CONNECTICUT DEPARTMENT OF PUBLIC HEALTH

Policy on Collecting Sociodemographic Data

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Connecticut Department of Public Health Policy on Collecting Sociodemographic Data

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Health Information Systems and Reporting Section Connecticut Department of Public Health Planning Branch http://www.ct.gov/dph

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.

RECORD ANALYZE REPORT COLLECT Federal Data Quantitative System & Qualitative Data DPH **Analysis** Collection Database Form Quality **Publications** Assurance Electronic Presentations Data

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 <u>and</u> 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 |
| | I |

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) | 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). |
| Gender | Male Female Other, specify | |
| Ethnicity | Hispanic or Latino Not Hispanic or Latino | 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. |
| Race | American Indian or Alaska Native Asian Black or African American Native Hawaiian or Other Pacific Islander White | The data collection form should allow selection of multiple race categories. The database should record all selections. |

When practical, self-reported information should be collected.

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

-continued-

| Data Element | Data Collecti | on Form Categories | Special Instructions |
|-----------------------|--------------------|----------------------------|--|
| | | | Only two types of ethnicity are defined in the |
| | | | 1997 OMB standard: "Hispanic or Latino" and |
| | | | "Not Hispanic or Latino." Collecting |
| A - | C | | information on ancestry provides additional |
| Ancestry ² | Specify ancestry | | information on persons who classify |
| | | | themselves as "Not Hispanic or Latino" as well |
| | | | as those who classify themselves as being of |
| | | | Spanish origin. |
| | Residential street | t address | |
| | Residential city/t | cown | |
| | Residential state | | |
| | Residential zip co | ode | *These data are derived from street address |
| Geography of | | | information. Some programs may already be |
| residence | Length of time at | current address | collecting these data instead of the residential |
| | J | | street address. |
| | 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).

-continued-

| Data Element | Data Collection Form Categories | | Special Instructions | |
|--------------|---------------------------------|-------------------------|--|--|
| | | | Some programs (e.g., those which provide services) may choose to ask about which languages a person speaks, uses at home, or | |
| | American Sign Language (ASL) | Korean | prefers to discuss or read about health-related | |
| | Armenian | Laotian | concerns. Determining the English proficiency | |
| | Chinese, Cantonese | Persian | level among its service population may also be | |
| | Chinese, Mandarin | Polish | a program requirement. | |
| | English | Portuguese | | |
| Language | French (incl. Cajun or Patois) | Russian | With the exception of ASL, the language | |
| | French Creole (e.g., Haitian) | Serbo-Croatian | categories listed here are derived from 2000 | |
| | Gujarathi | Spanish | U.S. Census data on the ability to speak | |
| | Khmer | Vietnamese | English by language spoken at home for the | |
| | | Other language, specify | 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. | |

-continued-

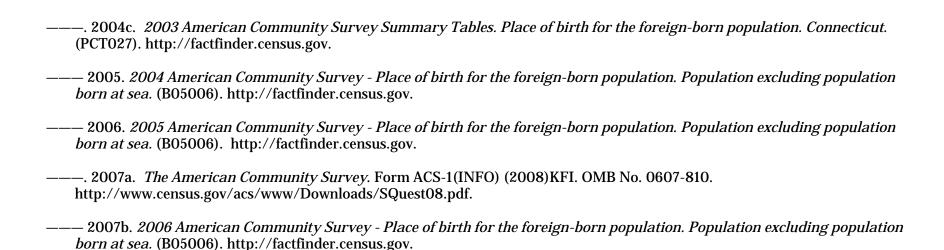
| Data Element | Data Collection Form Categories | Special Instructions | | |
|---------------|--------------------------------------|----------------------|--|--|
| | Country of birth | | | |
| | Language spoken at home | | | |
| Acculturation | English proficiency | | | |
| Acculturation | Preferred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

Other
sociodemographic
variables

Health insurance status
Marital/Partner status

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- ——. 2004a. Ancestry: 2000. Census 2000 Brief. http://www.census.gov/prod/2004pubs/c2kbr-35.pdf.
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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: Date of event: Date of event: Date of event: |
| Month Day Year 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 |

