

**Policy for Maintaining, Collecting, and
Presenting
Data on Race and Ethnicity**

July 2000

Rhode Island Department of Health

Office of Minority Health

Office of Health Statistics

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I. Policy Goals and Rationale

The mission of the Rhode Island Department of Health (HEALTH) is to protect and promote the health of the population and to prevent disease through lifestyle change, environmental protection, and health services delivery. Consistent, reliable racial and ethnic data are needed to fulfill the mission of HEALTH in terms of the development and implementation of effective prevention, treatment and other needed health programs, policies, and services. Collecting racial and ethnic data is important for the purposes of research, public health surveillance, program administration, and civil rights enforcement. In the analysis of such data, we can:

- Monitor trends of existing and emerging diseases among population groups;
- Monitor and track health status among population groups;
- Assess progress in improving health among all population groups;
- Assure nondiscriminatory health care access and treatment;
- Identify issues surrounding access to care and discrimination; and
- Track the extent to which members of minority groups are beneficiaries of and participants in Federally assisted programs.

The implementation of this policy will help satisfy the public's need for consistent and relevant racial and ethnic health data. This policy sets forth standards that will be useful in Rhode Island and also be sufficient for use in federal reporting. The guidelines range from instructions for minimum reporting to very detailed reporting and are formatted in sets that can be collapsed back into minimum set for use in federal reporting. Further, this policy establishes a framework for assessing the following outcomes relating to race and ethnicity data:

- ensure that data on race and ethnicity are collected in all health systems obtaining information relevant to public health outcomes;
- ensure that such data are collected and reported in a standardized manner; and
- address the various major health data omissions identified for select population groups.

II. Background and Methodology

The first policy guide for the collection of racial and ethnic data in Rhode Island was developed in 1988. This guide was developed in response to the lack of reliable minority health data needed to assess minority health status and to monitor

access and availability of care to minorities statewide. The purpose of the guide was to provide state agencies with guidelines for collecting data on racial and ethnic minorities in a uniform and standardized fashion. The original policy guide relied on guidance from the federal Office of Management and Budget's Statistical Directive 15 (commonly referred to as OMB Directive 15), which provided a set of minimum categories to be used for racial and ethnic data collection consistent with federal reporting requirements.

At a 1998 retreat of the Minority Health Advisory Committee, updating the policy guide to reflect Rhode Island's increasingly diverse population was identified as a priority. This guide would provide a common language for uniformity and comparability in collection and use of data on race and ethnicity. The following winter, work on a new guide began. A work-plan was developed by the Offices of Minority Health and Health Statistics that would provide a framework for the development of the policy. This work plan included four phases that would result in a new policy, with a target completion date of the fall of 1999.

Phase One: Formation of Workgroups

Two workgroups assisted in the creation of the policy: The Minority Health Advisory Committee (MHAC) Data Subcommittee and the Rhode Island Department of Health (HEALTH) Internal Data Policy Development Committee. The MHAC Data Subcommittee was a group comprised of members with a special interest in data, and the HEALTH Internal Data Policy Development Committee consisted of HEALTH staff who were responsible for collecting data and maintaining data bases. Both groups met on a monthly basis to review progress on the development of the guide and to provide feedback and input as components of the guide were completed.

Phase Two: Review Policies of Other Data Collectors

Three surveys were performed to determine how racial and ethnic data were collected around the state and within HEALTH and to assess the strengths and weaknesses of the current policy guide. The surveys went to:

1. State agencies including the Department of Environmental Management; the Department of Education; the Rhode Island State Police; the Department of Elderly Affairs; the Department of Mental Health, Retardation and Hospitals; the Department of Children, Youth and Families; the Department of Labor and Training; the Department of Human Services; the Department of Judicial Systems and Sciences; the State Attorney General's Office; and the University of Rhode Island.
2. Data collectors and database owners within HEALTH.
3. Members of the Minority Health Advisory Committee.

Finally, we reviewed the policies of other organizations. Those policies included: the U.S Department of Health and Human Services, the Centers for Disease Control and Prevention, the National Institute of Health, and the California Department of Public Health (the only other state health agency identified as having such a policy).

Phase Three: Determination of Variables to be Included in Policy

The updated guide includes a suggested format for the collection of data items that go beyond the minimum standard set forth by OMB Directive 15. These are items that focus on racial and ethnic subgroups and related variables such as income, family size, and language spoken at home. In the determination of which variables to include, questionnaires were given to members of the two work groups, as well as the MHAC, asking respondents to rank selected variables on a scale of one to four in the areas of usefulness and ease of collection. The most requested variables were then included in the policy.

