

The Collection of Race, Ethnicity, and Other  
Sociodemographic Data in Connecticut  
Department of Public Health Databases

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Keeping Connecticut Healthy

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## NOTES ON THIS PDF

After hardcopy printing, the following corrections to *The Collection of Race, Ethnicity, and Other Sociodemographic Data in Connecticut Department of Public Health Databases* were made and have been incorporated into this PDF version of the document.

- Page 11: In the second paragraph of the section entitled Race and Ethnicity Data, “infant mortality rate” was replaced with “mortality rate.” While infant mortality is an indicator of population health, it is not calculated using population estimates from the U.S. Census. Rather, the denominator used to calculate the infant mortality rate is the number of live births.
- Page 65: In Appendix D, the fourth category is “American Indian or Alaska Native, list names of principal or enrolled tribe.”

## **EXECUTIVE SUMMARY**

Although the nation's diversity has steadily increased over time and laws have been enacted that uphold the rights of all persons, health disparities persist in the United States. In the recommendations of its Policy Panel on Racial and Ethnic Health Disparities, the Connecticut Health Foundation noted that, "Eliminating racial and ethnic health disparities is a central challenge for our society – one that can be addressed over time through practical action, based on a comprehensive multi-level strategy" (Connecticut Health Foundation 2005). In 2006, the Connecticut Health Foundation awarded the Connecticut Department of Public Health (DPH) a two-year grant to improve the statewide infrastructure for documenting, reporting, and addressing health disparities among ethnic and racial minority residents. This initiative is known as The Connecticut Health Disparities Project.

As part of this project, 37 DPH databases were evaluated on the collection of race, ethnicity, and other sociodemographic data. Survey results demonstrate great variation in the collection of data that are crucial to monitoring and reporting health disparities. Only 16.2% of the databases surveyed complied with the 1997 U.S. Office of Management and Budget's *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity*. Collection of data on socioeconomic position, acculturation, and language was infrequent. While most databases collected residential address information, few used geocoding to assign a designation for geographic area of residence.

Several factors present challenges to changing and improving DPH data collection practices. They include: nonuse of standard categories across the federal agencies to which DPH reports, reliance on secondary data from larger datasets, limited information technology resources, limited funding to change data collection tools, and unreported demographic information.

Three equally important and interwoven areas – data collection and reporting practices, knowledge of federal standards, and information technology – must be addressed to improve the collection of data that can inform health disparities documentation, reporting, and subsequent elimination. This report provides specific recommendations for enhancing data collection and reporting, increasing knowledge and skills of data users, and increasing availability of information technology resources.

## **Recommendations at a Glance**

### *Enhance Data Collecting and Reporting*

1. Establish minimum data collection standards such that ethnic and racial categories in DPH data collection forms and electronic systems meet the basic requirements of the 1997 U.S. Office of Management and Budget's *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity*.
2. Establish ideal data collection standards such that programs with adequate resources can exceed the 1997 OMB standards and collect additional sociodemographic information that is related to program objectives (e.g., educational attainment, employment status, occupation, preferred language).
3. Create and implement a *DPH Data Collection and Use Policy* to standardize the collection and reporting of sociodemographic data across the organization.
4. Develop a DPH-level mechanism for geographic information system (GIS) management and routine performance of spatial analysis using residential address information.
5. Convene an ad hoc DPH workgroup to identify ways to encourage the collectors of health information (e.g., hospitals, clinics, physicians, laboratories) to enhance their reporting practices, data collection forms, and data systems to meet the 1997 OMB standards.
6. Amend the Connecticut Public Health Code to mandate that the report of reportable findings shall include ethnicity and race information collected in accordance with the 1997 OMB standards.

### *Increase Knowledge of Data Users and Reporters*

7. Provide training for DPH staff on the 1997 OMB minimum standards for collecting race and ethnicity data, and the *DPH Data Collection and Use Policy*.
8. Provide training for physicians and other reporters on the 1997 OMB minimum standards for collecting race and ethnicity data.

### *Enhance Information Technology*

9. Assess the technical capacity of DPH databases to meet or exceed the 1997 OMB standards.

## **LIST OF SURVEYED DATABASES**

AIDA	AIDS Institute Data Application
APB	Adult Lead Poisoning Database
ASTHMA	Health Assessment Record - Asthma Database
BCC	Connecticut Breast and Cervical Cancer Early Detection Program Database
BDR	Connecticut Birth Defects Registry
BIRTH	Birth Registry
BRFSS	Behavioral Risk Factor Surveillance Survey Database
CIRTS	Connecticut Immunization Registry and Tracking System
CLPPP	Child Lead Poisoning Prevention Program Surveillance System
CO	Carbon Monoxide Poisoning Database
CODES	Crash Outcome Data Evaluation System
CTR	Connecticut Tumor Registry
FICS	Foodborne Illness Complaint System
FMORT	Fetal Deaths Database
FSNED	Food Stamp Nutrition Education Database
HARS	HIV/AIDS Reporting System
HDIS	Hospital Discharge Abstract and Billing Database
HEPB	Hepatitis B Registry
HEPC	Hepatitis C Registry
HG	Mercury Poisoning Database
IDD	Reportable Infectious Diseases Database
LITP	Legal Induced Termination of Pregnancy Database
METAB	Metabolic Disorders Program Database
MORT	Death Registry
OIISS	Occupational Illness and Injury Surveillance System
OTO	Early Hearing Detection and Intervention Program Database
PRMS	Pregnancy Related Mortality Surveillance Database
QUIT	Connecticut QuitLine
SBHCD	School Based Health Center Database
STDNIS	Sexually Transmitted Diseases Management Information System
SWIS	Statewide WIC Information System
TIMS	Tuberculosis Information Management System
TRIMS	Tuberculosis Registry and Information Management System
VMORB	Varicella Morbidity Database
WISE	Well-integrated Screening and Evaluation for Women Across the Nation Program Database
YRBS	Connecticut School Health Survey Database - Youth Behavior Component
YTS	Connecticut School Health Survey Database - Youth Tobacco Component

## **ACRONYMS USED**

AIAN	American Indian or Alaska Native
BAA	Black or African American
CDC	U.S. Centers for Disease Control and Prevention
DHHS	U.S. Department of Health and Human Services
DPH	Connecticut Department of Public Health
DPH IT	DPH Information Technology Section
EPHT	Environmental Public Health Tracking Program
ICRWG	Interagency Committee Research Working Group
IT	Information Technology
NCHS	National Center for Health Statistics
NCVHS	National Committee on Vital and Health Statistics
NETSS	National Electronic Telecommunications System for Surveillance
NHOPI	Native Hawaiian or Other Pacific Islander
NNDSS	Nationally Notifiable Diseases Surveillance System
NOS	Not otherwise specified
OL-15C	Laboratory Report of Significant Findings
OMB	U.S. Office of Management and Budget
PB	Planning Branch
PD-23	Reportable Diseases Confidential Case Report Form
PHI	Public Health Initiatives Branch
PHIN	Public Health Information Network
REGS	Regulatory Services Branch
SDV	Sociodemographic variable
SEP	Socioeconomic position



## **INTRODUCTION**

Although the nation's diversity has steadily increased over time and laws have been enacted that uphold the rights of all persons, health disparities persist in the United States. In the recommendations of its Policy Panel on Racial and Ethnic Health Disparities, the Connecticut Health Foundation noted that, "Eliminating racial and ethnic health disparities is a central challenge for our society – one that can be addressed over time through practical action, based on a comprehensive multi-level strategy" (Connecticut Health Foundation 2005). In 2006 the Connecticut Health Foundation awarded the Connecticut Department of Public Health (DPH) a two-year grant to improve the statewide infrastructure for documenting, reporting, and addressing health disparities among ethnic and racial minority residents. This initiative, known as The Connecticut Health Disparities Project, has four objectives: 1) to evaluate the collection of ethnicity, race, and other relevant sociodemographic information across all DPH databases, and to make recommendations for the improvement of data collection; 2) to coordinate agency planning objectives related to the elimination of health disparities among racial/ethnic subpopulations; 3) to publish a comprehensive Connecticut health disparities surveillance report; and 4) to provide leadership in the development of a statewide network of researchers and policy analysts focused on the measurement of health disparities in Connecticut.

Accurate statistics are vital to the monitoring of health disparities. They provide us with the information needed to make important public health decisions, and to evaluate the impact of health policies and programs on population health. Public health tracking of disparities is an essential part of reducing the disease burden on vulnerable populations in Connecticut, identifying high-risk groups, formulating health care policy, and evaluating our state's progress toward health disparities elimination.

This report presents a historical review of race and ethnicity measurements and the results of a survey of DPH databases, conducted in December 2006 through January 2007, to evaluate the collecting and recording of data on race, ethnicity, age, gender, and other sociodemographic factors that affect the occurrence of health disparities in Connecticut. A long research tradition in public health has demonstrated the influence of social and economic factors (e.g., educational attainment level, income, occupation, and neighborhood

of residence) on population health, and also the importance of these factors in explaining racial and ethnic health disparities. The manner in which these factors are conceptualized, measured, and reported has implications for how we monitor, address, and ultimately eliminate health disparities in Connecticut and the United States.

# **BACKGROUND**

## **Racial and Ethnic Health Disparities**

Differential treatment on the basis of race has a long and problematic history in the United States. In *The Souls of Black Folk*, W.E.B. DuBois identified the problem of the twentieth century as “the problem of the color line” (DuBois 1903; Thomas 2001). Government-sanctioned treatment of indigenous peoples and non Anglo-Saxons as subhumans facilitated the creation and expansion of America.<sup>1</sup> Federal laws restricted or severely limited the influx of immigrants from non-Northern European countries.<sup>2</sup> State anti-miscegenation laws that prohibited interracial marriages and dictated the legitimacy status of offspring (Browning 1951; Pascoe 1996) were not rejected by the U.S. Supreme Court until 1967.<sup>3</sup> While Civil Rights legislation, social change, and increasing population diversity have made the “color line” less defined, the United States remains a persistently race conscious society.

Although the legal framework that sanctioned racism has been dismantled, differential treatment based on race remains a social reality for all Americans. This reality is present in healthcare, as evidenced by a major finding of the Institute of Medicine’s study of racial and ethnic healthcare disparities. Even after controlling for healthcare access-related factors such as insurance, ethnic and racial minorities were less likely to receive needed medical services than their White counterparts (Institute of Medicine 2003). Likewise, population-level, public health indicators illustrate racial and ethnic disparities in health outcomes. In 2004, the national infant mortality rate (IMR) was 6.78 per 1,000 live births, the lowest national rate ever recorded (Matthews and MacDorman 2007). The IMR was 5.7 per 1,000 live births for non-Hispanic white mothers and 13.6 per 1,000 live births for non-Hispanic black mothers. Connecticut mirrored the national trend with an infant mortality rate of 4.6 per 1,000 live births for mothers categorized as “White” and 13.4 per 1,000 live births for mothers reported as “Black or African American” in 2004 (DPH 2007).

But such differences in health outcomes among population subgroups cannot solely be explained by assignment to a racial or ethnic group. Structural factors like poverty and

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<sup>1</sup> See *Dred Scott v. Sanford*, 60 U.S. 393 (1856)

<sup>2</sup> e.g., Chinese Exclusion Act (1882), Immigration Act of 1924

<sup>3</sup> *Loving v. Virginia*, 388 U.S. 1 (1967)

geographic isolation have been shown to influence health outcomes (Brown, Ang, and Pebley 2007; Schulz et al. 2002). Improved description of health disparities requires inclusion of additional socioeconomic data in public health surveillance systems. This will provide important contextual information and better measures of exposures and responses to the economic and non-economic aspects of discrimination (Krieger et al. 1999).

## **Sociodemographic Factors and Health**

In addition to race and ethnicity, other sociodemographic data (e.g., age, gender, occupation) are routinely collected by public health agencies and inform public health practice, policy, decision-making, and resource allocation.

In *Shaping a Health Statistics Vision for the 21<sup>st</sup> Century*, the National Committee on Vital and Health Statistics (NCVHS), U.S. Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), and the U.S. Department of Health and Human Services (DHHS) Data Council state that to be most useful, health statistics must represent all factors that influence population health (Friedman et al. 2002). “In addition to representing all dimensions of health outcomes – including measures of functional status and wellbeing as well as disease in the population – health statistics must represent community characteristics, the natural environment, and cultural and political contexts” (DHHS et al. 2002).

Public health and social research demonstrate the important association of certain sociodemographic characteristics with differential health outcomes in members of the population (National Research Council 2004). Several of these constructs – race, ethnicity, socioeconomic position, acculturation, and geographic area of residence – are discussed below.

### *Race*

Many epidemiologists and others within scientific disciplines concerned with human health have questioned the scientific integrity of the concept of race as it relates to health risks, practices, and outcomes, and the assessment of race in practice (Bhopal et al. 1998; Fullilove 1998; Williams, 1997). Race is traditionally viewed as biological because the traits upon which it is typically based (e.g., skin color) are heritable. But genetic research demonstrates that racial categories have no biological basis (Garte 2002). Most human

genetic variation is distributed among individuals within populations, rather than among populations. Race, in fact, is a social construct.

The definition of race has changed over time and reflects the most popular/powerful ideologies of society at a given time period (Gossett 1963; Hirschman 2004; Lee 1993). Others in society assign racial status to an individual, and the criteria for race assignment are based on dominant societal ideas of what constitutes the separate categories. Marger notes that: "...people attach significance to the concept of race and consider it a real and important division of humanity. And, as long as people believe that differences in selected physical traits are meaningful, they will act on those beliefs, thereby affecting their interrelations with others" (1991: 23). "As long as being Black remains consequential for every aspect of life, and as long as racial status continues to reflect differences in power and desirable resources in society, it is important to assess race" (Williams and Jackson 2000).

### *Ethnicity*

Ethnicity, like race, is a social construct. "Ethnic group" refers to a culturally defined group, which may include common geographic origin, language, religion, shared traditions, values, symbols, literature, and food preferences (Polednak 1989 in Weeramanthri 2000:5). Morning notes that: "ethnicity is grounded in the discourse of cultural similarity and race in that of [claims about] biological commonality" (2005: 45). Ethnic groups exist within a larger society and have unique cultural characteristics. Group members perceive that they have a shared heritage. Also like race, ethnicity is an ascribed status and depends on assumption of a special bond between group members. In multiethnic societies, ethnic groups tend to congregate. Thus, the characteristics of ethnicity are "unique culture, sense of community, ethnocentrism, ascribed membership, and territoriality" (Marger, 1991:17).

There is great heterogeneity among so-called racial and ethnic groups. According to the CDC Race and Ethnicity Code Set 1.0 (CDC 2000), reported ancestry or origin from 24 different countries (e.g., Bhutan, Cambodia, India, Indonesia, Korea, Madagascar, Vietnam) can be aggregated into the race category "Asian." Likewise, the ethnicity category "Hispanic or Latino" does not define a culturally distinct group (Gimenez 1989; Hayes-Bautista and Chapa 1987).

### *Socioeconomic Position*

Many studies have shown that racial and ethnic disparities decrease after adjustment for some kind of social and economic status measure (Ansell et al. 1993; Eley et al. 1994; Frost et al. 1996; Lui 1998). Persons with high levels of income, education, or occupational status live longer and have lower rates of disease than their counterparts with lower socioeconomic status (Williams 1990). Socioeconomic position (SEP) "...refers to the economic and social factors that influence what positions individuals or groups hold within the structure of a society" (Galobardes et al. 2006:7), and how they evolve over an individual's lifetime. Some components of SEP are power, prestige, and economic resources. Its measures are education, housing characteristics, current income, wealth, occupation, and life history.

### *Acculturation*

Studies have demonstrated that degree of acculturation can be positively or negatively correlated with health outcomes and health behaviors (Lee, Sobal, and Frongillo 2000; Marmot and Syme 1976; Stimpson and Urrutia-Rojas 2007; Walker 2007). Acculturation is the complex process by which a person raised in another culture adapts to a new culture in which s/he is immersed. Recent immigrants may have little in common with members of the American racial or ethnic group that has been ascribed to them. The heterogeneity within each nationality group is further complicated by each group's unique immigration experience. Information on country of birth, immigration status, years of residence in the continental United States, and language use are used to characterize acculturation.

### *Geographic Area of Residence*

Where people live has important implications for their health. A growing body of research demonstrates that community characteristics influence individual behavior and health outcomes. The social and economic characteristics of a neighborhood determine, to a large extent, the residential environment including housing stock, access to goods and services, neighborhood stability, crime, public spaces, and degree of social control over individual behavior. Such community factors represent more than simply the aggregation of individual-level characteristics. The quality of housing and level of crime in a neighborhood, for example, can very likely influence an individual's health regardless of his or her own

economic status (Cubbin, LeClere, and Smith 2000; O'Campo, Xue, and Wang 1997; Pickett and Pearl 2001; Robert 1998; Robert 1999; Sampson and Lauritsen 1994).

The conversion of street address information into latitude and longitude, a process called geocoding, is used to map individual locations. These locations exist within larger geographic domains for which demographic, income, and business information collected by the U.S. Census Bureau or local agencies is available. Spatial analysis of public health data allows for the geographic mapping of health disparities. The Public Health Disparities Geocoding Project at Harvard University demonstrates that census tract-based socioeconomic measures (area-based socioeconomic measures) are useful for monitoring social inequalities in health (Krieger et al. 2005).

### **Race and Ethnicity Data**

As previously discussed, race and ethnicity data alone are not sufficient to accurately depict health disparities. However, these social constructs are so imbedded in our concepts of health that they are commonly used in health care, public health, and biomedical research to describe study populations and compare outcomes. Health disparities research would greatly benefit from better data on these social categories (Agency for Healthcare Research and Quality 2005; Hasnain-Wynia, Pierce, and Pittman. 2004; National Research Council 2004; Williams, Lavizzo-Mourey, and Warren 1994). Better race and ethnicity data can be achieved by using standard definitions, collection, and reporting practices.

The U.S. Census Bureau uses standard race and ethnicity data definitions, collection, and reporting practices. It collects vast amount of information on the population of the United States that is used to inform the business of federal government agencies with active roles in public health (e.g., Department of Agriculture, Department of Homeland Security Environmental Protection Agency). U.S. Census Bureau products, such as the population estimates from the decennial Census and the American Community Survey (ACS), are major sources of information that state public health departments use to calculate indicators of population health (e.g., mortality rate). The origin and content of the most recent standards used in the last decennial Census are discussed in the following section.

## *The U.S. Census*

The initial purpose of the U.S. Census was to enumerate the population for the apportionment of seats in the House of Representatives. Race classification was needed to get an accurate count of those entitled to representation.<sup>4,5</sup> Over time, additional questions were added to the Census because it offered standardized collection of information across the nation (U.S. Census Bureau 1998a).

Since 1790, the U.S. Bureau of the Census has been collecting, and changing each decade, racial and ethnic categories that provide denominators for social and demographic analysis (Anderson 1988). Reflecting the changes in prevailing ideologies, different question content, terminology, and formats have been used over the years. The race categories have included a mixture of various elements such as national origin, tribal affiliation, and descriptions of physical characteristics. Both observer and respondent self-identification have been used to collect data on race. Race classifications used in the Census from 1880 to 2000 (Anderson and Fienberg 2000; Lee 1993: 78; U.S. Census Bureau 1998b: 10) are shown in Appendix A.

The year 1970 marked the first time that the Census was formatted for completion by the respondent, and that questions about Spanish or Hispanic origin or descent were asked. Table A.2 in Appendix A shows the Census questions about Spanish or Hispanic origin for the 1970 to 2000 Censuses (Anderson and Fienberg 2000:101; U.S. Census Bureau 1998b: 12).

The 1980 and 1990 censuses used the race and ethnicity categories outlined in the U.S. Office of Management and Budget's (OMB) *Statistical Policy Directive No. 15 Race and Ethnic Standards for Federal Statistics and Administrative Reporting* published in 1977. The 2000 Census used the categories specified in the *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity* issued on October 30, 1997.

