

Contents

Preface <u>iii</u>
Introduction <u>1</u>
Policy and Procedures <u>1</u>
The Flow of Data <u>4</u>
Table 1. Elements of the Minimum and Ideal DPH Sociodemographic Data Standards5
Table 2. Minimum Standard <u>6</u>
Table 3. Ideal Standard <u>9</u>
References <u>20</u>

Appendices

<u>Appendix A</u>: Sociodemographic Data Collection Format according to the Minimum Standard <u>Appendix B</u>: Sociodemographic Data Collection Format according to the Ideal Standard

Preface

The mission of the Connecticut Department of Public Health is to protect and improve the health and safety of the people of Connecticut by: assuring the conditions in which people can be healthy; preventing disease, injury, and disability, and promoting the equal enjoyment of the highest attainable standard of health, which is a human right and a priority of the state.

To accomplish this mission, health data of the highest quality are needed. Data provide the foundation and evidence base of public health initiatives. To be most useful, health data and 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, and also design programs that address the demonstrated health needs of the population.

Public health and social research have long demonstrated the important association of certain sociodemographic characteristics with differential health outcomes in members of the population (National Research Council 2004). Characteristics (or factors) such as race, ethnicity, age, gender, and English language proficiency of individuals are routinely collected in public health surveillance systems. However, the comparability of these data across national, local, and inter- and intradepartmental systems is dependent on how data are collected, recorded, and reported.

The DPH *Policy on Collecting Sociodemographic Data* was first established in 2008, following a two-year review and assessment of DPH data collection and coding practices (Nepaul, Hynes, and Stratton 2007). In 2015, revisions to this policy were undertaken by the DPH Data Collection Quality Improvement Committee. Revisions include the addition of new data elements added to both the Minimum and Ideal Standards, as well as the reformatting of the original policy to conform to the DPH Policy Template, established in 2015. Effective April 1, 2017, revisions to the policy were approved by Commissioner Raul Pino. *The Connecticut Department of Public Health Policy and Procedures for Collecting Sociodemographic Data* (Policy HE-03-000) is available on the DPH Intranet as well as on the DPH Office of Health Equity and Health Disparities webpages.

New data elements added in 2017 to the Minimum Data Standard include: level of English proficiency, preferred spoken language, and veteran status. New data elements added to the Ideal Data Standard include: preferred written language, need for interpretation, disability status, sexual orientation, and gender identity.

Introduction

The Connecticut Department of Public Health Policy and Procedures for Collecting Sociodemographic Data – Users' Guide is a companion document that provides detailed description of the Minimum and Ideal Data Standards for the collection of sociodemographic data in Connecticut Department of Public Health (DPH) databases.

The Users' Guide outlines *The Connecticut Department of Public Health Policy and Procedures for Collecting Sociodemographic Data*, including its purpose, procedures and processes, and a description of the flow of data. The Guide also includes tables of the minimum and the ideal DPH sociodemographic data standards with special instructions for users regarding specifics of response categories for the standards, references, and appendices, which provide detailed formats for the Minimum and Ideal Standards.

Policy and Procedures

PURPOSE

The purpose of the Connecticut Department of Public Health (DPH) *Policy and Procedures for Collecting Sociodemographic Data* is to: 1) identify minimum and ideal standards for the collection of sociodemographic data in all DPH databases for which the unit of analysis is an individual (not an institution); and 2) set the expectation that all DPH databases will employ the minimum standard by December 31, 2020 unless granted an exemption.

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

DEFINITIONS

Minimum Standard for Sociodemographic Data Collection ("Minimum Standard") – The Minimum Standard specifies sociodemographic data elements that are considered to be a minimal set for collection in DPH databases. Public health research and evidence have long demonstrated the salience of these data elements, or population characteristics, for population-based health outcomes. They include respondent: age, sex/gender, ethnicity, race, level of English proficiency, preferred spoken language, and veteran status (Table 1).

