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Testimony Supporting H.B. No. 6424 An Act Revising Data Collection Requirements for Health Care Providers Connecting to the State-Wide Health Information Exchange

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Public Health Committee
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Dear Senator Abrams, Representative Steinberg, and esteemed members of the Public Health Committee,

My name is Tekisha Dwan Everette and I am testifying today in my role as the Executive Director of Health Equity Solutions. Health Equity Solutions is a nonprofit organization with a statewide focus on promoting policies, programs, and practices that result in equitable health care access, delivery, and outcomes for all people in Connecticut. Our vision is for every Connecticut resident to attain optimal health regardless of race, ethnicity, or socioeconomic status.

I offer Health Equity Solutions' (HES') **strong support for the standardized collection of race, ethnicity, and language data** through the statewide Health Information Exchange and **all health data collection efforts by the state**. Race, ethnicity, and language (REL) data is a critical component of evaluating health outcomes disparities and ensuring health equity for everyone. By consistently collecting and publishing health data broken down by race, ethnicity, and primary language the state can recognize and work to address how, where, and for whom disparities occur.

Why is REL data collection important, especially now?

The collection, processing, analyzing, and sharing of REL data is critical to identifying disparities, applying for funding, directing resources and planning, as well as targeting and evaluating interventions and services. As has been made abundantly clear in recent months, race, ethnicity, and age data are necessary during a pandemic to ensure that resources are targeted to the hardest hit communities. Without REL data, decisionmakers are drawn to one-size-fits-most solutions, which are likely to exacerbate the racial inequities that are deeply ingrained in our status quo. Health inequities are rooted in structural inequality that has privileged some individuals and communities and disenfranchised others. As a result of structural racism and its wide-reaching impacts, Black, Indigenous, Latino, and other people of color in Connecticut are more likely to live in densely populated neighborhoods, work wage-based jobs, have less wealth, lack health insurance, and suffer from chronic health conditions such as asthma and diabetes. The cumulative impact of these barriers to health is invisible unless we evaluate and seek to address health disparities.

Data provides us the information we need to make informed decisions and can improve and change lives. REL data provides us with the information we need to intentionally address systemic racism. For example, recently released COVID-19 vaccination data[1] highlights enormous disparities in vaccine administration in Connecticut. Even when assessing vaccine distribution by race and age to account for the higher proportion of older adults who are white, Black residents of our state are both disproportionately unvaccinated and disproportionately likely to suffer serious illness and death from COVID-19. A targeted and culturally sensitive approach could ameliorate this inequity. Having this data allows the state to evaluate whether or not efforts to promote equity in vaccine allocation are successful and to course correct as necessary.

While a preponderance of scientific research concludes that race has no biological value, its relevance to the lived experiences of individuals in our society makes REL data a necessary tool in efforts to dismantle systemic racism. Efforts to standardize and collect this data are not new, though this issue has seen a resurgence in interest as we grapple with increased awareness of systemic inequities and calls for anti-racist policymaking.[2]

We respectfully recommend the following:

- **Align REL data collection with best practices**, which include (1) that REL data be self-reported (as already specified in H.B. 6424), (2) offering the **option to select one or more ethnic or racial designations**, and (3) offering **an "other" designation** enabling people to write in identities not listed. These standards improve the accuracy of REL data,[3] because a person's identity cannot be assumed based on appearance and because people are more likely to volunteer this information when their identity is reflected in the options offered. For example, an individual who identifies as both Black and Indigenous may not be willing to choose only one of those categories. Similarly, people who identify with an identity not listed may choose to skip a request to identify their race or ethnicity if it is not among the available option. Offering the option to write in additional categories also allows the state to track shifting demographics and ensure the categories remain appropriate to Connecticut's demographics and honors every person's right to self-identify.
- **Align categories for REL data align with recommendations tested under Connecticut's State Innovation Model Community and Clinical Integration Program** (CCIP). These categories were collected by participating entities in this project and research on the categories was presented to the Office of Health Strategy in late 2018.[4] Since these categories have been tested by health providers in Connecticut, we know that collection of them is feasible. Further, they are more reflective of Connecticut's demographics than the Office of Minority Health (OMH) standards referenced in H.B. 6424. As recommended by the Agency for Healthcare Research and Quality the CCIP categories are more granular than the OMH standards without being as lengthy and complex as the comprehensive Centers for Disease Control and Prevention Health Level 7 Race and Ethnicity Code Set, which contains 900 race and 43 ethnicity codes. The CCIP categories were derived from American Community Survey data and include a total of 62 race and

