

CONNECTICUT DEPARTMENT OF PUBLIC HEALTH

**Policy on Collecting
Sociodemographic Data**

SEPTEMBER 2008

Connecticut Department of Public Health
Policy on Collecting Sociodemographic Data
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Introduction

The mission of the Connecticut Department of Public Health (DPH) is to protect and improve the health and safety of the people of Connecticut by assuring the conditions in which people can be healthy, promoting physical and mental health, and preventing disease, injury, and disability. To accomplish this mission, health data of the highest quality are needed. To be most useful, health statistics should represent all factors that influence population health (Friedman, Hunter, and Parrish 2002). Equipped with such information, public health agencies can describe the health of populations and the disparities within and between observed population groups.

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 factors such as race, ethnicity, age, and gender, are routinely collected in public health surveillance systems. However, the comparability of these data across national, local, and inter- and intra- departmental systems is dependent on how data are collected, recorded, and reported.

In October 2007, The Connecticut Health Disparities Project published results of an assessment of DPH databases entitled *The Collection of Race, Ethnicity, and Other Sociodemographic Data in Connecticut Department of Public Health Databases* (Nepaul, Hynes, and Stratton 2007). This report provides a comprehensive review of the data collection and coding practices associated with 37 DPH databases in 2006. Findings of the database assessment included:

- No standard ethnicity and race categories in use across DPH surveillance systems;
- Discrepancies between the labeling of categories on data collection forms, in databases, and on reports; and
- Limited use of geographic information systems (GIS) to map the distribution of health indicators.

Report recommendations included:

- Establishment of a minimum data collection standard that emphasizes collection of self-reported information on ethnicity and race as specified in the *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity* (Office of Management and Budget [OMB] 1997);
- Training for DPH staff and physicians, laboratorians, and other reporters of health data on the *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity*; and
- Routine performance of spatial analysis using residential address information and GIS.

The Minimum and Ideal Standards

This policy defines the minimum standard and an ideal standard for sociodemographic data collection for the Connecticut Department of Public Health. The minimum standard for ethnicity and race categories are specified in the 1997 federal Office of Management and Budget standards. To better monitor health disparities in Connecticut and the United States, the 1997 OMB categories must be used so that health-related ethnicity and race data are comparable within and across public health agencies and other social institutions. Indeed, federal mandates for Department of Health and Human Services (DHHS) programs to collect data on race, ethnicity, and primary language are anticipated (Kaiser Family Foundation 2007). Many DPH programs are funded by DHHS grants and will eventually be required, as a condition of funding, to collect and report information in accordance with the OMB standards that are applied to federal agencies.

The minimum standard for data collection defined herein applies to all Connecticut Department of Public Health programs and to all entities and/or individuals that are funded in whole or in part by the DPH to conduct surveillance or research, provide services, and/or generate reports of state health data. This policy does not require redundant data collection efforts. It allows exemptions when alternate sources of information exist that can accurately provide the data specified in the minimum standard and there are efficient means for obtaining such data. DPH will adhere to the minimum data collection standard on or before January 1, 2012.

The ideal standard for sociodemographic data collection includes the data elements outlined in the minimum standards as well as additional sociodemographic data elements.¹ Data elements included in the ideal standard that are useful for examining health disparities are: geographic area of residence, language, acculturation, and measures of socioeconomic position. Programs with interest and adequate resources should collect, record, and report these additional sociodemographic data to enhance the capacity of DPH to assess health disparities in Connecticut. Programs are encouraged to collect any or all of the additional data elements outlined in the ideal standard that inform ongoing or future work.

¹ The elements of the ideal standard are derived from the findings of the Panel on DHHS Collection of Race and Ethnicity Data documented in *Eliminating Health Disparities: Measurement and Data Needs* (National Research Council 2004), U.S. Standard Death Certificate, U.S. Standard Certificate of Live Birth, and review of the literature on the collection of data to inform health disparities research.