Ideal Standard for Sociodemographic Data Collection ("Ideal Standard") – The Ideal Standard includes the data elements specified in the Minimum Standard <u>and</u> additional data elements, which are known to be salient for health, and which can improve public health program activities

and enhance the description of health disparities. They include respondent: age, sex/gender, ethnicity and expanded ethnicity, ancestry, race and expanded race, geography of residence, level of English proficiency, language spoken at home, preferred spoken language for medical/health care, preferred written language, preferred written language for medical/health care, need for interpretation, country of birth, immigrant status, length of years in the United States, socioeconomic position, veteran status, disability status, sexual orientation, gender identity, and other sociodemographic data of program interest, such as marital/partner status, and health insurance coverage (Table 1).

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

POLICY

All DPH data systems will employ the Minimum Standard for collection of data on individuals. DPH will adhere to the Minimum Standard on or before December 31, 2020. Please see <u>Table 2</u> on page 6 for a complete list of the Minimum Standard elements. The Minimum Standard applies to all DPH programs, and to all entities and/or individuals that are funded in whole or in part by DPH, to conduct surveillance or research, provide services, and/or generate reports of state health data.

DPH programs are encouraged to collect, record, and report any or all of the additional data elements in the Ideal Standard that inform ongoing or future work, and to enhance the capacity of DPH to assess health disparities in Connecticut. Please see <u>Table 3</u> on page 9 for a complete list of the Ideal Standard elements. The Ideal Standard includes the all data elements outlined in the Minimum Standard, as well as additional sociodemographic data elements.

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

PROCEDURES

- The DPH Data Collection Quality Improvement Committee Chair(s) shall distribute an agency-wide notice about the revised *DPH Policy and Procedures for Collecting Sociodemographic Data*.
- This notice shall request all DPH staff members who manage databases (i.e. "data managers") to review their data collection forms and database fields/elements in light of the new policy.

- DPH data managers (or their supervisors) shall set a timetable for implementation of the new minimum standard if their database(s) do not already meet that standard.
- In cases where a data manager or supervisor believes that a particular database should be exempt from this policy, s/he will be required to set forth the rationale for an exemption to the DPH Data Quality Improvement Committee.

Possible Exemptions to the Minimum Standard:

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

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

PROCESS

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

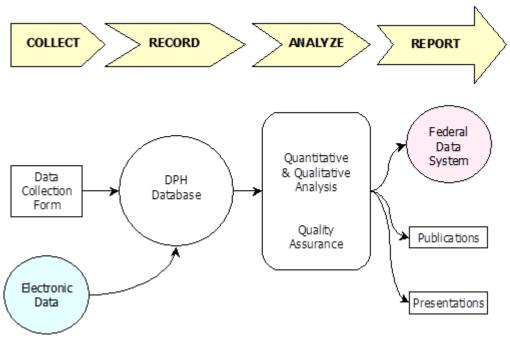
The review of the revised *DPH Policy and Procedures for Collecting Sociodemographic Data* policy will commence in October 2016. An action plan will be developed during the review process to achieve compliance, if feasible, of the identified databases in consultation with DPH database managers.

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

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 sent 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 and analyzing information from separate databases.

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

Minimum Standard	Ideal Standard
Age	Age
Sex/Gender	Sex/Gender
Ethnicity	Ethnicity and expanded ethnicity
Race	Ancestry
Level of English proficiency	Race and expanded race
Preferred spoken language	Geography of residence
Veteran status	Level of English proficiency
	Language spoken at home
	Preferred spoken language for medical/health care
	Preferred written language
	Preferred written language for medical/health care
	Need for interpretation
	Country of birth
	Immigrant status
	Length of years in the United States
	Socioeconomic position
	Veteran status
	Disability status
	Sexual orientation
	Gender identity
	Other sociodemographic data of program interest

Table 2. Minimum Standard¹

When practical, <u>self-reported</u> information should be collected.

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

 $^{^{\}scriptscriptstyle 1}$ See Appendix A for the question and answer formats.

