



Implementation Guide: Part 1

Data collection on race and ethnicity

A tool to advance health equity in Utah

Utah Department of Health and Human Services
Office of Health Equity
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Acknowledgements

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Purpose

Availability of high-quality race and ethnicity data is crucial to identify, understand, and monitor racial and ethnic health disparities and advance health equity in Utah.

The Utah Department of Health and Human Services (DHHS) Office of Health Equity (OHE) promotes a set of uniform data collection standards for race and ethnicity information conducted by, sponsored by, or reportable to DHHS as required by the Utah Health Code (Title 26 of the Utah Code).

A set of standards promotes consistent and comparable data on race and ethnicity across the state of Utah over time. This aligns with national culturally and linguistically appropriate services (CLAS) standards that promote accurate and reliable demographic data collection.¹ Uniform data collection improves data integrity and quality so relevant and reliable data is available for decision-making purposes. Standards enhance the ability to report, track, and to identify opportunities to address racial and ethnic health disparities. The DHHS Office of Health Equity standards can be found in the publication [Guidelines for data collection on race and ethnicity](#).²

This guide is designed to facilitate implementation of race and ethnicity data collection standards for Utah. It should be used along with the [Guidelines for data collection on race and ethnicity](#). This implementation guide covers best practices for designing data collection instruments to capture race and ethnicity information and how to explain confidentiality, privacy, and purpose of race and ethnicity data collection to respondents. Further guidance on analysis and how to report race and ethnicity data is forthcoming.

Guidance to design data collection instruments³

The following guidance includes examples to design questions on race and ethnicity. These are adapted from the federal Office of Management and Budget's (OMB) Provisional Guidance on the Implementation of the 1997 Standards for Federal Data on Race And Ethnicity.³

- **Communicate clear instructions that allow, but do not require, multiple responses to the race/ethnicity question.**

Instructions for questions on race/ethnicity must clearly tell respondents they may select or give multiple races. Based on research findings,⁵ the recommended forms for this instruction are “Mark all that apply” or “Select all that apply.” Other acceptable forms for this instruction are “Select one or more,” “Mark one or more,” or “Choose one or more.”

Other instructions may be needed, especially when a race/ethnicity question is integrated into an existing data collection instrument. For example, some mailed data collection instruments do not word questions in a personal way; i.e., rather than asking, “What is your age?” a questionnaire may simply have “Age” with a line for an entry. Similarly, if a form has an entry simply worded as “Race/ethnicity” with a line to enter information, then instructions should be included to communicate that multiple race/ethnicity responses are acceptable (e.g., “Race/ethnicity—list all that apply”). Regardless of exact wording, the instruction must be clear to the respondent.

Note that computer-based or web-based survey tools should be designed to accommodate a selection of one and more than one race.

- **For data collection efforts that require detailed race or ethnicity information, consider a two-part question or follow-up questions.**

For example, respondents who first report being of Native Hawaiian/Pacific Islander origin would then be asked if they identify as Chamorro, Native Hawaiian, Samoan, Tongan, etc.

For instance, a first question might ask, “Which one or more of the following would you say is your race or ethnicity? Would you say: American Indian or Alaska Native, Asian or Asian American, Black or African American, Hispanic or Latino/a/x, Native Hawaiian or Pacific Islander, or White?” A follow-up question might prompt, “If Pacific Islander, ask: Do you identify as Chamorro, Native Hawaiian, Samoan, Tongan, or other Pacific Islander?”

- **Consider the mode of administration/data collection format in the design of questions and instructions.**

Consider the various formats that data collection could take. Data collection may be an in-person interview, paper-based, telephone-based, web-based, or other electronic format.

In addition, surveys can often use more than one mode (e.g., an initial interview attempt is an in-person visit and a follow-up attempt is a telephone interview). Since questions should be designed with the mode in mind, there may be different versions of questions depending on the mode of administration.

For example, for a telephone interview, a question on race/ethnicity may be worded as, “I’m going to read a list of race and ethnicity categories. Please choose all categories that best indicate your race or ethnicity: American Indian or Alaska Native, Asian or Asian American, Black or African American, Hispanic or Latino/a/x, Native Hawaiian or Pacific Islander, or White.” A mail-in survey may read, “Please select all that apply from the following categories to describe your race/ethnicity.”