Exceptions to the Minimum Standard

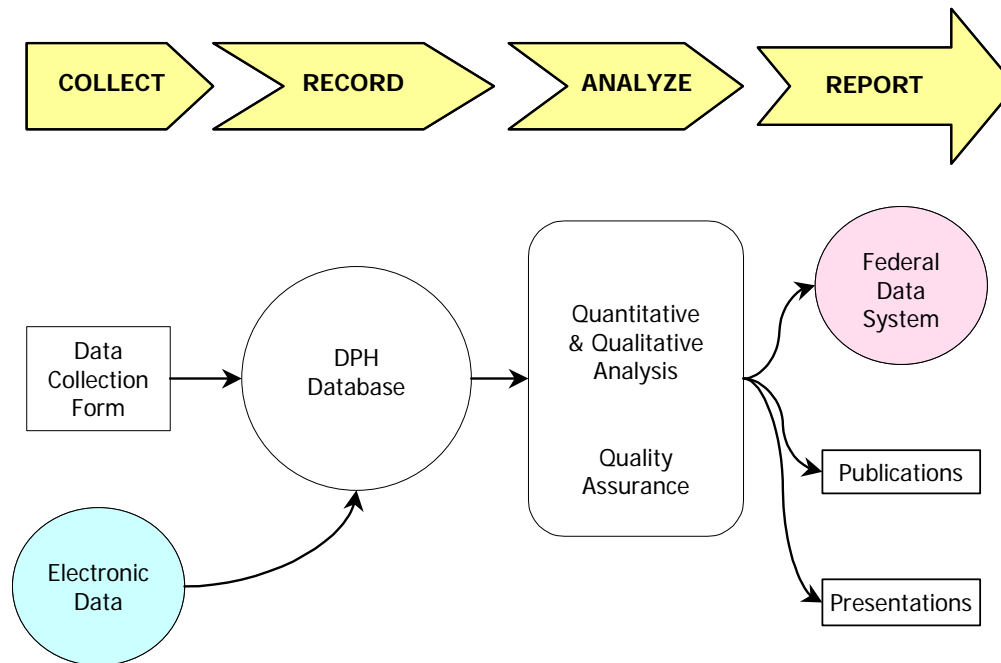
Surveillance, surveys, and research conducted by the DPH are exempt from adherence to the minimum standard for data collection if any of the following circumstances apply:

- 1) The program conducting the work is required by contract to use defined data collection protocols, instruments, algorithms, and/or databases that are explicitly precluded from modification by the grantor.
- 2) Data are supplied to the DPH by another entity that is not obligated by contract or legal mandate to collect the minimum data elements, or with whom the DPH has not established a Memorandum of Understanding on data collection in accordance with the 1997 OMB standards for the classification of race and ethnicity data.

The Flow of Data

Figure 1 is a general overview of how data move through DPH surveillance systems and registries. Self- or observer-reported sociodemographic data are collected about an individual and recorded on a standard reporting form. The form is mailed or faxed to DPH where the data are entered into a database. Alternatively, electronic data may originate from another source within DPH (e.g., Birth Registry, Death Registry) and/or an external entity (e.g., hospital, school-based health center, Department of Transportation) and are uploaded into a DPH database. These data are analyzed, interpreted, and summarized into a variety of outputs. Summary data may also be electronically transmitted to a federal data system.

Figure 1. The Flow of Data



At each point in this process, data may be lost or mistranslated. A way to mitigate the degradation of data quality is to standardize terms across data collection forms, databases, and reports. Consistent use of terms across data collection instruments and electronic systems facilitates generation of reports that can be easily interpreted. Moreover, consistent use of terms across systems facilitates combining information from separate databases.

Data Collection

The minimum sociodemographic data collection standard requires use of the race and ethnicity categories specified in *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity* published by the OMB in 1997. It also includes categories for the collection of information on age and gender. The ideal sociodemographic data collection standard includes the categories specified in the minimum standard and categories for additional sociodemographic data elements that can enhance the description of health disparities. Appendix A provides a format for collection of the data elements specified in the minimum standard. Appendix B provides a suggested format for collection of sociodemographic data according to the ideal standard. For additional information of the data elements discussed in this policy, see Suggested Reading.

Table 1. Elements of the Minimum and Ideal DPH Sociodemographic Data Standards

Minimum Standard	Ideal Standard
Age	Age
Gender	Gender
Ethnicity	Ethnicity and expanded ethnicity
Race	Ancestry
	Race
	Geography of residence
	Language
	Acculturation
	Socioeconomic position
	Other sociodemographic data of program interest

Minimum Standard

When practical, self-reported information should be collected.