This is a <u>suggested</u> 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: |

| Race | | | | |
|---------------------------------|-------------------------------|---------------------------|--------------------------------------|--|
| What is your race? Mark (x) one | e or more boxes t | to indicate what you cons | sider yourself to be. vii | |
| _ | | | | |
| American Indian or Alaska N | Native | | | |
| Print name of enrolled or p | rincipal tribe: | | _ | |
| ☐ Asian viii | | | | |
| Asian Indian | ☐ Chinese | ☐ Filipino | ☐ Japanese | |
| ☐ Korean | ☐ Taiwanese | ☐ Vietnamese | Other Asian – Print race: | |
| ☐ Black or African American | | | | |
| ☐ Native Hawaiian or Other Pa | acific Islander ^{ix} | | | |
| ☐ Guamanian or Chamorr | ro . | ☐ Samoan | Other Pacific Islander – Print race: | |
| ☐ White | | | | |
| Other, specify: | | | | |

| A | nce | stry |
|---|-----|------|
| | | |

| Ancestry | | |
|--|----------------------|---|
| | | The list of potential responses was created from review of 2002- cticut (U.S. Census Bureau 2003; 2004c; 2005; 2006; 2007b). |
| What is your ancestry or ethnic origin? (For example: Italia | ın, Irish, Jamaican, | Indian, Puerto Rican, Mexican, Brazilian, Haitian, Taiwanese, |
| German, Portuguese, Afghani, Filipino, Croatian, Vietname | ese, Ethiopian, Ame | rican, and so on.) |
| Print ancestry: | | |
| Geography of residence and related informati | ion | |
| Residential street address | | |
| This item was adapted from the 2000 U.S. Census Individ | ual 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? :y | earsmon | ths |
| <u>Household size</u> | | |
| This item was adapted from the American Community Sur | rvey (2007: 1) | |

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

| T | | |
|-----|------|-----|
| Lar | 1911 | age |
| | | |

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: | | | |
|---|-------------|--|--|
| ☐ American Sign Language (ASL) | ☐ Gujarathi | ☐ Portuguese | |
| ☐ Armenian | ☐ Khmer | Russian | |
| ☐ Chinese, Cantonese | ☐ Korean | ☐ Serbo-Croatian | |
| ☐ Chinese, Mandarin | Laotian | ☐ Spanish | |
| ☐ English | ☐ Persian | ☐ Vietnamese | |
| ☐ French (<i>incl. Cajun or Patois</i>) | ☐ Polish | ☐ Other language – Print name of language: | |
| ☐ French Creole (for example: Haitian) | | | |
| | | | |
| In general, which languages do you usually speak/use at home? – Mark (x) one or more boxes: | | | |
| ☐ American Sign Language (ASL) | ☐ Gujarathi | ☐ Portuguese | |
| ☐ Armenian | ☐ Khmer | Russian | |
| ☐ Chinese, Cantonese | ☐ Korean | ☐ Serbo-Croatian | |
| ☐ Chinese, Mandarin | Laotian | ☐ Spanish | |
| ☐ English | ☐ Persian | ☐ Vietnamese | |
| ☐ French (<i>incl. Cajun or Patois</i>) | Polish | ☐ Other language – Print name of language: | |
| ☐ French Creole (for example: Haitian |)) | | |

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

Preferred language

☐ Not at all

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:

| 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.: |
| <u>Immigration status</u> |
| 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: |

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).

| | <i>T</i> | | | | |
|---|---|--|---|--|--|
| What is the highest grade or l | level of school you completed? Mark (| x) one box. If currently enro | lled, mark the previous grade or highest degree | | |
| received.xi | | | | | |
| ☐ Never attended school or | only attended kindergarten |] High school graduate or G | ED | | |
| ☐ Grades 1 through 8 (Elementary) | | ☐ College 1 year to 3 years (Some college or technical school) | | | |
| ☐ Grades 9 through 11 (Some high school) | | ☐ College 4 years or more (College graduate) | | | |
| ☐ Grade 12 or GED (High sc | hool graduate) | | | | |
| Are you currently? | rom item 12.9 of the 2007 Behavioral | | _ | | |
| ☐ Employed for wages ☐ Out of work for more than 1 y | | | Retired | | |
| ☐ Self-employed ☐ Out of work for less than 1 year | | A Student | Other, specify: | | |
| <u>Occupation</u> | | | | | |
| This question was adapted fi | rom item 44 of the American Commu | nity Survey (2007). | | | |
| What type of work do/did Specify type of work. (For example of work) | you do? ample: registered nurse, supervisor of | order department): | | | |

| a • | • | • . • |
|------------|--------|----------|
| Socioecon | omic i | nasifian |
| | | |

