Guidelines for data collection on race and ethnicity

A tool to advance health equity in Utah

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Contents

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 collection on race and ethnicity across the state of Utah. 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 identify opportunities to address racial and ethnic health disparities.

Individual, social, and structural determinants affect the health of people. Relationships between these determinants and pathways to health equity and quality of life are outlined in the DHHS OHE Health Equity Framework. The uneven distribution of opportunities and resources impacts individual and community health and results in health inequities in society. To promote health, wellbeing, and quality of life, Utah's public health, healthcare, and social systems must be adequate and accessible for all Utahns regardless of race or ethnic background.

Guidelines outlined in this document apply to the Utah Department of Health and Human Services as appropriate during race and ethnicity data collection in health surveys, healthcare and program registration, vital records, health systems user feedback, internal surveys, etc.

To promote uniform and consistent race and ethnicity data collection this guidance is recommended for use across all Utah state agencies, organizations receiving state funding, local health departments, healthcare organizations, other local government agencies, and all other organizations working across the state of Utah.

Along with these guidelines for race and ethnicity data collection, DHHS OHE will provide additional guidance on best practices to analyze and report race and ethnicity data in future publications. In addition, DHHS OHE will furnish guidelines to standardize the collection of data on sexual orientation and gender identity, language, and disability.

Background

Why collect race and ethnicity data?

Race and ethnicity data help data analysts and epidemiologists create statistics by race and ethnicity. Measurement of health status and associated risk factors by racial and ethnic groupings can detect differences experienced by groups and provide understanding of whether those differences are increasing or decreasing. This knowledge can help public health agencies, health care providers, and service organizations improve awareness of the health status of the racial and ethnic minority populations they serve and to develop and evaluate interventions to decrease gaps. Availability of this information in a timely and reliable manner is critical to identify, understand, and monitor racial and ethnic health disparities and advance health equity in Utah.

What are health disparities?

Health disparities are differences in health outcomes closely linked to economic, socio-cultural, environmental, and geographic disadvantage.

What is health equity?

Health equity is the principle underlying the commitment to reduce and, ultimately, eliminate health disparities by addressing their determinants. Pursuit of health equity means striving for the highest possible standard of health for all people, with special attention to the needs of those communities at greatest risk for health disparities.

What are health inequities?

Health inequities are processes that create health disparities; inequities in society create disparities in health outcomes.

Decision-makers across local, state, tribal and federal levels may use these data to[2]:

- Examine differences in opportunities and outcomes in the health of populations groups
- Examine differences in healthcare quality between population groups
- Understand challenges faced by different groups in access to public health, healthcare, and social services
- Understand the causes and correlates of racial and ethnic health disparities and monitor progress in reduction
- Reduce inequitable exposure to harms such as environmental pollutants, unsafe street designs, and substance use and overdose
- Develop and tailor outreach, interventions, programs, or services for specific groups, including the use of culturally and linguistically appropriate services
- Plan and ensure the delivery of high-quality, person-centered[3,4] care and services
- Allocate funding for programs or services to address racial and ethnic health disparities
- Develop policies to improve equitable access to educational, economic, and community resources to facilitate healthy ways of living
- Evaluate programs and policies to ensure they are fair and equitable
- Monitor fair distribution of resources and opportunities for compliance with antidiscrimination laws, regulations, and policies

Decision-makers may include government officials, policymakers, public health agencies, healthcare organizations, researchers, advocacy groups, community organizations, etc.

Funding sources and accreditation agencies are increasingly focused on health disparities and health equity; thus, the collection of high-quality, standardized race and ethnicity data becomes more important.

> **Person-centered healthcare and services**
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> "Integrated people-centered health services means putting people and communities, not diseases, at the center of health systems, and empowering people to take charge of their own health rather than being passive recipients of services." [2]
>
> "Being patient-centered means providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions." [4]

What are racial and ethnic health disparities?

Health disparities are differences in health outcomes closely linked with economic, socio-cultural, environmental, and geographic disadvantage.[6]

Health disparities are the metrics used to measure and assess health equity. As a result, health equity cannot be achieved as long as health disparities persist. Health equity is the principle underlying the commitment to reduce and, ultimately, eliminate health disparities by addressing their determinants. Pursuit of health equity means striving for the highest possible standard of health for all people with special attention to the needs of those communities at greatest risk for health disparities.

How are racial and ethnic health disparities measured?