Data Element	Data Collection Form Categories	Special Instructions
Age	Date of birth <u>and</u> Date of event Age at time of event (years, months, days)	<i>Date of event may refer to the date of data collection, or another date of relevance to program objective (e.g., specimen date, date of diagnosis, date of form completion).</i>
Gender	Male Female Other, specify	
Ethnicity	Hispanic or Latino Not Hispanic or Latino	<i>The ethnicity question is always asked before the race question. Multiple ethnicity categories are not recorded. In other words, if “Hispanic or Latino” and “Not Hispanic or Latino” are selected, only “Hispanic or Latino” should be recorded.</i>
Race	American Indian or Alaska Native Asian Black or African American Native Hawaiian or Other Pacific Islander White	<i>The data collection form should allow selection of multiple race categories. The database should record all selections.</i>

Ideal Standard

When practical, self-reported information should be collected.

Data Element	Data Collection Form Categories	Special Instructions
Age	<i>Same as Minimum Standard</i>	
Gender	<i>Same as Minimum Standard</i>	
Ethnicity	Hispanic or Latino Cuban Mexican Puerto Rican South or Central American Other Spanish culture or origin, regardless of race (specify) Not Hispanic or Latino	<i>Programs that have direct community involvement may consider using expanded ethnicity categories.</i>
Race	American Indian or Alaska Native (specify tribal affiliation) Asian Asian Indian Chinese Filipino Japanese Korean Taiwanese Vietnamese Other Asian, specify Black or African American Native Hawaiian or Other Pacific Islander White Other, specify	<i>The data collection form should allow selection of multiple race categories. The database should record all selections.</i>

Ideal Standard

-continued-

Data Element	Data Collection Form Categories	Special Instructions
Ancestry ²	Specify ancestry	<p><i>Only two types of ethnicity are defined in the 1997 OMB standard: “Hispanic or Latino” and “Not Hispanic or Latino.” Collecting information on ancestry provides additional information on persons who classify themselves as “Not Hispanic or Latino” as well as those who classify themselves as being of Spanish origin.</i></p>
Geography of residence	Residential street address Residential city/town Residential state Residential zip code Length of time at current address	<p><i>*These data are derived from street address information. Some programs may already be collecting these data instead of the residential street address.</i></p>
	Longitude* U.S. Census FIPS Area key* Latitude* MatchCode*	

² The U.S. Census Bureau defines ancestry as a person’s ethnic origin, heritage, descent, or “roots,” which may reflect their place of birth, place of birth of parents or ancestors, and ethnic identities that have evolved within the United States (U.S. Census Bureau 2004a).

Ideal Standard

-continued-

Data Element	Data Collection Form Categories	Special Instructions
Language	American Sign Language (ASL) Armenian Chinese, Cantonese Chinese, Mandarin English French (incl. Cajun or Patois) French Creole (e.g., Haitian) Gujarathi Khmer Korean Laotian Persian Polish Portuguese Russian Serbo-Croatian Spanish Vietnamese Other language, specify	<p><i>Some programs (e.g., those which provide services) may choose to ask about which languages a person speaks, uses at home, or prefers to discuss or read about health-related concerns. Determining the English proficiency level among its service population may also be a program requirement.</i></p> <p><i>With the exception of ASL, the language categories listed here are derived from 2000 U.S. Census data on the ability to speak English by language spoken at home for the Connecticut population ages 5 years and older (U.S. Census Bureau 2004b). Categories were listed if the percent of persons who could “not at all” speak English was > 2.0% of the language-specific population.</i></p>

Ideal Standard

-continued-

Data Element	Data Collection Form Categories	Special Instructions
Acculturation	Country of birth Language spoken at home English proficiency Preferred language Immigration status Number of years in the United States	
Socioeconomic position	Educational attainment Employment status Occupation Personal income Household income Household size (number of persons)	
Other sociodemographic variables	Health insurance status Marital/Partner status	

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Suggested Reading

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Appendix A. Sociodemographic Data Collection Format According to the Minimum Standard

Age

The following items were adapted from the 2007 American Community Survey (U.S. Census Bureau 2007a: 2).

Age (in years):

and/or Date of birth: - -
Month Day Year

Date of event: - -
Month Day Year

Gender

Mark (x) one box:

Male Female Other, specify: _____

Ethnicity

This item is based on Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity (OMB 1997).

Mark (x) one box:

Hispanic or Latino Not Hispanic or Latino

Race

This item is based on Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity (OMB 1997).