For electronic data collection, research shows that the device used by a respondent has an impact on detailed reporting of race and/or ethnicity. There is a slightly significant decrease in detailed reporting for those who use a device with a smaller screen (i.e., phone or tablet) versus those with a larger screen.⁵

- **Provide definitions to the minimum race and ethnicity categories when possible.**

Definitions are particularly relevant when the minimum data standards for race and ethnicity are used. Individual interpretation of the six categories may differ, so definitions help improve consistency of responses. Provide definitions of the categories for self-administered forms if space and formatting limitations can be overcome. For interviewer-administered questions, the definitions should be readily available to the interviewer to help the respondent if needed. Web-based surveys can display main headings of racial and ethnic categories with definitions available by hovering over text. For race and ethnicity definitions, see the [Guidelines for data collection on race and ethnicity](#).

- **Use translated data collection forms to ensure inclusion of people from diverse backgrounds whenever possible.¹**

Data collection forms should be accessible to those with limited English proficiency. Forms translated into multiple languages can reduce bias that might result from limited English proficiency of respondents when collecting data by racial and ethnic groupings. Official language translation of data collection instruments should be used when available.

Survey questions written in plain language in English make it easier to translate into additional languages. When survey questions are written for high literacy levels, they may still not be accessible even when translated. In addition, the use of plain language helps avoid phrases/idioms that cannot be translated easily in a few words.

Attention to considerations of language access ensures language is not a barrier to complete surveys and people with limited English proficiency can be more accurately represented in data.

- **Include a clear statement of the socio-cultural and political basis of racial and ethnic groupings in public health data.³**

Provide a clear recognition of federal and/or state requirements to collect racial and ethnic data from individuals. Clearly explain that race and ethnicity have a social and cultural, rather than biological, basis.

Due to an expansion in biomedical and genetic research, some may mistake race and ethnicity as somehow genetic. The federally mandated racial and ethnic categories, however, are explicitly non-biomedical in origin.⁷

These are some sample statements that may be used:

- Race and ethnicity categories are socially defined and influenced by culture and politics. They do not have a biological basis. The federal/state government requires the collection of race and ethnicity data to monitor equal access to healthcare and social services.
- The federal/state government requires the collection of race and ethnicity data to monitor equal access in health, housing, education, employment, and other areas. The racial and ethnic categories set forth should not be interpreted as being primarily biological or genetic in reference.⁴
- The categories in the race and ethnicity classification are social-political constructs and should not be interpreted as scientific or anthropological in nature. The standards were developed to provide a common language for uniformity and comparability in the collection and use of data on race and ethnicity by federal agencies.⁴

- **Ensure data collection tools comply with the Americans with Disabilities Act (ADA) for accessibility⁸**

When data collection platforms and instruments are created for use with the public, it is critical to consider accessibility at the beginning and throughout the design phase.

The Americans with Disabilities Act (ADA) prohibits exclusion of persons with disabilities, indirectly or directly, from data collection because of their disability. Exclusion limits our knowledge and ability to identify and address health and social inequities. Data collection tools must be ADA accessible to all people. This means tools must be available in alternate formats so they can be accessed by people with a wide range of disabilities. Examples are readable PDFs online and additional time to fill out surveys. An inclusive environment should be fostered as different needs are identified and met.⁸

- **Consider asking a question about primary race/ethnicity to those who initially report two or more^{6,8}**

It is a requirement for data systems to allow respondents to select more than one race/ethnicity. However, data analysts may face challenges to provide information on multiple racial/ethnic groupings for public health assessment. Due to lack of consistent data, analysts may need to exclude records with more than one racial/ethnic category or assign these records to a single racial or ethnic group. The best method to assign a single race or ethnicity that honors self-identification is to include a question on single race/ethnicity or primary race/ethnicity for those who initially report two or more categories. Individuals who select multiple race/ethnicity categories can be asked an additional question about their primary race/ethnicity. By using the response to the primary racial/ethnic identity question, it may be easier for data analysts to create statistics that are comparable to previously collected data. However, many multiracial/multiethnic people may not be able to identify a primary race or ethnicity. Thus, it is important to allow people to indicate they do not have a primary identity. In these cases, bridging methods, which are sets of rules or statistical models that assign individuals reporting more than one race/ethnicity to one or more single racial/ethnic categories, may be necessary.

An example of how to ask respondents about primary race/ethnicity is given below.⁸ This example allows respondents to actively choose not to provide a primary race/ethnicity if it makes them uncomfortable.

If you marked **more than one** category to identify your race/ethnicity, is there **one** you think of as your **primary** racial or ethnic identity?