Phase Four: Submission of Policy for Internal and External Review

The final phase was to submit the policy for internal and external review. At this point, the policy was reviewed by HEALTH's Executive Committee, the Minority Health Advisory Committee, and HEALTH's Internal Data Policy Development Group for comment.

III. The Policy

This policy is applicable to all HEALTH programs and to all research, survey, surveillance and service activities funded, sponsored in whole or in part, and/or regulated by HEALTH with the exception of those described in section IV. The policy is as follows:

- **Inclusion of Race and Ethnicity-** Data on race and ethnicity of individuals will be included in all data collection and reporting activities covered by this policy.
- **Self-Identification-** Self- identification is the standard method for collection of data on race and ethnicity in all databases except for those exempted in Section IV (Policy Exceptions) below. Deviations from this standard will be acceptable only in cases where the use of self- identification is not possible or, where possible, is not feasible because it places an undue burden on the organization or the person responsible for collecting and/or reporting the data. Examples of persons for whom self-identification is not feasible include household surveys employing proxy respondents and medical care data reported from providers having no patient contact, e.g. laboratories. In such cases, the collection of race and ethnicity will be accomplished through the most accurate method that is both possible and feasible, such as identification by a parent or other family member. Identification by observation on the part of the data collector (e.g., medical provider, funeral director, etc.) is the least acceptable method of data collection and should be employed only when it is the sole method that is both possible and feasible. HEALTH staff will assist data managers in determining the most appropriate data collection methods for their databases and will support the rapid transition to those methods.
- **Minimum Standard of Racial and Ethnic Categories-** Race and ethnicity data will be collected in accordance with federal

policy as revised in 1997 by the Office of Management and Budget, to be effective January 1, 2000, and to be implemented no later than January 1, 2003, and any subsequent revisions. This document can be found in its entirety at:

www.whitehouse.gov/WH/EOP/OMB/html/misc-doc.htm

The minimum standard categories for racial and ethnic data collection are as follows:

Ethnic Categories:

- **Hispanic or Latino.** A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term, "Spanish origin," can be used in addition to "Hispanic or Latino."
- **Not Hispanic or Latino.** A person who is not of Hispanic origin.

Racial Categories:

- **American Indian or Alaska Native.** A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.
- **Asian.** A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand and Vietnam.
- **Black or African American.** A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."
- **Native Hawaiian or Other Pacific Islander.** A person having origins in any of the original peoples of Hawaii, Guam, Samoa or other Pacific Islands.
- **White.** A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Notes: 1.) The ethnicity question is always placed first or asked first. 2.) There is no "other race" category; however, such a category may be added if doing so results in improved data collection overall. 3.) It is required that individuals are given the option to select more than one race. This can be accomplished by including "mark one or more" in the instructions.

A. Data Collection Activities Covered by This Policy

This policy applies to the following types of data collection systems:

- All HEALTH data collection systems.
- All research, survey and surveillance activities funded by, sponsored in whole or in part by or regulated by HEALTH
- All service activities that are funded or sponsored in whole or in part by HEALTH.
- All applications, grants, and contract proposals submitted to HEALTH.
- All data submitted by regulated entities

B. Data Collection Formats

The recommended format for collecting racial and ethnic data is as follows:

Ethnicity:

- Hispanic or Latino
- Not Hispanic or Latino

Race:

Mark one or more

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

C. Use of the Standards for Record Keeping and Reporting

The minimum standard categories shall be used for reporting as follows:

- 1) **Data Reporting:** These standards shall be used for all statistical data collection that includes data on race and/or ethnicity, except when the collection involves a sample size such that data for small groups would be unreliable, or when the collection effort focuses on a specific racial or ethnic group.
- 2) **General program administrative and grant reporting:** These standards shall be used for all HEALTH administrative reporting or record keeping requirements.
- 3) **Civil rights and other compliance reporting:** These standards shall be used for civil rights and other compliance reporting. In all uses of health data for racial and ethnic groups, including those listed above, data shall be reported in a manner that is sensitive to the causes and antecedents of the health disparities experienced by minority populations. In no case shall such data be reported as to discriminate or stigmatize unfairly any population group because of its health status or patterns of behavior.