Mark (x) one or more boxes:

- American Indian or Alaska Native
 Asian
 Black or African American
 Native Hawaiian or Other Pacific Islander
 White

Appendix B. Suggested Format for Sociodemographic Data Collection According to the Ideal Standard

This is a suggested format for the collection of additional sociodemographic data. Programs may choose to collect whichever of the data elements outside of the minimum standard for which they have the resources and clear purpose to collect. However, the data elements of the minimum standard must still be collected.

Age

Same as minimum standard

Gender

Same as minimum standard

Ethnicity

This item is based on Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity (OMB 1997).

Are you of Hispanic, Latino, or Spanish origin? *Mark (x) one box:*

- No, not of Hispanic, Latino, or Spanish origin ⁱ
- Yes, Mexican, Mexican American, Chicano ⁱⁱ
- Yes, Puerto Rican ⁱⁱⁱ
- Yes, Cuban ^{iv}
- Yes, South or Central American ^v
- Yes, other Spanish culture or origin, regardless of race^{vi} – Print origin: _____

Appendix B. Suggested Format for Sociodemographic Data Collection According to the Ideal Standard

-continued-

Race

What is your race? Mark (x) one or more boxes to indicate what you consider yourself to be. ^{vii}

American Indian or Alaska Native

Print name of enrolled or principal tribe: _____

Asian ^{viii}

Asian Indian

Chinese

Filipino

Japanese

Korean

Taiwanese

Vietnamese

Other Asian – Print race: _____

Black or African American

Native Hawaiian or Other Pacific Islander ^{ix}

Guamanian or Chamorro

Samoan

Other Pacific Islander – Print race: _____

White

Other, specify: _____

Appendix B. Suggested Format for Sociodemographic Data Collection According to the Ideal Standard

-continued-

Ancestry

This question appeared in the 2000 U.S. Census (U.S. Census Bureau 2004a). The list of potential responses was created from review of 2002-2006 American Community Survey data on persons of foreign birth in Connecticut (U.S. Census Bureau 2003; 2004c; 2005; 2006; 2007b).

What is your ancestry or ethnic origin? (For example: Italian, Irish, Jamaican, Indian, Puerto Rican, Mexican, Brazilian, Haitian, Taiwanese, German, Portuguese, Afghani, Filipino, Croatian, Vietnamese, Ethiopian, American, and so on.)

Print ancestry: _____

Geography of residence and related information

Residential street address

This item was adapted from the 2000 U.S. Census Individual Census Report (2000: 2).

What is your current home address? – Fill in the blanks.

Street or road name: _____ Apartment number: _____

City/Town: _____ State: _____ Zip Code: _____

Length of time at current address

How long have you lived at this address? : _____ years _____ months

Household size

This item was adapted from the American Community Survey (2007: 1)

How many people are currently living or staying at this address?^x – Print number of people: _____

Appendix B. Suggested Format for Sociodemographic Data Collection According to the Ideal Standard

-continued-

Language

Primary Language

The following two questions were adapted from the 2003-4 National Health and Nutrition Survey (item ACQ.020). With the exception of ASL, the language categories listed here are derived from 2000 U.S. Census data on the ability to speak English by language spoken at home for the Connecticut population ages 5 years and older (U.S. Census Bureau 2004b). Categories were listed if the percent of persons who could “not at all” speak English was > 2.0% of the language-specific population.

In general, which languages do you speak/use? – Mark (x) one or more boxes:

- | | | |
|--|------------------------------------|---|
| <input type="checkbox"/> American Sign Language (ASL) | <input type="checkbox"/> Gujarathi | <input type="checkbox"/> Portuguese |
| <input type="checkbox"/> Armenian | <input type="checkbox"/> Khmer | <input type="checkbox"/> Russian |
| <input type="checkbox"/> Chinese, Cantonese | <input type="checkbox"/> Korean | <input type="checkbox"/> Serbo-Croatian |
| <input type="checkbox"/> Chinese, Mandarin | <input type="checkbox"/> Laotian | <input type="checkbox"/> Spanish |
| <input type="checkbox"/> English | <input type="checkbox"/> Persian | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> French (<i>incl. Cajun or Patois</i>) | <input type="checkbox"/> Polish | <input type="checkbox"/> Other language – Print name of language: _____ |
| <input type="checkbox"/> French Creole (<i>for example: Haitian</i>) | | |

In general, which languages do you usually speak/use at home? – Mark (x) one or more boxes:

