

Race in health research: Considerations for researchers and research ethics committees

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This article provides ethical guidance on using race in health research as a variable or in defining the study population. To this end, a plain, non-exhaustive checklist is provided for researchers and research ethics committees, preceded by a brief introduction on the need for justification when using race as a variable or in defining a study population, the problem of exoticism, that distinctions pertain between race, ethnicity and ancestry, the problematic naming of races, and that race does not serve well as a presumed biological construct in genetic research.

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Researchers have sought guidance on the issue of race in health research from the Faculty of Health Sciences Research Ethics Committee at the University of Pretoria, South Africa (SA). We presume that other ethics committees and researchers across SA may have had similar enquiries, and have also been concerned about using race as a variable or in defining the study population in health research. There have also been calls for greater institutional oversight regarding race-based scientific claims, averting a racialisation effect that may feature, for example, in pharmacogenomics and medication design.^[1] In response, we authored this working document on this rather sensitive issue, extracting guidance from a vast body of literature. We anticipate that not everyone may entirely agree with all the contents, but it may nonetheless be useful in deliberations through which the contentious aspects may further be considered and applied in specific contexts. Our point of departure, expounded elsewhere, is that the issue of race in health research is a matter of ethical deliberation applicable to a specific study.^[2]

From a vast literature on race, introduced for example in the SA volume *Fault Lines: A Primer on Race, Science and Society*,^[3] this article extracts rather high-level aspects that may serve as accessible guidance to researchers without unpacking the multiple intricacies and conceptual relations. We modestly confine the article to addressing the need for justification when using race as a variable or in defining a study population, the problem of exoticism, outlining distinctions between race, ethnicity and ancestry, the naming of races, and genetic research and variables that may be more suitable than race. Each of these issues is briefly introduced below to contextualise the subsequent checklist that researchers and research ethics committees may find useful.

Justification rather than a routine parameter

As is evident in several publications,^[4-7] the practice by which race is routinely included as a variable or a way to qualify a study population in health research is scientifically weak, and thereby strongly discouraged. Rather than a routine inclusion, if included at all, scholarly justification should be provided for this inclusion, whether it be scientific, social, political or otherwise. The scientific justification for this inclusion should not be a mere statistical association, for many other actual factors may underpin an apparent racial association (e.g. geographical, environmental, dietary, socioeconomic and other factors). The scientific objective is therefore not to mistake race for an actual variable when it is merely a proxy for another variable. The risk is that racial prejudice may be mistaken, overtly or tacitly, as a scientific justification.

Furthermore, researchers should carefully consider the most scientific way to define a study population, rather than assuming that a racial definition is the most appropriate. For example, when biological research on a particular topic has been done among Northern Americans or Europeans but not yet in Africa, the population for which there would be a paucity of research is a matter of geography or geography-related factors, and not necessarily that of race *per se*. Mere racial prevalence or assumptions of racial homogeneity in a given context in Africa (or Northern America and Europe) would not be a good enough scientific justification.

Requiring justification for using race as a variable or to qualify a study population should not be mistaken for dismissing the importance of race where it is indeed relevant. Among many examples of justified uses of race in health research, race may have value as a

parameter in the context of social and political categorisation to provide insight into health differences and inequities.^[8] In a recent article in the *Journal of the American Medical Association*,^[9] a middle ground is proposed instead of the view that race is a traumatic 'relic' that has no further place in research. Strategies should improve measurement, analysis and reporting of a construct that is lacking in exactly those areas. The authors suggest a four-tiered approach to future studies, encompassing a literature review to identify the potential role of race in a particular topic, diligent consideration of any other contributing factors should race be deemed a needed variable, caution against using the 'white race' as a normal reference and sensitive consideration to the impact of the race-related research. Similarly, Corbie-Smith *et al.*^[10] suggest that critical reflection on race conceptualisation, data collection, analysis and interpretation, and the importance thereof, should be rigorously and sensitively considered.

Exoticism and curiosity in 'them' v. 'us'

Underpinned by racial prejudice and a colonial mentality of supremacy, the history of science was marked with a curiosity in 'exotic' people, in 'them' being different (and lesser) than 'us'.^[11] Colonial curiosity regarding Saartjie Baartman is a good example. Observations of her buttocks and genitalia before and after her death were presented in medical publications during the 19th century both as pathological malformations and to some extent representative of the 'black' female. The 'malformations' were presented as scientific evidence of degeneracy, and evidence that 'they' were from the 'lowest' human species.^[12] Similarly, reference to race in titles of research studies was used to generate public interest. This has also occurred recently at two SA universities.^[13] Such dehumanising and offensive use of race should be rejected and expunged. Moreover, researchers should take care to avert generating this kind of interest in their research.