D. Presentation of Data on Race and Ethnicity

- 1) **Presenting Race and Ethnicity by the Standard Categories**
Displays of statistical, administrative and compliance data on race and ethnicity shall use the categories as described in this policy guide.
- 2) **Presenting Multiple Race Data**
It is strongly recommended that the combinations of multiple race responses (see Appendix B) be reported using the following methods:
 - a) One method is to provide separate totals for those reporting in the most common multiple race combinations and to collapse the data for other less frequently reported combinations. The specifics of the collapsed distributions would be dependent on the results of particular data collections.
 - b) A second method is to report the total selecting each particular race, whether alone or in combination with other races. These totals would represent upper bounds on the size of populations who identified with each of the racial categories. In some cases, this latter method could be used for comparing data collected under the old standards with data collected under the new standards.

IV. Policy Exceptions

Exemptions to this inclusion policy for data collection on race and ethnicity are as follows:

- 1) Research, survey, surveillance, and service directed to one or a limited number of minority racial or ethnic groups are not required to include all minimum standard categories specified in the revised federal directive but are encouraged to collect and report data on the subgroups within their targeted minority groups.
- 2) A services program may be exempted from the minimum standard categories for civil rights compliance reporting when the program is directed by Federal law to one or a limited number of minority racial or ethnic groups and would include data on only the minority groups or sub-groups to which the program was directed.
- 3) When data on particular racial and ethnic groups are considered statistically unreliable, then such racial and ethnic groups should not be reported separately unless accompanied by the appropriate caveats.
- 4) When the use of detailed racial and ethnic categories in the reporting and presentation of data involves sufficiently small numbers of individuals to pose a risk to the confidentiality of protected information, the requirement for protecting confidentiality will take precedence over the terms of this policy.
- 5) The HEALTH Director or a designee may grant special exemptions on a case by case basis.

V. Racial and Ethnic Data Collection Enhancement Options

A. Expanded Set

The expanded set is similar to the minimum set, but it provides categories for use when breaking out subgroups for various populations. While programs are not required to collect expanded set data, both the revised federal directive and HEALTH's data policy guide allow for the collection of these data, in order to better assess and document the health needs of subgroups. Programs may choose the combination of groups that best reflect their needs. These categories must be collapsed into the minimum categories for federal reporting.

Ethnicity Categories

Hispanic or Latino		
Puerto Rican	Dominican	Mexican
Guatemalan	Colombian	Other Hispanic or Latino
Not Hispanic or Latino		

Race Categories

Asian		
Chinese	Cambodian	Laotian
Hmong	Vietnamese	Filipino
Other Asian	Indian	
Black or African American		
American Black or African American	African	
Cape Verdean	Ethiopian	Ghanaian
Nigerian	Other African (specify)	

West Indian	Haitian
Native Hawaiian or Other Pacific Islander	
Native Hawaiian	Guamanian
	Other Pacific Islander

VII. Timeline and Effective Date

Timeline:

- Approval of HEALTH Executive Committee November 1999
- Public Comment Meeting May 8, 2000, 4:00 PM
- Submission of Written Comments Ends May 24, 2000
- Final Approval July 2000
- Effective Date July 1, 2000
- Implementation By January 1, 2003

VII. References

Tabulation Working Group Interagency Committee for the Review of Standards for Data on Race and Ethnicity. *Draft Provisional Guidance on the Implementation of the 1007 Standards for Federal Data on Race and Ethnicity.* (1999)

Rhode Island Department of Health and Urban League of Rhode Island. *Collection of Minority Health Statistics in Rhode Island: Policy Guide.* (1989)

U.S. Office of Management and Budget. *Statistical Directive No. 15: Race and Ethnic Standards for Federal Statistics and Administrative Reporting.* (1977)

U.S. Department of Health and Human Services. *Policy Statement on the Inclusion of Race and Ethnicity in DHHS Data Collection Activities.* (1997)

Office of Management and Budget. *Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity.* (1997)

University of California, San Francisco Family Health Outcomes Project. *Guidelines on Race/Ethnicity Data Collection, Coding and Reporting.* (1998)

Appendices

Appendix A: Comparison Table - Revisions to Race/Ethnicity Categories in OMB Directive 15

Appendix B: Sample Form for Multiple Race Reporting

Appendix C: Standardized Form for Collecting Race and Ethnicity Data

Appendix D: Other Related Variables

Appendix E: Bridging

Appendix F: Contributors to the Policy Guide

Appendix A: Comparison Table - Revisions to Race/Ethnicity Categories in OMB Directive 15

[Changes are in bold print in the right hand column.]

