



August 19, 2021

Via electronic mail to Jolie Matthews, [jmatthews@naic.org](mailto:jmatthews@naic.org)

Special (EX) Committee on Race and Insurance  
National Association of Insurance Commissioners  
444 North Capitol Street NW, Suite 700  
Washington, DC 20001

**RE: Comments on Principles for Data Collection**

To the Special (EX) Committee on Race and Insurance,

On behalf of The Leadership Conference on Civil and Human Rights, a coalition charged by its diverse membership of more than 220 national organizations to promote and protect the civil and human rights of all persons in the United States, we write in support of the Special (EX) Committee’s “Principles for Data Collection.” Through advocacy and outreach to targeted constituencies, [The Leadership Conference](#) works toward the goal of a more open and just society — an America as good as its ideals. Given the critical importance of comprehensive demographic data collection in addressing and working to mitigate health inequities, our coalition strongly supports the development of the “Principles for Data Collection.”

Collection and access to comprehensive demographic data across health care programs, providers and insurers is essential for health care professionals, policymakers, and other stakeholders to be able to identify, monitor, and develop targeted strategies to mitigate health inequities. Health status and health care quality and utilization disparities persist, and in some cases have widened across many demographics including race/ethnicity, socioeconomic status, gender identity, sexual orientation, disability status, and English proficiency. However, identifying disparities and effectively monitoring efforts to reduce them have been limited by a lack of specificity, uniformity, and quality in data collection and reporting procedures.

The collection of demographic data is critical as we have long known, and as was recently re-emphasized by Dr. Marcella Nunez-Smith, Chair of the Biden Administration’s COVID-19 Health Equity Task Force, who stated when discussing the need for data, “we cannot address what we cannot see.”<sup>1</sup>

The collection and analysis of comprehensive demographic data by insurers is important due to the scope and scale of the health care they are responsible for covering and the millions of individuals covered by their products. Analyzing demographic data is vital to developing and implementing effective prevention,

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<sup>1</sup> Alemany, Jacqueline. “Power Up: Biden will inherit a raging pandemic. This Yale doctor will be key to his efforts.” *The Washington Post*. <https://www.washingtonpost.com/politics/2021/01/19/power-up-biden-will-inherit-raging-pandemic-this-yale-doctor-will-be-key-his-efforts/>



intervention,  
and  
treatment



programs, facilitating the provision of culturally and linguistically appropriate health care, and identifying and tracking similarities and differences in performance and quality of care in various geographic, cultural, and ethnic communities. It is also important to develop meaningful standards to analyze the efficacy of data collection activities to ensure non-discrimination. All of these activities should be undertaken by insurers, with oversight by state insurance commissioners, to ensure insurers are paying for care that does not increase disparities or result in discrimination.

As we have seen throughout the COVID-19 pandemic, the lack of comprehensive and accurate data has exposed the country's challenges in identifying those most impacted by threats to their health and well-being as well as in developing targeted and appropriate interventions for communities at highest risk. For example, few states reported COVID-19 testing data by race/ethnicity. As new data emerged, we learned that Black, Hispanic, and American Indian and Alaska Natives were significantly disproportionately impacted by the virus. Preliminary Medicare COVID-19 data show that these Medicare beneficiaries had higher rates of infection and hospitalization compared to White beneficiaries.<sup>2</sup> Even before the pandemic, when compared to White people, people of color were in poorer health, were more likely to be uninsured and faced greater barriers to accessing health care. People of color were also more likely to have lower incomes and face financial challenges (although health and health care inequities cannot be explained solely by economic factors). While people of color were more likely to be exposed to COVID-19 for a number of structural reasons, including their overrepresentation in the essential worker sectors and limited opportunities to work from home, preexisting health conditions and health care inequities combined with additional barriers to accessing testing and treatment increased their risk of serious illness and death.<sup>3</sup>

The collection of high-quality demographic data — including race and ethnicity data of smaller populations, subgroups that comprise the larger demographic categories, and populations with multiple identities — is a critical first step in understanding and eliminating disparities in healthcare access and quality and health outcomes. The dearth of comprehensive disaggregated demographic data hinders our ability to identify and address health disparities as well as the structural racism that undermines health. Having accurate demographic data also helps covered entities plan how to provide language services and auxiliary aids and services for people with disabilities.

While the existence of health disparities has been well documented, the complex factors that contribute to and mitigate against them are still not fully understood. In part, this is due to a lack of high quality, large scale, and easily available data. For example, data on smaller racial and ethnic groups is often not extensive enough to lend itself to meaningful analysis. The use of broad demographic categories such as Asian American and Hispanic obscure critical inequities experienced by some of the subgroups that comprise them. Similarly, data is often not available for intersecting sub-populations that might experience multiple barriers to access.

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<sup>2</sup> CMS, *Preliminary Medicare COVID-19 Data Snapshot*, <https://www.cms.gov/research-statisticsdatabases/preliminary-medicare-covid-19-data-snapshot>.

<sup>3</sup> Kaiser Family Foundation, *Racial Disparities in COVID-19: Key Findings from Available Data and Analysis*, <https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-disparities-covid-19-keyfindings-available-data-analysis/>.



Demographic data can help insurers and insurance commissioners target interventions to the populations that need them most, tailor interventions to the specific needs of a community and prevent further discrimination. Demographic data collection is especially important as we move towards a health care payment system that rewards quality rather than quantity. And without granular, disaggregated race and ethnicity data, average improvement in the health outcomes could mask a lack of improvement or even deterioration in outcomes for a specific population.

We support the Special (EX) Committee's principles and highlight the importance of recommending standardized categories and definitions for all demographic variables. In particular, racial, ethnic and preferred language data should be collected at a granular level to allow for disaggregation, particularly for Asian Americans, Native Hawaiians and Pacific Islanders (AANHPI) and for Hispanics, and allow for the inclusion of Middle Eastern and Northern African (MENA) populations. This recommendation should not be diluted as it helps to ensure that these communities will receive the supports they need.

For more information, please contact June Zeitlin, The Leadership Conference ([zeitlin@civilrights.org](mailto:zeitlin@civilrights.org)) or the co-chairs of the Health Care Task Force, Mara Youdelman, National Health Law Program ([youdelman@healthlaw.org](mailto:youdelman@healthlaw.org)) and Sinsi Hernández-Cancio, National Partnership for Women & Families ([shc@nationalpartnership.org](mailto:shc@nationalpartnership.org)).

Sincerely,

A handwritten signature in black ink, appearing to read "Jesselyn McCurdy".

Jesselyn McCurdy  
Interim Executive Vice President for  
Government Affairs/Managing Director  
The Leadership Conference on Civil and Human Rights

A handwritten signature in black ink, appearing to read "Mara Youdelman".

Mara Youdelman  
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A handwritten signature in purple ink, appearing to read "Sinsi Hernández-Cancio".

Sinsi Hernández-Cancio  
Vice President for Health Justice  
National Partnership for Women & Families