A key component of health disparities measurement is disaggregating data by group. When disaggregated data is collected and reported, it is possible to identify health disparities. For example, in Utah, data on people who identify as Asian and people who identify as Native Hawaiian/Pacific Islander were historically collected in aggregate. However, when data from these groups were collected

separately, many health disparities were detected among people who identify as Native Hawaiian/Pacific Islander. This included a previously unknown higher rate of infant mortality in Native Hawaiian/Pacific Islander populations when compared with Utah overall. It is also important to acknowledge that significant diversity exists within each of the race and ethnicity categories and the use of broad categories masks health disparities among smaller subgroups and among multiracial and multiethnic communities.

The comparison group used to examine racial and ethnic health disparities is also important. The DHHS OHE compares race and ethnic groups to the overall Utah population or an overall Utah subpopulation. For example, racial and ethnic health disparities in diabetes would be determined by comparing the diabetes rate in adults of a particular racial or ethnic group to the diabetes rate in the overall Utah adult population and looking for differences.

> **Interpretation of race and ethnicity categories**
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> Race and ethnicity are not based on genetic differences between people.[5] With this in mind, it is important to offer context to health statistics by race and ethnicity to avoid assumptions of biological or genetic origins for health disparities, and instead look to social or structural causes.

Race and ethnicity categories and definitions

The federal Office of Management and Budget (OMB) categories for race and ethnicity,[7,8] adapted by OHE, are defined as follows:

American Indian/Alaska Native. A person with origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

Asian/Asian American. A person with 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/African American. A person with origins in any of the black racial groups of Africa.

Hispanic/Latino/a/x.* A person who is of Mexican, South or Central American, Cuban, Dominican, Puerto Rican, or other Spanish culture or origin, regardless of race. The term, "Spanish origin," can be used in addition to "Hispanic or Latino/a/x."

Native Hawaiian/Pacific Islander. A person with origins in any of the original peoples of Hawaii, Guam, Samoa, Tonga, or other Pacific Islands.

White. A person with origins in any of the original peoples of Europe, the Middle East, or North Africa.

The categories in this classification are social-political constructs and should not be interpreted as scientific or anthropological in nature. The standards were developed to provide a uniform and comparable common language in the collection and use of data on race and ethnicity by federal agencies.[5]

The OMB race and ethnicity categories represent broad population groups used for many statistical reporting and analytic purposes. These categories alone, however, are insufficient to highlight many health disparities and to target quality improvement efforts where they are most needed. Since disparities can exist within these broad OMB categories, there is value in collection and use of data with a substantially greater level of detail than mandated by the OMB standards, particularly in states with sizable racial and ethnic minority populations.[9,10]

 * The DHHS Office of Health Equity uses the term "Hispanic/Latino/a/x" to acknowledge the use of the terms "Latino", "Latina", and "Latinx" within different segments of the population.

Standards for race and ethnicity data collection

Data standards development process

The following guidance and standards adhere to the Office of Management and Budget (OMB) Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity[7] and the U.S. Department of Health and Human Services Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status.[11]

These guidelines were developed and adapted for Utah through:

- review of current federal data collection standards on race and ethnicity as the starting point for creating Utah-specific standards;
- review of the implications of research conducted by the U.S. Census Bureau on various dimensions of race and ethnicity data collection;
- examination of census data as it pertains to Utah when creating guidelines for more granular racial and ethnic data collection to show local representation;
- consultation with experts across the Utah Department of Health and Human Services offices and programs with experience in collection and analysis of demographic data; and
- engagement with community-based partners who serve racial and ethnic minority communities in Utah.

Data collection standards

This section outlines the following six (6) standards for race and ethnicity data collection:

1. Self-identification
2. Minimum categories
3. Question format
4. Multi-racial heritage
5. Additional granularity
6. Write-in option of "other"

1. Self-identification

Self-identification is the preferred way to get information about an individual's race and ethnicity. The surveyor should not tell an individual who they are, nor specify how an individual should classify themselves. Although race and ethnicity categories are explicitly defined, individuals may interpret the categories and use their own internal guide of race and ethnicity to answer in the way they believe is best.[12]

When self-reporting is not possible, race and ethnicity data may be collected from a knowledgeable proxy as appropriate and in compliance with applicable policies.

> "When an individual self-identifies as being from a certain population subgroup, it may also mean that the individual is more likely to have health beliefs, health care use patterns, and perspectives about the healthcare system that are common to that community."[13]

2. Minimum categories

The specified race and ethnicity categories provide a minimum set of requirements except when collection involves a sample of such size that the data on the smaller categories would be unreliable, or when the collection effort focuses on a specific racial or ethnic group.