Current Federal Requirements Based on OMB Directive 15, in effect since May 1977	Revised Federal Minimum Requirements To be implemented no later than January 1, 2003
RACE	RACE
<u>American Indian or Alaska Native.</u> A person having origins in any of the original peoples of North America, and who maintains cultural affiliation through tribal affiliations or community recognition.	<u>American Indian or Alaska Native.</u> A person having origins in any of the original peoples of North and South America (including Central America) , and who maintains tribal affiliation or community attachment .
<u>Asian or Pacific Islander.</u> A person having origins in any of the original peoples of the Far East, Southeast Asia, the Indian subcontinent, or the Pacific Islands. This area includes, for example, China, India, Japan, Korea, the Philippine Islands, and Samoa.	<u>Asian (new group does not include Pacific Islanders)</u> A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.
[There is no Native Hawaiian or Other Pacific Islander group in the current requirements.]	<u>Native Hawaiian or Other Pacific Islander.</u> A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

<u>Black</u> A person having origins in any of the Black racial groups of Africa.	<u>Black or African American.</u> A person having origins in any of the Black racial groups of Africa. Terms such as " Haitian" or " Negro" can be used in addition to " Black or African American" .
<u>White</u> A person having origins in any of the original peoples of Europe, North Africa, or the Middle East.	<u>White</u> A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.
<u>Multiple Race</u> Not currently an option.	<u>Multiple Race</u> A method of reporting more than one race should be adopted. This can mean multiple responses to a single question. (e.g., mark one or more... select one or more) A list of races should NOT include a multiracial category.
ETHNICITY	ETHNICITY
<u>Hispanic</u> A person of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish culture or origin, regardless of race.	<u>Hispanic or Latino.</u> A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term, " Spanish origin" can be used in addition to " Hispanic or Latino."
Not of Hispanic origin	Not of Hispanic or Latino origin

Appendix B: Sample Form for Multiple Race Reporting

		Individuals who marked YES, Hispanic or Latino	Individuals who marked NO, Not Hispanic or Latino	Individuals who did not provide ethnicity information
Individuals Who Marked <u>Only One</u> Race	1. White			
	2. Black or African American [Black]			
	3. Asian			
	4. American Indian or Alaska Native [AIAN]			
	5. Native Hawaiian or Other Pacific Islander [NHOPI]			
Individuals Who Marked TWO races	6. White & Black			
	7. White & Asian			
	8. White & AIAN			
	9. White & NHOPI			
	10. Black & Asian			
	11. Black & AIAN			
	12. Black & NHOPI			
	13. Asian & AIAN			
	14. Asian & NHOPI			
	15. AIAN & NHOPI			
Individuals Who Marked THREE or MORE races	16. All combinations			
Race Missing	17. Individuals who DID NOT provide race information			
Total	Total Population [Sum of rows 1-17]			

This form may be modified to include rows for individuals who marked specific combinations of three, four or five race groups.

This form is an adaptation of the Federal form RH-1 found in the Federal Policy Guide.

Appendix C: Standardized Form for Collecting Race and Ethnicity Data

1) Are you Hispanic or Latino? [*Mark "No" if not Hispanic or Latino.*]

- No, not Hispanic or Latino
- Yes, Hispanic or Latino

2) What is your race? [*Mark one or more.*]

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

Based on the race/ethnicity questions used with the 2000 U.S. Census.

Appendix D: Other Related Variables

It is known that analysis of other variables, such as those relating to socio-economic status, are useful when looking at health issues among population groups. This type of information is often collected in health data sets, and this policy sets forth a suggested standardized format for collecting such variables. The following are suggested questions that can be used to obtain these data.

Please check the box that best describes your annual household income.

- | | |
|--|--|
| <input type="checkbox"/> Less than \$5,000 | <input type="checkbox"/> \$25,000 - \$34,999 |
| <input type="checkbox"/> \$5,000 - \$9,999 | <input type="checkbox"/> \$35,000 - \$49,999 |
| <input type="checkbox"/> \$10,000 - \$14,999 | <input type="checkbox"/> \$50,000 - \$74,999 |
| <input type="checkbox"/> \$15,000 - \$24,999 | <input type="checkbox"/> \$75,000 - \$99,999 |
| | <input type="checkbox"/> \$100,000 or more |

Are you employed?

- Yes
- No

Please check the box that best describes your occupation.