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[1] CT Department of Public Health Immunization Program. *COVID-19 Vaccine Distribution in Connecticut—Update for 2/25/2021*. Retrieved from: https://data.ct.gov/stories/s/CoVP-COVID-Vaccine-Distribution-Data/bhcd-4mnv/

[2] Siegel, Karen. 2018. *Data to Promote Health Equity for Children and Families in Connecticut*. Connecticut Voices for Children. New Haven, CT. Retrieved from: https://ctvoices.org/wp-content/uploads/2018/02/Data-for-Health-Equity-FINAL.pdf

[3] Klinger, E., Carlini, S., Gonzalez, I. et al. 2015. *Accuracy of Race, Ethnicity, and Language Preference in Electronic Health Record*. J Gen Intern Med doi: https://dx.doi.org/10.1007%2Fs11606-014-3102-8 and Agency for Healthcare Research and Quality. Race, Ethnicity and Language Data: Standardization for Health Care Quality Improvement. Retrieved from: https://www.ahrq.gov/research/findings/final-reports/iomracereport/reldata3.html

[4] Health Equity Solutions. 2018. Recommendations for Granular Race & Ethnicity Data Collection. Presented to State Innovation Model Program Staff on November 2, 2018. Report available upon request.

ethnicity categories, inclusive of “other” options for each group. Further, the race categories recommended by the Office of Minority Health only offer granular options for people who identify as Asian, while the CCIP categories offer this level of specificity across racial and ethnic categories. For example, using the CCIP categories an individual could identify themselves as Arab, European, Portuguese, or Middle Eastern/Northern African rather than only having the option to identify as white or skip the question. The categories collected in the CCIP roll up to the Office of Management and Budget categories utilized in some federal reporting so that there is no need for complex data consolidation for reporting. In other words, the CCIP categories are specific enough to increase the likelihood of Connecticut residents seeing their identities reflected in the categories without adding administrative complexity.

- **Any Connecticut state agency collecting REL data in a context related to health should adopt the categories outlined above**. A recent report found that the five Connecticut state agencies examined by the research team each collected a different set of race and ethnicity categories.[5] If the state collected data in a standardized manner, cross-sector efforts to identify and address inequities would be more efficient and meaningful. Further, this would enhance the state’s ability to match data sets so that information on a person’s racial and ethnic identity can be collected once and then matched with data collected for other purposes and used, in keeping with the strict privacy protections already in place in our state, to advance health equity, evaluate our progress towards this goal, and course correct as necessary. Consider, for example, how importing REL data into COVID-19 case reporting and contact tracing efforts could have simplified one administrative hurdle to tracking equity during the pandemic and shortened the contact tracing questionnaire.

Addressing concerns about how REL data is used: Stringent guidelines are in place for the utilization of health data in our state.[6] Specifically, the Health Insurance Portability and Accountability Act of 1996 (HIPAA), protects health data. Further, state data management regulations suppress reporting any category with very small numbers to avoid unintentionally exposing the information of one individual or family unit. Finally, should there be any risk of this data being misused, organizations such as HES and our partners would immediately raise concerns with the responsible entity. **The reality is that REL data is already routinely collected and kept private by health care providers and state agencies**. This proposal simply standardizes how these existing processes are carried out so that the data can more effectively be used to promote equity at the population level.

Final thoughts: Without uniform, consistently collected and reported data on race, ethnicity, and primary language data it is impossible to effectively and fairly allocate state resources or to track progress in resolving disparities in health and well-being. Clear guidance on data collection now has the potential to facilitate intentionally antiracist policies, processes, and actions in the near term and well into the future. As written, this proposal would enable the state to leverage the Health Information Exchange to drive progress towards health equity. With the proposed amendments, this bill would allow Connecticut to intentionally identify and address inequities in health across sectors.

Thank you for the opportunity to testify in support of H.B. 6424. I can be reached with any questions at teverette@hesct.org or 860.937.6610.

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[5] Health Equity Data Analytics. 2020. Policy Recommendations Report: September 2020. Retrieved from: https://portal.ct.gov/-/media/OHS/docs/HEDA-Recommendations_-Sept2020.pdf

[6] See the Office of the Attorney General’s Privacy and Data Security Department: https://portal.ct.gov/AG/Departments/Privacy/The-Privacy-and-Data-Security-Department