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Marcella Nunez-Smith, MD, MHS
COVID-19 Health Equity Task Force
VIA Email: COVID19HETF@hhs.gov

Dear Dr. Nunez-Smith and members of the COVID-19 Health Equity Task Force,

Health Equity Solutions applauds the COVID-19 Health Equity Task Force's (Task Force) efforts to elevate health equity within the pandemic response and beyond. Quality granular race, ethnicity, and primary language data is a lynchpin to identifying and benchmarking disparities, informing concrete actions to address inequities experienced by minoritized communities, and ensuring that equity is at the forefront of policy and program design and decision making.

The priority the Task Force has placed on understanding the existing barriers to race, ethnicity, primary language, and disability (RELD) data collection and the discussed solutions align with efforts in Connecticut. Section 11 of Connecticut's recently enacted Public Act No. 21-35 standardizes the collection of race, ethnicity, and language (REL) data across state agencies that collect health-related data and among provider participants in the state's health information exchange. We are grateful for the opportunity to share the following recommendations for federal guidance and regulations. These recommendations are based on Health Equity Solutions' research leading up to the passage of this statute and implementation of Connecticut's statewide health information exchange.

Expand the discussion of disaggregated REL data collection to all federal agencies collecting REL data. Adopting federal standards for granular race and ethnicity data fields is a structural solution to address gaps in comprehensive and granular REL data for health outcomes and social determinants of health. Multiple public comments made at Task Force meetings have underscored the importance of leveraging the Task Force's preliminary SUD- and COVID-19-related recommendations and findings to establish unified federal standards encompassing all federal entities involved in REL data collection. We respectfully add our support and hope to situate this recommendation in a state context.

Consistent federal REL data standards across programs and agencies would clarify and facilitate the implementation of REL data collection in Connecticut. Such standards would also address potential barriers to cross-sector health equity initiatives. For example, *Connecticut's MYCT for Health and Human Services project* intends to streamline application processes for state-run services. Streamlined applications have been shown to widen accessibility of programs for eligible residents, benefit communities of color, and reduce administrative burdens, and may contribute to cost savings.[1,2,3] This effort may be complicated by conflicting federal requirements. As you are aware, enrollment applications for Medicaid and SNAP are governed by CMS and the USDA respectively, each with distinctive requirements and regulations for data collection and the granularity of data fields being

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[1] Code for America. (2019) "Bringing Social Safety Net Benefits Online: Examining Online Platforms for all 50 States." Retrieved from: https://www.codeforamerica.org/features/bringing-social-safety-net-benefits-online/?utm_source=General+eNews+11%2F14%2F2019&utm_campaign=eNews+11-14-2019&utm_

[2] Center on Budget and Policy Priorities and CLASP. (2018) "Improving SNAP and Medicaid Access: Medicaid Renewals." Retrieved from: https://www.cbpp.org/sites/default/files/atoms/files/11-30-18fa_asap_medicaid__renewals.pdf

[3] Wikle, S. (2018) "Using Administrative Advocacy to Improve Access to Public Benefits." Retrieved from: https://www.clasp.org/sites/default/files/paper%20with%20cover%20page.pdf and Code for America.

collected and publicly reported. Experiences in other states suggest that successful implementation of streamlined social services applications may be impeded by a lack of harmonization in REL data standards across agencies at the federal level, undercutting Connecticut's ability to collect granular REL data while improving efficiency and promoting equity.

Embed flexibility for states to tailor data collection standards to their specific demographic composition. PA No. 21-35 mandates that Connecticut use race and ethnicity data fields created for the state's Clinical and Community Integration Program. These fields were selected to reflect the state's demographics and were successfully piloted under the CT Office of Health Strategy's State Innovation Model. PA No. 21-35 also specifies that the data fields follow hierarchal mapping to align with the current Office of Management and Budget standards, as these serve as the REL data collection minimum standards. In addition to ensuring harmonization and integrity, the creation of granular federal REL standards could also serve as a "gold-standard" for minimum requirements. That said, new standards should not inhibit the ability of states to tailor their data fields to reflect their populations. For example, some advocates have suggested that the federal government should define the top six subgroups of each race/ethnicity category based on national population data, with a write in option for other subgroups.[4] However, this is inadequate as it imposes potential obstacles for states with varying demographics. The data fields Connecticut recently adopted are based on the state's census data and offer categories that more accurately reflect the experiences and outcomes of the majority of Connecticut's population than would a generic standard. Unlike the U.S. Office of Minority Health (OMH) standards which contain 15 categories, the CT standards include a total of 60 categories, including 19 fields that roll up to the OMB Asian race category and 20 data fields that roll up to the OMB Hispanic, Latino/a, or Spanish ethnicity category. Each state has a unique demographic composition and a fully expanded list of categories is cumbersome; therefore, we recommend that any federal standards for REL collection account for such diversity by emphasizing hierarchal mapping as a means of embedding flexibility within data fields. In other words, states should be able to collect categories they identify as relevant as long as they are able to be matched and/or aggregated to federal categories. That said, rollup schemes of ethnicities to OMB racial categories are not without their own set of challenges.[5] Federal guidance on imputation and aligning more granular or locally specific categories with federal categories would be valuable, particularly if developed in collaboration with states.