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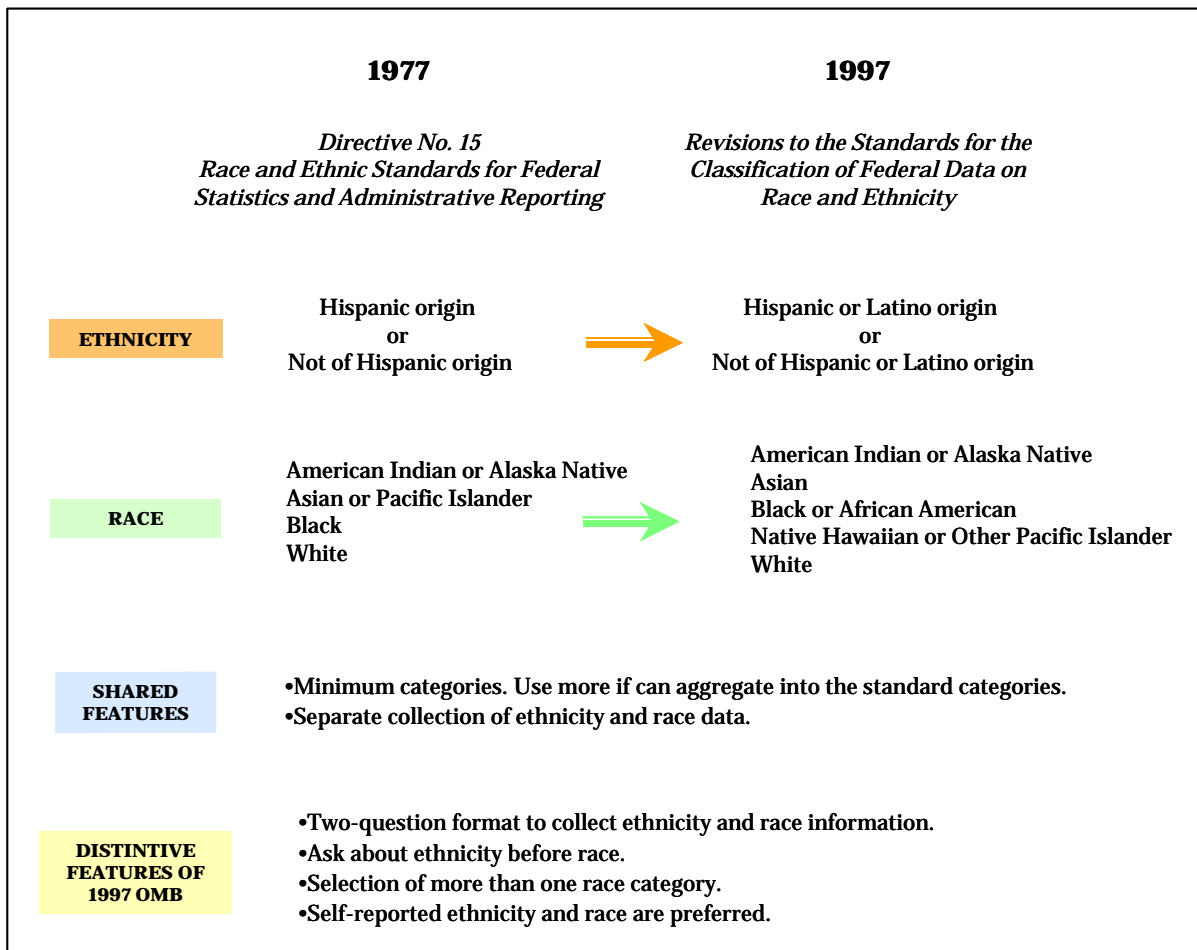
<sup>4</sup> Article 1, Section 2 of the U.S. Constitution: "Representatives and direct Taxes shall be apportioned among the several States which may be included within this Union, according to their respective Numbers, which shall be determined by adding to the whole Number of free Persons, including those bound to Service for a Term of Years, and excluding Indians not taxed, three fifths of all other Persons." The 14th Amendment, ratified in 1868, dispelled the practice of fractionation.

<sup>5</sup> The Framers of the Constitution regarded slaves as property and deemed that untaxed American Indians were not entitled to representation. Thus, a Black was equal to three-fifths of a White, and the number of American Indians could not count toward representation in Congress.



OMB Statistical Policy Directive No. 15 was the first attempt by the U.S. government to standardize race and ethnicity categories across all federal agencies. The standards were developed because federal agencies needed comparable, nonduplicative data to monitor the provisions of the Civil Rights Act of 1964, such as equal access to housing, health care services, and employment for groups that had historically experienced discrimination or differential treatment because of their race or ethnicity (Wallman et al. 2000). Another reason for the ethnicity component of the standards was to implement the requirements of Public Law 94-311 (15 U.S.C. 1516a), which deals with the collection of social and economic data on persons of Spanish origin or descent (OMB 1995). The standards took effect immediately and all reporters were to comply by January 1, 1980.

**Figure 1. Comparison of 1977 and 1997 OMB Standards**



In 1994, the OMB acknowledged criticisms that the 1977 standards did not reflect the nation's diversity and initiated a review process that included an open comment period and public hearings (OMB 1994). The Interagency Committee Research Working Group (ICRWG), co-chaired by the U.S. Census Bureau and the Office of Labor Statistics, conducted tests of race and ethnicity category options suggested by reviewers. Based on the research findings and public comment, the *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity* were issued on October 30, 1997 (OMB 1997). All producers of federal statistics, including the DHHS, were directed to adopt the standards no later than January 1, 2003. Figure 1 shows the minimum categories outlined in 1977 OMB directive number 15 compared to the categories specified in the 1997 revisions. The 1997 OMB categories are defined in Figure 2.

### **Figure 2. Definitions of 1997 OMB minimum categories**

*American Indian or Alaska Native.* A person having origins in any of the original peoples of North and South America (including Central America), and who maintains cultural identification through tribal affiliations or community attachment.

*Asian.* A person having origins in any of the original peoples of the Far East, Southeast Asia, the Indian subcontinent, including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

*Black or African American.* A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."

*Hispanic or Latino.* A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term, "Spanish origin," can be used in addition to "Hispanic or Latino."

*Native Hawaiian or Other Pacific Islander.* A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

*White.* A person having origins in any of the original peoples of Europe, North Africa, or the Middle East.

Source: OMB. 1997. Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity. *Federal Register*, 62:58789.

The 1997 OMB standards do not designate certain populations as “minority” groups, nor do they establish qualifications for category assignment (e.g. “one drop” rule).<sup>6</sup> They underscore that self-identification is the preferred method of data collection. Collection of data is not limited to the minimum categories defined in the standards; however, one should be able to aggregate any additional categories into the standard ones.<sup>7</sup>

The 1997 OMB standards state that the race categories are not mutually exclusive, so respondents are encouraged to select multiple race categories. Use of language such as “Select one or more” on data collection forms is suggested.<sup>8</sup> Use of separate questions about race and ethnicity, with the ethnicity question appearing first, is specified. This is known as the “two-question format” shown in Figure 3. This format is used when there is an opportunity for an individual to provide a self-report of race and ethnicity (e.g., telephone interview, self-administered survey).

**Figure 3. The two-question format**

**1) Are you Hispanic or Latino?**  
**Yes (Hispanic or Latino)**  
**No (Not Hispanic or Latino)**

**2) What is your race?**  
**American Indian or Alaska Native**  
**Asian**  
**Black or African American**  
**Native Hawaiian or Other Pacific Islander**  
**White**

Although self-reported information is preferred, the 1997 OMB standards make provisions for observer-reported information when obtaining self-report is not practical. Only if necessary and not otherwise practical, as in the case of death, the combined race and ethnicity format (“combined format”) may be used for the collection of race and ethnicity

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<sup>6</sup> The “one drop” rule refers to the practice of classifying persons by their percentage of African ancestry. Of nineteenth century origin, the terms typically associated with this practice include mulatto, quadroon, and octaroon (Mays et al. 2003).

<sup>7</sup> For example, in addition to using the ethnicity category “Hispanic or Latino,” a researcher may also choose to use the categories “Puerto Rican,” “Mexican,” and “Cuban” on data collection forms.

<sup>8</sup> While multiple race recording is encouraged, OMB did not accept the Interagency Committee Research Working Group recommendation that selection of multiple ethnicity categories be allowed. Selection of both “Hispanic or Latino” and “Not Hispanic or Latino” was not tested during the review process.

data. The combined format includes the following six categories: “American Indian or Alaska Native,” “Asian,” “Black or African American,” “Hispanic or Latino,” “Native Hawaiian or Other Pacific Islander,” and “White.” Multiple category selection is allowed. So long as confidentiality and data quality standards are not compromised, data on all combinations are presented.

### *Criticisms of the OMB Standards*

Despite their endorsement and adoption by the generators of national statistics such as the U.S. Census Bureau and the NCHS, there are several criticisms of the OMB standards. First, the succinctness of the categories makes the reification of race more convenient. Although the prevalence of disease risks, outcomes, and health practices differ across the broad racial and ethnic groups defined up by the OMB, proportionally greater variations in these measures exist within each of these groups (Horm et al. 1996; Lauderdale et al. 1997, 1998). Group members have heterogeneous history, culture, language, dietary preferences, physical attributes, and socioeconomic position, all of which translate into very different experiences, health behaviors, attitudes, and risks. The statistical aggregation of these populations into a single category masks important lifestyle and behavior differences, and resulting systematic differences in health outcomes. Second, although the OMB maintains that the categories have no scientific basis, it provides no statement on how they were initially derived. Third, the OMB directive and its application in the U.S. Census treat race and ethnicity as properties of the individual, ignoring the extent to which both are defined by the individual’s relation to this society at large (American Anthropological Association 1997).

### **Why the OMB Standards are Needed in Public Health**

So why apply the 1997 OMB standards for collection of race and ethnicity data using a minimum set of categories to state public health data systems? First, there is a social and symbolic meaning to race and ethnicity categorization that affects people’s perceptions and lived realities (Boudreax et al. 2003; Griffith 2005; Williams 1999). Second, a federal interest in using standard race and ethnicity categories is the redress of historic discrimination and prevention of potential contemporary instances that affect life courses (Wallman et al. 2000). Third, state and local public health departments depend on federal

funding and must meet grant requirements, which often entail specific reporting formats. Fourth, use of the OMB categories will enhance the quality of public health data. Hahn and Stroup (1994) note that public health professionals pay “keen attention” to case definitions in epidemiologic investigations and surveillance, and that this precision should also be applied to the demographic characterization of the populations under study. Adoption of federal race and ethnicity data standards is a step toward improving the comparability of race and ethnicity data across public health data sets. Fifth, regardless of whether or not they are accurate representations on the embodied experience of race, the 1997 OMB minimum categories are a common language that links national, state, and local health agency data systems.

To better monitor health disparities in the United States, the 1997 OMB categories must be used so that health-related ethnicity and race data are comparable across public health agencies and other social institutions. “Better data will move the U.S. closer to recognizing, monitoring, and eliminating health disparities, thereby ensuring quality health care and improved health status for all Americans” (NCHS Subcommittee on Populations 2005: 4).

## **METHODS**

This study assessed the *collection* of sociodemographic information in Connecticut DPH databases using a two-part electronic survey that was distributed to database managers. Databases were included in the assessment if they met the following criteria:

- Cases/records were individuals (not institutions).
- Health outcome, incidence, or prevalence information was collected.
- Sociodemographic information (e.g., ethnicity, race, socioeconomic position, insurance status, etc.) was collected.

The first part, the Health Database Questionnaire (HDQ), was distributed in December 2006 (see Appendix B). Item content of this survey was based on that of the Health Data Base Questionnaire used by Singh in 2003 to assess the capacity of DPH databases to monitor health disparities (unpublished report, Connecticut Department of Public Health). HDQs were pre-populated with data from the *2003 DPH Health Data Report* (Connecticut Department of Public Health 2003) and 2005 Environmental Public Health Tracking (EPHT) surveys. Before final distribution, the HDQ was pilot-tested by three database managers and refined based on their comments. The second part of the survey, the Age and Gender Supplement (AGEN), was patterned after the HDQ and distributed in January 2007 (see Appendix C).

The collection of data on race, ethnicity, age, gender, country of birth, length of stay in the U.S., health insurance status, Medicaid, Medicare, education, employment, occupation, income, household size, marital/partner status, immigration status, language, address, census tract, and census block was assessed. Survey respondents were also asked about the purpose of data collection, case definition, population, most recent year of data collection, number of records accumulated annually, and race and ethnicity data collection policy. They were encouraged to provide copies of data collection forms.

The participation of the DPH staff in the survey process was cultivated by formal and informal conversations between project staff and branch chiefs, section chiefs, program coordinators, and database managers. Project staff telephoned, e-mailed, and met in-person with survey respondents to solicit and clarify responses. Electronic surveys were converted

from MS Word 2000 to text files and individually imported into MS Access 2000. The Access tables were imported into SPSS v15.0 for analysis.

In February 2007, preliminary survey findings were discussed with Health Information Systems and Reporting Section staff and the Connecticut Health Disparities Project's Academic Advisory Group. Project staff also discussed the relationships of DPH databases to internal and external databases with key informants.

During June and July 2007, survey respondents and program managers were invited to review and comment on the refined database survey findings and study recommendations. These individuals were sent electronic versions of the 1997 OMB standards and drafts of the survey findings, detailed database descriptions, and recommendations. They were requested to review the documents and give comments in-person, by e-mail, and/or attend a one-hour long facilitated group discussion. Six group feedback sessions were conducted. Participants commented on the accuracy of database descriptions, clarified findings, and discussed the style, relevance, and potential impact of the proposed recommendations.

## FINDINGS

Thirty-seven databases met the study inclusion criteria (see Table 1). The response rate was 100%. Most databases (54.0%) were from the Public Health Initiatives Branch. No databases in Health Care Systems, Laboratory, Operations, Administration, or Local Health Administration met study inclusion criteria.

**Table 1. Databases by DPH Branch**

<b>DPH Branch</b>	<b>Abbreviation</b>	<b>Database</b>
Office of the Deputy Commissioner (ODC)	BCC	Connecticut Breast and Cervical Cancer Early Detection Program
	WISE	Well-Integrated Screening and Evaluation for Women Across the Nation (WISEWOMAN)
Planning (PB)	BRFSS	Behavioral Risk Factor Surveillance System
	BIRTH	Birth Registry
	CTR	CT Tumor Registry
	YRBS	Connecticut School Health Survey - Youth Behavior Component
	FMORT	Fetal Deaths
	HDIS	Hospital Discharge Abstract and Billing
	LITP	Legal Induced Termination of Pregnancy
MORT	Death Registry	
Public Health Initiatives (PHI)	AIDA	AIDS Institute Data Application
	ASTHMA	Health Assessment Record - Asthma
	BDR	Birth Defects Registry
	CIRTS	CT Immunization and Registry Tracking System
	CODES	Crash Outcome Data Evaluation System
	FSNED	Food Stamp Nutrition Education
	HARS	HIV/AIDS Reporting System
	HEPB	Hepatitis B
	HEPC	Hepatitis C
	IDD	Reportable Infectious Diseases
	METAB	Metabolic Disorders – Newborn Tracking System
	OTO	Early Hearing Detection & Intervention – Newborn Tracking System
	PRMS	Pregnancy Related Mortality Surveillance Database
	QUIT	CT Quitline
	SBHCD	School Based Health Centers
	STDMIS	Sexually Transmitted Diseases Management Information System
	SWIS	Statewide WIC Information System
	TIMS	Tuberculosis Information Management System
TRIMS	Tuberculosis Registry and Information Management System	
VMORB	Varicella Morbidity Database	
YTS	Connecticut School Health Survey - Youth Tobacco Component	
Regulatory Services (REGS)	APB	Adult Lead Poisoning Database
	CLPPP	Childhood Lead Poisoning Prevention Program
	CO	Carbon Monoxide Poisoning Database
	FICS	Foodborne Illness Complaint System
	HG	Mercury Poisoning Database
	OIISS	Occupational Injury and Illness Surveillance System



## **Database Attributes**

Survey respondents were asked to describe database attributes: the purpose or mandate for data collection, definition of a case or record in the database, the population covered, the most recent complete year of data available, the number of records accumulated annually, and whether or not a specific policy pertaining to the collection of race and ethnicity data was used.

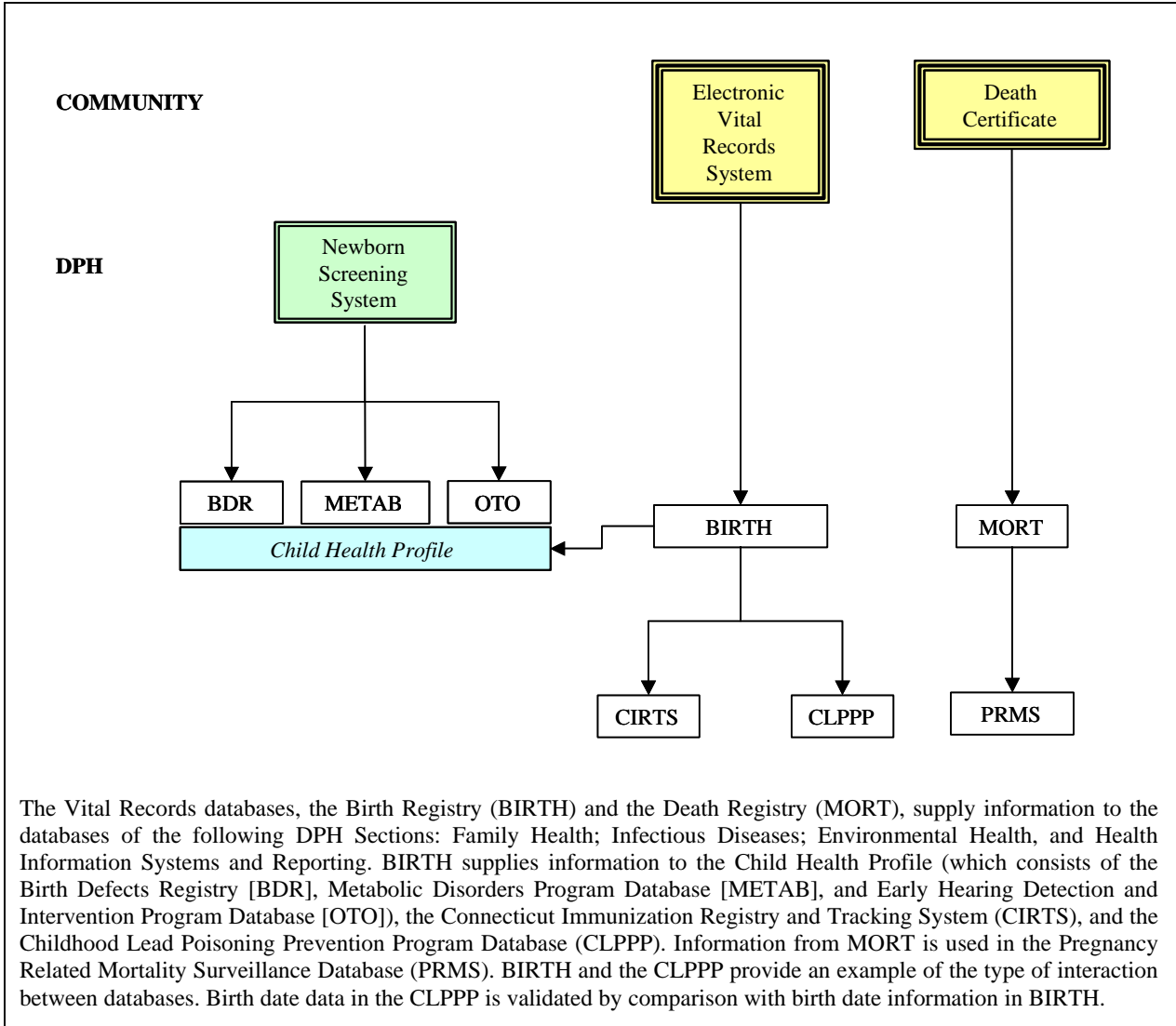
Twenty-six of the databases exist due to state or federal legislation for the report of specific data to the DPH. Databases associated with legislative mandates use the information collected to evaluate program performance, monitor contracts, and provide reports to state and federal entities. Of the 11 databases for which a legal mandate was not reported, purposes for maintaining databases are conditions of agreement with a funding agency, program evaluation, and/or program administration. For example, the database manager for the AIDS Institute Data Application responded: “Required by Centers for Disease Control. Used in Branch quarterly report, research reports, and is also used by the AIDS Program for program planning, contract monitoring, and quality assurance.”

The estimated number of records accumulated annually by the databases range from 15 for the Pregnancy Related Mortality Surveillance Database to 400,000 for the Hospital Discharge and Abstract Billing Database. The median of the estimated number of records accumulated annually is 4,500. Sixteen databases have a specific policy or guidelines for the collection of race and ethnicity data. Four databases (HIV/AIDS Reporting System, Hepatitis B Registry, Hepatitis C Registry, and Statewide WIC Information System) cited use of the 1997 OMB standards for the collection of race and ethnicity data. Appendices G, H, I, and J provide detailed information on case definition, population, and other attributes of each database.

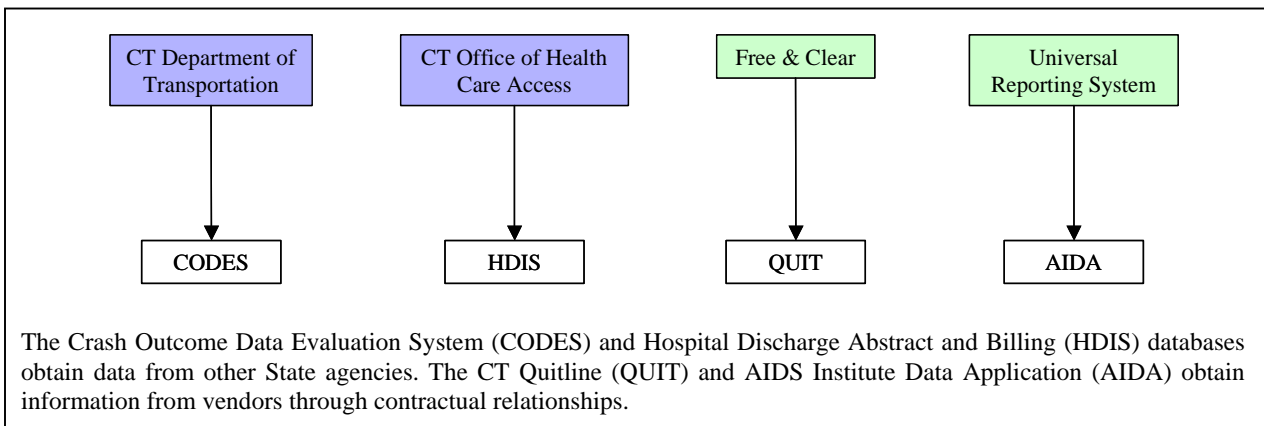
## **Database Relationships**

A DPH database is an organized collection of information that informs a specific public health focus area and related interventions. This information may be collected with special forms, imported from other databases, or both collected and imported. Some databases use specific variables from larger databases that reside within the DPH or other state agencies. Two use data supplied by an outside vendor through contractual relationships. Figures 4, 5, and 6 depict the types of unidirectional database relationships observed.