- | | |
|--|--|
| <input type="checkbox"/> Managerial and professional specialty | <input type="checkbox"/> Operators, fabricators and laborers |
| <input type="checkbox"/> Technical, sales and administrative support | <input type="checkbox"/> Farming, forestry and fishing |
| <input type="checkbox"/> Service occupations | <input type="checkbox"/> Self employed |
| <input type="checkbox"/> Precision production, craft and repair | <input type="checkbox"/> Retired |
| | <input type="checkbox"/> Not working |

Please check the box that describes the highest level of education you have completed.

- | | |
|--|--|
| <input type="checkbox"/> Less than 9 th grade | <input type="checkbox"/> Associate's degree |
| <input type="checkbox"/> 9 th to 12 th grade, no diploma | <input type="checkbox"/> Bachelor's degree |
| <input type="checkbox"/> High school graduate (includes GED) | <input type="checkbox"/> Master's degree or higher |

Please check the box of the primary language spoken in your home.

- | | |
|-------------------------------------|--|
| <input type="checkbox"/> English | <input type="checkbox"/> Korean |
| <input type="checkbox"/> Spanish | <input type="checkbox"/> Hmong |
| <input type="checkbox"/> Italian | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> Portuguese | <input type="checkbox"/> Russian |
| <input type="checkbox"/> French | <input type="checkbox"/> Other Language (please specify) |
| <input type="checkbox"/> Cambodian | |
| <input type="checkbox"/> Vietnamese | |
|
 | |
| <input type="checkbox"/> Laotian | |

Please check the box that best describes where you were born.

- Born in Rhode Island
- Born in a different state
- Born in a US territory/
commonwealth(specify)

- Born abroad of American parents
- Foreign born

What is your age in years?

- | | |
|--------------------------------|--------------------------------|
| <input type="checkbox"/> 0-4 | <input type="checkbox"/> 45-54 |
| <input type="checkbox"/> 5-9 | <input type="checkbox"/> 55-64 |
| <input type="checkbox"/> 10-14 | <input type="checkbox"/> 65-74 |
| <input type="checkbox"/> 15-19 | <input type="checkbox"/> 75-84 |
| <input type="checkbox"/> 20-24 | <input type="checkbox"/> 85+ |
| <input type="checkbox"/> 25-34 | |
| <input type="checkbox"/> 35-44 | |

What is your gender?

- Male
- Female

Please circle the number of people who live in your household.

1 2 3 4 5 6 7 8 9 10 11 or
more

Appendix E: Bridging

Note: The following is an excerpt from the Draft Provisional Guidance on the Implementation of the 1997 Standards for the Collection of Federal Data on Race and Ethnicity. This excerpt addresses the possible need for "bridging" data collected over time periods that include both methods of collecting data on race and ethnicity.

" Programs whose data are used to display time trends in economic, social and health characteristics by racial and ethnic groups may need to consider bridging methods to assist users in understanding the data collected under the new standard. For some period of time, referred to as the bridge period, programs may display historical data along with two estimates for the present time period. The first, a tabulation of the data collected under the new standard and the second, a 'bridging estimate' or prediction of how the responses would have been collected and coded under the old standards. Once the bridge period is over, the bridge estimates will no longer be needed.

"It should not be assumed that bridging is useful or required in every situation. Programs should carefully consider whether they need bridging estimates. Bridging estimates may not be needed if agencies can tolerate a 'break' in their data series or if comparison to another data series provides users with enough information about the change. If bridging estimates are not used, however, agencies should footnote the first occurrence of data collected under the new standard.

"There are at least two purposes of bridge estimates: (1) to help users understand the relationship between the old and new data series and (2) to provide consistent numerators and denominators for the transition period, before all data are available in the new format. If there is a need for bridging, agencies should carefully evaluate alternative methods."

Methods of bridging:

- (1) Deterministic whole assignment- uses fixed, deterministic rules for assigning multiple responses back to one and only one of the racial categories from the old standards.
- (2) Deterministic fractional assignment-Uses fixed, deterministic rules for fractional weighting of multiple race responses, that is, assigning a fraction to each one of the individual racial categories that are identified.
- (3) Probabilistic whole assignment- uses probabilistic rules for assigning multiple race responses back to one and only one of the previous racial categories.
- (4) All inclusive- Presents the percentages of the total number of respondent who identified with each group also are presented regardless of whether they also identified with any other group.

Appendix F: Contributors to the Policy Guide

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