- | | | |
|--|------------------------------------|---|
| <input type="checkbox"/> American Sign Language (ASL) | <input type="checkbox"/> Gujarathi | <input type="checkbox"/> Portuguese |
| <input type="checkbox"/> Armenian | <input type="checkbox"/> Khmer | <input type="checkbox"/> Russian |
| <input type="checkbox"/> Chinese, Cantonese | <input type="checkbox"/> Korean | <input type="checkbox"/> Serbo-Croatian |
| <input type="checkbox"/> Chinese, Mandarin | <input type="checkbox"/> Laotian | <input type="checkbox"/> Spanish |
| <input type="checkbox"/> English | <input type="checkbox"/> Persian | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> French (<i>incl. Cajun or Patois</i>) | <input type="checkbox"/> Polish | <input type="checkbox"/> Other language – Print name of language: _____ |
| <input type="checkbox"/> French Creole (<i>for example: Haitian</i>) | | |

Appendix B. Suggested Format for Sociodemographic Data Collection According to the Ideal Standard

-continued-

Language

This item was adapted from question 13c of the American Community Survey (2007a: 8).

English proficiency

How well do you speak English? – Mark (x) one box:

- Very well
- Well
- Not well
- Not at all

Preferred language

In what language do you prefer to read about health information? – Print name of language: _____

In what language do you prefer to hear about health information? – Print name of language: _____

Appendix B. Suggested Format for Sociodemographic Data Collection According to the Ideal Standard

-continued-

Acculturation

The following items were adapted from the 2000 U.S. Census (2000: 3) and also appear in the American Community Survey (2007a: 8).

Country of birth

Where were you born?

- In the United States— Print name of state: _____
- Outside of the United States – Print name of the foreign country or Puerto Rico, Guam, etc.: _____

Immigration status

Are you a citizen of the United States?

- Yes, born in the United States
- Yes, born in Puerto Rico, Guam, the U.S. Virgin Islands, or Northern Marianas
- Yes, born abroad of U.S. citizen parent or parents
- Yes, U.S. citizen by naturalization
- No, not a U.S. citizen

Length of years in the continental United States

(This question would be asked only of persons who reported a country of birth other than the United States.)

When did you come to live in the United States? – Print year:

Appendix B. Suggested Format for Sociodemographic Data Collection According to the Ideal Standard

-continued-

Socioeconomic position

Educational attainment

This question was adapted from item 12.8 of the 2007 Behavioral Risk Factor Surveillance Survey. Respondent directions appeared in the 2000 U.S. Census Individual Census Report (2000:2, item #11).

What is the highest grade or level of school you completed? Mark (x) one box. If currently enrolled, mark the previous grade or highest degree received.^{xi}

- | | |
|--|---|
| <input type="checkbox"/> Never attended school or only attended kindergarten | <input type="checkbox"/> High school graduate or GED |
| <input type="checkbox"/> Grades 1 through 8 (Elementary) | <input type="checkbox"/> College 1 year to 3 years (Some college or technical school) |
| <input type="checkbox"/> Grades 9 through 11 (Some high school) | <input type="checkbox"/> College 4 years or more (College graduate) |
| <input type="checkbox"/> Grade 12 or GED (High school graduate) | |

Employment status

This question was adapted from item 12.9 of the 2007 Behavioral Risk Factor Surveillance Survey.

Are you currently...?

- | | | | |
|---|---|--------------------------------------|--|
| <input type="checkbox"/> Employed for wages | <input type="checkbox"/> Out of work for more than 1 year | <input type="checkbox"/> A Homemaker | <input type="checkbox"/> Retired |
| <input type="checkbox"/> Self-employed | <input type="checkbox"/> Out of work for less than 1 year | <input type="checkbox"/> A Student | <input type="checkbox"/> Other, specify: _____ |

Occupation

This question was adapted from item 44 of the American Community Survey (2007).

What type of work do/did you do?

Specify type of work. (For example: registered nurse, supervisor of order department): _____

Appendix B. Suggested Format for Sociodemographic Data Collection According to the Ideal Standard

-continued-

Socioeconomic position

The following questions were adapted from item 12.10 of the 2007 BRFSS Questionnaire.

Personal income

What is your current annual income from all sources?

- | | |
|---|---|
| <input type="checkbox"/> Less than \$10,000 | <input type="checkbox"/> \$25,000 to less than \$35,000 |
| <input type="checkbox"/> \$10,000 to less than \$15,000 | <input type="checkbox"/> \$35,000 to less than \$50,000 |
| <input type="checkbox"/> \$15,000 to less than \$20,000 | <input type="checkbox"/> \$50,000 to less than \$75,000 |
| <input type="checkbox"/> \$20,000 to less than \$25,000 | <input type="checkbox"/> \$75,000 or more |

Household income

What is your annual household income?