- In accordance with federal OMB standards, the DHHS OHE minimum categories for race are: American Indian/Alaska Native, Asian/Asian American, Black/African American, Native Hawaiian/Pacific Islander, and White. These categories must be presented as a multi-select choice option so respondents can choose multiple categories if applicable.
- In accordance with federal OMB standards, DHHS OHE minimum categories for ethnicity are: Hispanic/Latino/a/x and Not Hispanic/Latino/a/x.

The OMB categories for race and ethnicity, adapted by DHHS OHE for Utah, are defined as follows:

American Indian/Alaska Native. A person with origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

Asian/Asian American. A person with 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/African American. A person with origins in any of the black racial groups of Africa.

Hispanic/Latino/a/x.* A person who is of Mexican, South or Central American, Cuban, Dominican, Puerto Rican, or other Spanish culture or origin, regardless of race. The term, "Spanish origin," can be used in addition to "Hispanic or Latino/a/x."

Native Hawaiian/Pacific Islander. A person with origins in any of the original peoples of Hawaii, Guam, Samoa, Tonga, or other Pacific Islands.

White. A person with origins in any of the original peoples of Europe, the Middle East, or North Africa.

The categories in this classification are social-political constructs and should not be interpreted as scientific or anthropological in nature. The standards have been developed to provide a uniform and comparable common language in the collection and use of data on race and ethnicity by federal agencies.[7]

* The DHHS Office of Health Equity uses the term "Hispanic/ Latino/a/x" to acknowledge the use of the terms "Latino", "Latina", and "Latinx" within different segments of the population.

3. Question format

Collect data on race and ethnicity in a combined format. Overall, this format produces the highest data quality. Both race (including multiple responses) and ethnicity should be collected when appropriate and feasible, although the selection of one category by a respondent in the combined format is acceptable. A combined format presents 6 minimum race/ethnicity categories, with the optional addition of an "Other Race or Ethnicity" category and a "decline to answer" category. See Appendix A for a sample race and ethnicity data collection template.

> **Minimum Combined Format Data Standard**
>
> What is your race/ethnicity? (Select all that apply.)
>
> ___ 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):
>
> _____
>
> ___ Prefer not to answer

In limited instances, race and ethnicity data may need to be collected separately. An explanation of how to do this is provided in Appendix B.

4. Multi-racial heritage

When self-reporting or other self-identification approaches are used, respondents should be offered the option of selecting one or more racial designations to identify their multi-racial heritage. People who identify with more than one race may choose to report multiple races. Recommended instructions which accompany the race/ethnicity question include "mark all that apply" and "select all that apply". There is no "multi-racial" category.

5. Additional granularity

In accordance with federal OMB standards, DHHS OHE encourages additional granularity where it is supported by sample size; as long as the additional detail can be aggregated back to the minimum standard set of race and ethnicity categories. Agencies and organizations must consider the feasibility and practicality of collecting more granular race and ethnicity data. See Section 4 for additional guidance.

The detailed race and ethnicity categories roll up to the minimum standard six (6) race and ethnicity categories: American Indian/Alaska Native, Asian/Asian American, Black/African American, Hispanic/Latino/a/x, Native Hawaiian/Pacific Islander, and White. Respondents are instructed to mark all categories that apply (i.e., they are able to select more than one race/ethnicity category).

Additional granularity data standard

What is your race/ethnicity? (Select all that apply.)

___ American Indian/Alaska Native
___ Canadian Inuit, Metis, or First Nation
___ Indigenous Mexican, Central American, or South American
___ Some other American Indian/Alaska Native (please specify):
_____

These categories roll up to the American Indian/Alaska Native category of the minimum standard

___ Asian Indian
___ Chinese
___ Filipino/a
___ Japanese
___ Korean
___ Vietnamese
___ Some other Asian/Asian American (please specify):
_____

These categories roll up to the Asian/Asian American category of the minimum standard

___ African American
___ Black African
___ Black Caribbean
___ Some other Black (please specify):
_____

These categories roll up to the Black/African American category of the minimum standard

___ Central American
___ Mexican, Mexican American, Chicano/a
___ South American
___ Spanish/Spaniard
___ Some other Hispanic/Latino/a/x (please specify):
_____

These categories roll up to the Hispanic/Latino/a/x category of the minimum standard

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Additional granularity data standard (contd.)