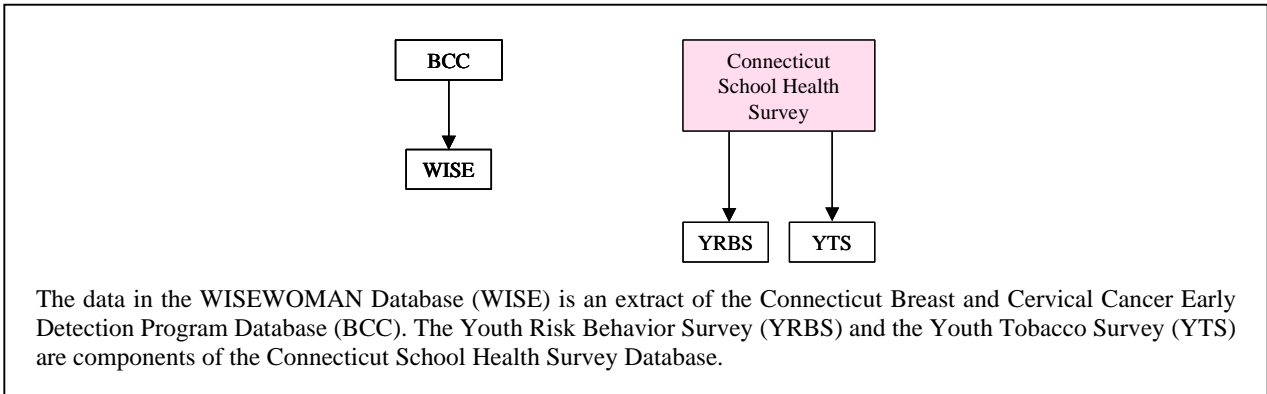
**Figure 4. Relationships with Vital Records databases**



**Figure 5. Relationships with external data sources**



**Figure 6. Relationships between internal data sources**



Understanding database relationships is important when considering what modifications to data collection practices are attainable, determining where changes in practices are possible, estimating the impact of changes, and identifying resources needed to implement new practices.

### **Data Collection Form Review**

The purpose of the survey was to assess the collection of sociodemographic information. Accordingly, the instrument was designed under the assumption that the categories recorded in databases were the same as those present on data collection forms. Primary and secondary data collection forms for 78.4% of the databases were reviewed and compared with survey responses, database coding dictionaries, and digital images of database entry screens. Comparison demonstrated that the race categories reported on the surveys did not always match those on data collection forms. Appendices G, H, J, and I contain endnotes that distinguish between race categories used on data collection forms and those recorded in databases.<sup>9</sup>

### **Race Categories**

All 37 databases include race categories. Use of the 1997 OMB categories varies within and between databases. The following distinctions, based on the race category labels defined in the federal standards, were applied. First, neither “American Indian,” “Native American,” nor “American Indian/Alaskan Native” is equivalent to the label “American

<sup>9</sup> Because the primary objective of this study was the collection of race and ethnicity data, discrepancies between data collection form categories and reported database categories for other sociodemographic information (e.g., age, gender) were not assessed.

Indian/Alaska Native.” Second, “Asian/Pacific Islander” is not equivalent to either “Asian” or “Native Hawaiian or Other Pacific Islander.” Third, neither “African American” nor “Black” is equivalent to “Black or African American.” Fourth, “Native Hawaiian or Pacific Islander” is equivalent to “Native Hawaiian or Other Pacific Islander.” Fifth, the label “Caucasian” is not the same as the label “White.”

Thirteen databases, (Breast and Cervical Cancer, WISEWOMAN, Behavioral Risk Factor Surveillance, Connecticut Tumor Registry, Death Registry, Pregnancy Related Mortality Surveillance, Youth Risk Behavior Survey, AIDS Institute Data Application, HIV/AIDS Reporting System, CT Quitline, School Based Health Center, Statewide WIC Information System, and Youth Tobacco Survey) use some or all of the race categories defined in the 1997 OMB standards. Category frequencies are displayed in Table 2.

**Table 2. Reported 1997 OMB Race Category Use (n=37)**

<b>Category</b>	<b>No.</b>	<b>%</b>
American Indian or Alaska Native	20	54.1
Asian	20	54.1
Black or African American	15	40.5
Native Hawaiian or Other Pacific Islander	11	29.7
White	35	94.6

Two databases (Crash Outcome Data Evaluation System and Foodborne Illness Complaint System) use “Hispanic” as a race category rather than an ethnicity category. Three (Asthma, Connecticut Immunization Registry and Tracking System, and Youth Tobacco Survey) use a combined race/ethnicity format (e.g., White, non-Hispanic). Detailed race category labels and frequencies are shown in Table D.1 (see Appendix D).

The 1997 OMB standards encourage the collection and reporting of information on multiple race identity. Nineteen survey respondents reported that the selection of more than one race category was allowed on data collection forms; however, only 11 reported actually recording the multiple selections in their databases. Among the 18 databases that do not allow selection of multiple race categories on data collection forms, only three (Hepatitis B Registry, Hepatitis C Registry, and the Infectious Diseases Database) reported that they were “planning” to collect multiple race entries in a manner consistent with the 2000 U.S. Census.

## **Ethnicity Categories**

Respondents were asked about the collection of information on Hispanic or Latino ethnicity. According to the 1997 OMB standards, the ethnicity categories “Hispanic or Latino origin” and “Not of Hispanic or Latino origin” should be used.

Many of the databases use the OL-15C<sup>10</sup> (Laboratory Report of Findings, see Appendix E)<sup>11</sup> and/or PD-23 (Reportable Disease Confidential case Report Form, see Appendix F)<sup>12</sup> for data collection. Examination of the forms shows the term “Hispanic” followed by three checkboxes marked “Yes,” “No,” and “Unknown.” Therefore, databases that rely on the OL-15C or PD-23 for primary data are not compliant with the 1997 OMB standards with respect to the collection of ethnicity data. So while 32 databases reported collecting Hispanic/Latino ethnicity data, only eight (Behavioral Risk Factor Surveillance, Connecticut Tumor Registry, HIV/AIDS Surveillance, Death Registry, Pregnancy Related Mortality Surveillance, Youth Risk Behavioral Survey, School Based Health Center, and Statewide WIC Information System) actually use the ethnicity categories specified in 1997 OMB. Detailed information on the ethnicity categories used by the databases surveyed is presented in Appendices G, H, I, and J.

With respect to Hispanic/Latino ethnicity subcategories, ten databases (AIDS Institute Data Application, Birth Defects Registry, Birth Registry, Connecticut Tumor Registry, Fetal Mortality, Legal Induced Termination of Pregnancy, Metabolic Disorders Program, Early Hearing Detection and Intervention Program, Death Registry, and Pregnancy Related Mortality Surveillance) reported using “Cuban,” “Mexican,” and “Puerto Rican.” The Connecticut Tumor Registry also uses “Central and South American (except Brazil)” as a Hispanic/Latino ethnicity subcategory. Four databases (Birth Registry, Fetal Deaths, Death Registry, and School Based Health Center) allow reporting of more than one Hispanic/Latino ethnicity subcategory. The School Based Health Center Database records all ethnicity

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<sup>10</sup> Section 19a-36-A3 of the Connecticut Public Health Code mandates that laboratories are responsible for notifying the DPH of reportable laboratory findings. Section 19a-36-A4 of the Connecticut Public Health Code states that each laboratory report of significant findings should include the race/ethnicity of the person affected.

<sup>11</sup> Databases that use information from the OL-15C are: APB, CLPPP, CO, HARS, HEPB, HEPC, HG, IDD, STDNIS, TIMS, TRIMS, and VMORB.

<sup>12</sup> Medical providers notify the DPH of reportable diseases/conditions using the Reportable Disease Confidential case Report Form PD-23 as required by Section 19a-36-A4 of the Connecticut Public Health Code.

subcategories. The Connecticut Tumor Registry was the only database that reported use of Spanish surname matching<sup>13</sup> in the event of unknown ethnicity.

### **Report of Race/Ethnicity**

The 1997 OMB directive states that in addition to using the race and ethnicity categories specified, race and ethnicity should be self-reported. Table 3 shows the types of reporting relied on by the databases. These categories are not mutually exclusive.

**Table 3. Report of race/ethnicity (n=37)**

<b>Type of report</b>	<b>No.</b>	<b>%</b>
Self	29	78.4
Observer	15	40.5
Both	10	27.0
Unknown	3	8.1

In follow-up discussions, database managers expressed different opinions about how demographic data may be considered self- or observer-reported. Some stated that physician-collected information is more likely to be self-reported because people oftentimes fill in a patient questionnaire while waiting to see a clinician. Others disagreed, stating that people may not be asked to self-identify, or may be classified by an observer based on physical appearance and/or surname. Refer to Appendices G-J for details on the report of race/ethnicity for each database.

### **Use of the 1997 OMB Standards**

Use of the 1997 OMB standard categories collected for each database, in alphabetic order by DPH Branch, is shown in Table 4. One checkmark indicates use of the category label as defined in the 1997 OMB standards (see Figure 2). Two checkmarks indicate use of

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<sup>13</sup> The U.S. Census Bureau generates a list of common “Spanish” surnames using the reported last name, geographic area, and Hispanic/Latino ethnicity of Census respondents. Last names are ranked based on frequency and relative proportions of householders who report Hispanic origin in a specific geographic area (Perkins 1993). Studies demonstrate that ethnic classification bias is reduced when surnames and medical records are used together to classify cases as Hispanic (Morgan et al. 2004; Stewart et al. 1999). The CTR uses the North American Association of Central Cancer Registries’ Hispanic/Latino Identification Algorithm (NHIA), which includes Spanish surname matching, to determine ethnicity when the information is not otherwise available (NAACCR Latino Research Work Group 2005). Polednak (1996) discusses how the CTR used the 1980 Census list of Spanish surnames to estimate breast cancer incidence in Hispanic women.

additional category labels that can be aggregated into a single standard category. A checkmark in the last column indicates that all standard race categories were used in data collection, multiple race categories are recorded, and data are self-reported. Six databases (16.2%) – Behavioral Risk Factor Surveillance Survey, Connecticut Tumor Registry, Death Registry, Pregnancy Related Mortality Surveillance, Youth Risk Behavior Survey, and Statewide WIC Information System – met or exceeded the 1997 OMB standards for collecting data on race and ethnicity. Of the four databases that reported using the 1997 OMB standards for data collection, only the Statewide WIC Information System demonstrated compliance. Twelve databases used “American Indian” instead of “American Indian or Alaska Native.” Eight databases used the old 1977 OMB directive number 15 category, “Asian/Pacific Islander,” instead of the separate categories “Asian” and “Native Hawaiian or Other Pacific Islander.” Two databases used a category that contained the term “Oriental.” Most (54.1%) of the databases used “Black” instead of “Black or African American.”

### **Age**

All 37 databases include information on age. Six record age groups: Food Stamp Nutrition Education, Legal Induced Termination of Pregnancy, Connecticut Quitline, Sexually Transmitted Diseases Management Information System, Tuberculosis Information Management System, and Tuberculosis Registry and Information Management System.<sup>14</sup> Twenty-two databases record a date from which age is calculated. Of these, five (Breast and Cervical Cancer, WISEWOMAN, Connecticut Tumor Registry, Death Registry, and Infectious Diseases) also record age in years. Many databases collect and record more than one type of age information (see Appendices G, H, I, and J).

**Table 4. Databases collecting age (n=37)**

<b>Category</b>	<b>No.</b>	<b>%</b>
Years	19	51.3
Months	3	8.1
Weeks	2	5.4
Days	3	8.1
Age groups	6	16.2
Date of birth	22	59.5
Date of death	2	5.4

<sup>14</sup> These databases do not use the same age groups.

**Table 5. Data collection by 1997 OMB standards**

Database	AIAN	Asian	BAA	NHOPI	White	Records multiple races	Ethnicity terms	Any Self Report	1997 OMB
<b>Office of the Deputy Commissioner</b>									
BCC		✓	✓	✓	✓	✓		✓	
WISE		✓	✓	✓	✓	✓		✓	
<b>Planning</b>									
BIRTH					✓			✓	
BRFSS	✓	✓	✓	✓	✓	✓	✓	✓	✓
CTR	✓	✓✓	✓	✓✓	✓	✓	✓✓	✓	✓✓
FMORT		✓✓	✓		✓			✓	
HDIS		✓			✓				
LITP		✓✓			✓				
MORT	✓✓	✓✓	✓	✓✓	✓	✓	✓✓	NA	✓✓
YRBS	✓	✓	✓	✓	✓	✓	✓	✓	✓
<b>Public Health Initiatives</b>									
AIDA	✓	✓	✓	✓	✓			✓	
ASTHMA		✓					*	UNK	
BDR		✓			✓			✓	
CIRTS		✓					*	✓	
CODES					✓			UNK	
FSNED			✓		✓			✓	
HARS		✓	✓	✓	✓	✓	✓	✓	
HEPB	✓				✓			✓	
HEPC	✓				✓			✓	
IDD	✓				✓			✓	
METAB		✓			✓			✓	
OTO		✓			✓			✓	
PRMS	✓✓	✓✓	✓	✓✓	✓	✓	✓✓	NA	✓✓
QUIT	✓	✓✓	✓	✓✓	✓			✓	
SBHCD	✓	✓	✓	✓	✓		✓✓	✓	
STDMIS	✓				✓			✓	
SWIS	✓	✓	✓	✓	✓	✓	✓	✓	✓
TIMS	✓	✓			✓			✓	
TRIMS	✓	✓			✓			✓	
VMORB					✓			✓	
YTS	✓	✓	✓	✓	✓	✓	*	✓	
<b>Regulatory Services</b>									
APB	✓	✓		✓	✓	✓		✓	
CLPPP	✓	✓		✓	✓			✓	
CO	✓				✓			✓	
FICS					✓			✓	
HG	✓				✓			✓	
OIISS		✓			✓			✓	

**AIAN** American Indian or Alaska Native ✓ Uses the minimum number of categories  
**BAA** Black or African American ✓✓ Exceeds the minimum number of categories  
**NHOPI** Native Hawaiian or Other Pacific Islander \* Use of the combined format  
 Meets 1997 OMB standards for data collection **NA** Not applicable  
**UNK** Unknown



## Gender

Thirty-three databases record gender information. The remaining four databases (Breast and Cervical Cancer, Legal Induced Termination of Pregnancy, Pregnancy Related Mortality Surveillance, and WISEWOMAN) do not record gender because they collected information on females only. Gender data collection categories, which are not mutually exclusive, are listed in Table 6.

**Table 6. Databases collecting gender (n=37)**

Category	No.	%
Female	33	89.2
Male	33	89.2
Intersex	1	2.7
Transsexual	1	2.7
Transgender	1	2.7

Four respondents (Hepatitis B, Hepatitis C, Infectious Diseases, and Carbon Monoxide Poisoning) report use of “fill-in- the blank” fields for gender data collection. The AIDS Institute Data Application is the only database that records the category “Transgender.” The Connecticut Tumor Registry uses the categories “Intersex” and “Transsexual.” Sixteen databases allow recording of “Unknown” for gender. Twenty-five databases use the term “sex” instead of “gender.”

## Additional Sociodemographic Information

Respondents were asked about the collection of other sociodemographic information in their databases including: health insurance status, Medicaid status, Medicare status, educational attainment, employment status, occupation, personal income, household income, number of persons in household, marital/partner status, immigration status, and language spoken at home. These sociodemographic variables (SDVs) have been divided into the following types of indicators: health insurance, socioeconomic position and related characteristics, acculturation and language, and geography of residence. Responses are summarized in Table 7. Consult Appendices G, H, I, and J for specific types of sociodemographic information collected by the surveyed databases.

**Table 7. Databases collecting additional sociodemographic information (n=37)**

<b>Indicators</b>	<b>Variable Name</b>	<b>No.</b>	<b>%</b>
<b>Health insurance</b>	Health insurance status	12	32.4
	Medicaid status	12	32.4
	Medicare status	6	16.2
<b>Socioeconomic position and related characteristics</b>	Educational attainment	16	43.2
	Employment status	12	32.4
	Occupation	13	35.1
	Personal income	2	5.4
	Household income	3	8.1
	Number of persons in household	5	13.5
<b>Acculturation and language</b>	Country of birth	10	27.1
	Immigration status	2	5.4
	Language spoken at home	5	13.5
<b>Geography of residence</b>	Length of residence at current address	6	16.2
	Street address	27	73.0
	City/Town	29	78.4
	County	20	54.1
	State	35	94.6
	Zip code	30	81.1

Geography of residence indicators are the most frequently recorded, while measures of acculturation and language are the least recorded in databases. Five databases (Birth Registry, Childhood Lead Poisoning Prevention Program, Connecticut Tumor Registry, Fetal Mortality, Death Registry, and Pregnancy Related Mortality Surveillance) report some geocoding of residential address information. The Birth Registry, Fetal Mortality, Death Registry, and Pregnancy Mortality databases report use of geocoding to determine local area of residence relative to the census tract and census block level.<sup>15</sup> The Connecticut Tumor Registry and Childhood Lead Poisoning Prevention Program geocode to the census tract level only.

#### *Completeness of Sociodemographic Information*

Survey respondents were asked to estimate the completeness of specific sociodemographic variables in their databases using a five-point rating scale. Mean estimates are shown in Table 8.

<sup>15</sup> Birth and death records predating 1999 have not been geocoded.

**Table 8. Estimates of the completeness of collected sociodemographic information**

<b>Rating Scale</b>		<b>Variable</b>	<b>No.</b>	<b>Mean Score</b>
5.....	80 to 100%	Race	37	4.3
4.....	61 to 80%	Hispanic ethnicity	34	4.0
3.....	41 to 60%	Health insurance status	12	4.2
2.....	21 to 40%	Medicaid status	11*	3.9
1.....	0 to 20%	Medicare status	6	4.3
		Educational attainment	16	4.7
		Employment status	12	4.2
		Occupation	13	4.1
		Personal income	2	5.0
		Household income	3	5.0
		Number of persons in household	5	5.0
		Marital/Partner status	11*	4.9
		Country of birth	10	4.1
		Immigration status	2	5.0
		Language spoken at home	5	3.8
		Street address	27	4.9
		City/Town	29	5.0
		County	19*	4.6
		State	35	5.0
		Zip code	29*	4.8

\* One missing response

The estimated completeness of age and gender data was not assessed. On average, respondents estimated that at least 61 to 80% of the sociodemographic information sought is obtained and recorded in their databases. Additional information is needed to identify how to obtain missing data, and evaluate the importance of frequently incomplete types of sociodemographic information to program objectives.

### **Barriers to Change**

DPH programs and surveillance systems are part of a complex network that includes community, healthcare, foundation, municipal, state, and federal stakeholders, who oftentimes have different interests and degrees of influence. These factors must be accounted for when considering changes to DPH systems. Survey respondents were asked to describe what, if any, barriers there might be to changing the race, ethnicity, or other sociodemographic fields in their databases and/or implementing recommended changes. They identified: 1) need to comply with grantor requirements, 2) use of data from other

sources, 3) limited information technology resources, 4) limited finances to fund changes, 5) limited staff to implement changes, 6) use of immutable software applications, 7) incomplete knowledge about 1997 OMB standards, 8) incomplete data reporting, and 9) reluctance to overburden data collectors. During the report draft review process, the state epidemiologist discussed the challenge of getting the diverse and numerous reporting sources (e.g., hospitals, laboratories) to change their data collection forms and to get the forms completed by personnel (e.g., physicians, clerical staff).

### *Grantor Requirements*

There was broad consensus among respondents that changes to the reporting format are hindered by grantor requirements. A frequently made comment was: “We must comply with standards set by the CDC.” Twenty-seven percent of database managers reported that their systems must comply with specific CDC data reporting requirements. The database manager for the Connecticut Breast and Cervical Cancer Early Detection Program and WISEWOMAN databases reported that any changes made to the databases would have to correspond with methods outlined in a CDC data manual. Changes to data collection forms would have to go through a CDC approval process prior to reprinting. Likewise, the Connecticut Tumor Registry database manager responded, “[The] Registry would need to retain fields required by [the] contractor [National Cancer Institute] (NCI), in order to be consistent with other SEER registries and other U.S. cancer registries in the North American Association of Central Cancer Registries.”

### *Use of Data from Other Sources*

Relationships with external data sources were identified by four databases (see Figure 5). For these databases, changes to data collection may involve complex negotiations between staff at several administrative levels and/or amendments to contracts or memoranda of understanding. “CODES [Crash Outcome Data Evaluation System] is a collection of data from other databases. Changing the way information is collected means going back to the original source and ask[ing] for a systematic change within that organization.”

### *Limited Information Technology Resources*

Nine database survey respondents (Connecticut Breast and Cervical Cancer Early Detection Program [BCC], WISEWOMAN [WISE], Birth Registry [BIRTH], Fetal Mortality [FMORT], Death Registry [MORT], Connecticut Immunization Registry and Tracking System [CIRTS], Early Hearing Detection and Intervention Program [OTO], Tuberculosis Information Management System [TIMS], and Tuberculosis Registry and Information Management System [TRIMS], identified scarcity of IT (information technology) resources as a limiting factor in changing data collection systems. BIRTH, BCC and WISE have the problem of limited financial resources and use of unsupported or old technology for which there is limited technical assistance. For BIRTH, DPH IT Section staff cannot make desired changes to proprietary code owned by the Electronic Vital Records System (EVRS) vendor. Citing similar issues, the BCC and WISE data manager stated: “Currently, the databases are in Visual FoxPro, a program no longer supported. Any change to the structure of the database and/or extraction code has to be performed by a DPH employee in another program who is the only DPH employee familiar with Visual FoxPro programming.”

For databases like Varicella Morbidity (VMORB) that do not require DPH IT Section support, program staff identified time as a limiting factor. Program personnel have routine responsibilities that must be addressed before time can be dedicated to making modifications, educating users and reporters, and pilot testing.

