

The Reporting of Race and Ethnicity in Medical and Science Journals

Comments Invited

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For many years and increasingly in the last year, *JAMA* and the *JAMA Network* journals have published many important articles addressing disparities and racism in medical education, research, and health care¹⁻⁹ and highlighting initiatives to help address deep-rooted inequities.¹⁰⁻¹⁶ In these articles, as in others, terminology, usage, and word choice are critically important, especially when describing people and when discussing race and ethnicity. Inclusive language supports diversity and conveys respect. Language that imparts bias toward or against persons or groups based on characteristics or demographics must be avoided.

The indistinct construct of racial and ethnic categories has been increasingly acknowledged, and the important sensitivities and controversies related to use of these terms in medical and health research, education, and practice have been progressively recognized. Accordingly, for articles published in medical and science journals, language and termi-

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nology must be accurate, clear, and precise, and must reflect fairness, equity, and consistency in use and reporting of race and ethnicity.

The *AMA Manual of Style: A Guide for Authors and Editors*¹⁷ provides extensive guidance to authors and editors who write, edit, and publish in the biomedical literature, including specific guidance regarding usage and reporting of race and ethnicity. This resource includes recommendations on publishing research, review, and opinion articles and addresses manuscript preparation and formatting, references, data presentation in tables and figures, ethical and legal considerations, study design and statistics, proper use of medical nomenclature, and correct and preferred usage of common words and phrases. The *AMA Manual of Style* committee (which is composed of members of the *JAMA Network* editorial staff) regularly reviews and updates recommendations and policies. For example, last year, new terms were added for COVID-19 and SARS-CoV-2 and, along with other major style manuals, changes were made to recommend consistent capitalization of terms for all racial and ethnic categories.

Over the past 8 months, the committee has been revising the entire subsection on race/ethnicity in the section on inclusive language of the *AMA Manual of Style*. This revision was based on research by the committee members, followed by ex-

ternal review from leading scholars and researchers, who provided thoughtful input and represented diverse opinions (and yet, did not always agree with one another). This revised section on inclusive language addresses correct and preferred usage of terms related to race and ethnicity, sex and gender, sexual orientation, age, socioeconomic status, and persons with diseases, disorders, or disabilities.

We now seek continued and wider review of the revision to the subsection on race/ethnicity. The proposed revised section is published below, and we are requesting additional comment and feedback on ways this guidance could be improved for authors, editors, and readers of the medical literature.

Section 11.12.3. Race/Ethnicity

Definitions

Merriam-Webster defines *race* as “any one of the groups that humans are often divided into based on physical traits regarded as common among people of shared ancestry” and provides the following example from the US Census Bureau: “First, the [2020 US Census] question [about *race*] is based on how you identify. Second, the *race* categories generally reflect social definitions in the US

and are not an attempt to define *race* biologically, anthropologically, or genetically. We recognize that the *race* categories include racial and national origins and sociocultural groups.”¹⁸ The American Sociological Association defines *ethnicity* as “shared culture, such as language, ancestry, practices, and beliefs.”¹⁹ The Oxford English Dictionary defines *ethnicity* as “[t]he fact or state of belonging to a social group that has a common national or cultural tradition.”²⁰ In the US, ethnicity may refer, for example, to Hispanic or Latino/a/x people. Outside of the US, other terms of ethnicity may apply within specific nations. Although race is a social construct and its utility in understanding biology is limited, its significance as a sociopolitical lens through which to study racism and inequity is important. Ethnicity is also primarily a social construct and some have argued against “arbitrary separation of race and ethnicity, instead of using a mutually exclusive single race/ethnicity variable.”²¹ Terms used to define and describe race and ethnicity have changed with time based on shifts in sociocultural factors. This guidance is presented with that understanding, and updates have been and will continue to be provided as needed.

Concerns, Sensitivities, and Controversies

There are many examples of associations between race or ethnicity and health outcomes, but these outcomes may also be

intertwined with ancestry and heritage, as well as socioeconomic, structural, institutional, cultural, demographic, or other factors.^{12,22} Thus, discerning the role of these factors is difficult. For example, a person's genetic or ancestral heritage may convey certain health-related predispositions (eg, cystic fibrosis in persons of Northern European descent and sickle cell disease seen among people whose ancestors come from sub-Saharan Africa, India, Saudi Arabia, and Mediterranean countries). Also, certain groups may bear a disproportionate burden of disease compared with other groups, but this may reflect inequities. For example, according to the US National Cancer Institute, the rates of cervical cancer are higher among Hispanic/Latina women and Black/African American women than among women of other racial or ethnic groups, with Black/African American women having the highest rates of death from the disease, but social determinants of health and health inequities are also associated with a high prevalence of cervical cancer among these women.²³

Identifying the race or ethnicity of a person or group of participants may provide information about the generalizability of the results of a study. However, many people may identify with more than one race/ethnicity; therefore, categories should not be considered absolute or viewed in isolation.

