside improved collection of other demographic data such as race and ethnicity. This information is critical to achieving the goals of Workstream 5 and the Special Committee. We also want to acknowledge that sexual orientation is a subset under the category of sex. As the *Principles for Data Collection* notes, the National Academies of Sciences, Engineering, and Medicine has [convened](#) an expert panel to “develop clear guidelines outlining the guiding principles and best practices for collecting sexual orientation and gender identity information in research and non-research surveys, along with medical and other administrative records,” as well for “measuring sex as a non-binary construct” that includes variations in sex characteristics. The National Academies previously [recommended](#) collection of SOGISC data across a variety of health settings and record systems. We expect that the results of this convening will be important to the efforts of insurers, regulators, and the NAIC, and we urge you to continue to build on current practices over time by improving identifiers and getting the most up to date information from experts in the frontline of SOGISC data collection.

We also urge you to look to the experiences in several states that already require insurers to collect SOGISC and other demographic data. The *Principles for Data Collection* document already reflects the fact that Covered California added SOGI questions to its marketplace application. And states such as Oregon recently enacted [new legislation](#) that will soon require coordinated care organizations, healthcare providers, and health insurers to collect data on race, ethnicity, preferred spoken and written languages, disability status, sexual orientation and gender identity. All insurers should have the capability to collect, maintain, and report these data, which are already often collected by other health system entities, such as hospitals and clinician practices that use electronic medical record (EMR) systems. Recognizing the importance of SOGI data to the provision of healthcare services, the US Department of Health and Human Services recently adopted a new version of the [US Core Data for Interoperability \(USCDI\)](#) that includes sexual orientation and gender identity as core elements. Some insurers have also already developed [new tools](#) to leverage SOGISC data elements to improve the experience of their diverse enrollees, such as the ability for transgender and nonbinary clients to include their authentic names, pronouns, and gender identities in their insurance record, and to avoid inappropriate denials of care for transgender, nonbinary, and intersex individuals based on sex coding.

Again, we are grateful for your commitment to racial justice and health equity. The emphasis on data collection and the draft *Principles for Data Collection* are fundamental steps in addressing

barriers and the needs of many communities with historically marginalized identities. These principles, if actualized, would better ensure that all patients receive high-quality health care and coverage needed to live full, healthy and authentic lives. Please do not hesitate to reach out for more feedback or to request any expertise.

We look forward to our continued partnership in this effort.

Signed,

1. Advocates for Youth
2. Athlete Ally
3. Center for American Progress
4. Center for LGBTQ Economic Advancement & Research (CLEAR)
5. Families USA
6. Family Equality
7. GLAAD
8. GLMA: Health Professionals Advancing LGBTQ Equality
9. Human Rights Campaign
10. interACT: Advocates for Intersex Youth
11. Justice in Aging
12. LGBT Technology Partnership & Institute
13. Lyon-Martin Health Services
14. Movement Advancement Project (MAP)
15. National Black Justice Coalition
16. National Center for Transgender Equality
17. National Equality Action Team (NEAT)
18. National Health Law Program
19. National LGBT Cancer Network
20. National LGBTQ Task Force
21. National Women's Law Center
22. Out2Enroll
23. Pride at Work
24. The TransLatin@ Coalition
25. The Trevor Project
26. Transgender Legal Defense & Education Fund
27. Transhealth Northampton
28. Whitman-Walker Institute
29. Woodhull Freedom Foundation