___ Chamorro
___ Native Hawaiian
___ Samoan
___ Tongan
___ Some other Pacific Islander (please specify):
_____

These categories roll up to the Native Hawaiian/Pacific Islander category of the minimum standard

___ White European
___ Middle Eastern/North African
___ Some other White (please specify):
_____

These categories roll up to the White category of the minimum standard

___ Some other race/ethnicity (please specify):
_____

___ Prefer not to answer

Chamorro vs. Guamanian

"Chamorros are the indigenous people of the Mariana Islands of which Guam is the largest and southernmost on an island chain."[15] Based on research and stakeholder feedback, the U.S. Census Bureau removed the term "Guamanian" from the race question on the 2020 Census, retaining "Chamorro" as the preferred term.[16]

For data collection efforts requiring detailed race or detailed ethnicity information, surveyors should consider collecting this information through a two-part question or follow-up questions. For example, respondents who first identify as Native Hawaiian/Pacific Islander would then be asked if they identify as Chamorro, Native Hawaiian, Samoan, Tongan, or other Pacific Islander. For further information about data collection instrument design, see the Implementation guide for data collection on race and ethnicity.

6. Write-in option of "other"[17]

Agencies and organizations may include a write-in category option of "some other race/ethnicity" or "other" to surveys with an open-ended request to specify. This respondent-specified race must then be coded to the minimum race/ethnicity categories before results are publicly reported. The OMB 1997 Standard does not provide a recommendation for this category, but authorizes its use on the U.S. Census. Including an "other" category and asking people to specify their race can facilitate understanding the perspective of respondents who do not identify with any of the standard groupings.

Decision-making guidance for granular race and ethnicity data collection

There is recognized value in collection and use of disaggregated race and ethnicity data that is more granular than the minimum requirements. Significant diversity of races, ethnicities, ancestries, and cultures exists within each of the minimum categories. This translates into a wide variation in health histories and experiences, and the use of broad race and ethnicity categories will, at times, obscure health disparities among smaller subgroups. Through collection and data analysis at a more granular level, health disparities that would otherwise be undetected or ignored may be identified and addressed.[18]

Disaggregating data within race and ethnicity categories has the power to create the kind of visibility and inclusion to advance health equity. Providing categories for additional granularity may help individuals feel their racial and ethnic identities are better represented. Additionally, better responses to race and ethnicity questions generates more accurate data. High-quality, disaggregated data on race and ethnicity can guide the design and application of community-specific programs and policies that reduce and eliminate racial and ethnic health disparities and inequities. By improving data disaggregation, government officials, policymakers, public health agencies, healthcare organizations, researchers, advocacy groups, and community organizations, can better influence the health environments, behaviors, and outcomes of diverse communities.[18]

It is important, however, to balance the desire to build a more robust practice of disaggregating racial and ethnic data with concerns about privacy and confidentiality; the added complexity and expense to data collection, analysis, and reporting; and the technical capacity of systems to keep up with innovations. Observe the following recommendations to help determine whether more granular data collection is a feasible pursuit.

Considerations for granular race and ethnicity data collection

The following guidance is offered to data managers, researchers, and practitioners to incorporate into a decision-making process to determine the feasibility of disaggregated race and ethnicity data collection. The considerations below are not presented in order of importance nor order of operations. Activities are overlapping and build on each other.

- **Articulate a clear purpose for the need for disaggregated race/ethnicity data.**

Agencies and organizations interested in granular race/ethnicity data collection must be able to explain how the additional information will enhance their understanding and analysis of health status among populations served. They must be able to explain the application of disaggregated data toward the goal of health and wellbeing improvement and health equity advancement. Creation of a written data analysis and evaluation plan in the early stages of planning may facilitate a deeper understanding of the purpose and application of disaggregated race and ethnicity data.

In addition, agencies and organizations should anticipate implications of the use and application of disaggregated data including potential benefits and negative consequences that could arise. This process may help them engage in honest dialogue with communities and discuss anticipated challenges and potential solutions.

- **Assess capacity to collect, analyze, and report disaggregated race and ethnicity data**

Granular data collection may be possible in some instances but not in all cases. Agencies and organizations must honestly assess their capacity to collect, analyze, and report granular data. These assessments should cover staff time and expertise, availability of resources, and the capability and interoperability of data systems.