In addition to the survey responses and feedback discussions, project staff had conversations with the Public Health Information Network (PHIN)<sup>16</sup> coordinator, Environmental Public Health Tracking (EPHT) coordinator, and a supervising epidemiologist in the Health Information Systems and Reporting Section. These key informants discussed the tension between the limitations of the DPH technology infrastructure and the needs of database managers. The situation of the Vital Records Division’s databases illustrates how critical modern information systems are to the fabrication of public health data products.

The Birth Registry is fed information through the Electronic Vital Records Solution (EVRS). The National Center for Health Statistics wants all states to adhere to its 2003 standards for reporting births and deaths. As the national health statistics agency, NCHS

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<sup>16</sup> PHIN is a CDC national initiative to improve the capacity of public health agencies to use and exchange electronic information using standards and defined technical requirements. See <http://www.cdc.gov/phn/index.html> for more information.

monitors the health status of the population and identifies disparities in health status by race/ethnicity, socioeconomic status, region, and sociodemographic characteristics.<sup>17</sup> The Connecticut Birth Registry data files continue to be submitted to NCHS utilizing the 1988 NCHS standards due to the limitations of the current database and the lack of funding to modify it. DPH can report deaths to NCHS according to NCHS 2003 reporting standards, but the death registration process in Connecticut remains paper-based. Changes can be made to the Death Registry, but funding is required to update the death certificate form and the data entry system.<sup>18</sup> There is also an issue of funding and technical support to transition to a more functional database than the Access database currently used for death registration. Neither the Birth Registry nor the Death Registry can currently meet the mandates of the Intelligence Reform and Terrorism Prevention Act of 2004 (Public Law 108-458) or the Real ID Act of 2005<sup>19</sup> (Public Law 109-13).

Unfortunately, the Vital Records databases are not unique in their need for more resources to improve performance to adequate levels. The DPH PHIN Workgroup conducted an assessment of applications used by DPH staff between January and April 2007. A sample of 98 applications (which is not inclusive of all databases in the agency) was assessed for criticality to agency function, level of IT Section support, and Enterprise-Wide Technical Architecture (EWTA).<sup>20</sup> Of the 37 databases that completed the Health Database Questionnaire, according to the PHIN Workgroup report (Bryant et al. 2007), the following eight databases have no assigned DPH IT Section or outside vendor support: Breast and Cervical Cancer, WISEWOMAN, Death Registry, Hospital Discharge, Legal Induced Termination of Pregnancy, Birth Defects Registry, Newborn Screening System (Metabolic Disorders and Early Hearing Detection and Intervention), and Childhood Lead Poisoning Prevention Program.

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<sup>17</sup> NCHS reports inform national public health initiatives like *Healthy People 2010*.

<sup>18</sup> Currently, an outside vendor keys in the demographics from the death certificate and sends the record to DPH where the cause of death is entered. Next, data are sent to NCHS, which assigns the ICD-10 codes. The coded information is then sent to DPH.

<sup>19</sup> This Act is Division B of the Emergency Supplemental Appropriations Act for Defense, the Global War on Terror, and Tsunami Relief.

<sup>20</sup> Per CGS 4d-2 (c), the State of Connecticut Department of Information Technology (DOIT) developed the State Technical Architecture that sets the technical and product standards, system design principles, guidelines, and best practices to support the strategic direction of the State of Connecticut (DOIT 2001).

If a system is not EWTA compliant, it will not meet the PHIN standards. The DPH PHIN Workgroup found that 90% of operating systems were not EWTA-compliant. Of these, 93% have databases that are not EWTA-compliant. Among the 37 databases that completed the Health Database Questionnaire, the following 16 were not EWTA-compliant: Birth Registry, Connecticut Tumor Registry, Child Lead Poisoning Prevention Program Surveillance System, Death Registry, Hospital Discharge, Legal Induced Termination of Pregnancy, AIDS Institute Data Application, Birth Defects Registry, Newborn Screening System (Metabolic Disorders and Early Hearing Detection and Intervention), Hepatitis B Registry, Hepatitis C Registry, Sexually Transmitted Diseases Management Information System, Statewide WIC Information System, Tuberculosis Information Management, and Tuberculosis Registry and Information Management System.

#### *Immutable Software*

CDC-issued surveillance software was identified as another barrier related to information technology. Changes to existing fields and addition of new fields are difficult or not possible because of how the applications were developed by the CDC. The HIV/AIDS Reporting System (HARS), Sexually Transmitted Diseases Management Information System (STDMIS), Infectious Diseases Database (IDD), and Tuberculosis Information Management System (TIMS) use such software. If changes are made, electronic transmission of data to CDC information systems will be adversely affected.

#### *Incomplete Knowledge about the 1997 OMB Standards*

During feedback sessions, database managers and users commented on the paucity of knowledge about the 1997 OMB standards within DPH. Indeed, upon seeing a draft version of Table 5, several people were surprised to see that their databases were not checked as using “Black or African American” because they thought that “Black” was sufficient. Several individuals reported that when seeking guidance about which ethnicity and race fields should be used in data collection forms and/or databases, they have been instructed to use the same fields that are present in NETSS (National Electronic Telecommunications System for

Surveillance), a major system used to report core surveillance data on national notifiable diseases to the CDC.<sup>21</sup>

### *Incomplete Data Reporting*

Incomplete reporting and non-reporting of information were reported as challenges to sociodemographic data collection by seven of those surveyed. According to a respondent for the Infectious Diseases Database, “The biggest barrier is that the people who fill out the report forms do not fill out the sections on race and ethnicity.” All surveillance systems that rely on passive surveillance encounter this problem.

### *Reluctance to Overburden Data Collectors*

Respondents also expressed a reluctance to overburden data collectors with additional questions. In feedback discussions, several participants expressed the belief that physicians and other data collection form completers are reluctant to ask individuals for race and ethnicity information. The survey respondent for the Pregnancy Related Mortality Surveillance Database stated, “The administrative burden associated with expanding or changing the data collected is a key factor. This pertains both to the DPH staff and to the hospital staff and others who collect these data.” The manager of the Asthma Database wrote: “The completeness of reporting may decrease if the data collection becomes more complicated.” The Food Stamp Nutrition Education Database manager thought that asking additional questions about sociodemographic information might adversely affect the willingness of individuals to participate in education programs.

### *Changing Data Collection Forms and Standards Used by Reporters*

The DPH provides reporters with standard reporting forms (e.g., OL-15C, PD-23). But the information to populate these forms is derived from data collection forms and systems developed by reporters for their primary business functions. The state epidemiologist wrote: “Passive reporting systems rely on reporting sources to both collect and report data on race and ethnicity. Not all hospitals collect race and ethnicity data – nor do so in a standard way – on their patient admission profile forms. Many laboratories do not include standard race and ethnicity categories on forms they use for physicians to order tests. When reporting

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<sup>21</sup> DPH uses a version of the NETSS software application version that does not contain the ethnicity and race categories defined in the 1997 OMB standards.



positive test results, laboratories only have the information they collect. In order to get standardized information from hospitals and laboratories, they need to modify their basic forms to include this information in the currently recommended format and then to actively collect that information. This is a formidable undertaking that will take time and resources, and which might not get full participation.”

## **DISCUSSION**

This assessment of DPH databases reveals great variation across systems in the collection of race, ethnicity, age, gender, and other sociodemographic information relevant to health outcomes. Data collection schemes were compared to the 1997 Office of Management and Budget's *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity*. Compliance with the 1997 OMB standards was defined as: 1) collection of self-reported race and ethnicity data, 2) use of a two-question format that assesses ethnicity separate from race, and 3) use of the race and ethnicity categories specified in the 1997 OMB standards. In addition, collection of information on age, gender, health insurance, socioeconomic position, acculturation, and geographic area of residence was assessed. Detailed information on each database survey participant is located in Appendices G, H, I, and J.

Analysis of the survey responses reveals several areas of concern: 1) multifaceted data collection issues; 2) dependence of some databases on other, larger databases; 3) lack of adherence to the 1997 OMB standards within and among federal agencies; 4) inclusion of variables was determined by database purpose, function, and funding requirements; 5) limited use of gender terms; and 6) limited use of geocoding.

### **Data Collection Issues**

#### *Data Collection Form Categories Differ from Recorded or Reported Categories*

Appendices G, H, J, and I contain endnotes that distinguish between race categories used on data collection forms and those recorded in databases. When presented with the discrepancy between what is on a data collection form and what is recorded in a database, one person remarked: "We report the right categories, but collect different ones." The discord between what is actually collected versus what is recorded or reported is an important area to address. Establishing consistency across data collection, recording in databases, and reporting, is essential to accurate characterization of health disparities.

#### *Abbreviation of Categories on Forms*

The abbreviation and/or exclusion of some category labels (or parts of them) as in the case of "Black or African American" shortened to "Black," reflects the need to save space on

data collection forms. One feedback session participant stated: “It is economical to shorten terms on a worksheet [data collection form]. These are practical considerations.” For example, laboratories use the OL-15C to report significant findings (see Appendix E ). This single legal-sized page, triplicate form lists the confirmatory tests that indicate reportable diseases. The PD-23 form is a single letter-sized page, triplicate form (see Appendix F). Physicians and other clinical office staff use it to report conditions of public health importance. The demographics sections of these forms are very small compared to the sections for clinical information. Increasing the number of options in one section lessens the chances of fitting everything onto one page.<sup>22</sup>

### *Missed Opportunities for Self-Report*

Both observer- and self-reported race/ethnicity data were reportedly collected by 27% of the databases. More information is needed on how data are collected by form completers. The occurrence of racial misidentification of individuals in public health surveillance and administrative databases (Bertolli et al. 2007; Kressin et al. 2003) suggests that there are missed opportunities to ask individuals how they identify themselves.

The use and nonuse of the ethnicity categories delineated in the 1997 OMB standards illustrate the intricacies of collecting observer- and/or self-reported data. Three databases (Crash Outcome Data Evaluation System [CODES], Foodborne Illness Complaint System [FICS], and Youth Tobacco Survey [YTS]) use the term “Hispanic” as a race category rather than an ethnicity one. CODES data is imported from other sources,<sup>23</sup> so there is no way to change the practice of using “Hispanic” as a racial category unless the data providers collect the information in a different way. In the case of the FICS, data are collected by a state or local health department employee either face-to-face or over the telephone. The YTS is self-administered.<sup>24</sup> These modes of data collection, in-person or telephone interview and self-administration, provide opportunities for self-report using the preferred two-question format outlined in the 1997 OMB standards.

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<sup>22</sup> Single-page forms reduce the amount of paper that is faxed, photocopied, and stored.

<sup>23</sup> Data from the Connecticut Department of Transportation are combined with CHIME data from the Connecticut Hospital Association.

<sup>24</sup> Interestingly, the YTS invites respondents to select multiple categories for self-description; however, the question immediately following it is: “Which *one* of these groups BEST describes you?”

### *Missed Opportunities to Use the Two-Question Format*

The Asthma Database and Connecticut Immunization Registry and Tracking System use a combined race/ethnicity format. Provided that the six specified categories are used, the 1997 OMB standards allow this practice for observer-collected data (OMB 1997). The Asthma Database contains information on children enrolled in Connecticut schools that is reported by school nurses. Use of the combined format in this situation of observer-reported information is allowed by the federal standards. But the Connecticut Immunization Registry and Tracking System data on race and ethnicity are reported by a parent/guardian. This is an instance in which use of the preferred, two-question format is preferred.

### **Dependence on Other Databases**

The dependence of program- and/or intervention-specific databases on information from other databases underscores the importance of quality data collection in major systems like the Birth Registry. On its own, the Birth Registry is an important repository of vital statistics information. Figure 4 shows that it also supplies information to the Child Health Profile, Connecticut Immunization Registry and Tracking System, and Childhood Lead Poisoning Prevention Program. If there are data issues in the Birth Registry, the databases downstream that use the registry data for field population or confirmation will be affected. Upstream data quality affects the quality of data downstream.

### **Federal Practices Affect State Practices**

Federal agencies supply state health departments with funding and tools to collect public health surveillance data. In return, state health departments report program administration and performance data to federal agencies. Accordingly, one would expect that the majority of databases surveyed would be found in compliance with the federal standards. However, this was not the case.

Although 51.4% of the databases are federally funded, only 16.2% of those surveyed were found to be in accord with the 1997 OMB standards. Many DPH programs receive funding from the CDC, which is an agency within the DHHS. Not all CDC programs have adopted the 1997 OMB standards. This is evident in the tools provided to state health data collectors. Of the four databases that were applications created by the CDC (HIV/AIDS Reporting System [HARS], Infectious Diseases Database [IDD], STD Management

Information System [STDMIS], and Tuberculosis Information Management System [TIMS]), none complied with the 1997 OMB standards.<sup>25</sup> In contrast, the Statewide WIC Information System, funded by the USDA Food and Nutrition Program, met the 1997 OMB standards. Friedman and colleagues (2000) state: “State public health agencies will need standardization in implementing the OMB standards across and within all federal agencies with responsibilities for public health data collection to engender consistent race and ethnicity data collection in diverse information systems.” Some feedback discussion participants felt that if the CDC does not demonstrate compliance with the 1997 OMB standards and does not require it, there was little reason for the DPH to use the standard categories. However, a DPH Branch chief stated that even if all federal agencies are not in compliance with the 1997 OMB standards, DPH databases should make an effort to meet the standards.

### **Multiple Factors Affect Inclusion of Sociodemographic Information**

The collection of information on health insurance, socioeconomic position and related characteristics, acculturation and language, and geography appeared to vary with how data might inform program-specific activities.

#### *Determination of Eligibility to Receive Services*

The Connecticut Breast and Cervical Cancer Education Program provides free screening and diagnostic services to medically underserved women. To determine eligibility, information about age, health insurance, and income are collected.

#### *Information for Follow-up Investigation*

The Tuberculosis Control Program collects information on employment status and occupation of active tuberculosis cases. These data inform contact investigations that identify individuals who may have been recently exposed to tuberculosis bacteria and are at high risk for developing active disease.

#### *Fulfillment of Grantor Requirements*

Differences in sociodemographic data collection may also be attributed to the reporting requirements of federal funders. The Behavioral Risk Factor Surveillance Survey and Youth Risk Behavior Survey exemplify how the source of funding determines the

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<sup>25</sup> HARS would have met the 1997 OMB standard, but “Alaskan Native” is used instead of “Alaska Native.”

variables collected. These surveys are fully funded by the CDC and require use of a standard, core set of questions.<sup>26</sup> In this way, the CDC assures that BRFSS data are comparable across the nation. Similarly, the Statewide WIC Information System must collect income information and use all of the 1997 OMB categories because of federal reporting requirements. This requirement is built into the data system such that an application for service cannot be processed without the completion of all required fields.

### **Limited Use of Gender Categories**

Analysis of questions about gender demonstrates that few databases use terms beyond “Female” and “Male.” Most notably, the Birth Registry does not use the category “Intersex.” The definition and prevalence of intersex are controversial topics (Blackless et al. 2000; Sax 2002). The prevalence of intersex births is of interest to public health researchers because they may be the result of environmental factors such as hormone disruptors (Skakkebaek, Rajpert-De Meyts, and Main 2001). But because the category “Intersex” is not included on the birth registration form, enumeration of intersex births in Connecticut using vital statistics data is not currently possible. In addition, use of the categories “Transgender” and “Transsexual” in databases that collect information on adults may enhance the activities of DPH programs like those of the Infectious Diseases Section that monitor sexual transmission of disease or investigate disease clusters.

### **Limited Use of Geocoding**

While the vast majority (73%) of the DPH databases surveyed collect residential street address information, only five (13.5%) report some geocoding of this information. The value of geocoding for public health surveillance purposes has been demonstrated by numerous studies (Krieger et al. 2003a; 2003b; 2005), and some states and municipalities have made extensive use of geocoded public health data such as the state of Washington (Washington State Department of Health) and New York City (Karpati et al. 2004; New York Department of Health and Mental Hygiene).

Most public health databases in the United States and Connecticut have yet to incorporate adequate measures of social status or economic position so that the effects of these factors on specific indicators of mortality and morbidity can be reliably measured and

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<sup>26</sup> In the case of the BRFSS, states can select additional modules of questions to be asked of their residents.

monitored on a routine basis (Krieger, Williams, and Moss 1997). Such monitoring would be of great value in tracking health disparities related to income, education, race, and ethnicity. The Harvard Geocoding Project has demonstrated that use of geographic information systems (GIS) technology, specifically the geocoding of residential address and comparison with the U.S. Census derived area-based measures of socioeconomic position, can be a practical solution to limited or absent socioeconomic data in public health databases (Krieger et al. 2005; Krieger et al. 2007). Also, theoretical models have been developed that explain how group-level and individual-level theoretical models interact in shaping health outcomes. Such multilevel analyses hold promise for integrating the macro- and micro-level factors that influence population health (Diez-Roux 1998; Cubbin, LeClere, and Smith 2000; Pickett and Pearl 2001).

### **Moving Forward**

In concert, the observed data collection practices and barriers to change identified by DPH staff present difficult, yet not insurmountable challenges to the elucidation of health disparities in Connecticut. Several factors will enable the DPH to better characterize health disparities in Connecticut. They include: 1) enhancing data collection and reporting practices, 2) increasing the knowledge of DPH staff and data reporters about data collection standards, and 3) enhancing information technology resources.

## **RECOMMENDATIONS**

Recommendations from this study are the direct result of careful analysis of survey findings and follow-up discussion sessions with the surveyed database managers and other interested DPH staff. Recommendations fall into three equally important and interwoven areas: 1) data collection and reporting practice, 2) knowledge of federal reporting standards, and 3) information technology.

### **Enhance Data Collecting and Reporting**

#### 1. Establish minimum data collection standards.

Ethnic and racial categories in DPH data collection forms and electronic systems should, at a minimum, meet the basic requirements of the 1997 Office of Management and Budget *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity*.

- a) Encourage self-report of ethnicity and race whenever possible.
- b) Data collection forms should include the following ethnicity categories:
  - Hispanic or Latino
  - Not Hispanic or Latino
- c) Data collection forms should include the following race categories:
  - American Indian or Alaska Native
  - Asian
  - Black or African American
  - Native Hawaiian or Other Pacific Islander
  - White
- d) Selection of multiple race categories should be encouraged on all data collection forms.
- e) Categories on data collection forms, database dictionaries, and data reports should match.

#### 2. Establish ideal data collection standards.

In addition to meeting the requirement of the minimum standards (see above), databases with adequate resources should consider:

- a) Use of additional race and ethnicity categories and free text responses that can aggregate into the 1997 OMB standard categories (e.g., Connecticut Tumor Registry).



- b) Allow selection of and record multiple race categories.
  - c) Incorporate educational attainment, employment status, and preferred language.
  - d) Include residential address to facilitate geocoding.
  - e) Incorporate additional indicators of socioeconomic position (e.g., household income, personal income, and number of persons in household) if germane to program objectives.
  - f) Incorporate expanded gender categories (e.g., intersex, transgender, transsexual) if relevant to program objectives.
3. Create and implement a *DPH Data Collection and Use Policy* to standardize the collection and reporting of sociodemographic data across the organization.

A DPH data collection and use policy is needed to standardize the collection of race, ethnicity, and other important sociodemographic information. A DPH data policy would define the minimum categories for the collection of race, ethnicity, age, gender, socioeconomic position, and geographic data in all DPH databases. All DPH employees who collect, enter, analyze, and report data would be required to review the policy and demonstrate comprehension. The state health departments of Rhode Island and Washington have data policies that could serve as models.

4. Develop a DPH-level mechanism for geographic information system (GIS) management and routine performance of spatial analysis using residential address information.

Routine geocoding of residential address information will enable analyses using area-based socioeconomic indicators collected in the U.S. Census. Research demonstrates that analyses based on the linkage of geocoded residential address information and U.S. Census area-based measures of socioeconomic position (e.g., occupation, income, poverty, wealth, education, crowding, and segregation) provide useful information about disease patterns and health outcomes that can illuminate health disparities.

5. Convene an ad hoc DPH workgroup to identify ways to encourage the collectors of health information (e.g., hospitals, clinics, physicians, laboratories) to enhance their reporting practices, data collection forms, and data systems to meet the 1997 OMB standards.

6. Amend the Connecticut Public Health Code to mandate that the report of reportable findings shall include race and ethnicity information collected in accordance with the 1997 OMB standards.

Section 19a-36-A4 of the Connecticut Public Health Code (PHC) defines the content of reporting and reporting of reportable diseases and laboratory findings to the DPH.

Section 19a-36-A4(b)(1) of the PHC should be amended to read:

Each report of reportable findings shall include the name, address, age, sex, and if known, **ethnicity and race of the person affected in accordance with the U.S. Office of Management and Budget's *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity***, the name and address of the attending physician, the identity of the infectious agent or other reportable laboratory findings, and the method of identification.

### **Increase Knowledge of Data Users and Reporters**

7. Provide training for DPH staff on the 1997 OMB minimum standards for collecting race and ethnicity data and the *DPH Data Collection and Use Policy*.
8. Provide training of physicians, laboratorians, and other reporters on the 1997 OMB minimum standards for collecting race and ethnicity data.

In order to increase the quantity and quality of data reported to the DPH, efforts must be made to educate physicians, laboratorians, and other reporters about the 1997 OMB standards. Specifically, they should be made aware that: 1) self-reported race information should be collected, 2) "Hispanic or Latino" is not a racial category, 3) the 1997 OMB standards are important to ensure the comparability of data, 4) better data to the DPH means higher quality information about the health status of all Connecticut residents, and 5) reporting this information in a consistent fashion will help Connecticut and the DHHS make progress toward the *Healthy People 2010* goal of health disparities elimination.