Table 2. Minimum Standard -continued-

Data Element	Data Collection Categori	es	Special Instructions
Level of English	Very well		Federal laws affirm the right
proficiency	Well		of persons with limited
	Not well		English proficiency (LEP) to
	Not at all		have meaningful access to
	Unknown		federally-funded or federally-
			supported services. Primary
			language data collection will
			assist DPH programs target
			and serve populations, comply
			with civil rights and health
			care access laws, and reduce
			health disparities.
Preferred spoken	Albanian	Italian	With the exception of ASL and
language	American Sign Language	Korean	English, the languages listed
	Arabic	Polish	here are derived from the
	Chinese, Cantonese	Portuguese	IPUMS USA database on the
	Chinese, Mandarin	Russian	ability to speak English by
	English	Spanish	language spoken at home for
	French	Vietnamese	the Connecticut population
	Greek	Other language;	ages 5 years and older
	Haitian Creole	specify:	(American Community Survey
			2012-2016). Languages were
			identified by counts of
			Connecticut residents who
			spoke "No English" and
			English "Not Well."

Table 2. Minimum Standard –continued

Data Element	Data Collection Categories	Special Instructions
Veteran status	Yes	Per Title 38 of the Code of
	No	Federal Regulations, refers to
		"a person who served in the
		active military, naval, or air
		service and who was
		discharged or released under
		conditions other than
		dishonorable." Person could
		have served full-time with the
		Army, Navy, Air Force, Marine
		Corps, or Coast Guard; or
		served <u>active duty</u> with a
		National Guard or Reserve
		unit, the Public Health Service
		Environmental Services
		Administration, National
		Oceanic and Atmospheric
		Administration, or U.S.
		Merchant Marine.

Table 3. Ideal Standard²

When practical, <u>self-reported</u> information should be collected.

Data Element	Data Collection Categories	Special Instructions
Age	Same as Minimum Standard	
Sex/Gender	Same as Minimum Standard	
Ethnicity	Hispanic or Latino	Programs that have direct
	Cuban	community involvement may
	Mexican	consider using expanded
	Puerto Rican	ethnicity categories.
	South or Central American	
	Other Hispanic/Latin culture or origin,	
	regardless of race; specify:	
	Not Hispanic or Latino	
Race	American Indian or Alaska Native; specify	The data collection form
	tribal affiliation:	should allow selection of
	Asian	multiple race categories. The
	Asian Indian Korean	database should record all
	Chinese Taiwanese	selections.
	Filipino Vietnamese	
	Japanese Other Asian; specify:	
	Black or African American	
	Native Hawaiian or Other Pacific Islander	
	White	
	Other race; specify:	
		1

 $^{^{\}rm 2}$ See Appendix A for the question and answer formats.

Table 3. Ideal Standard -continued-

Data Element	Data Collection Categories	Special Instructions
Ancestry ³	Specify ancestry	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 Hispanic or Latino
Geography of	Residential street address	*These data are derived from
residence	Residential city/town	street address information.
	Residential state	Programs may already be
	Residential zip code	collecting these data instead
	Length of time at current address	of the residential street
	Longitude [*]	address.
	Latitude*	
	U.S. Census FIPS Area key*	
	MatchCode*	

³ 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).

Table 3. Ideal Standard -continued-

Data Element	Data Collection Categori	es	Special Instructions
Preferred written	Albanian	Italian	When choosing questions
language	American Sign Language	Korean	from the Ideal Standard
	Arabic	Polish	options, each DPH program
	Chinese, Simplified	Portuguese	should consider the source of
	Chinese, Traditional	Russian	the question, and pay close
	English	Spanish	attention to the
	French	Vietnamese	programmatic and
	Greek	Other language;	surveillance needs of the
	Haitian Creole	specify:	specific program. These
			optional questions are
			included as Appendix B.
Preferred written	Albanian	Italian	When choosing questions
language for	American Sign Language	Korean	from the Ideal Standard
medical/health	Arabic	Polish	options, each DPH program
care	Chinese, Simplified	Portuguese	should consider the source of
	Chinese, Traditional	Russian	the question, and pay close
	English	Spanish	attention to the
	French	Vietnamese	programmatic and
	Greek	Other language;	surveillance needs of the
	Haitian Creole	specify:	specific program. These
			optional questions are
			included as Appendix B.
			I

