

**Region I
Minority Health Data
Workgroup**

CT, MA, ME, NH, RI, VT

**Departments of Health
and Region I DHHS**

Work Group Members

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Region I

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Background

2/28/01 -- DHHS Region I brought together the six New England states' Healthy People 2010 (HP2010) coordinators, Minority Health coordinators, and data analysts.

Background Continued

- **Two Workgroups were formed**
 - **HP2010 Leading Health Indicators**
 - Membership includes State BRFSS and HP2010 coordinators, State Mental Health Authority representatives, State Department of Education representatives, researchers, State Health Policy Analysts, NECON
 - **Minority Health Data**
 - Membership includes State HP2010, BRFSS, and Minority Health coordinators, and State Health Policy Analysts

Minority Health Data Workgroup

- Membership from all six NE states
- Formed to address how State Health Departments will work on minority health data issues, especially those raised by the 1997 OMB revised standards
- Meet via monthly conference calls
- Facilitated by DHHS
- Recognized need for Native American Health data subgroup

Native American Health Data Subgroup

- Formed to address lack of Native American Health data
- Representation from tribal health representatives
- Massachusetts and Maine are now working to establish collaborative relationships with tribes re: health data

Goals of the Minority Health Data Workgroup

- Coordinate New England States' efforts to address minority health data issues related to the HP2010 goal of reducing disparities
 - Review current data collection practices and plans to meet OMB revised standards
 - Coordinate future efforts to collect and analyze minority health data
 - Support states and tribes in collaborating on Native American data collection

Process of the Minority Health Data Workgroup

- Conduct Survey of NE states to:
 - Evaluate progress towards implementation of 1997 revised OMB data collection guidelines
 - Identify and classify sources of error in reporting race and ethnicity in various datasets
 - Assess progress in development of plans for bridging data from old to revised OMB reporting standards

Process of the Minority Health Data Workgroup (cont'd)

- 17 major data sets were selected for examination -- most held by each of the six participating New England state Health Departments

17 Datasets Examined

AIDS

Adult Tobacco Survey

Birth Registry

BRFSS

Cancer Registry

Childhood Lead

Death Statistics

HIV

Hospital Discharge Data

Medicaid

Newborn Screening

PRAMS

STD

TB

WIC

YRBS

Youth Tobacco Survey

Information Collected for Each Dataset

Type of Data Set
Population based
Programmatic
Disease Specific
Other
Ethnicity identifiers:
Hispanic
Others, identify:
What races does the data set collect?
White
Black/African American
Asian
American Indian/Alaskan Native
Native Hawaiian + other Pacific Islander
Other, Specify:
Is this data set consistent with 1997 revised race-ethnicity guidelines?
Is this data set used to analyze health outcomes by race/ethnicity over time?
Does this data set have any bridging plan in place?
Is race/ethnicity data in this data set critically limited or biased?

Results So Far

We are a work in progress

1997 Revised OMB Standards

When self identification is used:

- a method for reporting more than one race should be adopted
 - this method should NOT be a “multiracial” category, but rather a multiple response to a single question
- a two question format should be used, with the Hispanic origin question preceding the race question

1997 Revised Standards Cont.

- when self identification is **NOT** used (i.e: observer, proxy or record based)
 - a method for reporting **more than one race** should be adopted
 - this method should **NOT** be a “multiracial” category, but rather a multiple response to a single question
 - a two question format should be used, with the **Hispanic origin question preceding** the race question
 - a one question format may be used, with “Hispanic” as a race category

Consistency With the '97 Guidelines As of 11/02

- 35% consistency across the 17 data sets.
- 31% of data sets have revisions underway and will be consistent soon.
- 20% not applicable (do not have race data or the data set is outside the control of the health department).
- Although many of the data sets the states utilize are not *consistent* with the 1997 OMB guidelines, all are making progress toward making them *consistent*.
- There are numerous technical complexities with making the data sets compliant. The deadline for compliance for the WIC dataset, for example, was pushed back a year by the Federal government because of technical issues.