- Yes. Please select your primary racial or ethnic identity:
 - American Indian/Alaska Native
 - Asian/Asian American
 - Black/African American
 - Hispanic/Latino/a/x
 - Native Hawaiian/Pacific Islander
 - White
 - Some other race or ethnicity (please specify): _____
- No. I do not have just one primary racial or ethnic identity.
- N/A. I only checked one category.
- Don't know.
- Prefer not to answer.

Guidance to explain confidentiality, privacy, and purpose of race and ethnicity data collection to respondents⁸

It may be sensitive or uncomfortable for some people to provide race and ethnicity data. It is personal information, so it is important to explain why demographic information is collected and how that information is protected.

The following guidance to explain confidentiality, privacy, and purpose of race and ethnicity data collection is reproduced from the Oregon Health Authority Office of Equity and Inclusion's [Race, Ethnicity, Language and Disability \(REALD\) Implementation Guide](#)⁸ and [Reporting REALD Data on COVID-19 Encounters: Implementation Guide for Health Systems/Providers](#).⁹

General guidance to collect race and ethnicity data includes the following:⁹

- Use common sense
- Allow people to respond and use as much of their own descriptions as possible
- Respect their descriptions (or choices if you provide categories)
- Avoid words that may be considered confrontational
- If a person does not want to answer a question, move to the next question

Research conducted to test different types of messages asking patients about their racial and ethnic identity found that respondents felt more comfortable providing information when the messaging centered around improvement in the quality of services. They felt least comfortable providing information because of a personal gain or government recommendation.⁸

The following are three examples of scripts for surveyors to use when collecting race or ethnicity data. The goal of these types of messages is to increase comfort and reduce non-response rates.^{8,9} It is important that people who collect data understand the value of the messaging in obtaining high-quality data.

First, begin with a clear explanation of this type of messaging, such as:⁸

- “We ask everyone about their race and ethnicity. The goal is to help us make sure everyone receives the highest quality of care.”
- “We want to make sure all our patients get the best care possible. We would like you to tell us your race and ethnicity background so we can review the treatment all patients receive. We want to make sure everyone gets the highest quality of care.”

If the individual seems hesitant, try a message such as:⁹

- “Everyone is asked the same questions. The information helps us make sure we provide the best services to everyone.”
- “We want to guarantee everyone receives the highest quality of services. We also want to ensure the best care possible. That is why we ask everyone about their race and ethnicity.”

Examples of what **not** to say or communicate include:⁸

- “I have to ask you these questions because the government says I do.”
- “This will help us hire staff to better meet your needs.”
- “This will help us make sure **you** get the best possible care (or services).”

It is also important to explain that the information stays confidential. For example, use a version of the script below:⁸

- “The only people who see this are registration staff, administrators, and people who work in quality improvement and oversight. Your privacy is protected by law.”

Some individuals may be uncomfortable with a question or wonder why you need to ask a question. Some examples of how to respond include:⁹

- Individual: How should I answer this question?
Suggested answer: I can't tell you how to answer the question. Please answer however you identify. If you are uncomfortable answering the question, you may decline to answer. If you don't know, you can to choose “unknown” or “I don't know.”
- Individual: It's none of your business.
Suggested answer: I understand why you might feel that way. You do have the opportunity to answer or no to answer each individual question. But, it's important we have a chance to hear from you.
- Individual: (When asked about primary race) I really can't choose.
Suggested answer: It's okay to have more than one racial or ethnic identity. Is there one you relate more closely to? If not, you can choose to say multiracial, unknown, or no primary race.

The following guidance was provided by the U.S. Census Bureau's [Additional Instructions for Respondents](#)¹⁰ to help guide respondents when answering race and ethnicity questions for the census. Surveyors may find this information useful and adapt it accordingly.

“I know you might have questions when you give this information. Here are some guidelines for how to answer these questions:”

- “Your answer should be based on how you identify. Each person can decide how to answer.”
- “You can choose where to report your identity and which boxes to mark, or not mark.”
- “You don't have to mark a checkbox category to enter a response in the write-in area. You can enter your specific identity or identities in any of the write-in response areas on the race or the Hispanic origin question.”
- “You can choose one or more boxes for the race or races you identify with and enter your origins in the write-in space.”
- “If you don't know the answer, please move on to the next question.”

Conclusion

The Utah Department of Health and Human Services (DHHS) will advocate for, support, and serve all individuals and communities in Utah. We will ensure all Utahns have fair and equitable opportunities to live safe and healthy lives. Data collection using standardized categories and methodology improves the ability to identify and address health disparities. With accurate data, a more comprehensive picture of the circumstances and experiences of all Utahns will emerge through the depth and detail of high-quality disaggregated data.

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