PURPOSE:

The purpose of the Connecticut Department of Public Health (DPH) Policy and Procedures for Collecting Sociodemographic Data is to: 1) identify minimum and ideal standards for the collection of sociodemographic data in all DPH databases for which the unit of analysis is an individual (not an institution); and 2) set the expectation that all DPH databases will employ the minimum standard as soon as practical unless granted an exemption.

The minimum standard categories for race and ethnicity established by the federal Office of Management and Budget (OMB, 1997) must be used so that health-related ethnicity and race data are comparable within and across public health agencies and other social institutions. In addition, the DPH Policy and Procedures for Collecting Sociodemographic Data (Policy, policy) incorporates other federal mandates that require U.S. Department of Health and Human Services (DHHS) programs and their grantees to collect data on race, ethnicity, primary language, and disability status (U.S. DHHS, 2011).

DEFINITIONS:

Minimum Standard for Sociodemographic Data Collection ("Minimum Standard") – The Minimum Standard specifies sociodemographic data elements that are considered to be a minimal set for collection in DPH databases. Public health research and evidence have long demonstrated the salience of these data elements, or population characteristics, for population-based health outcomes. They include respondent: age, sex/gender, ethnicity, and race, level of English proficiency, preferred spoken language, and veteran status.

Ideal Standard for Sociodemographic Data Collection ("Ideal Standard") – The Ideal Standard includes the data elements specified in the Minimum Standard and additional data elements, which are known to be salient for health, and which can improve public health program activities and enhance the description of health disparities. They include respondent: age, sex/gender, ethnicity and expanded ethnicity, ancestry, race and expanded race, geography of residence, level of English proficiency, language spoken at home, preferred spoken language for medical/health care, preferred written language, preferred written language for medical/health care, need for interpretation, country of birth,
immigrant status, length of years in the United States, socioeconomic position, veteran status, disability status, sexual orientation, gender identity, and other sociodemographic data of program interest, such as marital/partner status, and health insurance.

DPH Data Collection Quality Improvement Committee — This DPH standing committee was established in October 2013. Its purpose is to: 1) ensure adherence to the current Policy and any subsequent data policy documents; 2) annually conduct a review of a subset of existing and new DPH databases and databases that are in development to ascertain if DPH data collection standards are being met. The subset to review will be identified by the Committee based on need and the year the database was established; and 3) make changes to the DPH Policy through an annual review. The DPH Data Collection Quality Improvement Committee is comprised of members from different programs/sections throughout the agency, including: Health Statistics and Surveillance, Tumor Registry, Vital Records, Infectious Diseases, Chronic Diseases, Community, Family, and Health Equity, Injury Prevention Office, Environmental Health, Practitioner Licensing and Investigation, Emergency Medical Services, Office of Healthcare Access, Public Health Laboratory, and Information Technology.

POLICY:

All DPH data systems will employ the Minimum Standard for collection of data on individuals. DPH will adhere to the Minimum Standard on or before December 31, 2020. The Minimum Standard applies to all DPH programs, and to all entities and/or individuals that are funded in whole or in part by DPH, to conduct surveillance or research, provide services, and/or generate reports of state health data.

DPH programs are encouraged to collect, record, and report any or all of the additional data elements in the Ideal Standard that inform ongoing or future work, and to enhance the capacity of DPH to assess health disparities in Connecticut. The Ideal Standard includes all data elements outlined in the Minimum Standard, as well as additional sociodemographic data elements.

This policy does not require redundant data collection efforts. It allows exemptions when alternate sources of information exist that can accurately provide the data specified in the Minimum Standard and there are efficient means for obtaining such data.

The DPH Policy and Procedures for Collecting Sociodemographic Data — Users’ Guide, which is a companion document to this policy, provides: 1) a format for collection of the data elements specified in the Minimum Standard; 2) a suggested format for collection of sociodemographic data according to the Ideal Standard; 3) an overview of the flow of DPH data collection and reporting process; and 4) references for all documents cited in the Policy and Procedures and the Users’ Guide.

PROCEDURES:

- DPH data managers (or their supervisors) shall set a timetable for implementation of the new minimum standard if their database(s) do not already meet that standard.

- In cases where a data manager or supervisor believes that a particular database should be exempt from this policy, then s/he will be required to set forth the rationale for an exemption to the DPH Data Quality Improvement Committee.
Exemption Criteria to the Minimum Standard including, but not limited to:

Surveillance, surveys, and research conducted by DPH are exempted from adherence to the Minimum Standard for data collection if any of the following circumstances apply:

1) The program conducting the work is required by contract to use defined data collection protocols, instruments, algorithms, and/or databases that are explicitly precluded from modification by the grantor.

2) Data are supplied to DPH by another entity that is not obligated by contract or legal mandate to collect the minimum data elements, or with whom DPH has not established a Memorandum of Understanding on data collection in accordance with the 1997 OMB standards for the classification of race and ethnicity data.

PROCESS:

The DPH Data Collection Quality Improvement Committee is charged with conducting an annual review of existing and new DPH databases and databases that are in development to ascertain if DPH data standards are being met. This process was established as part of the Committee Charter, and has been conducted since October 2013. Databases will be prioritized in the following manner:

1. New databases and databases in development,
2. Major and/or parent databases,
3. Databases that DPH has control or the authority to modify to achieve compliance to the Policy.

The review of the selected subset of databases for compliance to this Policy will commence in January 2017. An action plan will be developed during the review process to achieve compliance, if feasible, of the identified databases in consultation with DPH database managers. The database manager’s Section Chief will receive notice and a copy of the action plan. The action plan consists of the following steps:

1. Determining if DPH has control of the database and the authority to make changes to comply with the Policy. If it is found that DPH does not have the control or authority to make database changes, the process is complete.

2. If DPH is able to make database changes and the changes are appropriate to the purpose and goals of the program, the database manager estimates the cost, time and resources needed to make the said changes.

3. With respect to these factors, if it is determined that said changes are feasible to make, a reasonable timeframe to institute the changes is put into place. If the program deems it is not feasible to make the needed changes, a petition for database exemption will be considered.

4. Any petitions for database exemption will be considered, and recommendations made, by the DPH Data Collection Quality Improvement Committee on a rolling basis as the petitions are submitted.