

# Rethinking Race and Ethnicity in Biomedical Research

Using race and ethnicity to categorize individuals is ingrained in American society, including in health care and biomedical research, and these characteristics impact identity and how individuals experience the world. Although these social attributes have no biological basis—meaning race and ethnicity do not explain genetic variation, nor do they determine disease onset and progression—they are still regularly used in biomedical research, sometimes in harmful ways. Even so, these attributes can be useful in some circumstances, especially if carefully considered and tailored throughout the research process. Given this complexity, researchers need guidance in deciding if, when, and how to use race and ethnicity in their work.

The Doris Duke Foundation and the Burroughs Wellcome Fund asked the National Academies of Sciences, Engineering, and Medicine to convene a committee to assess the current use of racial and ethnic categories in biomedical research, review existing guidance, and provide recommendations to guide future use. *Rethinking Race and Ethnicity in Biomedical Research* provides nine actionable recommendations and associated resources for advancing the responsible use of race and ethnicity. The recommendations provide detailed guidance for researchers on how to decide whether race and ethnicity should be used, decision-making data that should be included in applications and publications, how to conduct research responsibly and with a clear scientific rationale, best practices for developing health technologies, and approaches to support sustained community engagement.

## USE OF RACE AND ETHNICITY IN BIOMEDICAL RESEARCH

The U.S. Office of Management and Budget (OMB) provides federal agencies with standard categories for collecting race and ethnicity



data. In biomedical research, these categories are often required for reporting research participant enrollment demographics and are found in readily available datasets. Although the OMB directive explicitly states that these categories are sociopolitical constructs, their intended purpose is often misunderstood or conflated with use in scientific analyses. This has contributed to a persistent misconception that humans can be divided into biologically separate groups, an idea known as “race science” which has been disproven by decades of research. In fact, clusters of genetic variants—such as the high propensity of sickle cell disease among Black individuals—are due to geographic distribution or ancestry rather than race. In addition, individual characteristics like skin or eye color can be partially explained through genetic inheritance but are complex traits that are oversimplified by racialized associations.

Although race and ethnicity are not rooted in biology, they do shape social realities and lived experiences, and their manifestations—including health disparities and structural racism—can be correlated with biological systems and health. The report concludes that race has been emphasized at the expense of exploring concepts like racism which may more directly impact health, and existing evidence will need to be rebuilt to specifically consider the role of racism and other related concepts (see **Conclusion 6-12** in the report).

#### **PARTNERING WITH COMMUNITIES**

Thoughtful and sustained community engagement and partnerships are essential for conducting research aligned with ethical and scientific principles and must become part of the scientific process, rather than viewed as an exercise that is beneficial but optional. Additionally, only individuals can share how race, ethnicity, and related concepts impact their experiences—vital data for research focusing on topics like health disparities—and community engagement efforts should be designed to accommodate community contexts like the sovereignty of American Indian or Alaska Native Tribes. Therefore, the report recommends that

- Researchers collecting and using race and ethnicity data should partner with relevant communities

to optimize authentic, continuous, and sustained engagement, undergirded by mutual trust (see **Recommendation 7** in the report); and

- Funders should provide resources and timelines that encourage these collaborations and require, as appropriate, community engagement plans in applications (see **Recommendation 9** in the report).

#### **APPROPRIATE USE OF RACE AND ETHNICITY THROUGHOUT THE BIOMEDICAL RESEARCH PROCESS**

The report concludes that deciding to either use or omit race and ethnicity has advantages and disadvantages and requires careful deliberation (see **Conclusion 6-1** in the report). Even for well-intentioned purposes, like recruiting a diverse cohort, the correct approach to using race and ethnicity will depend on the research question and specific context. The report recommends that researchers evaluate and decide whether the use of race and ethnicity is appropriate and scientifically justified at every stage in the biomedical research process, including

- Identifying how the historical or social context affects the evidence base,
- Understanding the context and requirements for partnering with specific communities,
- Considering potential benefits or harms of collecting race and ethnicity information,
- Refraining from making unsupported inferences related to racial and ethnic categories, and
- Articulating these decisions and their limitations in all publications (see **Recommendation 1** in the report).

Once researchers decide to use race and ethnicity in their work, they should thoughtfully consider whether these attributes are being used as a proxy—or stand-in—for another variable, such as social determinants of health, that would better address the research question. If race and ethnicity are the appropriate attributes, the researcher should provide an operational definition