Recognize individuals with multiple racial and/or ethnic identities within data collection questions. Despite evidence showing that employing two distinct questions about ethnicity and race leads to lower overall response rates and hierarchal mapping challenges,[6] particularly among Latina/o communities,[7, 8] multiple federal agencies continue to require this format.[9] Currently 11 states offer a combined race/ethnicity question on either their paper or online Medicaid application.[10] We recommend that all individuals be permitted to select more than one race or ethnicity so that residents are able to better

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[4] California Pan-Ethnic Health Network and Prevention Institute: Template Response to Office of Management and Budget Request for Information on Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government https://cpehn.org/assets/uploads/2021/06/CPEHN-PI-Template-Response-to-OMB-RFI-on-Equity-6-29-2021-FINAL.docx

[5] Agency for Healthcare Research and Quality: Chapter 3: Defining Categorization Needs for Race and Ethnicity Data. May 2018. https://www.ahrq.gov/research/findings/final-reports/iomracereport/reldata3a.html

[6] Ibid.

[7] Urban Institute: Research Methods and Data Analytics. https://www.urban.org/urban-wire/separating-race-ethnicity-surveys-risks-inaccurate-picture-latinx-community

[8] State Health Access Data Assistance Center: New York State of Health Pilot Yields Increased Race and Ethnicity Question Response Rates. https://www.shvs.org/new-york-state-of-health-pilot-yields-increased-race-and-ethnicity-question-response-rates/

[9] U.S. Census Bureau: 2015 National Content Test Race and Ethnicity Analysis Report, https://apps.npr.org/documents/document.html?id=4316468-2015nct-Race-Ethnicity-Analysis

[10] State Health Access Data Assistance Center: Collection of Race, Ethnicity, Language (REL) Data in Medicaid Applications: A 50-state Review of the Current Landscape. https://www.shvs.org/resource/collection-of-race-ethnicity-language-rel-data-in-medicaid-applications-a-50-state-review-of-the-current-landscape/

see their identities reflected in the options. Establishing a similar standard would be in line with evidence-based practices and support more complete, inclusive, and comprehensive data collection that will help to address data integrity.

Disaggregate all racial and/or ethnic categories. While the preliminary recommendations set forth by the Data, Analytics, and Research Subcommittee and approved by the full Task Force focus on disaggregating the Asian American and Pacific Islander and American Indian/Alaska Native racial categories, we recommend that the creation of federal granular REL standards be predicated on full disaggregation across all racial and/or ethnic categories. In some ways, the Office of Minority Health race and ethnicity data standards attempted more detailed collection by including 6 subgroup fields for the Asian category. More recently, OMH released a request for information (RFI) on Best Practices for Advancing Cultural Competency, Language Access and Sensitivity Toward Asian Americans and Pacific Islanders, prioritizing a focus on data collection, utilization, and reporting and crystalizing this commitment to granular data collection for the AAPI community. A concerted focus on AAPI communities is an appropriate response to essentialized treatment of these diverse ethnic groups, which has perpetuated the invisibility of serious and nuanced health disparities. The lack of resources and services to address the needs of Asian ethnic communities require particular attention. We also recognize similar systemic erasure of certain ethnic subgroups beyond those categorized under the Asian racial category (e.g., Middle Eastern and North African essentialized to white). Thus, we recommend the Task Force expand disaggregation to all racial/ethnic groups to better reflect the identities of all residents living in the United States.

Lastly, the successful passage of PA No. 21-35 was in part based on the standards disaggregating all racial/ethnic categories. Some members of the Asian community feared unintended, adverse discriminatory consequences when an earlier draft employed the existing OMH categories with disaggregation limited to the Asian race category. Choosing standards which disaggregated all racial and ethnic categories helped to alleviate some of these concerns.

Overall, federal standards for disaggregating REL data by uniform and granular categories would expand the visibility and voice of communities, enhance our capacity to evaluate disparities, and provide quality evidence to drive systems change through responsive policies and funding. To better understand the intersectionality of identities and how this plays a role in the experience of structural health inequities there is a need for better demographic data for REL and beyond including improved disability and sexual orientation and gender identity (SOGI) data collection.

We acknowledge the complexities of undertaking this work and thank you for your active commitment to dismantling systemic racism and embedding equity in federal systems, practices, and policies. Transforming our systems to be equitable and inclusive is a shared responsibility across the nation and we are grateful for your leadership.

Thank you for your time and attention,

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Tekisha Everette, PhD
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