In undertaking a population survey, for example, the detailed enumeration of racial and ethnic subgroups can be an expensive and complex operation. More questions and more respondents require more resources. Better pre-testing, larger and more stratified samples, surveys administered in more languages, additional items in limited questionnaire space, greater outreach efforts to hard-to-contact households, more diverse and culturally competent staff, and more sophisticated coding to integrate previously unrelated databases are all improvements that will take larger budgets to achieve.[18] Therefore, it is important to determine relative costs and benefits of more granular data collection.

The agency or organization must determine whether it can obtain the additional resources necessary to collect and analyze information about a wide range of racial and ethnic groups, and to reliably connect this information to important health variables.[18] Additionally, more granular data collection may result in small population numbers, which may not be shareable depending on the agency's suppression guidance.

- **Consult existing data to construct initial categories for disaggregated race and ethnicity data**

Agencies and organizations who endeavor to collect disaggregated race and ethnicity data from individuals should select categories to most accurately reflect the make-up of the populations they serve. To determine which categories to use, a helpful starting point is archival data. Sources of data may include:

  ○ An agency or organization's own demographic data collected on populations served
  ○ U.S. Census Bureau race, ethnicity, and ancestry data filtered by local geography
  ○ Recent reports published by the state of Utah, local health departments, and other agencies

- **Engage with communities who may be most impacted by data disaggregation activities**

Archival data on demographics should be supplemented by the knowledge and expertise of the communities served. Agencies and organizations can identify community leaders or groups who serve different racial and ethnic minority populations for insight on important subpopulations within these communities. In addition, inclusion of groups that seem to face the highest health disparities, greatest barriers to care, and least access to resources— those who are often overlooked—should be given due consideration. Valuable insight can be gained through opportunities to talk directly to community members to learn about their lived experiences and how they make decisions.

Agencies and organizations should thoroughly communicate the potential benefits, costs, and risks of increased data disaggregation among communities.[18] It is important to be honest about all known implications of disaggregated data collection and reporting up front and to take responsibility for mitigation of negative consequences if they do occur.

Agencies and organizations can use this process of community consultation as a way to strengthen relationships and to reach out to new, perhaps non-traditional partners. Investment in partnerships through mentoring, technical assistance, capacity building, and two-way dialogue builds genuine relationships. These activities help leverage support to reach people who bear the greatest burden of health disparities and address health needs in the greater context of social needs. Integrating lived experiences into solutions improves the ability of all partners to advance health equity.

- **Ensure privacy of respondents in data disaggregation of small populations**

Agencies and organizations should assess whether granular data collection will introduce privacy concerns. In granular data and data disaggregation collection practices, they must ensure the

confidentiality of respondents' data and comply with their privacy and suppression guidance.

Some community members may be hesitant to share their data. They may feel they are being asked to provide personal information that is unnecessary or even risky for them to share. At times, the best decision is not to collect granular race and ethnicity data and use only the minimum categories instead.

Agencies and organizations must work through these concerns in partnership with communities so community members know their best interests are being considered in the effort to achieve the benefits of disaggregated data.

> "Widespread collection of disaggregated race/ethnicity data on government questionnaires may spark privacy concerns, especially for members of smaller populations. For example, stratifying health and vital statistics by disaggregated race/ethnicity and locality may inadvertently reveal respondents' identities."[19]

- **Document and share lessons learned to build capacity in granular data collection and use**

Agencies and organizations can promote a learning and growth mindset by documentation and examination of failures and successes.[20] Sharing knowledge with stakeholders as a part of this process advances inclusive and informed decision-making across sectors. Action on lessons learned creates opportunities to reassess strategies to improve the quality, availability, and use of disaggregated data.

Agencies and organizations should also create opportunities for community partners to provide feedback on the processes and results of disaggregated data collection. It is valuable to include communities, who are the ultimate beneficiaries, in these processes.

Examples of disaggregated race and ethnicity data collection categories for Utah-specific detailed additional granularity

The DHHS Office of Health Equity (OHE) encourages agencies and organizations to go through a thorough decision-making process to determine whether granular data on race and ethnicity would be feasible to collect, analyze, and report.

Once agencies and organizations determine additional granularity in race and ethnicity data would be beneficial, they can refer to DHHS OHE's examples of disaggregated race and ethnicity categories relevant to Utah, presented below, as a starting point. Organizations will likely need to use different categories or even more detailed categories than the ones compiled by DHHS OHE given below.

Examples presented on the following page are based mainly on population data for Utah obtained from the U.S. Census Bureau. Some important racial and ethnic minority groups that are small in population may not be represented. Furthermore, because most granular race and ethnicity categories are national origins, most pan-national ethnicities and races, such as Arab, are not represented as they cannot be classified under a single broad race or ethnicity category. In the example of Arab ethnicity, a person who is Arab may identify within any number of categories, such as White, Black, or Asian. In this case, a person would self-identify their race, then write in their Arab identity in an "other" category.