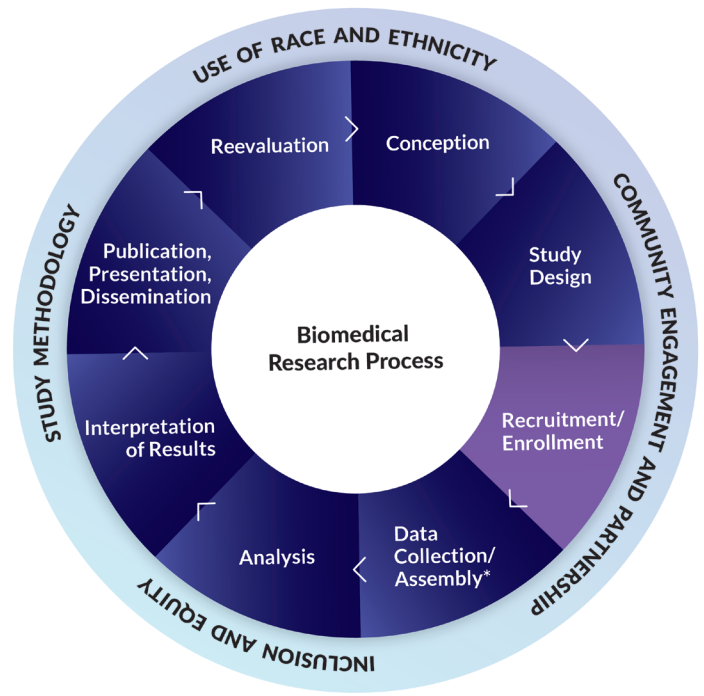
of race and ethnicity in all applications, manuscripts, and related products, including an explanation of their rationale and attributes of data provenance (see **Recommendation 2** in the report). Researchers should also strive to identify which concepts often conflated with race or ethnicity are relevant to their study, and once identified, select applicable measures (see **Recommendation 4** and **Table 6-1** in the report).

Ensuring appropriate inclusion should be considered at each stage of the study process. Participants are often left out of analyses due to missing race and ethnicity data, small group sizes, a lack of categories that adequately fit their identity, or selection of multiple race and ethnicity categories. The report encourages considering methods that retain as much information about individuals as possible while acknowledging the statistical and practical challenges surrounding small group sizes. The report recommends all racial and ethnic category inclusions and exclusions for analyses be based on scientific rationale motivated by the research question and that researchers should

- Consider oversampling for smaller populations to ensure their inclusion in analysis;
- Justify the choice of reference population; and
- Avoid aggregating participants into nonspecific categories like “Other” or “non-White,” as this approach can overlook diverse experiences and inappropriately reinforce White as the norm (see **Recommendation 5** in the report).

Researchers should also consider the inclusion and analysis of multiracial and multiethnic participants at every stage of the research process, including

- Ensuring that participants can select multiple races, ethnicities, or ancestries; and
- Using a classification scheme that includes multiracial and multiethnic people and is based on the research question or context (see **Recommendation 6** and **Table 5-1** in the report).



**Use of Race and Ethnicity**

- Disaggregate race and ethnicity
- Define concepts and measurements
- Disclose limitations

**Community Engagement and Partnership**

- Build trust
- Sustain community partnerships
- Ensure transparency
- Respect data sovereignty
- Form interdisciplinary study teams, including community members

**Inclusion and Equity**

- Account for time for outreach
- Ensure equitable benefit sharing with the community
- Incorporate multi-racial and multi-ethnic individuals

**Study Methodology**

- Collect more granular data
- Use appropriate categories and measurements for analysis
- Disclose limitations of legacy datasets

- Applies to all studies
- May not apply to studies not recruiting participants
- Should be considered at every research stage

\*Researchers conducting observational studies with existing data may enter the cycle here but should consider data provenance and prior stages.

**FIGURE 1** Key considerations for the use of race and ethnicity throughout the biomedical research process.

To help operationalize this report’s recommendations, the committee identified questions that researchers should thoughtfully consider at each stage of the biomedical research process, illustrated in Figure 1 (see **Box 6-1** in the report for the questions).

**SUPPORTING THE APPROPRIATE USE OF RACE AND ETHNICITY IN BIOMEDICAL RESEARCH**

Advancing the responsible use of race and ethnicity is not the sole responsibility of individual study teams. The report specifically identifies biomedical technology as a field that must operate transparently at every stage of the development, application, and evaluation

of tools that may influence health—including clinical algorithms and artificial intelligence-enabled medical devices—by assessing and reporting on technology performance across a range of racial and ethnic groups (see **Recommendation 3** in the report).

Funders, sponsors, publishers, and editors of biomedical research should also provide consistent guidelines to assist researchers and promote the thoughtful use of race, ethnicity, and related concepts, including

- Requiring researchers to provide a scientific rationale for their use of race and ethnicity, describe data provenance, and acknowledge limitations; and

- Encouraging those developing health technologies to provide datasets, algorithms, and code in an open-source format (see **Recommendation 8** in the report).

#### LOOKING AHEAD

When implemented, this report's recommendations have the potential to improve the scientific rigor of biomedical research, mitigate bias that continues to affect research and health care, and build lasting trust among researchers and community members. These changes do not need to be daunting—this is an exciting opportunity to ensure that race and ethnicity are used responsibly and do not cause any more harm.

To learn more about this report, visit our website at [nationalacademies.org/Race-in-Biomed](https://nationalacademies.org/Race-in-Biomed).

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#### FOR MORE INFORMATION

This Consensus Study Report Highlights was prepared by National Academies staff based on the Consensus Study Report *Rethinking Race and Ethnicity in Biomedical Research* (2024).

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