Table 3. Ideal Standard -continued-

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Data Element	Data Collection Categori	es	Special Instructions
Need for	Albanian	Italian	When choosing questions
interpretation	American Sign Language	Korean	from the Ideal Standard
	Arabic	Polish	options, each DPH program
	Chinese, Cantonese	Portuguese	should consider the source of
	Chinese, Mandarin	Russian	the question, and pay close
	English	Spanish	attention to the
	French	Vietnamese	programmatic and
	Greek	Other language;	surveillance needs of the
	Haitian Creole	specify:	specific program. These
			optional questions are
			included as Appendix B.
Other indicators	Country of birth		The U.S. Census uses these
related to non-	Immigration status		items as indicators of
U.S. born status	Number of years in the U	Inited States	"acculturation." An
			expanded discussion of the
			term acculturation may be
			found in The Collection of
			Race, Ethnicity and Other
			Sociodemographic Data in
			Connecticut Department of
			Public Health Databases
			(Nepaul et al., 2007).

Table 3. Ideal Standard -continued-

Data Element	Data Collection Categories	Special Instructions
Socioeconomic	Educational attainment	
position	Employment status	
	Occupation	
	Personal income	
	Household income	
	Household size (number of persons)	
Veteran status	Yes; currently	Same as Minimum Standard.
	Yes; in the past	
	No; except for initial/basic training	
	No; never	
Disability status 1	Difficulty hearing	This is a six-item set of
	Difficulty seeing	questions that should stay as a set. The questions and
	Difficulty concentrating, remembering, or	answer categories should not
	making decisions	be changed.
	Difficulty walking or climbing stairs	
	Difficulty dressing or bathing	
	Difficulty doing errands	
		I

Table 3. Ideal Standard -continued-

Data Element	Data Collection Categories	Special Instructions
Disability status 2	Limited due to physical, mental, or	This is a seven-item set of
	emotional problems	questions that should stay as a set. The questions and
	Any health problems requiring special	answer categories should
	equipment	not be changed.
	Difficulty seeing	
	Difficulty concentrating, remembering, or	
	making decisions	
	Difficulty walking or climbing stairs	
	Difficulty dressing or bathing	
	Difficulty doing errands	
Sexual orientation 1	Straight	Respondent can answer with
	Lesbian or gay	either the number or the text/word. Other response
	Bisexual	options that are not read bu
		allowed include "Other," "Don't know/ Not sure," or
		"Refused."
Sexual orientation 2	Gay /Lesbian or gay	Response options vary by sex
	Straight	(male/female).
	Bisexual	
	Something else	
	I don't know the answer	
Other	Health insurance status	1
sociodemographic	Marital/Partner status	
variables		

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Appendix A. Minimum Sociodemographic Data Collection Standards Format

Age
The following items were adapted from the 2017 American Community Survey (U.S. Census Bureau).
Age (in years):or-
Date of birth: and- Date of event: Month Day Year Month Day Year
Sex/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) and the Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status (US DHHS, 2011).
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
Language – level of English proficiency
This item is based on Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement (Institute of Medicine [IOM], 2009).
Mark (x) one box:
How well do you speak English?
☐ Very well ☐ Well ☐ Not well ☐ Not at all ☐ Unknown

Appendix B. Minimum Sociodemographic Data Collection Standards Format –continued–