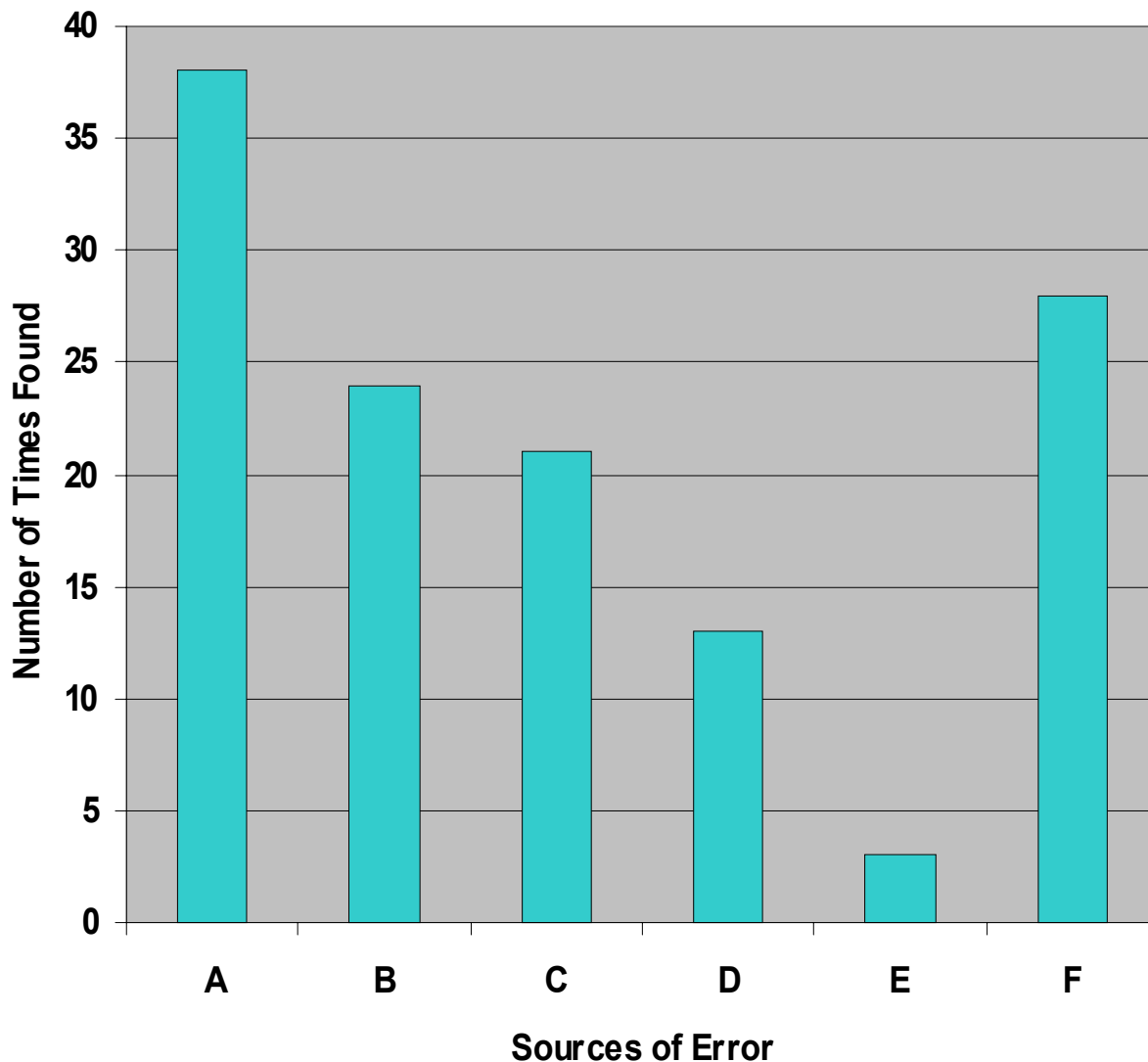
Issues in Meeting 1997 OMB Standards

- State health departments do not have control of all data sets. In practical terms this means that staff at the agencies/organizations that own the data have varying levels of commitment to meeting the 1997 Revised Guidelines.
- Many of these data sets are not required to meet the guidelines because they are not financed with federal funds.
- Data bases are static. Race and ethnicity are fluid social constructs.
- Financial Resources are needed to update databases and to train those involved in data collection.

Sources of Error

- Definition:
Condition in the data collection system that may lead to error in the ascertainment, collection and/or tabulation of race in health analyses.
- There are many different sources or causes of error with regard to minority status (race and ethnicity) in health data.
- Dealing with potential sources of errors is particularly difficult when measuring a social construct such as race.