## **Enhance Information Technology Resources**

9. Assess the technical capacity of DPH databases to become compliant with the 1997 OMB standards.

The State of Connecticut Department of Information Technology is collaborating with the DPH IT Section to enhance and make available the tools that DPH database managers need to collect, maintain, and report data. Assessing the technical capacity for changes to and/or addition of database fields and codes can inform these efforts and the development of strategies for databases to meet or exceed the 1997 OMB standards. Technical capacity assessment would entail a survey of database managers and IT Section staff that have system development or data management responsibilities. Survey findings would help programs identify steps and resources needed to implement the recommended changes and estimate associated costs. Moreover, the survey process would complement DPH staff education efforts around the importance of accurate racial, ethnic, and other sociodemographic data to inform the portrait of health disparities in Connecticut.

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## APPENDIX A

### Race and Ethnicity in the U.S. Census

**Table A.1. U.S. Census Race Classifications, 1880 – 2000\***

<b>1880</b>	White; Black; Mulatto; Chinese; and Indian
<b>1890</b>	White; Black; Mulatto; Quadroon; Octoroon; Chinese; Japanese; and Indian
<b>1900</b>	White; Black; Chinese; Japanese; and Indian
<b>1910</b>	White; Black; Mulatto; Chinese; Japanese; Indian; and Other
<b>1920</b>	White; Black; Mulatto; Chinese; Japanese; Indian; and Other
<b>1930</b>	White; Negro; Mexican; Indian; Chinese; Japanese; Filipino; Hindu; Korean; and Other
<b>1940</b>	White; Negro; Indian; Chinese; Japanese; Filipino; Hindu; Korean; and Other
<b>1950</b>	White; Negro; American Indian; Japanese; Chinese; Filipino; and Other
<b>1960</b>	White; Negro; American Indian; Japanese; Chinese; Filipino; Hawaiian; Part Hawaiian; Aleut; Eskimo; and Other, etc.
<b>1970</b>	White; Negro or Black; Indian (Amer.); Japanese; Chinese; Filipino; Hawaiian; Korean; and Other
<b>1980</b>	White; Black or Negro; Japanese; Chinese; Filipino; Korean; Vietnamese; Indian (Amer.); Asian Indian; Hawaiian; Guamanian; Samoan; Eskimo; Aleut; and Other
<b>1990</b>	White; Black or Negro; Indian (Amer.); Eskimo; Aleut; Asian or Pacific Islander (API); Chinese; Filipino; Hawaiian; Korean; Vietnamese; Japanese; Asian Indian; Samoan; Guamanian; and Other
<b>2000</b>	White; Black, African Am. or Negro; American Indian or Alaska Native– <i>Print name of enrolled or principal tribe</i> ; Asian Indian; Chinese; Filipino; Japanese; Korean; Vietnamese; Other Asian – <i>Print race</i> ; Native Hawaiian; Guamanian or Chamorro; Samoan; Other Pacific Islander – <i>Print race</i> ; and Some other race– <i>Print race</i>

\* Categories are listed in their order of appearance on the Census data collection form.

*Sources:*

Anderson, Margo and Stephen E. Fienberg, 2000. Race and ethnicity and the controversy over the U.S. Census.

Lee, Sharon M. 1993. Racial classifications in the U.S. census: 1890-1990.

U.S. Census Bureau. Photographs, The Photo Zone, Historical Forms and Questions: 1880.

U.S. Census Bureau. 1998b. Uses for Questions on the Census 2000 Forms: Basic facts about us.

**APPENDIX A**  
**Race and Ethnicity in the U.S. Census**

Table A.2. U.S. Census Ethnicity Questions, 1970 – 2000\*

<b>Year</b>	<b>Question</b>
<b>1970</b>	Is this person's origin or descent? <i>Fill one circle.</i> Mexican Puerto Rican Cuban Central American Other Spanish No, none of these
<b>1980</b>	Is this person of Spanish/Hispanic origin or descent? <i>Fill one circle.</i> No (not Spanish/Hispanic) Yes, Mexican, Mexican-Amer., Chicano Yes, Puerto Rican Yes, Cuban Yes, other Spanish/Hispanic
<b>1990</b>	Is this person of Spanish/Hispanic origin? <i>Fill one circle for each person.</i> No (not Spanish/Hispanic) Yes, Mexican, Mexican-Amer., Chicano Yes, Puerto Rican Yes, Cuban Yes, other Spanish/Hispanic (Print one group, for example: Argentinean, Colombian, Dominican, Nicaraguan, Salvadoran, Spaniard, and so on.)
<b>2000</b>	Is this person Spanish/Hispanic/Latino? <i>Mark the "No" box if not Spanish/Hispanic/ Latino.</i> No, not Spanish/Hispanic/Latino Yes, Mexican, Mexican Am., Chicano Yes, Puerto Rican Yes, Cuban Yes, other Spanish/Hispanic/Latino — Print group.

\*Responses are listed in their order of appearance on the census data collection form.

*Sources:*

- Anderson, Margo and Stephen E. Fienberg, 2000. Race and ethnicity and the controversy over the U.S. Census.
- U.S. Census Bureau. Photographs, The Photo Zone, Historical Forms and Questions: 1970.
- U.S. Census Bureau. 1980 Census of the United States.
- U.S. Census Bureau. Official 1990 U.S. Census Form
- U.S. Census Bureau. 1998b. Uses for Questions on the Census 2000 Forms: Basic facts about us.
- U.S. Census Bureau. United States Census 2000.

## APPENDIX B

### The Connecticut Health Disparities Project Health Database Questionnaire

**Instructions:** Please fill in all blank fields. To simplify the survey process, certain fields have been pre-filled based on available information. For those pre-filled fields, please confirm that the information entered is correct, and change it if it is not accurate. Please use a separate questionnaire to report information for each database in your unit. If you have questions about this survey, contact Ava Nepaul at ext. 8239. Please e-mail the completed questionnaire to: [ava.nepaul@po.state.ct.us](mailto:ava.nepaul@po.state.ct.us), or send via interdepartmental mail to: Ava Nepaul, Health Information Systems and Reporting Section, 410 Capitol Avenue, MS #11PSI.

1. Name of the database:
2. Name of the DPH data manager:
3. Name of the DPH contact person:
4. Name of the person completing this questionnaire:
  - 4a. Title:
  - 4b. Phone extension:
  - 4c. E-mail address:
5. What is the purpose or mandate for the data collection for this database?
  - 5a. Legislative (Please provide citation):
  - 5b. Other (please specify):
6. What is the definition of a case or record in this database?
7. What is the population covered by this database (e.g., AIDS patients, gender, age group etc.)?
8. Please specify the most recent complete year available for this database:
9. Approximately how many records are accumulated per year?
10. Do you use a specific policy that pertains to the collection of race and ethnicity data?  
 Yes             No
  - 10a. If “Yes”, please include a copy of the policy when you submit the completed survey, or type an excerpt of the policy here:

**APPENDIX B**

11. Does your database include information on racial categories?

- Yes                       No [Go to Q. 14]

12. What racial categories are in this database? Please check “Yes” if the label reflects the exact wording. If your database has a category that is not listed, please type it in the space for “Other racial categories used”.

<u>Category</u>	<u>Yes</u>	<u>No</u>	If a different label is used, please list exact wording below: _____
White	<input type="checkbox"/>	<input type="checkbox"/>	
Black/African American	<input type="checkbox"/>	<input type="checkbox"/>	
Asian	<input type="checkbox"/>	<input type="checkbox"/>	
American Indian/Alaska Native	<input type="checkbox"/>	<input type="checkbox"/>	
Native Hawaiian/Pacific Islander	<input type="checkbox"/>	<input type="checkbox"/>	
Unknown	<input type="checkbox"/>	<input type="checkbox"/>	
Other racial categories used (Please list)	<input type="checkbox"/>	<input type="checkbox"/>	

13. Do you allow an individual to report more than one race?

Yes → 13a. Are all the categories reported recorded in your database?

- Yes                       No

No → 13b. Is your section or unit planning to collect multiple race entries in this database to provide consistency with the 2000 U.S. Census race questions?

- Yes                       No



If “Yes”, please specify:

14. Is a Hispanic/Latino ethnic category included as a separate field in this database?

- Yes                       No

15. Is Spanish-surname matching used to indicate Hispanic/Latino ethnicity?

- Yes                       No

**APPENDIX B**

16. What Hispanic/Latino ethnicity subcategories are included in this database?

<u>Category</u>	<u>Yes</u>	<u>No</u>	<u>If a different label is used, please list exact wording below:</u>
Hispanic and Non-Hispanic only	<input type="checkbox"/>	<input type="checkbox"/>	
Cuban	<input type="checkbox"/>	<input type="checkbox"/>	
Mexican	<input type="checkbox"/>	<input type="checkbox"/>	
Puerto Rican	<input type="checkbox"/>	<input type="checkbox"/>	
Unknown	<input type="checkbox"/>	<input type="checkbox"/>	
Other Hispanic/Latino subcategories used (Please list)	<input type="checkbox"/>	<input type="checkbox"/>	

17. Do you allow an individual to report more than one Hispanic/Latino ethnicity subcategory?

Yes                       No

17a. Are all of the subcategories reported recorded in your database?

Yes                       No

18. Other than Hispanic/Latino, are other ethnic categories included in this database?

Yes                       No

18a. If “Yes”, please list:

19. Is your race/ethnicity data self-reported and/or observer-reported?

19a. Self-reported             Yes     No     Unknown

19b. Observer-reported       Yes     No     Unknown



If “Yes”, please specify by whom:

19c. Comment (optional)

20. Do you collect information on country of birth?

Yes                       No

21. Do you collect information on length of time in the United States (excluding Puerto Rico and other U.S. Commonwealths and territories)?

Yes                       No

**APPENDIX B**

22. Do you collect information on any of the following sociodemographic variables in this database?

<u>Information</u>	<u>Yes</u>	<u>No</u>	<u>If a different label is used, please list exact wording below:</u>
Health insurance status	<input type="checkbox"/>	<input type="checkbox"/>	
Medicaid status	<input type="checkbox"/>	<input type="checkbox"/>	
Medicare status	<input type="checkbox"/>	<input type="checkbox"/>	
Educational attainment	<input type="checkbox"/>	<input type="checkbox"/>	
Employment status	<input type="checkbox"/>	<input type="checkbox"/>	
Occupation	<input type="checkbox"/>	<input type="checkbox"/>	
Personal income	<input type="checkbox"/>	<input type="checkbox"/>	
Household income	<input type="checkbox"/>	<input type="checkbox"/>	
Number of persons in household	<input type="checkbox"/>	<input type="checkbox"/>	
Marital/Partner status	<input type="checkbox"/>	<input type="checkbox"/>	
Immigration status	<input type="checkbox"/>	<input type="checkbox"/>	
Language spoken at home	<input type="checkbox"/>	<input type="checkbox"/>	
Other (Please specify)	<input type="checkbox"/>	<input type="checkbox"/>	

23. Do you collect information on any of the following geographic units in this database?

<u>Unit</u>	<u>Yes</u>	<u>No</u>
Street address of residence	<input type="checkbox"/>	<input type="checkbox"/>
City/Town of residence	<input type="checkbox"/>	<input type="checkbox"/>
County of residence	<input type="checkbox"/>	<input type="checkbox"/>
State of residence	<input type="checkbox"/>	<input type="checkbox"/>
Zip code of residence	<input type="checkbox"/>	<input type="checkbox"/>

24. Do you collect information on length of residence at current address?

Yes                       No

25. If you collect street address information, do you geocode the address to determine:

<u>Unit</u>	<u>Yes</u>	<u>No</u>	
Census tract	<input type="checkbox"/>	<input type="checkbox"/>	
Census block	<input type="checkbox"/>	<input type="checkbox"/>	
Other	<input type="checkbox"/>	<input type="checkbox"/>	If "Yes", please list:



**APPENDIX B**

26. For the conditions monitored by this database, are you aware of any other relevant sociodemographic variables that could link race and ethnicity to health outcomes?

Yes                       No [Go to Q. 27]

26a. If “Yes”, please list variables:

26b. Do you or others analyzing this database routinely use any of the variables identified in Q26a. to help explain differences in health outcomes by race and/or ethnicity?

Yes                       No



If “Yes”, please list variables used:

27. Completeness of race/ethnicity and related sociodemographic information is a common problem in many health databases. What is your best estimate of the completeness of the following information in your database? Use the following rating system:

Not applicable (not a database variable).....	<b>9</b>
80 to 100% complete.....	<b>5</b>
61 to 80% complete.....	<b>4</b>
41 to 60% complete.....	<b>3</b>
21 to 40% complete.....	<b>2</b>
0 to 20% complete.....	<b>1</b>

Variable

**Completeness**

- Race
- Hispanic ethnicity
- Health insurance status
- Medicaid status
- Medicare status
- Educational attainment
- Employment status
- Occupation
- Personal income
- Household income
- Number of persons in household
- Marital/Partner status
- Country of birth
- Immigration status
- Language spoken at home
- Street address
- Town
- County
- State
- Zip code

## **APPENDIX B**

28. Information from this survey will be used to help develop policy recommendations for the collection of race, ethnicity, and related sociodemographic information in DPH databases. Please describe what, if any, barriers there might be to changing the race and ethnicity or other sociodemographic fields currently collected in your database, and/or implementing recommended changes:
29. Additional comments (optional):
30. If possible, please forward a copy of your database intake form to:  
Ava Nepaul, Health Information Systems and Reporting Section, 410 Capitol Avenue,  
MS #11PSI or e-mail [ava.nepaul@po.state.ct.us](mailto:ava.nepaul@po.state.ct.us).
31. Date survey completed (M/D/YYYY):

## APPENDIX C

### The Connecticut Health Disparities Project Health Database Questionnaire Age & Gender Supplement

**Instructions:** Please fill in all blank fields. Please contact Ava Nepaul at ext. 8239 should you have any questions or comments.

1. Name of the database:
2. Name of person completing this survey supplement:
3. Does this database include information on age?  Yes  No [Go to Q4.]

3a. If Yes, which categories are used to collect this information?

Category	Yes	No	Comment
Fill in the blank age in years	<input type="checkbox"/>	<input type="checkbox"/>	
Fill in the blank age in months	<input type="checkbox"/>	<input type="checkbox"/>	
Fill in the blank age in weeks	<input type="checkbox"/>	<input type="checkbox"/>	
Fill in the blank age in days	<input type="checkbox"/>	<input type="checkbox"/>	
Select an age group	<input type="checkbox"/>	<input type="checkbox"/>	Specify ranges:
Unknown	<input type="checkbox"/>	<input type="checkbox"/>	
Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	Specify:

Is this age data self-reported and/or observer-reported?

3b. Self-reported  Yes  No  Unknown

3c. Observer-reported  Yes  No  Unknown



If “Yes”, please specify by whom:

3d. Comment (optional)

4. Does your database include information on gender?

Yes  No [Go to Q6.]

If Yes, which categories are used?

Category	Yes	No	Comment
Fill in the blank	<input type="checkbox"/>	<input type="checkbox"/>	
Female	<input type="checkbox"/>	<input type="checkbox"/>	
Male	<input type="checkbox"/>	<input type="checkbox"/>	
Intersex	<input type="checkbox"/>	<input type="checkbox"/>	
Transgender	<input type="checkbox"/>	<input type="checkbox"/>	
Transsexual	<input type="checkbox"/>	<input type="checkbox"/>	
Unknown	<input type="checkbox"/>	<input type="checkbox"/>	
Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	Specify:

## APPENDIX C

Is this gender data self-reported and/or observer-reported?

4b. Self-reported       Yes     No     Unknown

4c. Observer-reported     Yes     No     Unknown



If “Yes”, please specify by whom:

4d. Comment (optional)

5. On the data collection form, which term is used?

Sex                     Gender                     Other, please specify:

6. Additional comments:

7. Date survey supplement completed: (M/D/YYYY):

**APPENDIX D**  
**Detailed Survey Results**

**Table D.1. Reported Race Data Collection Categories (n=37)**

<b>Corresponding 1997 OMB Race Category*</b>	<b>Category</b>	<b>No.</b>	<b>%</b>
American Indian or Alaska Native (AIAN)	Alaskan/Native American	1	2.7
	American Indian	10	27
	American Indian or Alaska Native	18	49
	American Indian or Alaska Native, list name of principal or enrolled tribe	2	5.4
	American Indian/Alaskan Native	3	8.1
	American Indian/Eskimo/Aluet	1	2.7
	None	2	5.4
Asian	As. Indian; Other Asian; multiple nationalities	1	2.7
	Asian	20	54
	Asian Indian; Chinese; Filipino; Japanese; Korean; Vietnamese; Other As.	1	2.7
	Asian Indian; Chinese; Filipino; Japanese; Korean; Vietnamese; Other As. (specify, free text)	2	5.4
	Asian/Pacific Islander	8	22
	Chinese, Filipino, Japanese, Other Asian (specify, free text)	1	2.7
	Multiple nationality list includes Asian, NOS & Oriental, NOS	1	2.7
	Oriental/Asian	1	2.7
	None	2	5.4
Black or African American (BAA)	African Am not Hispanic	1	2.7
	Black	20	54.1
	Black, non-Hispanic	1	2.7
	Black/African American	15	40.5
Native Hawaiian or Other Pacific Islander (NHOPI)	Asian/Pacific Islander	8	22
	Hawaiian	1	2.7
	Hawaiian/Pacific Islander	2	5.4
	Native Hawaiian or Other Pacific Islander	11	30
	Native Hawaiian; Guamanian or Chamorro; Samoan; Other PI (specify, free text)	2	5.4
	Native Hawaiian; Other Pacific islander; Other Micronesian; multiple nationalities	1	2.7
	Other Pacific Islander	1	2.7
	Pacific Islander	1	2.7
	Pacific Islander and SEER categories	1	2.7
	None	9	24.3
White	White	35	94.6
	White, non-Hispanic	1	2.7
	White, not of Hispanic origin	1	2.7
None	Hispanic	2	5.4

\* See question #12 of the *Health Database Questionnaire*. The information presented here does not imply that the reported categories are equivalent to the categories outlined in the 1997 OMB standards.