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

| <u>Personal income</u> What is your current annual income from all so | ources? |
|---|--|
| _ | |
| ☐ Less than \$10,000 | ☐ \$25,000 to less than \$35,000 |
| S10,000 to less than \$15,000 | S35,000 to less than \$50,000 |
| S15,000 to less than \$20,000 | S50,000 to less than \$75,000 |
| \$20,000 to less than \$25,000 | \$75,000 or more |
| | |
| <u>Household income</u> | |
| What is your annual household income? | |
| ☐ Less than \$10,000 | $\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ $ |
| \$10,000 to less than \$15,000 | \$35,000 to less than \$50,000 |
| \$15,000 to less than \$20,000 | \$50,000 to less than \$75,000 |
| \$20,000 to less than \$25,000 | ☐ \$75,000 or more |
| _ , , , , , , , , , , , , , , , , , , , | , |
| <u>Household size</u> (see p. 19) | |

| Other sociodemographic information | | |
|--|------------|---|
| Health insurance | | |
| This item was adapted from question 3.1 of the 2007 BRFSS Questions | naire. | |
| Do you have any kind of health care coverage including health insurance ☐ Yes ☐ No | e, prepai | d plans such as HMOs, or government plans such as Medicaid? |
| This question was adapted from item HIQ.030 of the 2003-4 National | l Health a | and Nutrition Examination Survey. |
| What kind of health insurance or health care coverage do you have? Incaccidents, or dental care.) Exclude private plans that only provide extra 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 | | |
| b. Private health care plan purchased directly | | |
| c. Private health insurance plan through a state or local government | _ | _ |
| program or community program | | |
| d. Medicare | | |
| e. Medigap (private insurance supplement to Medicare) | | |
| f. Medicaid | | |
| g. Children's Health Insurance Program (HUSKY) | | |
| h. Military health care/ VA | | |
| i. CHAMPUS/TRICARE/CHAMP - VA | | |
| j. Indian Health Service | | |
| k. State-sponsored health plan, specify plan name: | | |
| l. Other government program specify plan name: | | |
| m. Single service plan (e.g., dental, vision, prescriptions) | | |

Other sociodemographic information

| Marital/Partner | status | |
|--------------------------------|--|---|
| This item was ada | apted from question 12.6 of the 2 | 007 Behavioral Risk Factor Surveillance Survey. |
| What is your curre | ent marital or partner status? | |
| Married | ☐ In a civil union ^{xiii} | ☐ A member of an unmarried couple |
| ☐ Separated | ☐ Never married | □ Widowed |
| Divorced | Other, specify: | |
| | | |
| | | |
| | | |
| | | |
| ⁱ Adapted from 2003 | 3 revision of the <i>U.S. Standard Certi</i> | ficate of Death. |
| ii Ibid. | | |
| ⁱⁱⁱ Ibid. | | |
| iv Ibid. | | |
| v This phrase appea | rs in the definition of "Hispanic or La | atino" in Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity (OMB |
| 1997: 58789). | | |
| vi Ibid. | | |
| vii Question from Ce | ensus 2000 - Individual Census Repo | ort (2000: 1; item #6). Please note that unlike the survey cited, the race categories listed here appear in |

- viii The Asian subgroups listed below, except for "Taiwanese," appear on the U.S. Standard Certificate of Death.
- $^{\mathrm{ix}}$ The subcategories of "Native Hawaiian or Other Pacific Islander," which are listed below, appear on the $\emph{U.S. Standard Certificate of Death.}$
- ^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.

alphabetic order.

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