HEALTH
EQUITY
SOLUTIONS

Achieving Health Equity:
The Importance of Collecting Race, Ethnicity and Language Data

While Connecticut ranks the 5th healthiest state in the nation[1], many segments of the population experience significant and persistent disparities in their health and well-being. In many cases, we do not fully know the extent of these disparities due to a lack of timely and actionable data on specific populations. To achieve health equity and ensure residents have the opportunity to be and stay healthy, we must move toward having the data necessary to target interventions. The lack of uniformity and limited access to timely data on socio-demographic factors, the most salient being race, ethnicity, and language (REL), represents a serious challenge to achieving equity in the state. Standardized, expanded, uniform, and timely REL data has the capability of revealing problems and finding solutions that promote positive health outcomes for all people in Connecticut.

Issue Statement:

The collection of race, ethnicity and language (REL) data is a critical component of evaluating health outcomes among various populations and ensuring health equity for everyone. However, while some REL data are collected in clinical and non-clinical health settings throughout the state, it is inconsistent, fragmented, siloed, dated, and limited in use. It is often challenging to answer questions about the prevalence of health disparities beyond the standard OMB 5 racial and ethnic reporting categories (American Indian/Alaska Native, Asian/Native Hawaiian Other Pacific Islander, Black, Hispanic, and White). Because of this, the specific and targeted needs of populations are masked by aggregated data thereby missing the complete picture of health in our state and limiting the effectiveness of targeted interventions.

To achieve greater understanding of disease burden, health status, and health outcomes, and to best shape the planning, implementation, and delivery of services, REL data should be collected in a standardized way across all entities collecting health data within the state. This data should be publicly available and actionable at the clinical and non-clinical intervention level. To the extent possible, all reporting based on state collected data should be both aggregated and disaggregated by REL categories and regularly made available. Without uniform, consistently collected and reported, disaggregated and publicly available REL data, it is impossible to effectively and fairly allocate state resources. Furthermore, without REL data, it is impossible to track progress in resolving disparities in health and well-being.

Policy Proposal:

I. Standardize what data is being collected:

To facilitate the standardized collection of race, ethnic, and primary language (REL) data, HES proposes that any state agency collecting data on or related to health be required to collect race, ethnicity, language data in a standard, uniform format that accounts for the diversity present in Connecticut. Such REL data would be uniform and consistently collected, across all identified agencies to ensure interoperability—so that data can be shared, compared, and stratified to identify and address disparities. All REL information collected should be voluntarily self-reported by the individual.

II. Expand what data is being collected:

REL data collection should include the ethnic/ancestry groups both residing and immigrating into our state based on available research. Information on language will further assist us in developing culturally and linguistically appropriate interventions. Primary language data would be collected in a standard, uniform format employing language codes set by the International Organization for Standardization.

All expanded race and ethnic data collected would be capable of being aggregated into the federal OMB race and ethnicity standards in order to comply with and integrate with federal data systems. As standard practice, since the last US Census, individuals would be able to report more than one race, and individuals from smaller subgroups without a formatted ethnicity/ancestry code would have an opportunity to write in their ethnicity under an “Other” code to ensure data on smaller minority subgroups.

III. Publicly report de-identified and disaggregated data:

Such data should be disaggregated and publicly accessible in a manner consistent with the provisions of the Health Insurance Portability and Accountability Act (HIPPA) privacy rules as outlined in federal regulation (45 CFR 164.514).

All REL data collected by the state agencies in accordance with the provisions above would be openly accessible and shared in a readable fashion within and across agencies, as well as to researchers, non-profits, and members of the public. All REL data should comply with efforts in the state to make data available across and among agencies and queried at an individual level. This data would be considered high value data and would be analyzed to make and publish reports on existing and emerging disparities and would be reported annually to the Office of Policy and Management.

Conclusion:

Connecticut is a leader in health, yet the collection of race, ethnicity and language data remains inconsistent, fragmented, siloed, dated and limited in use. States across the country, including Massachusetts, California, Minnesota and North Carolina have successfully been able to implement policies and standards that collect REL data to better serve their residents. Connecticut has an opportunity to join this group and be a leader in REL data collection to better identify health disparities, design and target interventions and improve the overall health of all its residents.

[1] United Health Foundation. (2017). Annual report: Executive summary. Retrieved from https://assets.americashealthrankings.org/app/uploads/ahr_annual_report_2017_executive_summary_120417a.pdf