# APPENDIX E

## Laboratory Report of Significant Findings (OL-15C)

<b>Laboratory Report of Significant Findings</b> Diseases Relating to Public Health - Form OL-15C <small>For information or to order forms call: (860) 509-7994 rev. 1/2006</small>		<b>Connecticut Department of Public Health</b> 410 Capitol Avenue, MS #11FDS P.O. Box 340308 Hartford, CT 06134-0308				
Patient Last Name: _____ First: _____ D.O.B. ____/____/____ Age: ____ Street Address: _____ City: _____ State/Zip Code: _____ Patient Telephone: ( ) _____ Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Hispanic: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown Race: <input type="checkbox"/> White <input type="checkbox"/> Black <input type="checkbox"/> Asian/Pacific Islander <input type="checkbox"/> American Ind./Alaska Native <input type="checkbox"/> Other <input type="checkbox"/> Unknown Occupation: _____ Name and address of workplace: _____ Attending Physician Last Name: _____ First: _____ Address: _____ Telephone: ( ) _____						
Person Reporting: _____ Lab Telephone: _____ Submitting Laboratory: (name/address or label) _____		Specimen collection date: ____/____/____ Date laboratory finding reported to physician: ____/____/____ Date OL-15C completed: ____/____/____ Hospital Chart No: _____ Lab No: _____ Source/Type specimen: _____ Submitted to state lab: (see reverse) <input type="checkbox"/> Yes <input type="checkbox"/> No				
<table style="width: 100%; border: none;"> <tr> <td style="width: 50%; border: none; vertical-align: top;"> <ul style="list-style-type: none"> <li><input type="checkbox"/> AIDS (report only to the State)</li> <li><input type="checkbox"/> CD4+ T-lymphocyte counts &lt; 200 cells/<math>\mu</math>L _____ cells/<math>\mu</math>L</li> <li><input type="checkbox"/> CD4+ count &lt; 14% of total lymphocytes _____ %</li> <li><input type="checkbox"/> Babesiosis <input type="checkbox"/> IFA <input type="checkbox"/> IgM (titer) _____ IgG (titer) _____</li> <li><input type="checkbox"/> Blood smear<sup>1</sup> <input type="checkbox"/> PCR <input type="checkbox"/> Other _____</li> <li><input type="checkbox"/> Carboxyhemoglobin <math>\geq</math> 9% _____ % COHb</li> <li><input type="checkbox"/> Chancroid _____</li> <li><input type="checkbox"/> Chickenpox, acute <input type="checkbox"/> IgM <input type="checkbox"/> Culture</li> <li><input type="checkbox"/> PCR <input type="checkbox"/> DFA <input 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anti-HD</li> <li><input type="checkbox"/> HIV infection (report only to the State)<sup>5,6</sup></li> <li><input type="checkbox"/> HIV infection in persons of all ages<sup>5</sup></li> <li><input type="checkbox"/> Influenza <input type="checkbox"/> Culture <input type="checkbox"/> Type A <input type="checkbox"/> Type B <input type="checkbox"/> Type Unk.</li> <li><input type="checkbox"/> Rapid test <input type="checkbox"/> Type A <input type="checkbox"/> Type B <input type="checkbox"/> Type Unk.</li> <li><input type="checkbox"/> RT-PCR <input type="checkbox"/> Type A <input type="checkbox"/> Type B <input type="checkbox"/> Type Unk.</li> <li><input type="checkbox"/> Lead poisoning (blood lead <math>\geq</math> 10 <math>\mu</math>g/dL)</li> <li><input type="checkbox"/> Finger stick lead level _____ <math>\mu</math>g/dL</li> <li><input type="checkbox"/> Venous lead level _____ <math>\mu</math>g/dL</li> <li><input type="checkbox"/> Legionellosis</li> <li><input type="checkbox"/> Culture 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serologic change (titers) _____</li> <li><input type="checkbox"/> Lymphocytic choriomeningitis virus infection</li> <li><input type="checkbox"/> Malaria/blood parasites<sup>1,2</sup> _____</li> <li><input type="checkbox"/> Measles (Rubeola) (titer)<sup>7</sup> _____</li> <li><input type="checkbox"/> Meningococcal disease, invasive<sup>1,3</sup></li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Mercury poisoning</li> <li><input type="checkbox"/> Urine <math>\geq</math> 35 <math>\mu</math>g/g creatinine _____ <math>\mu</math>g/g</li> <li><input type="checkbox"/> Blood <math>\geq</math> 15 <math>\mu</math>g/L _____ <math>\mu</math>g/L</li> <li><input type="checkbox"/> Mumps (titer) _____</li> <li><input type="checkbox"/> Neonatal bacterial sepsis<sup>9</sup> spp _____</li> <li><input type="checkbox"/> Pertussis (titer)</li> <li>DFA Smear <input type="checkbox"/> Positive <input type="checkbox"/> Negative</li> <li>Culture <input type="checkbox"/> Positive <input type="checkbox"/> Negative</li> <li><input type="checkbox"/> Pneumococcal disease, invasive<sup>1,3</sup></li> <li>Oxacillin disk zone size _____ mm</li> <li>MIC to penicillin _____ <math>\mu</math>g/mL</li> <li><input type="checkbox"/> Poliomyelitis _____</li> <li><input type="checkbox"/> Rabies _____</li> <li><input type="checkbox"/> Rocky Mountain spotted fever</li> <li><input type="checkbox"/> Rubella (titer) _____</li> <li><input type="checkbox"/> SARS-CoV infection<sup>10</sup> <input type="checkbox"/> IgM/IgG</li> <li><input type="checkbox"/> PCR _____ (specimen) <input type="checkbox"/> Other _____</li> <li><input type="checkbox"/> <i>Staphylococcus aureus</i> infection with MIC to vancomycin <math>\geq</math> 4 <math>\mu</math>g/mL<sup>1</sup></li> <li>MIC to vancomycin _____ <math>\mu</math>g/mL</li> <li><input type="checkbox"/> <i>Staphylococcus aureus</i> disease, invasive<sup>3</sup></li> <li>methicillin-resistant Date pt. admitted ____/____/____</li> <li><input type="checkbox"/> <i>Staphylococcus epidermidis</i> infection with MIC to vancomycin <math>\geq</math> 4 <math>\mu</math>g/mL<sup>1</sup></li> <li>MIC to vancomycin _____ <math>\mu</math>g/mL</li> <li><input type="checkbox"/> Syphilis</li> <li><input type="checkbox"/> RPR (titer) _____ <input type="checkbox"/> FTA _____</li> <li><input type="checkbox"/> VDRL (titer) _____ <input type="checkbox"/> MHA _____</li> <li><input type="checkbox"/> Trichinosis _____</li> <li><input type="checkbox"/> Tuberculosis<sup>1</sup></li> <li>Specimen type _____</li> <li>AFB Smear <input type="checkbox"/> Positive <input type="checkbox"/> Negative</li> <li>If positive <input type="checkbox"/> Rare <input type="checkbox"/> Few <input type="checkbox"/> Numerous</li> <li>Culture <input type="checkbox"/> <i>Mycobacterium tuberculosis</i> only</li> <li><input type="checkbox"/> Other mycobacterium (specify M.) _____</li> <li><input type="checkbox"/> Typhus _____</li> <li><input type="checkbox"/> Yellow Fever _____</li> </ul>					
<p style="text-align: center;"><b>SPECIFIC DISEASES RELATING TO FOODBORNE ILLNESS ACTIVE SURVEILLANCE NETWORK (FoodNet)</b></p> <table style="width: 100%; border: none;"> <tr> <td style="width: 50%; border: none; vertical-align: top;"> <ul style="list-style-type: none"> <li><input type="checkbox"/> Campylobacteriosis (species) _____</li> <li><input type="checkbox"/> Cryptosporidiosis (method of ID) _____</li> <li><input type="checkbox"/> Cyclosporiasis (method of ID) _____</li> <li><input type="checkbox"/> <i>Escherichia coli</i> O157 infection<sup>1</sup></li> <li><input type="checkbox"/> Listeriosis<sup>1</sup></li> </ul> </td> <td style="width: 50%; border: none; vertical-align: top;"> <ul style="list-style-type: none"> <li><input type="checkbox"/> Salmonellosis<sup>1,2</sup> (serogroup/serotype) _____</li> <li><input type="checkbox"/> Shiga-toxin related disease<sup>1</sup></li> <li><input type="checkbox"/> Shigellosis<sup>1,2</sup> (serogroup/species) _____</li> <li><input type="checkbox"/> <i>Vibrio</i> infection<sup>1</sup> (species) _____</li> <li><input type="checkbox"/> Yersiniosis (species) _____</li> </ul> </td> </tr> </table>				<ul style="list-style-type: none"> <li><input type="checkbox"/> Campylobacteriosis (species) _____</li> <li><input type="checkbox"/> Cryptosporidiosis (method of ID) _____</li> <li><input type="checkbox"/> Cyclosporiasis (method of ID) _____</li> <li><input type="checkbox"/> <i>Escherichia coli</i> O157 infection<sup>1</sup></li> <li><input type="checkbox"/> Listeriosis<sup>1</sup></li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Salmonellosis<sup>1,2</sup> (serogroup/serotype) _____</li> <li><input type="checkbox"/> Shiga-toxin related disease<sup>1</sup></li> <li><input type="checkbox"/> Shigellosis<sup>1,2</sup> (serogroup/species) _____</li> <li><input type="checkbox"/> <i>Vibrio</i> infection<sup>1</sup> (species) _____</li> <li><input type="checkbox"/> Yersiniosis (species) _____</li> </ul>	
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Patient status when specimen collected: <input type="checkbox"/> Hospitalized <input type="checkbox"/> Outpatient <input type="checkbox"/> Unk. If hospitalized, Hospital Name: _____ Date Admitted: ____/____/____ If outpatient, was patient later hospitalized? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unk. Date Discharged: ____/____/____						
<table style="width: 100%; border: none;"> <tr> <td style="width: 33%; border: none; vertical-align: top;"> <ol style="list-style-type: none"> <li>1. Send isolate, culture, or slide to the State Laboratory for confirmation. For Shiga-toxin, send broth culture from which positive Shiga-toxin test was made. For HIV and hepatitis A, send <math>\geq</math> 0.5 mL residual serum to the State Laboratory.</li> <li>2. Specify species/serogroup.</li> <li>3. Sterile site isolates. Sterile site defined as blood, CSF, pericardial fluid, pleural fluid, peritoneal fluid, joint fluid, bone, internal body site (lymph node, brain, heart, liver, spleen, kidney, pancreas, or ovary), vitreous fluid, or other normally sterile site; includes muscle for invasive group A streptococcal disease.</li> </ol> </td> <td style="width: 33%; border: none; vertical-align: top;"> <ol style="list-style-type: none"> <li>4. Report all positive anti-HCV with signal to cutoff ratio, all positive RIBA, but only confirmatory PCR tests.</li> <li>5. Report any tests indicative of HIV infection including antibody, antigen, PCR-based and viral load tests with name and street address.</li> <li>6. Report all HIV viral load test results, including those with no virus detectable, with name and street address.</li> <li>7. Report all IgM titers, but only IgG titers that are considered significant by the laboratory performing the test.</li> </ol> </td> <td style="width: 33%; border: none; vertical-align: top;"> <ol style="list-style-type: none"> <li>8. Report by telephone to the Department of Public Health, weekdays 860-509-7994; weekends and evenings 860-509-8000.</li> <li>9. Report all bacterial isolates from blood or CSF obtained from an infant &lt;7 days old.</li> <li>10. Send residual serum, sputum, stool or other specimen testing positive for SARS-CoV to the State Laboratory for confirmation.</li> <li>11. Send all <i>Vibrio</i> isolates to the State Laboratory for confirmation.</li> </ol> </td> </tr> </table>				<ol style="list-style-type: none"> <li>1. Send isolate, culture, or slide to the State Laboratory for confirmation. For Shiga-toxin, send broth culture from which positive Shiga-toxin test was made. For HIV and hepatitis A, send <math>\geq</math> 0.5 mL residual serum to the State Laboratory.</li> <li>2. Specify species/serogroup.</li> <li>3. Sterile site isolates. Sterile site defined as blood, CSF, pericardial fluid, pleural fluid, peritoneal fluid, joint fluid, bone, internal body site (lymph node, brain, heart, liver, spleen, kidney, pancreas, or ovary), vitreous fluid, or other normally sterile site; includes muscle for invasive group A streptococcal disease.</li> </ol>	<ol style="list-style-type: none"> <li>4. Report all positive anti-HCV with signal to cutoff ratio, all positive RIBA, but only confirmatory PCR tests.</li> <li>5. Report any tests indicative of HIV infection including antibody, antigen, PCR-based and viral load tests with name and street address.</li> <li>6. Report all HIV viral load test results, including those with no virus detectable, with name and street address.</li> <li>7. Report all IgM titers, but only IgG titers that are considered significant by the laboratory performing the test.</li> </ol>	<ol style="list-style-type: none"> <li>8. Report by telephone to the Department of Public Health, weekdays 860-509-7994; weekends and evenings 860-509-8000.</li> <li>9. Report all bacterial isolates from blood or CSF obtained from an infant &lt;7 days old.</li> <li>10. Send residual serum, sputum, stool or other specimen testing positive for SARS-CoV to the State Laboratory for confirmation.</li> <li>11. Send all <i>Vibrio</i> isolates to the State Laboratory for confirmation.</li> </ol>
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# APPENDIX F

## Reportable Disease Confidential Case Report Form (PD-23)

State of Connecticut

Reportable Disease Confidential Case Report Form PD-23

(rev 1/2006)

Department of Public Health  
410 Capitol Avenue, MS#11FDS  
P.O. Box 340308  
Hartford, CT 06134-0308

YEAR

NOTE: Check this box to request additional forms, or call the information number below.

For information or weekday disease reporting, call (860) 509-7994. For reporting on evenings, weekends, and holidays, call (860) 509-3000.

Patient Name (Last)		(First)		(MI)	Age	Birth Date		Patient's Telephone	
Address (No. and Street)		(City or Town)			(State)		(Zip Code)		
Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Unknown	Race: <input type="checkbox"/> American Indian/Alaskan Native <input type="checkbox"/> Asian/Pacific Islander <input type="checkbox"/> Black <input type="checkbox"/> Other <input type="checkbox"/> Unknown	Hispanic: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Is patient pregnant? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		Did patient die of this illness? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown			
Name and address of workplace, school or day care					Is patient a: (please check) <input type="checkbox"/> Health care worker <input type="checkbox"/> Student/Day care attendee <input type="checkbox"/> Day care worker <input type="checkbox"/> Food handler				
Disease Name		Onset Date		Diagnosis Date		Symptoms: <input type="checkbox"/> Jaundice <input type="checkbox"/> Flu-like <input type="checkbox"/> Discrete Onset <input type="checkbox"/> Fatigue			
Is this condition work related? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown						ALTs: <input type="checkbox"/> >7 times UL normal <input type="checkbox"/> AST:			
If yes, occupation: _____						IgM anti-HAV: <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not Done			
Confirmatory laboratory data, immunization status, dates and comments (be specific):						HbSAg: <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not Done			
						IgM anti-HBc: <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not Done			
						Anti-HCV: <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not Done			
						HCV confirmed by: <input type="checkbox"/> signal to cut off >3.8 <input type="checkbox"/> RISA <input type="checkbox"/> PCR			
						Chronic Carrier: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown			
						Pregnant sexual partner: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown			
Physician's name and address: _____ Telephone: (____) _____						Risk Factors: <input type="checkbox"/> IDU ( <input type="checkbox"/> present <input type="checkbox"/> past) <input type="checkbox"/> Blood Transfusion < July 1992 <input type="checkbox"/> Hemodialysis			
						<input type="checkbox"/> Multiple sex partners <input type="checkbox"/> Perinatal (infected mom to baby)			
						<input type="checkbox"/> Contact w/ infected person ( <input type="checkbox"/> household <input type="checkbox"/> sexual)			
						<input type="checkbox"/> Incarcerated ( <input type="checkbox"/> present <input type="checkbox"/> past) <input type="checkbox"/> MSM (men who has sex with men)			
						Vaccine: Completed hepatitis A vaccine series <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown			
						Completed hepatitis B vaccine series <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown			
If hospitalized, hospital:		For Local Health Department Use				Lyme Disease			
Name		Will follow-up be conducted?				Erythema migrans Physician diagnosed EM $\geq$ 50mm (-2 in): <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown Lesion: <input type="checkbox"/> Single <input type="checkbox"/> Multiple			
City		<input type="checkbox"/> Yes <input type="checkbox"/> No				Rheumatologic Arthritis (objective joint swelling): <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown			
State						Neurologic Bell's palsy or other cranial neuritis: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown			
Date Admitted		Case status:				Radiculoneuropathy: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown			
Date Discharged		1 <input type="checkbox"/> Confirmed				Lymphocytic Meningitis: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown			
Patient ID #		2 <input type="checkbox"/> Probable				Encephalitis/Encephalomyelitis: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown			
		3 <input type="checkbox"/> Suspect				Antibody to B. burgdorferi higher in CSF than serum: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown			
		4 <input type="checkbox"/> Unknown				Cardiologic 2nd or 3rd degree AV block: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown			
						Lyme disease laboratory results:			
						Eliisa (EIA) <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Equivocal <input type="checkbox"/> Not Done			
						IFA <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Equivocal <input type="checkbox"/> Not Done			
						Western Blot <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Equivocal <input type="checkbox"/> Not Done			

(Please print)

Name of person completing report: \_\_\_\_\_  
Address: \_\_\_\_\_  
Telephone: (\_\_\_\_) \_\_\_\_\_ Report Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

## APPENDIX G

### Surveyed Databases in the Office of the Deputy Commissioner

#### BCC

#### Connecticut Breast and Cervical Cancer Early Detection Program Database

<i>HP 2010 Focus Area</i>	Cancer
<i>Brief Description</i>	Surveillance data on unserved or underserved women who received a screening mammogram, clinical breast exam, Pap test, or any combination of these three screening exams through a program funded by the CDC and the DPH. The Breast and Cervical Cancer Early Detection and Treatment Referral Program is required by state statute.
<i>DPH Branch</i>	Office of the Deputy Commissioner
<i>DPH Section</i>	Comprehensive Cancer/Multicultural Health
<i>Records Accumulated Annually</i>	9,000
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	Connecticut Breast and Cervical Cancer Early Detection Program Enrollment Form
<i>Data Types Collected</i>	
Report of race/ethnicity	Self
Ethnicity	Hispanic Yes, No, or Don't Know
Race <sup>i</sup>	(Mark one or more responses) American Indian or Alaskan Native Asian Black or African American Native Hawaiian or Pacific Islander White
Age	Fill in the blank (years) Date of birth
Gender	None (only females)
Socioeconomic position and related characteristics	Education Employment status Personal income Household size
Acculturation and language	None
Geography of residence	Street address City/Town State Zip code
Other relevant sociodemographic information	Health insurance status Medicaid Medicare



## APPENDIX G

### Surveyed Databases in the Office of the Deputy Commissioner

<b>WISE</b>	
<b>Well-Integrated Screening and Evaluation for Women Across the Nation</b>	
<i>HP 2010 Focus Areas</i>	Diabetes Heart disease and stroke
<i>Brief Description</i>	Surveillance data on women enrolled in the Connecticut Breast and Cervical Cancer Early Detection Program (see BCC) who are provided services through WISEWOMAN. Services include blood pressure, cholesterol, and diabetes screening.
<i>DPH Branch</i>	Office of the Deputy Commissioner
<i>DPH Section</i>	Multicultural Health/Comprehensive Cancer
<i>Records Accumulated Annually</i>	850
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	Connecticut Breast and Cervical Cancer Early Detection Program Enrollment Form
<i>Data Types Collected</i>	
Report of race/ethnicity	Self
Ethnicity	Hispanic Yes, No, or Don't Know
Race <sup>ii</sup>	(Mark one or more responses) American Indian or Alaskan Native Asian Black or African American Native Hawaiian or Pacific Islander White
Age	Fill in the blank (years) Date of birth
Gender	None (only females)
Socioeconomic position and related characteristics	Education Employment status Personal income Household size
Socioeconomic position and related characteristics	Education Employment status Personal income Household size
Acculturation and language	None
Geography of residence	Street address City/Town State Zip code
Other relevant sociodemographic information	Health insurance status Medicaid Medicare

## **APPENDIX G**

### **Surveyed Databases in the Office of the Deputy Commissioner**

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<sup>i</sup> The Connecticut Breast and Cervical Cancer Early Detection Program Database records the following race categories: American Indian or Alaskan Native; Asian; Black or African American; Native Hawaiian or Pacific Islander; White; and Unknown.

<sup>ii</sup> The WISEWOMAN Database records the following race categories: American Indian or Alaskan Native; Asian; Black or African American; Native Hawaiian or Pacific Islander; White; and Unknown.

## APPENDIX H

### Surveyed Databases in the Planning Branch

<b>BIRTH</b>	
<b>Birth Registry</b>	
<i>HP 2010 Focus Area Focus Area*</i>	Maternal, infant, and child health Vital statistics
<i>Brief Description</i>	Live births in Connecticut. Hospitals or towns transmit birth, legal, and/or medical information to the DPH. These data are entered into the Electronic Vital Records System (EVRS). Reporting required by state statutes. Summary reports sent to the National Center for Health Statistics (NCHS).
<i>DPH Branch</i>	Planning
<i>DPH Section</i>	Health Information Systems and Reporting
<i>Records Accumulated Annually</i>	42,000
<i>Race and Ethnicity Data Collection Policy</i>	Vital Records Vision 2000 (VRV2000) guidelines
<i>Data Collection Form</i>	State of Connecticut Department of Public Health Birth Certificate Worksheet
<i>Data Types Collected</i>	
Report of race/ethnicity	Self
Ethnicity	Hispanic origin Specify type of Hispanic origin: Cuban, Mexican, Puerto Rican, or Other (specify)
Race <sup>i</sup>	American Indian Black White Other (specify)
Age	Date of birth
Gender	Female Male Unknown
Socioeconomic position and related characteristics	Education Occupation
Acculturation and language	Country of birth
Geography of residence	City/Town County State Zip code
Other relevant sociodemographic information	Health insurance status Marital/Partner status Length of residence at current address

\* Not an *HP 2010* focus area.

## APPENDIX H

### Surveyed Databases in the Planning Branch

<b>BRFSS</b>	
<b>Behavioral Risk Factor Surveillance Survey</b>	
<i>Focus Area*</i>	Survey research
<i>Brief Description</i>	Voluntary responses to ongoing telephone survey of adults coordinated by the CDC and conducted nationwide. Data is used to determine the prevalence of major behavioral risks that are associated with premature morbidity and mortality, identify emerging health issues, and document health trends including health screening practices. No legal mandate.
<i>DPH Branch</i>	Planning
<i>DPH Section</i>	Health Information Systems and Reporting
<i>Records Accumulated Annually</i>	5,000
<i>Race and Ethnicity Data Collection Policy</i>	CDC survey-specific data collection rules published in <i>2005 BRFSS Calculated Variables and Risk Factors</i>
<i>Data Collection Form</i>	2006 BRFSS Questionnaire
<i>Data Types Collected</i>	
Report of race/ethnicity	Self
Ethnicity	Hispanic or Latino Yes, No, Don't know/Not sure, or Refused
Race <sup>ii</sup>	(Check all that apply) American Indian or Alaska Native Asian Black or African American Native Hawaiian or Other Pacific Islander White Other (specify, free text)
Age	Fill in the blank (years)
Gender	Female Male
Socioeconomic position and related characteristics	Education Employment status Household income Household size
Acculturation and language	None
Geography of residence	City/Town County State Zip code
Other relevant sociodemographic information	Health insurance status Marital/Partner status

\* Not an *HP 2010* focus area.