DHHS OHE encourages organizations and agencies to spend time to understand and engage with communities to determine which additional race and ethnicity categories best reflect respondent population identities in order to substitute or replace the categories suggested by DHHS OHE. Additional race/ethnicity categories must be further identified or vetted with communities, stakeholders, and other experts so they correspond to the make-up of local populations.

The main requirement to use additional granularity for data collection is to aggregate additional categories back into the minimum race and ethnicity categories.

American Indian/Alaska Native

For surveyors interested in collecting additional granularity for American Indian/Alaska Native populations, the recommended first step is consultation with the Utah Department of Health and Human Services Office of American Indian/Alaska Native Health & Family Services. A Tribal consultation policy is in place between DHHS and federally-recognized tribes of Utah and the Urban Indian Center of Salt Lake, which is based on consultation, communication, and cooperation with each tribal government. For more information about the Tribal consultation policy or collecting detailed race and ethnicity data from people who are American Indian/Alaska Native tribal members, contact the DHHS Office of American Indian/Alaska Native Health & Family Services.

Additional granularity options exist for American Indian/Alaska Native tribal affiliation and descendancy. Additional granularity will be considered on a case-by-case basis through formal consultation with the tribes of Utah and the Urban Indian Center of Salt Lake.

Asian/Asian American

In the side panel are example categories for additional detail for the Asian/Asian American race category. In this approach, population data from the following Census ancestry table were consulted: *U.S. Census Bureau 2015–2019 ACS 5-Year Estimates, Table B02018 "Asian Alone Or In Any Combination By Selected Groups."*

This table presents the 9 most populous Asian/Asian American sub-groups in Utah. Some surveyors may find it useful to collapse these and other Asian/Asian American sub-groups into regions of cultural similarity such as "Southeast Asian" or "South Asian." Consideration should also be given to whether there is a need to represent specific populations such as refugee populations. Seek guidance on additional categories from community groups and regional or local level data.

An open-ended response option of "other, please specify" can be offered to elicit responses from individuals who do not identify with the available categories. An open-ended response option can help data collectors understand the limitations of the categories offered and identify new or emerging categories that may be useful to add in the future.

__ Asian Indian
__ Cambodian
__ Chinese
__ Filipino/a
__ Japanese
__ Korean
__ Laotian
__ Thai
__ Vietnamese
__ other Asian/Asian American
   (please specify):
   _____

Other response options:
__ other Southeast Asian
__ other South Asian

Black/African American

In the side panel are example categories for additional detail for the Black/African American race category. In this approach, population data from the following Census ancestry table were consulted: *U.S. Census Bureau 2016–2020 ACS 5-Year Estimates, Table B04006 "People Reporting Ancestry."*

This table presents the most populous Black/African American sub-groups in Utah with populations of more than 700. Consideration should also be given to whether there is a need to represent specific populations such as refugee populations. Seek guidance on additional categories from community groups and regional or local level data.

An open-ended response option of "other, please specify" can be offered to elicit responses from individuals who do not identify with the available categories. An open-ended response option can help data collectors understand the limitations of the categories offered and identify new or emerging categories that may be useful to add in the future.

__ African American
__ Ethiopian
__ Jamaican
__ Kenyan
__ Somali
__ Sudanese
__ other Black African
__ other Black Caribbean
__ other Black (please specify):
_____

Hispanic/Latino/a/x

In the side panel are example categories for additional detail for the Hispanic/Latino/a/x ethnicity category. In this approach, population data from the following Census ancestry table were consulted: *U.S. Census Bureau 2015–2019 ACS 5-Year Estimates, Table B03001 "Hispanic Or Latino Origin By Specific Origin."*

This table presents the 9 most populous Hispanic/Latino/a/x sub-groups in Utah. Some surveyors may find it useful to collapse these and other Hispanic/Latino/a/x sub-groups into regions of geographical proximity such as "Central American" or "South American." Consideration should also be given to whether there is a need to represent specific populations such as refugee populations. Seek guidance on additional categories from community groups and regional or local level data.

An open-ended response option of "other, please specify" can be offered to elicit responses from individuals who do not identify with the available categories. An open-ended response option can help data collectors understand the limitations of the categories offered and identify new or emerging categories that may be useful to add in the future.