In addition, there is concern about the use of race in clinical algorithms and some health-based risk scores and its applicability to some groups. For example, the use of race to estimate glomerular filtration rates has become controversial for several reasons.^{2,4,24} The Framingham Risk Score was originally developed from a cohort of US White, middle-class participants in the Framingham Heart Study, and it may not accurately estimate risk in other racial and ethnic populations. Similar concerns have been raised about genetic risk studies based on specific populations or that do not include participants from underrepresented groups (eg, a genome-wide association study that reports a genetic association with a specific disease or disorder based solely on a population of European descent).²⁵ Use caution in interpreting or generalizing findings from studies of risk based on populations of individuals representing specific or limited racial and ethnic categories.

Guidance for Reporting Race/Ethnicity in Research Articles

The JAMA Network journals include the following guidance for reporting race/ethnicity and other demographic information in research articles in the Instructions for Authors²⁶:

Demographic Information: Aggregate, deidentified demographic information (eg, age, sex, race/ethnicity, and socioeconomic indicators) should be reported for research reports along with all prespecified outcomes. Demographic variables collected for a specific study should be indicated in the Methods section. Demographic information assessed should be reported in the Results section, either in the main article or in an online supplement or both. If any demographic characteristics that were collected are not reported, the reason should be stated. Summary demographic information (eg, baseline characteristics of study participants) should be reported in the first line of the Results section of Abstracts.

Race/Ethnicity

With regard to the collection and reporting of demographic data on race/ethnicity:

- The Methods section should include an explanation of who identified participant race/ethnicity and the source of the classifications used (eg, self-report, investigator observed, database, electronic health record, survey instrument).
- If race/ethnicity categories were collected for a study, the reasons that these were assessed also should be described in the Methods section. If required by the funding agency, that should be noted.
- Race/ethnicity of the study population should be reported in the Results section.

Examples

Race was self-reported by study participants, and race categories (White and Black) were defined by investigators based on the US Office of Management and Budget's Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity. Given that racial residential segregation is distinctively experienced by Black individuals in the US, the analytical sample was restricted to participants who self-identified as Black.

Reporting race and ethnicity in this study was mandated by the US National Institutes of Health, consistent with the Inclusion of Women, Minorities, and Children policy. Individuals participating in the poststudy survey were categorized as Hispanic, Black, or White based on the Department of Health and Human Services' Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status. Children's race and ethnicity were based on the parents' report.

Race and ethnicity data were collected because adverse pregnancy outcomes, including post-cesarean delivery complications, may be higher among Black women, and these data allowed assessment for potential differential effectiveness of negative pressure wound dressings by race.

Three samples were used to characterize the ages (range, 8-80 years) at which self-reported non-Hispanic Black (n = 4973), non-Hispanic White (n = 8886), and Hispanic (n = 3888) populations transitioned between ideal blood pressure, prehypertension, and hypertension across the life course. We excluded individuals who self-reported being non-Hispanic Asian and other race or ethnicity (which included those who were non-Hispanic American Indian or Alaska Native and non-Hispanic Native Hawaiian or other Pacific Islander) because of small sample sizes.

Additional Guidance for Use of General Racial/Ethnic Terms

The general term *minorities* should be avoided when describing groups or populations; instead, specify with terms such as *racial or ethnic minority groups*. Other terms such as *underserved groups* or *underrepresented populations* may be used provided the categories of individuals included are defined. *Marginalized groups* can be suitable in certain contexts if the rationale for this designation is provided.

The nonspecific group label "other" is sometimes used for comparison in data analysis, but it may also be a "convenience"

grouping or label that should be avoided unless it was a pre-specified formal category in a database or research instrument. In such cases, the categories included in “other” groups should be defined and reported. Authors are advised to be as specific as possible when reporting on racial and ethnic categories (even if these categories contain small percentages). If the numbers in some categories are so small to potentially identify study participants, the specific numbers and percentages do not need to be reported provided that this is noted. For cases in which the group “other” is used but not defined, the author should be queried for further explanation.

The terms *multiracial*, *mixed race*, and *multiethnic* are acceptable in reports of studies if the specific categories these terms comprise are defined. If the criteria for data quality and confidentiality are met, at a minimum, the number of individuals identifying with more than 1 race should be reported. Authors are encouraged to provide greater detail about the distribution of multiple race responses.

Other terms may enter the lexicon as descriptors or modifiers for racial and ethnic categories of people. For example, the terms *people of color* and *brown* have been introduced. While these terms may be used colloquially (eg, within an opinion article), it may be helpful to describe or define the categories included. These terms should not be used in reports of research, unless the terms are included in a database on which a study is based or specified in a research data collection instrument (eg, survey questionnaire).

Capitalization

The names of races, ethnicities, and tribes should be capitalized, such as *Black*, *African American*, *White*, *Hispanic*, *Latino*, *Asian*, *American Indian*, *Alaska Native*, and *The Gond*. There may be sociopolitical instances in which context may merit exception to this guidance, for example, in an opinion piece for which capitalization could be perceived as inflammatory or inappropriate (eg, “white supremacy”). When used colloquially in an opinion piece, the term *brown* does not need initial capitalization; however, if used with other racial categories (eg, *Black*), it may need to be capitalized.

