

A critical reexamination of race and ethnicity population descriptors in human neuroscience research

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Introduction: Race & ethnicity population descriptors in human neuroscience research

- Decades of research have explored the ethical and legal issues associated with categorizing humans with respect to “race” & “ethnicity” in biomedical research. [1]
- Ethics research has shaped policies about how academic journals report findings by race and ethnicity, and how biobanks utilize these categories. [2]
- Reporting of race and ethnicity in neuroscience research is infrequent and inconsistent, estimated race reported 10%; ethnicity reported 4% in neuro studies. [3]
- Critical need to apply lessons from this broader discussion of race and ethnicity categorization in human neuroscience research as participant pools strive for greater diversity and representativeness.

A Challenge: Definitions and usage of population descriptors are being revisited

- How participants’ race and ethnicity is measured, reported, and documented in data sharing is in flux.
- In 2023, NASEM Committee on the Use of Race, Ethnicity, and Ancestry as Population Descriptors in Genomics Research provides new guidance [4] — *adaptation for neuroscience research needed*.
- For first time since 1997, in March 2024 U.S. Office of Management and Budget (OMB) revised Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity [5] — *implications for neuroscience research not explored*.

Need: Guidance for Researchers

- Guidance on (1) determining which population descriptors to use, and (2) consistent operationalization of those descriptors across research teams, funders, and publication outlets.



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Multiple Methods: (1) Analysis of NASEM Report; (2) Analysis of OMB Directive No. 15 revisions; and (3) Scoping review of literature providing guidance on use of population descriptors in neuro research.

Applying NASEM Report to Neuro:

- Move away from using racial identity as a proxy or as a monolith for appropriate consideration of population diversity.
- Do not rely on race as a proxy for other environmental moderators and exposures.
- Report’s focus on genetics/genomics research is deeply informative but not dispositive for guiding the use of population descriptors in human neuroscience research.

Applying OMB Report to Neuro:

- New OMB guidance will require revisions to participant self-reporting of race and ethnicity.
- No guidance on *when* to utilize these categories.

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Scoping Review Findings:

- Following PRISMA guidelines, PubMed + Google Scholar search (conducted May 2024) of publications since 2010.
- Inclusion: articles addressing use of race & ethnicity population descriptors in neuroscience research
- Identified only 5 publications on point.
- **Conclusion: No consensus guidance for neuro research community on when and how to measure, analyze, and report race and ethnicity.**

Recommendations:

- (1) Re-examine current practice on measuring, reporting, and using race/ethnicity variables.
- (2) Develop new guidance for how race and ethnicity are to be measured and reported, including how to harmonize datasets.
- (3) New guidance should be co-created in partnership with affected communities.

Next Steps:

- Delphi process with national working group to develop guidance on use of population descriptors in neuroscience research.
- Develop and validate Common Data Element categories, with community stakeholder network convenings for input on CDE development.



References & Additional Resources:
Scan QR Code for References and link to REACH for BRAIN project website