__ Argentinean
__ Colombian
__ Guatemalan
__ Mexican, Mexican American, Chicano/a
__ Peruvian
__ Puerto Rican
__ Salvadoran
__ Spanish/Spaniard
__ Venezuelan
__ Other Hispanic/Latino/a/x (please specify):
_____

Other response options:
__ other Central American
__ other South American
__ other Caribbean

Native Hawaiian/Pacific Islander

In the side panel are example categories for additional detail to the Native Hawaiian/Pacific Islander race category. In this approach, population data from the following Census ancestry table were consulted: *U.S. Census Bureau 2016–2020 ACS 5-Year Estimates, Table B02019 "Native Hawaiian And Other Pacific Islander Alone Or In Any Combination By Selected Groups."*

This table presents the most populous Native Hawaiian/Pacific Islander sub-groups in Utah with populations of more than 700. Consideration should also be given to whether there is a need to represent specific populations such as refugee populations. Seek guidance on additional categories from community groups and regional or local level data.

An open-ended response option of "other, please specify" can be offered to elicit responses from individuals who do not identify with the available categories. An open-ended response option can help data collectors understand the limitations of the categories offered and identify new or emerging categories that may be useful to add in the future.

__ Chamorro
__ Fijian
__ Micronesian/Marshallese/
Palauan (COFA communities)
__ Native Hawaiian
__ Samoan
__ Tongan
__ other Pacific Islander (please specify):
_____

White

In the side panel are example categories for additional detail for the White race category. This approach presents broad geographic groupings. Another approach would be to present ancestries/countries of origin based on population size in Utah, which can be determined from the following Census ancestry table: *U.S. Census Bureau, Table B04006, "People Reporting Ancestry."* Consideration should also be given to whether there is a need to represent specific populations such as refugee populations. Seek guidance on additional categories from community groups and regional or local level data.

An open-ended response option of "other, please specify" can be offered to elicit responses from individuals who do not identify with the available categories. An open-ended response option can help data collectors understand the limitations of the categories offered and identify new or emerging categories that may be useful to add in the future.

__ Eastern European
__ Middle Eastern/North African
__ Scandinavian/Nordic
__ Slavic
__ Western European
__ White American
__ White Australian/New
Zealander
__ other White (please specify):
_____

Open-ended race/ethnicity question

In addition to the use of granular race/ethnicity categories to better capture disaggregated data, surveyors may want to consider the inclusion of an open-ended question on race, ethnicity, country of origin, or ancestry. Such a question may look like the one in the side panel.

An open-ended response option can help data analysts understand the limitations of the categories offered and identify new or emerging categories that may be useful to add in the future.

How do you identify your race, ethnicity, country of origin, or ancestry? Please specify.

_____

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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Appendix A: Race and ethnicity data collection template

Utah Department of Health & Human Services
Health Equity

Race and ethnicity data collection template

These questions are optional and your answers are confidential. We would like you to tell us your race and ethnicity so that we can identify and address health differences.

1. How do you identify your **race, ethnicity, country of origin, or ancestry**?

_____

2. Which of the following describes your **racial or ethnic identity**? Please check **all** that apply.

American Indian/Alaska Native
- ☐ American Indian/Alaska Native
- ☐ Indigenous Mexican, Central American, or South American
- ☐ Canadian Inuit, Metis, or First Nation
- ☐ Some other American Indian/Alaska Native (specify below):

_____

Asian/Asian American
- ☐ Asian Indian
- ☐ Chinese
- ☐ Filipino/a
- ☐ Japanese
- ☐ Korean
- ☐ Vietnamese
- ☐ Some other Asian/Asian American (specify below):

_____

Black/African American
- ☐ African American
- ☐ Black African
- ☐ Black Caribbean
- ☐ Some other Black (specify below):

_____

*The DHHS Office of Health Equity uses the term "Hispanic/Latino/a/x" to acknowledge the use of the terms "Latino", "Latina", and "Latinx" within different segments of the population.