Sources of Error (Cont.)



- A.** Non-Self Report
 - B.** Coding Does not Allow Entry of Self-Reported Choices
 - C.** Small Numbers
 - D.** High # Incompletes or Unknowns
 - E.** Unsure how Data were Collected
 - F.** Single Choice of Race Only
- Out of 102 possible

Bridging

- Method for taking data collected under the new standard and making it comparable to data collected under the old standard. Practically speaking, this involves reassigning individuals who report multiple races into single race categories.

Issues Around Bridging

- There are technical challenges involved with converting multiple responses to the census categories into a single race for both the numerators and the denominators.
- Data sets that have adopted the Revised Guidelines have translated multiple responses into the best race response categories.
- It takes financial resources to complete bridging.
- There are feasibility issues with stability of small numbers which can preclude bridging.

BRFSS Summary

- 6 out of 6 states are consistent with the 1997 guidelines.
- Example of Bridging:
 - The numerator data collected will be consistent with the new Census denominator data. States are asking the ‘best race’ question for those who select more than one race. This data will be used with the new bridged denominators that the Census/NCHS will be using in the 2000 MARS file.
- Sources of Error:
 - Small numbers.
 - Coding does not allow for data entry of self-reported choices.

Death Certificate Summary

- 3 out of 6 states consistent with the 1997 guidelines.
- Example of bridging problem:
 - States are awaiting guidance from NCHS on bridging. The death certificate is problematic as states have different timetables for implementing revised certificates. Collecting information of multiple races is a challenge because funeral directors report this information.
- Sources of Error:
 - Non-self report.
 - Single choice of race only.
 - Coding does not allow for entry of self-reported choices.

Youth Tobacco Survey Summary

- 4 out of 6 states compliant.
- Example of Bridging: Similar to BRFSS.
- Sources of Bias:
 - Coding does not allow entry of self-reported choices.
 - Small numbers.
 - Coding does not allow for entry of self-reported choices.

Issues We Face

- It is important to collect racial and ethnic data in ways that will improve policy planning and program implementation.
- Health departments don't own or have control over some data sets such as hospital discharge. This lack of control affects our ability to implement quality assurance on the databases and to effect desired public health analyses.
- More work needs to be done to understand and eliminate sources of error including the training of personnel who actually collect the data.

Where Do We Go From Here ?

- Our work group will meet in January to develop a report of our findings.
- We hope to make recommendations that will improve the quality of the data from the point it is collected onward. Resources are needed to improve the quality and consistency of the data we collect. Training of data entry people and physicians is a key issue.
- We will continue to work on bridging plans; sharing methods to help each other achieve effective, reliable bridging in our analyses.

Questions?

Detail on Sources of Error

Data Set	CT	MA	ME	NH	RI	VT
AIDS	A/F	A	C	A/F	None	A/B/F
ATS	NA	E	NA	None	NA	C
Birth Registry	F	None	None	A/F	None	B/F
BRFSS	C	B	None	None	C	C
Cancer Registry	A/F	A/E	A/D	A/F	A/D	A?/B/D/F
Childhood Lead	F	A	C	B/C/E	A/D	B/C/D
Death Statistics	A/F	A	None	A/F	A	B/F
HIV	A/F	A	None	A/F	D	A?/B/D/F
Hospital Discharge	A/F	A/B	NA	A/F	A/D	A?/B/D/F

A. Non-Self Report
B. Coding Does Not Allow Entry Of Self-Reported Choices
C. Small Numbers
D. High Numbers of Unknowns/ Incompletes
E. Unsure How Data Was Collected
F. Single Choice of Race Only

Detail on Sources of Error Cont.

Data Set	CT	MA	ME	NH	RI	VT
Medicaid	NA	B	No	NA	NA	A?/B?/F
Newborn Screening	A	B	A/C/D	A/C/D	None	N/A
PRAMS	NA	NA	C	NA	#	B/F
STD	B/F	B	C	A/F	A/D	A/B/F
TB	None	No race/ethnicity data collected	C	A/F	A/D	A/B/F
WIC	A/F	B	C	B/C/D/F	#	A/F
YRBS	NA	B	C	None	C	B/C
YTS	None	B	C	None	C	B/C

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 # Possible Underreport of American Indians