Language – preferred spoken language			
This item is based on Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement (IOM, 2009).			
Mark (x) one box:			
Which language do you feel most comfortable speaking?			
Albanian	☐ Italian		
American Sign Language	Korean		
Arabic	Polish		
Chinese, Cantonese	Portuguese		
Chinese, Mandarin	Russian		
English	Spanish		
Greek	☐ Vietnamese		
Haitian Creole	Other Language; specify:		
Veteran status			
This item is based on the 2000-2012 American Community Surveys (U.S. Census Bureau).			
Mark (x) one box:			
Have you ever served on <u>active duty</u> in the U.S. Armed Forces, military Reserves, or National			
Guard? Active duty does not include training for the Reserves or National Guard, but DOES			
include activation, for example, for the Persian Gulf War.			
(For Death Certificates only: Ever served in U.S. Armed Forces?)			
Yes No			

Appendix B. Suggested Ideal Sociodemographic Data Collection Standards Format

This is a <u>suggested</u> format for the collection of additional sociodemographic data. Programs may choose to collect data elements outside of the minimum standard for which they have the resources and a clear purpose. The data elements of the minimum standard however must still be collected.

Age
Same as minimum standard
Sex/Gender
Same as minimum standard
Ethnicity
This item is based on Revisions to the Standards for the <u>Classification of Federal Data on Race and Ethnicity (OMB 1997)</u> and the <u>Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status (US DHHS, 2011)</u> .
Are you of Hispanic or Latino origin? Mark (x) one box:
☐ No, not of Hispanic or Latino origin ⁱ
Yes; Mexican, Mexican American, or Chicano ii
Yes; Puerto Rican ⁱⁱⁱ
Yes; Cuban ^{iv}
Yes; South or Central American
Yes; of other Hispanic or Latin culture or origin, regardless of race; specify:

Race			
What is your race? Mark (x)	one or more boxes to	indicate what you consider yourself to be. v	
American Indian or Alas	ka Native; specify name	e of enrolled or principal tribe:	
Asian ^{vi}			
Asian Indian	Chinese	☐ Filipino ☐ Japanese	
☐ Korean	Taiwanese	Vietnamese	
Other Asian; speci	fy:	<u>_</u>	
Black or African America	an		
Native Hawaiian or Othe	er Pacific Islander ^{vii}		
Guamanian or Cha	morro Samoan	Other Pacific Islander; specify:	
White			
Other; specify:			
Ancestry			
This question appeared in the 2000 U.S. Census. The list of potential responses was created from			
review of 2017-2019 American Community Survey data on persons of foreign birth in Connecticut (U.S. Census Bureau).			
,			
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, Am	erican, etc.)		
Self-reported ancestry:			

Geography of residence and related information					
Residential street address					
This item was adapted from the 2000 U.S. Census Individual Census Report.					
What is your current home address? (Fill in fields below)					
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					
<u>Household size</u>					
This item was adapted from the 2017 American Community Survey.					
Including yourself, how many people are currently living or staying at this address?					

Language – preferred spoken language for medical/health care
Source: DPH 2009
In what language do you prefer to hear about health information? Print name of language:
Source: Henry Ford Health System 2011
What language do you feel most comfortable using when discussing your health care?
Print name of language:
Source: Cambridge Health Alliance 2007
In what language do you prefer to discuss health-related concerns? Print name of language:
Source: IOM 2009, Agency for Healthcare Research and Quality (AHRQ) 2010
What language do you feel most comfortable speaking with your doctor or nurse?
Print name of language:
Source: IOM 2009, AHRQ 2010
In what language do you prefer to receive your medical care? Print name of language:
Source: IOM 2009, AHRQ 2010
What language do you want us to speak to you in? What language do you feel most comfortable
speaking?
Print name of language:
Source: IOM 2009, AHRQ 2010
What language do you prefer to speak when you come to the medical center? Print name of
language:

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

ii Ibid.

iii Ibid.

iv Ibid.

^v Note that unlike the *Census 2000 - Individual Census Report* survey cited, the race categories listed here appear in alphabetic order.

vi The Asian subgroups listed below, except for "Taiwanese," appear on the U.S. Standard Certificate of Death.

vii The subcategories of "Native Hawaiian or Other Pacific Islander" appear on the *U.S. Standard Certificate of Death.*