Hispanic/Latino/a/x*
- ☐ Central American
- ☐ Mexican, Mexican American, Chicano/a
- ☐ South American
- ☐ Spanish/Spaniard
- ☐ Some other Hispanic/Latino/a/x (specify below):

_____

Native Hawaiian/Pacific Islander
- ☐ Chamorro
- ☐ Native Hawaiian
- ☐ Samoan
- ☐ Tongan
- ☐ Some other Pacific Islander (specify below):

_____

White
- ☐ White European
- ☐ Middle Eastern/North African
- ☐ Some other White (specify below):

_____

Other responses
- ☐ Some other Race/Ethnicity (specify below):

_____

- ☐ Prefer not to answer

3. If you picked **more than one** category to identify your race/ethnicity, is there **one** you think of as your **primary** racial or ethnic identity?
- ☐ Yes. Please circle your primary racial or ethnic identity above
- ☐ I do not have just one primary racial or ethnic identity
- ☐ N/A. I only selected one from the available options
- ☐ Don't know
- ☐ Prefer not to answer

This template has been adapted from the Oregon Health Authority's *Reporting REALD Data on COVID-19 Encounters: Implementation Guide for Health Systems/Providers*

Appendix B: Two-question format for collecting data on race and ethnicity

Although the Utah standard for collecting race and ethnicity data is to use a combined format, in some instances, separate questions for race and ethnicity may be necessary.

When using a two-question format, ask ethnicity <u>first</u> and race <u>second</u>. This order is important to avoid confusion and improve response rate among those who identify themselves as Hispanic or Latino/a/x. Asking ethnicity first also reduces reporting of "other race".[21]

Minimum Two-Question Format Data Standard

Ethnicity Data Standard

Are you Hispanic, Latino/a/x, or of Spanish origin?
___ Yes
___ No

Race Data Standard

What is your race? (Select all that apply.)

___ American Indian/Alaska Native   ___ Native Hawaiian/Pacific Islander
___ Asian/Asian American   ___ White
___ Black/African American   ___ Some other race or ethnicity (please specify):
___ Prefer not to answer

        _____

In some instances, a hybrid of the two-question format and combined format may be used when there is a need to satisfy multiple requirements with race and ethnicity data collection. In this case, a question on ethnicity would be asked first, and then the combined question for race and ethnicity would be asked second. An example of this is as follows:

Are you Hispanic, Latino/a/x, or of Spanish origin?
___ Yes
___ No

What is your race/ethnicity? (Select all that apply.)

___ American Indian/Alaska Native   ___ Hispanic/Latino/a/x
___ Asian/Asian American   ___ Native Hawaiian/Pacific Islander
___ Black/African American   ___ White
___ Prefer not to answer   ___ Some other race or ethnicity (please specify):

        _____

Appendix C: Additional research and resources

The following research studies and resources are provided for the purpose of gaining further clarity and in-depth understanding of topics related to the capture of racial and ethnic data in the United States:

- Results of the U.S. Census Bureau's National Content Test, which researched multiple key dimensions for improving data on race and ethnicity.
  - United States Census Bureau. (2017). *2015 National Content Test Race and Ethnicity Analysis Report: A New Design for the 21st Century*. Retrieved from: www2.census.gov/programs-surveys/decennial/2020/program-management/final-analysis-reports/2015nct-race-ethnicity-analysis.pdf

- Summary of findings from a forum held by the U.S. Census Bureau on the inclusion of a 'Middle Eastern/North African' category for race and ethnicity data collection.
  - Buchanan, A., Marks, R., & Figueroa, M. A. (2015, May 29). Meeting Summary and Main Findings. 2015 Forum on Ethnic Groups from the Middle East and North Africa. Population Division U.S. Census Bureau, Washington. Retrieved from: https://www.census.gov/content/dam/Census/library/working-papers/2015/demo/MENA-Forum-Summary-and-Appendices.pdf

- Census Bureau Diversity Index & Prevalence mapping:
  - www.census.gov/newsroom/blogs/random-samplings/2021/08/measuring-racial-ethnic-diversity-2020-census.html

- Robert Wood Johnson Foundation: Better Data for Better Health
  - Charting a Course for an Equity-Centered Data System - Recommendations from the National Commission to Transform Public Health Data Systems: www.rwjf.org/en/library/research/2021/10/charting-a-course-for-an-equity-centered-data-system.html
  - The Opportunity Atlas: www.opportunityatlas.org

- Utah Department of Health and Human Services Office of Health Equity
  - Language and Culture Resources: https://healthequity.utah.gov/language-and-culture/
  - Culturally and Linguistically Appropriate Services (CLAS) Standards Toolkit https://healthequity.utah.gov/wp-content/uploads/2022/02/CLASTOOLKIT.pdf
  - Language Translation Manual: https://healthequity.utah.gov/wp-content/uploads/2022/02/TranslationManual.pdf
  - Language Translation Toolkit: https://healthequity.utah.gov/wp-content/uploads/2022/02/TranslationToolkit.pdf