## APPENDIX H

### Surveyed Databases in the Planning Branch

<b>CTR</b>	
<b>Connecticut Tumor Registry</b>	
<i>HP 2010 Focus Area</i>	Cancer
<i>Brief Description</i>	Reportable tumors in Connecticut residents. State mandated activity. Data reported annually to the National Cancer Institute (NCI) Surveillance Epidemiology and End Results (SEER) program
<i>DPH Branch</i>	Planning
<i>DPH Section</i>	Tumor Registry
<i>Records Accumulated Annually</i>	21,000
<i>Race and Ethnicity Data Collection Policy</i>	SEER Program data rules and coding specifications and North American Association of Central Cancer Registries (NAACCR) guidelines
<i>Data Collection Form</i>	None submitted; Chart abstraction
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Observer
Ethnicity	Spanish, Hispanic, and Latino Cuban, Mexican, Puerto Rican, and South or Central American (except Brazil) Non-Spanish/Non-Hispanic Other, specified Spanish/Hispanic Origin Spanish surname matching; Unknown
Race <sup>iii</sup>	American Indian/Alaska Native [Asian] Asian Indian, Pakistani, Chinese, Hmong, Japanese, Kampuchean, Korean, Laotian, Thai, Vietnamese, and Other Asian including Asian not otherwise specified (NOS) and Oriental NOS Black or African American [Native Hawaiian/Other Pacific Islander] Chamorran, Fiji Islander, Filipino, Guamanian NOS, Hawaiian, Melanesian NOS, Micronesian NOS, New Guinean, Pacific Islander, Polynesian NOS, Samoan, Tahitian, and Tongan White Other Unknown
Age	Date of birth; Fill in the blank (years)
Gender	Female Male Intersex Transsexual Unknown
Socioeconomic position and related characteristics	Occupation
Acculturation and language	Country of birth
Geography of residence	City/Town; Street address; State; County; Country
Other relevant sociodemographic information	Marital/Partner status

## APPENDIX H

### Surveyed Databases in the Planning Branch

<b>FMORT</b>	
<b>Fetal Deaths Database</b>	
<i>HP 2010 Focus Area</i>	Maternal, infant, and child health
<i>Brief Description</i>	Activity mandated by state statute. Fetal death, defined as no respiration, heart action, pulsation of umbilical cord, or movement of voluntary muscle before extraction or expulsion from the womb, which occurs 20 or more weeks after gestation. Hospitals report information to the DPH. Data are entered into the Electronic Vital Records System (EVRS). Summary reports sent semi-annually to the National Center for Health Statistics (NCHS).
<i>DPH Branch</i>	Planning
<i>DPH Section</i>	Health Information Systems and Reporting
<i>Records Accumulated Annually</i>	275
<i>Race and Ethnicity Data Collection Policy</i>	Vital Records Vision 2000 (VRV2000) guidelines
<i>Data Collection Form</i>	None submitted
<i>Data Types Collected</i>	
Report of race/ethnicity	Observer
Ethnicity	Hispanic and Non-Hispanic Hispanic origin, specify identity Cuban, Mexican, and Puerto Rican Hispanic origin, identity not stated Unknown Not reported Not classifiable
Race <sup>iv</sup>	American Indian [Asian] Chinese, Japanese, and Other Asian (specify, free text) Black or African American Hawaiian Filipino White Other races (specify, free text) Not reported
Age	Date of delivery
Gender	Female Male
Socioeconomic position and related characteristics	Education Occupation
Acculturation and language	Country of birth
Geography of residence	City/Town County State Zip code
Other relevant sociodemographic information	Marital/Partner status

## APPENDIX H

### Surveyed Databases in the Planning Branch

HDIS	
Hospital Discharge Abstract and Billing Database	
<i>Focus Area*</i>	Hospital discharge data
<i>Brief Description</i>	Persons discharged from non-Federal, short-term, acute care hospitals in Connecticut, excluding cases discharged from emergency departments. Data supplied by hospitals through the Connecticut Office of Health Care Access (CT OHCA). Legislatively mandated.
<i>DPH Branch</i>	Planning
<i>DPH Section</i>	Health Information Systems and Reporting
<i>Records Accumulated Annually</i>	400,000
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	None (data extract)
<i>Data Types Collected</i>	
Report of race/ethnicity	Observer
Ethnicity	Spanish /Hispanic origin Non-Spanish/Non-Hispanic origin Unknown
Race <sup>v</sup>	American Indian/Eskimo/Aleut Asian Black Hawaiian/Pacific Islander White Other Non-White
Age	Fill in the blank (years)
Gender	Female Male Unknown
Socioeconomic position and related characteristics	None
Acculturation and language	None
Geography of residence	City/Town State Zip code
Other relevant sociodemographic information	Health insurance status Medicaid Medicare

\* Not an *HP 2010* focus area.

## APPENDIX H

### Surveyed Databases in the Planning Branch

<b>LITP</b>	
<b>Legal Induced Termination of Pregnancy Database</b>	
<i>HP 2010 Focus Area</i>	Family planning
<i>Brief Description</i>	Occurrences of legal abortion in Connecticut. Required by state public health regulation.
<i>DPH Branch</i>	Planning
<i>DPH Section</i>	Health Information Systems and Reporting
<i>Records Accumulated Annually</i>	12,000
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	Report of Induced Termination of Pregnancy (Abortion) Performed in Connecticut
<i>Data Types Collected</i>	
Report of race/ethnicity	Observer
Ethnicity	Hispanic origin Yes, No, or Unknown Cuban, Mexican, Puerto Rican, or Other (specify)
Race <sup>vi</sup>	American Indian [Asian] Asian Indian, Chinese, Japanese, Korean, and Vietnamese [Native Hawaiian/Other Pacific Islander] Filipino and Other Pacific Islander Black White Other (specify)
Age	Fill in the blank (years) Select an age group Unknown
Gender	None (only females)
Socioeconomic position and related characteristics	Education
Acculturation and language	Language spoken at home
Geography of residence	State
Other relevant sociodemographic information	Marital/Partner status

\* Not an *HP 2010* focus area.



## APPENDIX H

### Surveyed Databases in the Planning Branch

<b>MORT</b>	
<b>Death Registry</b>	
<i>Focus Area*</i>	Vital statistics
<i>Brief Description</i>	Deaths in Connecticut residents as recorded on Connecticut Certificate of Death. Reporting required by state statutes. Summary reports sent to the National Center for Health Statistics (NCHS).
<i>DPH Branch</i>	Planning
<i>Records Accumulated Annually</i>	29,500
<i>Race and Ethnicity Data Collection Policy</i>	Connecticut Death Certificate
<i>DPH Section</i>	Health Information Systems and Reporting
<i>Data Collection Form</i>	Connecticut Death Certificate
<i>Data Types Collected</i>	
Report of race/ethnicity	Observer
Ethnicity	Spanish/Hispanic/Latino Cuban Mexican, Mexican American, and Chicano Puerto Rican Not Spanish/Hispanic/Latino Other Spanish/Hispanic/Latino, specify (free text)
Race <sup>vii</sup>	American Indian or Alaska Native, Name of the enrolled or principal tribe [Asian] Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, and Other Asian (specify, free text) Black or African American [Native Hawaiian/Other Pacific Islander] Native Hawaiian, Guamanian or Chamorro, Samoan, and Other Pacific Islander (specify, free text) White Other (specify, free text) Not reported/Not indicated
Age	Fill in the blank (years, months, days) Date of birth Date of death Unknown
Gender	Female Male
Socioeconomic position and related characteristics	Education Occupation
Acculturation and language	Country of birth
Geography of residence	City/Town County State Zip code
Other relevant sociodemographic information	Marital/Partner status

\* Not an *HP 2010* focus area.

## APPENDIX H

### Surveyed Databases in the Planning Branch

<b>YRBS</b>	
<b>Connecticut School Health Survey - Youth Behavior Component</b>	
<i>Focus Area*</i>	Survey research
<i>Brief Description</i>	Responses of a random sample of Connecticut high school students to the Youth Risk Behavioral Survey. Conducted nationwide on an annual basis, the YRBS informs the CDC Youth Risk Behavior Surveillance System. The system monitors priority health risk behaviors that contribute markedly to the leading causes of death, disability, and social problems among youth and adults in the United States. Partially funded by the CDC. No legal mandate.
<i>DPH Branch</i>	Planning
<i>DPH Section</i>	Health Information Systems and Reporting
<i>Records Accumulated Annually</i>	2,250
<i>Race and Ethnicity Data Collection Policy</i>	CDC survey-specific data collection rules
<i>Data Collection Form</i>	Student Questionnaire: Connecticut School Health Survey, Youth Behavior Component
<i>Data Types Collected</i>	
Report of race/ethnicity	Self
Ethnicity	Hispanic or Latino Yes or No
Race <sup>viii</sup>	(select one or more responses) American Indian or Alaska Native Asian Black or African American Native Hawaiian or Other Pacific Islander White
Age	Fill in the blank (age in years)
Gender	Female Male
Socioeconomic position and related characteristics	Education Employment status
Acculturation and language	None
Geography of residence	State
Other relevant sociodemographic information	None

\* Not an *HP 2010* focus area.

<sup>i</sup> The Birth Registry Database records the following race categories: American Indian; Black or African American; Chinese; Filipino; Hawaiian; Japanese; Not reported; Other Asian; Other races; and White.

## **APPENDIX H**

### **Surveyed Databases in the Planning Branch**

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<sup>ii</sup> The Behavioral Risk Factor Surveillance Survey Database records the following race categories: American Indian or Alaska Native; Asian; Black or African American; Native Hawaiian or Other Pacific Islander; White; Other (free text); Don't know/Not sure; Missing; and Refused.

<sup>iii</sup> The Connecticut Tumor Registry Database records the race categories listed.

<sup>iv</sup> The Fetal Deaths Database records the race categories listed.

<sup>v</sup> The Hospital Discharge Abstract and Billing Database is a data extract that contains the ethnicity and race categories listed.

<sup>vi</sup> The categories of the data collection form match those recorded in the Legal Inducted Termination of Pregnancy Database.

<sup>vii</sup> The Death Registry Database records the race categories shown.

<sup>viii</sup> The Youth Behavior Component of the Connecticut School Health Survey records the following race categories: American Indian or Alaska Native; Asian; Black or African American; Native Hawaiian or Other Pacific Islander; White; Other; and Unknown.

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

<b>AIDA</b>	
<b>AIDS Institute Data Application</b>	
<i>Focus Area*</i>	HIV
<i>Brief Description</i>	Information is collected on individuals who receive HIV/AIDS prevention counseling, HIV testing, and care at publicly funded sites in Connecticut. AIDA data is extracted at each site from the Universal Reporting System (URS), an automated, confidential tracking system developed by Defran Systems, Inc. The required data are sent in aggregate form to the CDC.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	AIDS and Chronic Diseases
<i>Records Accumulated Annually</i>	50,000
<i>Race and Ethnicity Data Collection Policy</i>	CDC race and ethnicity categories
<i>Data Collection Form</i>	None (data extract)
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Observer
Ethnicity	Hispanic Cuban, Mexican, and Puerto Rican Non-Hispanic Unknown Other
Race <sup>i</sup>	American Indian/Alaska Native Asian Black or African American Native Hawaiian/Pacific Islander White Unknown/Unreported More than one race
Age	Date of birth
Gender	Female Male Transgender
Socioeconomic position and related characteristics	Education Employment status Household income Household size
Acculturation and language	Language spoken at home Country of birth
Geography of residence	None
Other relevant sociodemographic information	Health insurance status Medicaid Medicare Marital/Partner status

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

<b>ASTHMA</b>	
<b>Health Assessment Record - Asthma</b>	
<i>Focus Area*</i>	Respiratory diseases
<i>Brief Description</i>	Statewide system for school-based asthma surveillance based on the School Health Assessment Record (HAR). Contains information on Connecticut children entering school, in grades six or seven, and in grades ten or eleven. Reporting of physician diagnosis of asthma on the HAR is required by state statute.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Health Education, Management and Surveillance
<i>Records Accumulated Annually</i>	18,000
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	Asthma Reporting Form 2006-2007
<i>Data Types Collected</i>	
Report of race/ethnicity	Observer
Ethnicity	“Hispanic/Latino” is a race category
Race <sup>ii</sup>	American Indian Asian Black, non-Hispanic Hispanic/Latino White, non-Hispanic Other Not reported/Not indicated
Age	Fill in the blank (years) Unknown
Gender	Female Male Unknown
Socioeconomic position and related characteristics	None
Acculturation and language	None
Geography of residence	None
Other relevant sociodemographic information	None

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

<b>BDR</b>	
<b>Birth Defects Registry</b>	
<i>HP 2010 Focus Area</i>	Maternal, infant, and child health
<i>Brief Description</i>	Birth defects surveillance data. Data reported by birth hospitals as required by state statute. Demographic information is crosschecked with the Electronic Birth Certificate from the Electronic Vital Records System (EVRS). Component of the Child Health Profile.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Family Health
<i>Records Accumulated Annually</i>	1,750
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Forms</i>	Hospital Record form in electronic reporting system; See BIRTH; Birth Defect Registry Reporting Form
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Unknown if observer reports
Ethnicity	Hispanic origin* Specify type of Hispanic origin: Cuban, Mexican, Puerto Rican, or Other (specify)
Race <sup>iii</sup>	American Indian Asian Black Hispanic White Other
Age	Date of birth
Gender	Female Male Unknown
Socioeconomic position and related characteristics	Education Employment status Occupation
Acculturation and language	None
Geography of residence	Street address City/Town County State Zip code
Other relevant sociodemographic information	Health insurance status Marital/Partner status

\*Information on Hispanic origin is collected when “Hispanic” is selected as a race category.

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

<b>CIRTS</b>	
<b>Connecticut Immunization Registry and Tracking System</b>	
<i>HP 2010 Focus Area</i>	Immunization and infectious diseases
<i>Brief Description</i>	The repository of all childhood immunization events for children ages 0 to 6 years in the state. Reporting of immunization records to this registry is mandated by state statute.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Infectious Diseases
<i>Records Accumulated Annually</i>	43,000
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	None submitted
<i>Data Types Collected</i>	
Report of race/ethnicity	Self
Ethnicity	Hispanic is a race category
Race <sup>iv</sup>	American Indian Asian African American, not of Hispanic origin Hispanic Pacific Islander White, not of Hispanic origin Unknown Unsure Not specified
Age	Date of birth
Gender	Female Male Unknown
Socioeconomic position and related characteristics	Education
Acculturation and language	Country of birth
Geography of residence	Street address City/Town County State Zip code
Other relevant sociodemographic information	Medicaid Marital/Partner status

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

#### CODES

#### **Crash Outcome Data Evaluation System**

<i>HP 2010 Focus Area</i>	Injury and violence prevention
<i>Brief Description</i>	Links motor vehicle crash records from the Connecticut Department of Transportation (DOT) to health outcomes data using hospital discharge data, emergency department (ED) visit records, and CHIME data from the Connecticut Hospital Association. No legislative mandate.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Health Education, Management and Surveillance
<i>Records Accumulated Annually</i>	200,000
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	None (data extract)
<i>Data Types Collected</i>	
Report of race/ethnicity	Unknown if self and/or observer reports
Ethnicity	Spanish/Hispanic is a race category
Race <sup>v</sup>	Spanish/Hispanic American Indian Oriental/Asian Black Hawaiian/Pacific Islander White Other Race Other non-White Unknown
Age	Date of birth
Gender	Female Male Unknown
Socioeconomic position and related characteristics	None
Acculturation and language	None
Geography of residence	None
Other relevant sociodemographic information	None



## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

#### FSNED

#### **Food Stamp Nutrition Education Database**

<i>HP 2010 Focus Area</i>	Maternal, infant, and child health Nutrition and overweight
<i>Brief Description</i>	Aggregate data on children participating in state nutrition education programs at Head Start and School Readiness sites. Data only recorded on those participants whose parents/guardians have given written consent. These data inform program evaluation efforts.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Health Education, Management and Surveillance
<i>Records Accumulated Annually</i>	200
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	None submitted
<i>Data Types Collected</i>	
Report of race/ethnicity	Self
Ethnicity	Hispanic Non-Hispanic
Race <sup>vi</sup>	Asian/Pacific Islander Black/African American White Other
Age	Select an age group
Gender	Female Male
Socioeconomic position and related characteristics	None
Acculturation and language	None
Geography of residence	State
Other relevant sociodemographic information	None

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

<b>HARS</b>	
<b>HIV/AIDS Surveillance Database</b>	
<i>HP 2010 Focus Area</i>	HIV
<i>Brief Description</i>	HIV/AIDS cases reported by Connecticut providers. Case reports on all HIV and AIDS cases are forwarded to the CDC. Database supplied by the CDC. Mandated by state statute.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	HIV Surveillance/Hepatitis
<i>Records Accumulated Annually</i>	1,500
<i>Race and Ethnicity Data Collection Policy</i>	1997 OMB Revisions to Statistical Policy Directive No. 15
<i>Data Collection Forms</i>	Adult HIV/AIDS Confidential Case Report and OL-15C
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Observer
Ethnicity	Hispanic or Latino Not Hispanic or Latino Unknown
Race <sup>vii</sup>	American Indian/Alaskan Native Asian Black or African American Native Hawaiian or Other Pacific Islander White Other, specify Unknown
Age	Date of birth Date of death
Gender	Female Male Unknown
Socioeconomic position and related characteristics	None
Acculturation and language	Country of birth
Geography of residence	Street address City/Town County State Zip code
Other relevant sociodemographic information	Health insurance status Medicaid Medicare

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

<b>HEPB</b>	
<b>Hepatitis B Registry</b>	
<i>HP 2010 Focus Area</i>	Immunization and infectious diseases
<i>Brief Description</i>	Clinically and/or laboratory confirmed cases of hepatitis B infection. Additional clinical information collected from physicians since 2004. Follow-up information collected on all newly reported cases. Reporting mandated by state statute. Case reports sent to the CDC.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	HIV Surveillance/Hepatitis
<i>Records Accumulated Annually</i>	550
<i>Race and Ethnicity Data Collection Policy</i>	1997 OMB Revisions to Statistical Policy Directive No. 15
<i>Data Collection Forms</i>	OL-15C and Follow-up of Hepatitis B Laboratory Reports
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Observer
Ethnicity	Hispanic Yes, No, or Unknown
Race <sup>viii</sup>	American Indian/Alaska Native Asian/Pacific Islander Black White Other Unknown
Age	Fill in the blank (years)
Gender	Female Male Unknown
Socioeconomic position and related characteristics	None
Acculturation and language	Country of birth
Geography of residence	Street address City/Town County State Zip code
Other relevant sociodemographic information	None

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### Surveyed Databases in the Public Health Initiatives Branch

<b>HEPC</b>	
<b>Hepatitis C Registry</b>	
<i>HP 2010 Focus Area</i>	Immunization and infectious diseases
<i>Brief Description</i>	Clinically and/or laboratory confirmed cases of hepatitis C infection. Additional clinical information collected from physicians in New Haven County since 2005. Reporting mandated by state statute. Case reports sent to the CDC.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	HIV Surveillance/Hepatitis
<i>Records Accumulated Annually</i>	4,500
<i>Race and Ethnicity Data Collection Policy</i>	1997 OMB Revisions to Statistical Policy Directive No. 15
<i>Data Collection Forms</i>	OL-15C and Follow-up of Hepatitis C Laboratory Reports
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Observer
Ethnicity	Hispanic Yes, No, or Unknown
Race <sup>ix</sup>	American Indian/Alaska Native Asian/Pacific Islander Black White Other Unknown
Age	Fill in the blank (years) Unknown
Gender	Female Male Unknown
Socioeconomic position and related characteristics	None
Acculturation and language	None
Geography of residence	Street address City/Town County State Zip code
Other relevant sociodemographic information	None

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### Surveyed Databases in the Public Health Initiatives Branch

<b>IDD</b>	
<b>Reportable Infectious Diseases Database</b>	
<i>HP 2010 Focus Area</i>	Immunization and infectious diseases
<i>Brief Description</i>	Reports of confirmed cases of nationally notifiable infectious diseases in Connecticut residents. Disease reporting mandated by state statute. Case criteria defined by the Council of State and Territorial Epidemiologists (CSTE) and the CDC. Part of the Nationally Notifiable Diseases Surveillance System (NNDSS). National Electronic Telecommunications System for Surveillance (NETSS) software supplied by the CDC used to record cases and transmit reports to the CDC.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Infectious Diseases
<i>Records Accumulated Annually</i>	1,700
<i>Race and Ethnicity Data Collection Policy</i>	National Electronic Disease Surveillance System standard
<i>Data Collection Forms</i>	OL-15C and PD-23
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Observer
Ethnicity	Hispanic Yes, No, or Unknown
Race <sup>x</sup>	American Indian/Alaska Native Asian/Pacific Islander Black White Other, specify Unknown
Age	Fill in the blank (years, months, weeks, days) Date of birth Unknown
Gender	Fill in the blank Female Male Unknown
Socioeconomic position and related characteristics	None
Acculturation and language	None
Geography of residence	Street address City/Town County State Zip code
Other relevant sociodemographic information	None

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

#### METAB

#### **Metabolic Disorders - Newborn Tracking System**

<i>HP 2010 Focus Area</i>	Maternal, infant, and child health
<i>Brief Description</i>	Record of newborn infant health screening required by state law. Tests recorded include: hypothyroidism, galactosemia, sickle cell disease, maple syrup urine disease, homocystinuria, biotinidase deficiency, congenital adrenal hyperplasia, phenylketonuria (PKU) and other metabolic disorders. Data collected from birth hospitals via electronic reporting. Component of the Child Health Profile.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Family Health
<i>Records Accumulated Annually</i>	43,000
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Forms</i>	Hospital Record form in electronic reporting system; see BIRTH
<i>Data Types Collected</i>	
Report of race/ethnicity	Unknown if self and/or observer reports
Ethnicity	Hispanic origin* Cuban, Mexican, and Puerto Rican
Race <sup>xi</sup>	American Indian Asian Black Hispanic White Other
Age	Date of birth
Gender	Female Male Unspecified
Socioeconomic position and related characteristics	None
Acculturation and language	None
Geography of residence	Street address City/Town State Zip code
Other relevant sociodemographic information	Age of mother

\*Information on Hispanic origin is collected when “Hispanic” is selected as a race category.

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

#### OTO

#### **Early Hearing Detection and Intervention**

<i>HP 2010 Focus Area</i>	Maternal, infant, and child health
<i>Brief Description</i>	Record of universal newborn hearing screening required by state statute. Part of the Child Health Profile.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Family Health
<i>Records Accumulated Annually</i>	43,000
<i>Race and Ethnicity Data Collection Policy</i>	CDC reporting guidelines
<i>Data Collection Forms</i>	Hospital Record form in electronic reporting system; see BIRTH
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Unknown if observer reports
Ethnicity	Hispanic origin* Cuban, Mexican, and Puerto Rican
Race <sup>xii</sup>	American Indian Asian Black Hispanic White Other
Age	Date of birth
Gender	Female Male
Socioeconomic position and related characteristics	Education
Acculturation and language	None
Geography of residence	Street address City/Town County State Zip code
Other relevant sociodemographic information	Age of mother

\*Information on Hispanic origin is collected when “Hispanic” is selected as a race category.

