

FROM THE NAIC CONSUMER REPRESENTATIVES

To: Special (EX) Committee on Race and Insurance Workstream Five (Health)
Jolie Matthews

Date: August 19, 2021

Re: Draft Principles for Data Collection

Thank you for the opportunity to comment on the draft Principles for Data Collection for the Special (EX) Committee on Race and Insurance – Workstream Five. We, the undersigned consumer representatives, fully support these draft Principles and reiterate the need for systemic collection of demographic data by insurers and insurance regulators.

Enhanced data collection is long overdue and necessary to advance racial justice and health equity. The expanded collection and reporting of comprehensive data by race and ethnicity is foundational to addressing inequities and discrimination in coverage. Without data on, say, enrollment, claims denials, complaints, or producer demographics by race and ethnicity (among other factors), regulators and policymakers simply cannot have a full and complete picture of their markets or the ability to assess systemic challenges or biases. Without a full and complete picture, inequities can persist, and policymakers may miss opportunities to address the needs of impacted populations. Contrary to suggestions that this data cannot or should not be collected because it could enable discrimination, full and proper enforcement of nondiscrimination, civil rights, and unfair trade practices protections *depends* on the collection of this data so regulators and policymakers can assess systemic bias and take action as needed.

To truly advance racial justice, insurers and regulators must be willing to undertake long-term, sustained action on data collection. We acknowledge that at present some insurers may face operational challenges to data collection. However, the work and success of the Centers for Medicare and Medicaid Services (CMS) and other federal agencies in fostering a robust set of resources for collection, analysis, and reporting of data for health policymaking shows that such concerns can be addressed and do not justify inaction.

Given the lack of standardized data collection practices across states and insurers, the NAIC plays a key coordination role in these efforts. We especially applaud Workstream Five for identifying best practices on how to better ask and improve the collection of demographic data on race, ethnicity, preferred language, sex (including sexual orientation and gender identity), and disability and the need to maintain data protections and privacy as necessary to protect individual identities. With respect to the draft Principles, we make the following specific comments:

- On the “data collection” principles under (c) on page 1, we recommend the following edits to help make a distinction between the disclosure of data by prospective insurers and enrollees versus reporting of this data by insurers and plans.
 - (c) The disclosure of demographic data by prospective insureds and enrollees must always be voluntary and based on self-identification or disclosure. Submission of such information should always be optional. Prospective insureds and enrollees may be required to answer these questions so long as a “prefer not to answer” option is included. Self-identification remains optional even though health insurance companies should be required to report the information that they collect.

- The draft does not reflect a dedicated resource list regarding the collection of data on race and ethnicity. We recommend that the following resources be included in the next version:
 - Asian & Pacific Islander American Health Forum (2021). *Policy Recommendations: Health Equity Cannot be Achieved without Complete and Transparent Data Collection and the Disaggregation of Data*. <https://www.apiahf.org/wp-content/uploads/2021/02/APIAHF-Policy-Recommendations-Health-Equity.pdf>
 - State Health and Value Strategies (2021). *Collection of Race, Ethnicity, Language (REL) Data in Medicaid Applications: A 50-State Review of the Current Landscape*. <https://www.shvs.org/wp-content/uploads/2021/05/SHVS-50-State-Review-EDITED.pdf>
 - US Census Bureau (2017). *2015 National Content Test Race and Ethnicity Analysis Report: A New Design for the 21st Century*. <https://assets.documentcloud.org/documents/4316468/2015nct-Race-Ethnicity-Analysis.pdf>
 - Institute of Medicine (for AHRQ) (2021). *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. <https://www.ahrq.gov/research/findings/final-reports/iomracereport/index.html>
 - McGee, M.G. (2020). *Race, Ethnicity, Language and Disability (REALD) Implementation Guide*. <https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le7721a.pdf>

- We want to emphasize the importance of one of the resources that is already included in the draft Principles titled [Health Equity Cannot Be Achieved Without Complete and Transparent Data Collection and the Disaggregation of Data](#). This 2021 resource was developed by five national civil rights organizations in the wake of the pandemic. After a landscape analysis followed by partnership with four states, these organizations identified best practices and concrete recommendations for legislative changes, regulatory changes,

policy guidance, and policy actions to encourage improved subgroup data disaggregation by more racial and ethnic categories. These recommendations reflect the growing consensus that the five broad categories in which data is currently and primarily collected—Black, White, American Indian/Alaska Native, Latinx, and Asian American/Pacific Islander—mask and thus perpetuate key disparities by ignoring entire populations and subgroups.

- We recommend that the draft Principles note additional best practices for the collection of data on race and ethnicity and the need for cross-tabulation of data to identify patterns and make data more actionable. Best practices include combining questions on race and ethnicity, including options that correspond to the specific racial and ethnic identities in the state; including at least 15 different race identifications in alignment with Department of Health and Human Services standards and the model application developed by CMS and used by Healthcare.gov; allowing the selection of more than one race and ethnicity without a requirement to prioritize a single answer; development of a standard rubric for “rolling up” granular categories to broader ones to address privacy concerns; training on how to ask these questions appropriately, including information about why the questions are being asked; and making answers to the questions mandatory while embedding a “prefer not to answer” option so that self-identification remains optional.
- We also encourage the Appendix to include recommendations in the event that demographic data collection remains low after best practices are implemented. If this occurs, 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 (by, for example, adjusting online forms to require enrollees to provide an answer—including “prefer not to answer”—before proceeding to the next screen).
- We believe that insurers should collect better demographic data about the providers in their network and that doing so would aid regulators’ ability to assess whether insurers meet network adequacy requirements. These requirements should extend to any community-based organizations and other entities that insurers contract with and that interact with or otherwise serve prospective or actual enrollees. These recommendations are equally important for and relevant to other Workstream Five efforts to improve provider networks, provider directories, and cultural competency.

As this work continues, the NAIC may want to engage experts in demographic data collection who can further advise these efforts; we can make recommendations where helpful. These efforts should also be informed by what we believe will be forthcoming federal guidance on ways to increase the collection of data on race, ethnicity, and language, among other factors.

While we fully support the draft Principles, we continue to encourage Workstream Five to develop a white paper on this topic. Data collection can raise complex issues that we believe should be fully discussed and documented through an open and transparent process. The process of developing a white paper could also help inform state and industry approaches and serve as an evergreen resource that the NAIC could build on over time as data collection practices evolve.

Thank you again for your leadership and we look forward to continuing to work with you, your staff, and NAIC staff on these important issues. Please contact Katie Keith at katie@out2enroll.org or Karen Siegel at ksiegel@hesct.org with any questions.

Sincerely,

Jamille Fields Allsbrook
Courtney Bullard
Bonnie Burns
Lucy Culp
Deborah Darcy
Yosha Dotson
Eric Ellsworth
Justin Giovannelli
Marguerite Herman
Anna Schwamlein Howard
Janay Johnson

Katie Keith
Rachel Klein
Natasha Kumar
Sarah Lueck
Dorianne Mason
Erin Miller
D Ojeda
Carl Schmid
Karen Siegel
Matthew Smith
Andrew Sperling

Harry Ting
Wayne Turner
Jackson Williams
Silvia Yee