Adjectival Usage for Specific Categories

Racial and ethnic terms should not be used in noun form (eg, *Blacks*, *Whites*, *Hispanics*, or *Asians*); the adjectival form is preferred (eg, *Black patients*, *White participants*, *Hispanic children*, or *Asian women*) because this follows AMA style regarding person-first language. Most combinations of proper adjectives derived from geographic entities are not hyphenated when used as noun or adjective formations; therefore, do not hyphenate terms such as *Asian American*, *African American*, and *Mexican American* as nouns or compound modifiers (eg, *African American patient*).

Geographic Origin and Regionalization Considerations

Awareness of the relevance of geographic origin and regionalization associated with racial and ethnic designations is important. In addition, preferred usage may change about the most appropriate designation. For example, the term *Caucasian* had historically been used to indicate the term *White*,

but it is technically specific to people from the Caucasus region in Eurasia and thus should not be used except when referring to people from this region.

The terms *African American* or *Black* may be used to describe participants in studies involving populations in the US, following how such information was recorded or collected for the study or author preference. However, the 2 terms should not be used interchangeably in reports of research unless both terms were formally used in the study, and the terms should be used consistently within a specific article. When a study includes individuals of African ancestry in the diaspora, the term *African American* may not be suitable because it may obscure cultural and linguistic nuances and national origins, such as Dominican, Haitian, and those of African sovereign states (eg, Nigerian, Kenyan, Sudanese).

In reference to persons indigenous to North America (and their descendants), *American Indian* or *Alaska Native* is generally preferred to the broader term *Native American*. However, the term *Indigenous* is also acceptable. There are also other specific designations, such as *Native Hawaiian* and *Pacific Islander*. If appropriate, specify the nation or peoples (eg, *Navajo*, *Nez Perce*, *Iroquois*, *Inuit*, *Samoan*, *Guamanian*). Many countries have specific categories for Indigenous people (eg, *First Nations* in Canada and *Aboriginal* in Australia). Capitalize the first word and use lowercase for *people* when describing persons who are Indigenous or Aboriginal (eg, *Indigenous people*, *Indigenous peoples of Canada*, *Aboriginal people*). Lowercase *indigenous* when referring to objects, such as *indigenous plants*.

Hispanic, *Latino* or *Latina*, *Latinx*, or *Latine* are panethnic terms that have been used for people living in the US of Spanish-speaking or Latin American descent or heritage, but as with other terms, they can include people from other geographic locations. *Hispanic* historically has been associated with people from Spain or other Spanish-speaking countries in the Western hemisphere (eg, Mexico, Puerto Rico, Cuba, Central and South America); however, individuals and some government agencies may prefer to specify country of origin.^{27,28} *Latino* or *Latina* (from a linguistic perspective *Latino* is masculine and *Latina* is feminine) are broad terms that have been used for people who have descended from Mexico and some countries in Central America, South America, and the Caribbean, but again, individuals may prefer to specify their country of origin.^{27,28} When possible, a more specific term (eg, *Mexican*, *Mexican American*, *Latin American*, *Cuban*, *Cuban American*, *Puerto Rican*, *Guatemalan*) should be used. However, as with other ethnic categories, the formal terms used in research collection should be used for reports of studies. The terms *Latinx* and *Latine* are acceptable as gender-inclusive or nonbinary terms for people of Latin American cultural or ethnic identity in the US. However, editors should avoid reflexively changing *Latino* and *Latina* to *Latinx* or vice versa and should follow author preference.

Description of people as being of African descent or European descent is acceptable if those terms were used in formal research. However, it is preferable to identify a specific country or region of origin when known and pertinent to the study.

Example

For the GWAS discovery stage, study participants of African ancestry were recruited from Ghana, Nigeria, South Africa, and the US, where the same phenotype definition was applied to diagnose primary open-angle glaucoma. The second validation meta-analysis included individuals with primary open-angle glaucoma and matched control individuals from Mali, Cameroon, Nigeria (Lagos, Kaduna, and Enugu), Brazil, Saudi Arabia, the Democratic Republic of the Congo, Morocco, and Peru.

Similarly, it is generally preferable to describe persons of Asian ancestry according to their country or regional area of origin (eg, *Cambodian, Chinese, Indian, Japanese, Korean, Sri Lankan, East Asian, Southeast Asian*). Note that *Asian* and *Asian American* (and *Chinese, Chinese American*, and so on) are not equivalent or interchangeable.

Abbreviations

Generally, abbreviations of categories for race and ethnicity should be avoided unless necessary because of space constraints (eg, in tables and figures). If used, any abbreviations should be clearly explained parenthetically or in table/figure footnotes or legends.

Summary

The *AMA Manual of Style* committee welcomes review and comments that will improve the goal of this guidance to encourage fairness, equity, consistency, and clarity in use and reporting of race and ethnicity in the medical and science literature. Continual review of the language used to describe race and ethnicity is critically important as societal norms change. We invite feedback through April 12, 2021, by sending comments to stylemanual@jamanetwork.org.

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