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

#### PRMS

#### **Pregnancy Related Mortality Surveillance**

<i>HP 2010 Focus Area</i>	Maternal, infant, and child health
<i>Brief Description</i>	Cases of pregnancy-related mortality in Connecticut women. Activity required of Health Resources and Services Administration (HRSA) Title V Block Grant recipients. The Connecticut Death Registry (MORT) informs this database.
<i>DPH Branch</i>	Public Health Initiatives Planning
<i>DPH Section</i>	Family Health Health Information Systems and Reporting
<i>Records Accumulated Annually</i>	15
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	Connecticut Death Certificate
<i>Data Types Collected</i>	
Report of race/ethnicity	Observer
Ethnicity	Spanish/Hispanic/Latino Cuban Mexican, Mexican American, and Chicano Puerto Rican Not Spanish/Hispanic/Latino Other Spanish/Hispanic/Latino, specify (free text)
Race <sup>xiii</sup>	American Indian or Alaska Native, Name of the enrolled or principal tribe [Asian] Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, and Other Asian (specify, free text) Black or African American [Native Hawaiian/Other Pacific Islander] Native Hawaiian, Guamanian or Chamorro, Samoan, and Other Pacific Islander (specify, free text) White Other (specify, free text) Not reported/Not indicated
Age	Date of birth Age last birthday
Gender	None (only females included)
Socioeconomic position and related characteristics	Education Occupation
Acculturation and language	Country of birth
Geography of residence	County State Zip code
Other relevant sociodemographic information	Marital/Partner status Time at current address



## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

<b>QUIT</b>	
<b>Connecticut QuitLine</b>	
<i>HP 2010 Focus Area</i>	Tobacco use
<i>Brief Description</i>	Extract of aggregate data on Connecticut residents who use a telephone-based tobacco use cessation program, Free & Clear.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Health Education, Management and Surveillance
<i>Records Accumulated Annually</i>	1,200
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	None (summary data report)
<i>Data Types Collected</i>	
Report of race/ethnicity	Self
Ethnicity	Hispanic Non-Hispanic Does not know, Refused, Not collected, or Not asked
Race <sup>xiv</sup>	American Indian or Alaskan Native [Asian] Asian Indian, Cambodian, Chinese, Hmong, Japanese, Korean, Laotian, Pakistani, Taiwanese, Thai, Vietnamese, Other Asian, and Indonesian Black/African American [Native Hawaiian/Other Pacific Islander] Filipino, Native Hawaiian, Samoan, Tongan, Tahitian, Maori, Guamanian/Chamorro, Other Micronesian (e.g. Marshallese, Palauan, Pohnpeian, Chuukese, Yapese), Fijian, and Other Pacific Islander White Does not know Refused Not collected
Age	Fill in the blank (years) Select an age group Refused Not collected
Gender	Female Male Refused Not collected Not asked
Socioeconomic position and related characteristics	Education
Acculturation and language	None
Geography of residence	City/Town State Zip code
Other relevant sociodemographic information	Health insurance status Medicaid Medicare

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

<b>SBHCD</b>	
<b>School Based Health Center Database</b>	
<i>HP 2010 Focus Area</i>	Educational and community-based programs
<i>Brief Description</i>	Risk behavior, health screening, administrative, and physical and mental health data on students, ages 3-20 years, who use school-based health centers (SBHCs) funded by the Connecticut DPH. These comprehensive primary health care facilities are located within or on the grounds of schools. SBHCs are state-licensed outpatient facilities.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Family Health
<i>Records Accumulated Annually</i>	20,000
<i>Race and Ethnicity Data Collection Policy</i>	DPH recommendation to school-based health centers
<i>Data Collection Form</i>	SBHC Enrollment Form – Race and Ethnicity (recommended format for documenting race and ethnicity)
<i>Data Types Collected</i>	
Report of race/ethnicity	Self
Ethnicity	Hispanic or Latino Central American, Cuban, Mexican, Puerto Rican, South American, or Spanish Origin Unspecified Hispanic Not Hispanic or Latino origin
Race <sup>xv</sup>	American Indian or Alaska Native Asian Black or African American Native Hawaiian or Other Pacific Islander White Unknown Other
Age	Date of birth
Gender	Female Male
Socioeconomic position and related characteristics	Education
Acculturation and language	Language spoken at home
Geography of residence	State
Other relevant sociodemographic information	Health insurance status Medicaid

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

<b>STDMIS</b>	
<b>Sexually Transmitted Diseases Management Information System</b>	
<i>HP 2010 Focus Area</i>	Sexually transmitted diseases
<i>Brief Description</i>	Sexually transmitted disease surveillance and case management database for reportable sexually transmitted diseases in Connecticut residents. Activities required by state statute. Part of Nationally Notifiable Diseases Surveillance System (NNDSS). STD*MIS software supplied by the CDC and used to record cases and transmit weekly morbidity reports to the CDC via the NETSS.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Infectious Diseases
<i>Records Accumulated Annually</i>	14,000
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Forms</i>	OL-15C; Sexually Transmitted Disease Confidential case Report (STD-23); Congenital Syphilis (CS) Case Investigation and Report; Field Record; Interview Report
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Observer
Ethnicity	Hispanic Yes, No, or Unknown
Race <sup>xvi</sup>	American Indian/Alaska Native Asian/Pacific Islander Black White Other, specify Unknown
Age	Fill in the blank (years) Select an age group
Gender	Female Male Unknown
Socioeconomic position and related characteristics	None
Acculturation and language	None
Geography of residence	Street address City/Town County State Zip code
Other relevant sociodemographic information	None

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### Surveyed Databases in the Public Health Initiatives Branch

#### SWIS

#### **Statewide WIC Information System**

<i>HP 2010 Focus Area</i>	Maternal, infant, and child health Nutrition and overweight
<i>Brief Description</i>	Database of Connecticut residents enrolled in Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). Program provision required by federal Child Nutrition Action of 1966. Participation determined by federal guidelines.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Health Education Management and Surveillance
<i>Records Accumulated Annually</i>	60,000
<i>Race and Ethnicity Data Collection Policy</i>	1997 OMB Revisions to Statistical Policy Directive No. 15
<i>Data Collection Form</i>	None submitted
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Observer
Ethnicity	Hispanic/Latino Not Hispanic/Latino
Race <sup>xvii</sup>	American Indian or Alaska Native Asian Black or African American Native Hawaiian or Other Pacific Islander White
Age	Date of birth
Gender	Female Male
Socioeconomic position and related characteristics	Employment status Household income Household size
Acculturation and language	Language spoken at home
Geography of residence	Street address City/Town County State Zip code
Other relevant sociodemographic information	Medicaid

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

<b>TIMS</b>	
<b>Tuberculosis Information Management System</b>	
<i>HP 2010 Focus Area</i>	Immunization and infectious diseases
<i>Brief Description</i>	Tuberculosis (TB) surveillance and case management database for active TB disease. Program activities required by state statutes. TIMS software supplied by the CDC is used to record cases and transmit reports to the CDC.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Infectious Diseases
<i>Records Accumulated Annually</i>	120
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Forms</i>	Tuberculosis Surveillance Report (TB-86); OL-15C; Tuberculosis Register; Pediatric Tuberculosis Surveillance Form; Tuberculosis in the Foreign Born Surveillance Form; Report of Verified Case of Tuberculosis (RVCT)
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Observer
Ethnicity	Hispanic Non-Hispanic Unknown
Race <sup>xviii</sup>	American Indian/Alaska Native Asian Black White
Age	Fill in the blank (years) Select an age group
Gender	Female Male
Socioeconomic position and related characteristics	Employment status Occupation
Acculturation and language	Country of birth Immigration status Length of stay in United States
Geography of residence	Street address City/Town County State Zip code
Other relevant sociodemographic information	Health insurance status Marital/Partner status Time at current address

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

<b>TRIMS</b>	
<b>Tuberculosis Registry and Information Management System</b>	
<i>HP 2010 Focus Area</i>	Immunization and infectious diseases
<i>Brief Description</i>	Database for the management of TB targeted testing and latent TB infection treatment (LTBI). Contains information on persons with LTBI who are contracts to active TB cases or have comorbid HIV infection. These conditions are reportable by state statute.
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Infectious Diseases
<i>Records Accumulated Annually</i>	2,000
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Forms</i>	Tuberculosis Surveillance Report (TB-86) and OL-15C
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Observer
Ethnicity	Hispanic Non-Hispanic Unknown
Race <sup>xix</sup>	American Indian/Alaska Native Asian Black White
Age	Fill in the blank (years) Select an age group
Gender	Female Male
Socioeconomic position and related characteristics	Employment status Occupation
Acculturation and language	Country of birth Immigration status Length of stay in United States
Geography of residence	Street address City/Town County State Zip code
Other relevant sociodemographic information	Health insurance status Marital/Partner status Time at current address

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

#### VMORB

#### **Varicella Morbidity Database**

<i>HP 2010 Focus Area</i>	Immunization and infectious diseases
<i>Brief Description</i>	Varicella (chickenpox) infection is a mandatory reportable condition and significant laboratory finding. This database records limited clinical information on and laboratory reports of acute Varicella infection in Connecticut residents. Supplement to the Reportable Infectious Diseases Database (IDD).
<i>DPH Branch</i>	Public Health Initiatives
<i>DPH Section</i>	Infectious Diseases
<i>Records Accumulated Annually</i>	1,750
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Forms</i>	Varicella Case Report Form and OL-15C
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Unknown if observer reports
Ethnicity	Hispanic Non-Hispanic Unknown
Race <sup>xx</sup>	Alaskan/Native American Asian/Pacific Islander Black White Unknown Other, specify
Age	Fill in the blank (years, months, weeks, days) Unknown
Gender	Female Male Unknown
Socioeconomic position and related characteristics	None
Acculturation and language	None
Geography of residence	Street address City/Town County State Zip code
Other relevant sociodemographic information	None

## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

#### YTS

#### Connecticut School Health Survey - Youth Tobacco Component

<i>HP 2010 Focus Area</i>	Survey research
<i>Brief Description</i>	Responses of a random sample of Connecticut middle and high school students to the Youth Tobacco Component of the Youth Risk Behavioral Survey. This comprehensive survey of tobacco use, access, cessation, knowledge, attitudes, and exposure is partially funded by the CDC. No legal mandate.
<i>DPH Branch</i>	Public Health Initiatives Planning
<i>DPH Section</i>	Health Education, Management and Surveillance Health Information Systems and Reporting
<i>Records Accumulated Annually</i>	4,350
<i>Race and Ethnicity Data Collection Policy</i>	CDC survey-specific data collection rules
<i>Data Collection Form</i>	Student Questionnaire: 2007 Connecticut School Health Survey – Youth Tobacco Component
<i>Data Types Collected</i>	
Report of race/ethnicity	Self
Ethnicity	“Hispanic or Latino” is a race category
Race <sup>xxi</sup>	American Indian or Alaska Native Asian Black or African American Hispanic or Latino Native Hawaiian or Other Pacific Islander White Other
Age	Fill in the blank (years)
Gender	Female Male
Socioeconomic position and related characteristics	Education
Acculturation and language	None
Geography of residence	State
Other relevant sociodemographic information	None

\* Not an *HP 2010* focus area.



## APPENDIX I

### Surveyed Databases in the Public Health Initiatives Branch

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- <sup>i</sup> The AIDS Institute Data Application is a data extract that contains the ethnicity and race categories listed.
- <sup>ii</sup> The Asthma Database records the ethnicity and race categories indicated.
- <sup>iii</sup> The Birth Defects Registry Database records the same race categories as the Birth Registry, which are: American Indian; Black or African American; Chinese; Filipino; Hawaiian; Japanese; Other Asian; Other races; White; and Not reported.
- <sup>iv</sup> The Connecticut Immunization Registry and Tracking System records the race categories listed.
- <sup>v</sup> The Crash Outcome Data Evaluation System is a data extract that contains the race categories listed.
- <sup>vi</sup> The Food Stamp Nutrition Education Database records the ethnicity and race categories listed.
- <sup>vii</sup> The HIV/AIDS Surveillance Database records the ethnicity and race categories listed.
- <sup>viii</sup> The Hepatitis B Registry Database records the following race categories: Asian/Pacific Islander; Black; Native American; White; Other; and Unknown.
- <sup>ix</sup> The Hepatitis C Registry Database records the following race categories: American Indian; Asian/Pacific Islander; Black; White; Other; and Unknown.
- <sup>x</sup> The Reportable Infectious Diseases Database records the following race categories: Asian/Pacific Islander; Black; Native American; White; Other; and Unknown.
- <sup>xi</sup> The Newborn Screening System Metabolic Disorders Database records the race categories shown.
- <sup>xii</sup> The Newborn Screening System Early Hearing Detection and Intervention Database records the race categories listed.
- <sup>xiii</sup> The Pregnancy Related Mortality Surveillance Database records the ethnicity and race categories listed.
- <sup>xiv</sup> The vendor that supplies information to the Connecticut Quitline reported these race categories.
- <sup>xv</sup> The School Based Health Center Database records the ethnicity and race categories listed.
- <sup>xvi</sup> The Sexually Transmitted Diseases Management Information System records the following race categories: Amer. Indian/Alaskan; Asian; Black/African Amer.; Hawaiian/Pac. Islander; White; Multiple races; Other; and Unknown.
- <sup>xvii</sup> The Statewide WIC Information System records the ethnicity and race categories listed.
- <sup>xviii</sup> The Tuberculosis Information Management System records the following race categories: American Indian or Alaska Native; Asian (subcategories: Asian Indian; Bangladeshi; Bhutanese; Burmese; Cambodian; Chinese; Taiwanese; Filipino; Hmong; Indonesian; Japanese; Korean; Iwo Jiman; Moldovian; Nepalese; Laotian; Malaysian; Okinawan; Pakistani; Sri Lankan; Thai; Vietnamese; Singaporean; and Madagascan); Black or African American; Native Hawaiian or Pacific Islander; White; and Unknown.
- <sup>xix</sup> The Tuberculosis Registry and Information Management System records the following race categories: Am. Native; Asian; Black; Pac. Isl.; White; and Unknown.
- <sup>xx</sup> The Varicella Morbidity Database records the ethnicity and race categories shown.
- <sup>xxi</sup> The database for the Youth Tobacco Component of the Connecticut School Health Survey records the race categories listed.

## APPENDIX J

### Surveyed Databases in the Regulatory Services Branch

<b>APB</b>	
<b>Adult Lead Poisoning Database</b>	
<i>HP 2010 Focus Area</i>	Environmental health
<i>Brief Description</i>	Laboratory or physician reports of elevated blood lead levels in individuals aged 16 years or older. Reporting of elevated blood lead level ( $\geq 10\mu\text{g/dL}$ ) is mandated by state statute. Demographic and laboratory information extracted from Childhood Lead Poisoning Prevention Program Surveillance System (CLPPP).
<i>DPH Branch</i>	Regulatory Services
<i>DPH Section</i>	Environmental Epidemiology and Occupational Health Assessment
<i>Records Accumulated Annually</i>	750
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Forms</i>	Lead Poisoning Prevention & Control Program Laboratory Report and OL-15C
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Unknown if observer reports
Ethnicity	Hispanic Non-Hispanic Unknown
Race <sup>i</sup>	American Indian/Alaska Native Asian Black Native Hawaiian/Pacific Islander White Unknown
Age	Date of birth
Gender	Female Male Unknown
Socioeconomic position and related characteristics	Employment status Occupation
Acculturation and language	Language spoken at home
Geography of residence	Length of residence at current address Street address City/Town State Zip code
Other relevant sociodemographic information	Medicaid

## APPENDIX J

### Surveyed Databases in the Regulatory Services Branch

#### CLPPP

#### Childhood Lead Poisoning Prevention Program Surveillance System

<i>HP 2010 Focus Area</i>	Environmental health
<i>Brief Description</i>	Contains laboratory results of blood lead level tests on Connecticut residents. Reporting this data is required by state statute. Also contains epidemiological and environmental data that has been acquired during case investigations of lead poisoning in children.
<i>DPH Branch</i>	Regulatory Services
<i>DPH Section</i>	Environmental Health
<i>Records Accumulated Annually</i>	86,000
<i>Race and Ethnicity Data Collection Policy</i>	Mandatory reporting of information requested by the Commissioner of Health. See CGS Sec. 19a-110. Report of lead poisoning.
<i>Data Collection Forms</i>	Lead Poisoning Prevention & Control Program Laboratory Report and OL-15C
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Unknown if observer reports
Ethnicity	Hispanic Non-Hispanic Unknown
Race <sup>ii</sup>	American Indian/Alaska Native Asian Black Native Hawaiian/Pacific Islander White Unknown
Age	Date of birth
Gender	Female Male
Socioeconomic position and related characteristics	None
Acculturation and language	None
Geography of residence	Street address City/Town State Zip code
Other relevant sociodemographic information	Medicaid

## APPENDIX J

### Surveyed Databases in the Regulatory Services Branch

#### CO

#### Carbon Monoxide Poisoning Database

<i>HP 2010 Focus Area</i>	Environmental health
<i>Brief Description</i>	Significant laboratory finding of elevated carboxyhemoglobin ( $\geq 9\%$ ) in Connecticut residents. Reporting mandated by state statute.
<i>DPH Branch</i>	Environmental Epidemiology and Occupational Health Assessment
<i>DPH Section</i>	Regulatory Services
<i>Records Accumulated Annually</i>	100
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	OL-15C
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Observer
Ethnicity	Hispanic Yes, No, or Unknown
Race <sup>iii</sup>	American Indian/Alaska Native Asian/Pacific Islander Black White Other Unknown
Age	Fill in the blank (years)
Gender	Female Male Fill in the blank
Socioeconomic position and related characteristics	Occupation
Acculturation and language	None
Geography of residence	Street address City/Town State Zip code
Other relevant sociodemographic information	None

## APPENDIX J

### Surveyed Databases in the Regulatory Services Branch

#### FICS

#### Foodborne Illness Complaint System

<i>HP 2010 Focus Area</i>	Environmental health Food safety
<i>Brief Description</i>	Complaints of suspected foodborne illness in Connecticut residents or patrons of Connecticut food establishments. Not legislatively mandated.
<i>DPH Branch</i>	Regulatory Services
<i>DPH Section</i>	Environmental Health
<i>Records Accumulated Annually</i>	200
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	Foodborne Alert Complaint Form
<i>Data Types Collected</i>	
Report of race/ethnicity	Self
Ethnicity	“Hispanic” is a race category
Race <sup>iv</sup>	Black Hispanic White Other
Age	Select an age group Date of birth
Gender	Female Male Unknown
Socioeconomic position and related characteristics	Occupation
Acculturation and language	None
Geography of residence	Street address City/Town State Zip code
Other relevant sociodemographic information	None

## APPENDIX J

### Surveyed Databases in the Regulatory Services Branch

**HG**

#### **Mercury Poisoning Database**

<i>HP 2010 Focus Area</i>	Environmental health
<i>Brief Description</i>	Significant laboratory finding of elevated blood ( $\geq 15\mu\text{g/L}$ ) or urine mercury ( $\geq 35\mu\text{g/g}$ creatinine) concentration in Connecticut residents. Reporting mandated by state statute.
<i>DPH Branch</i>	Regulatory Services
<i>DPH Section</i>	Environmental Epidemiology and Occupational Health Assessment
<i>Records Accumulated Annually</i>	40
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	OL-15C
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Observer
Ethnicity	Hispanic Yes, No, or Unknown
Race <sup>v</sup>	American Indian/Alaska Native Asian/Pacific Islander Black White Other Unknown
Age	Date of birth
Gender	Female Male
Socioeconomic position and related characteristics	Employment status Occupation
Acculturation and language	None
Geography of residence	Street address City/Town State Zip code
Other relevant sociodemographic information	None

## APPENDIX J

### Surveyed Databases in the Regulatory Services Branch

<b>OIISS</b>	
<b>Occupational Illness and Injury Surveillance System</b>	
<i>HP 2010 Focus Area</i>	Occupational safety and health
<i>Brief Description</i>	Physician reports of occupational illness or injury in individuals who reside or work in Connecticut. Reporting mandated by state statute.
<i>DPH Branch</i>	Regulatory Services
<i>DPH Section</i>	Environmental Epidemiology and Occupational Health Assessment
<i>Records Accumulated Annually</i>	2,000
<i>Race and Ethnicity Data Collection Policy</i>	None reported
<i>Data Collection Form</i>	Physician's Report of Occupational Disease
<i>Data Types Collected</i>	
Report of race/ethnicity	Self Unknown if observer reports
Ethnicity	Hispanic Yes, No, or Unknown
Race <sup>vi</sup>	American Indian Asian Black White Other Unknown
Age	Date of birth
Gender	Female Male
Socioeconomic position and related characteristics	Employment status Occupation
Acculturation and language	None
Geography of residence	Street address City/Town State Zip code
Other relevant sociodemographic information	None

## **APPENDIX J**

### **Surveyed Databases in the Regulatory Services Branch**

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- <sup>i</sup> The Adult Lead Poisoning Database records the ethnicity and race categories listed.
- <sup>ii</sup> The Childhood Lead Poisoning Prevention Program Database records the ethnicity and race categories shown.
- <sup>iii</sup> The Carbon Monoxide Poisoning Database records the ethnicity and race categories shown.
- <sup>iv</sup> The Foodborne Illness Complaint System Database records the following race categories: American Indian/Alaska Native; Asian/Pacific Islander; Hispanic; White; and Other.
- <sup>v</sup> The Mercury Poisoning Database records the ethnicity and race categories shown.
- <sup>vi</sup> The Occupational Illness and Injury Surveillance System records the ethnicity and race categories listed.