- | | |
|---|---|
| <input type="checkbox"/> Less than \$10,000 | <input type="checkbox"/> \$25,000 to less than \$35,000 |
| <input type="checkbox"/> \$10,000 to less than \$15,000 | <input type="checkbox"/> \$35,000 to less than \$50,000 |
| <input type="checkbox"/> \$15,000 to less than \$20,000 | <input type="checkbox"/> \$50,000 to less than \$75,000 |
| <input type="checkbox"/> \$20,000 to less than \$25,000 | <input type="checkbox"/> \$75,000 or more |

Household size (see p. 19)

Appendix B. Suggested Format for Sociodemographic Data Collection According to the Ideal Standard

-continued-

Other sociodemographic information

Health insurance

This item was adapted from question 3.1 of the 2007 BRFSS Questionnaire.

Do you have any kind of health care coverage including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?

Yes No

This question was adapted from item HIQ.030 of the 2003-4 National Health and Nutrition Examination Survey.

What kind of health insurance or health care coverage do you have? Include those that pay for only one type of service (nursing home care, accidents, or dental care.) Exclude private plans that only provide extra cash while hospitalized. If you have more than one kind of health insurance, just select the first kind. ^{xii}

Mark “Yes” or “No” for each type of coverage in items a – m.

	Yes	No
a. Private health insurance plan through employer or workplace	<input type="checkbox"/>	<input type="checkbox"/>
b. Private health care plan purchased directly	<input type="checkbox"/>	<input type="checkbox"/>
c. Private health insurance plan through a state or local government program or community program	<input type="checkbox"/>	<input type="checkbox"/>
d. Medicare	<input type="checkbox"/>	<input type="checkbox"/>
e. Medigap (private insurance supplement to Medicare)	<input type="checkbox"/>	<input type="checkbox"/>
f. Medicaid	<input type="checkbox"/>	<input type="checkbox"/>
g. Children’s Health Insurance Program (HUSKY)	<input type="checkbox"/>	<input type="checkbox"/>
h. Military health care/ VA	<input type="checkbox"/>	<input type="checkbox"/>
i. CHAMPUS/TRICARE/CHAMP - VA	<input type="checkbox"/>	<input type="checkbox"/>
j. Indian Health Service	<input type="checkbox"/>	<input type="checkbox"/>
k. State-sponsored health plan, specify plan name: _____	<input type="checkbox"/>	<input type="checkbox"/>
l. Other government program specify plan name: _____	<input type="checkbox"/>	<input type="checkbox"/>
m. Single service plan (e.g., dental, vision, prescriptions)	<input type="checkbox"/>	<input type="checkbox"/>

Appendix B. Suggested Format for Sociodemographic Data Collection According to the Ideal Standard

-continued-

Other sociodemographic information

Marital/Partner status

This item was adapted from question 12.6 of the 2007 Behavioral Risk Factor Surveillance Survey.

What is your current marital or partner status?

- Married In a civil union^{xiii} Divorced Widowed
 Separated Never married A member of an unmarried couple
 Divorced Other, specify: _____

ⁱ Adapted from 2003 revision of the *U.S. Standard Certificate of Death*.

ⁱⁱ Ibid.

ⁱⁱⁱ Ibid.

^{iv} Ibid.

^v This phrase appears in the definition of “Hispanic or Latino” in *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity* (OMB 1997: 58789).

^{vi} Ibid.

^{vii} Question from *Census 2000 - Individual Census Report* (2000: 1; item #6). Please note that unlike the survey cited, the race categories listed here appear in alphabetic order.

^{viii} The Asian subgroups listed below, except for “Taiwanese,” appear on the *U.S. Standard Certificate of Death*.

^{ix} The subcategories of “Native Hawaiian or Other Pacific Islander,” which are listed below, appear on the *U.S. Standard Certificate of Death*.

^x Adapted from the *American Community Survey* (2007: 1).

^{xi} N.B. More detailed education level categories appear in the American Community Survey.

^{xii} See *2003-4 NHANES* item HIQ.030.

^{xiii} This category has been added to reflect current state law (see Public Act No. 05-10: An Act Concerning Civil Unions).