Race is not the same as ethnicity nor ancestry

Race should not be confused with ethnicity (or vice versa), and 'ethnicity' should not be taken as the politically correct term, a proxy, or a disguise of race. An extensive conceptual clarification is not the purpose here. By a broad outline instead, one may recognise that both race and ethnicity are social constructs by which people are categorised: for race, the categorisation is mainly based on a set of apparent physical characteristics deemed socially important, while ethnicity mainly concerns shared culture and traditions.^[14] It is therefore possible that people may have 'racial' similarity but ethnic differences. The converse is also possible: people may have racial differences but be similar ethnically. For example, we have a number of races in SA, but we certainly have many more ethnicities, expressed in part by the many languages spoken. Furthermore, all people of the same ethnicity are not necessarily of the same race; for example, when parents adopt a child from a different racial group than theirs and the adopted child is brought up in the ethnic tradition of the parents. What would such a parent tell his or her child regarding the child's ethnicity, and how would such child self-identify? These questions raise the issue on how ethnicity is identified: self-identification by an individual or by a group may diverge from identification by 'outsiders', e.g. anthropologists or people from another ethnicity. This potential

divergence prompted the anthropologist Ronald Cohen to suggest that claims concerning ethnic identity are often colonialist practices resulting from relations between colonised peoples and nation-states.^[15] Although race and ethnicity may correlate in some contexts, as in some nation-states, conflating these in SA may be particularly misleading.

Ancestry should neither be conflated with race nor with ethnicity,^[8] although these may correlate partially in some contexts and are sometimes used interchangeably in, for example, forensic anthropology.^[16] Ancestry necessarily concerns identification within a genealogical history,^[8] which is not necessarily restricted to a single race nor ethnicity in each of the preceding generations.

The point here that distinctions between race, ethnicity and ancestry pertain and these should not be mistaken as if finding the (politically) correct term for the same construct were at issue, but it concerns more substantively that for which each of these terms stands. Once the appropriate construct is discerned, however, the naming of it also matters, as we address next specifically for 'race'.

The naming of race

Historically, races have been named in problematic and unethical ways. Examples are the use of the names of continents and from rejected colonial racial theory (e.g. 'caucasian'). Using the names of continents to designate a racial group overtly or implicitly reinforces the view that the legitimate inhabitation or citizenship of a continent would be exclusively the prerogative of a particular race, with other races thus being 'lesser' or mere visitors to the continent. This is demeaning if not offensive to the less prevalent races that inhabit a continent, some with ancestry going back for centuries and even millennia. For example, using 'European' as a designation of race is in defiance of the fact that various races have inhabited Europe for millennia. Similarly, the designation 'African' as if it designates a race is ethically problematic. Compare all other continents for which it would be considered racist if one can only be Asian, North American, South American or Australian when of a particular race. Factually, inhabitants of Africa have comprised of various races throughout millennia (consider, for example, the San and Northern African peoples). Instead of 'African', 'Black African' is commonly used as a designation in SA. However, this too may pose challenges ethically, depending on the context. Underscoring the problems of using the names of continents in designating race, furthermore, is the lack of clarity on how many generations someone's ancestors would need to have inhabited a continent before a continental designation would be deemed appropriate. Moreover, ancestry is not synonymous with race (see above).

The designation 'caucasian' should be avoided as it invokes the debunked 18th century racial theory by which the inhabitants of the Caucasus Mountains between the Caspian and the Black Sea were purported to be the superior race from which all other 'degenerate' races would stem.^[17]

Race does not serve well as a presumed biological construct in genetic research

Concerns about race in genetic research are summarised well in an article published in *Science*, titled 'Taking race out of human genetics'.^[18] The National Human Genomics Research Institute states:^[18]

'Race is a fluid concept used to group people according to various factors, including ancestral background and social identity. Race is

also used to group people that share a set of visible characteristics, such as skin colo[u]r and facial features. Though these visible traits are influenced by genes, the vast majority of genetic variation exists within racial groups and not between them. Race is an ideology and for this reason, many scientists believe that race should be more accurately described as a social construct and not a biological one.'

Instead of denying the social derivations of race and presuming that it would mainly be a biological construct, human genetic studies may alternatively find useful a composite set of criteria in identifying more biologically accountable variables (e.g. objective skin colour measurements, genes associated with skin pigment, geographical location of ancestors over a minimum number of generations, etc.).

Recommendations for using race, ethnicity or ancestry in genetics research made by Ali-Khan *et al.*^[19] include that the concepts of race, ethnicity and ancestry be defined and differentiated in the context of the specific research. They recommend a comprehensive explanation of the methods used for genetic ancestry imputations, including assumptions made, algorithms and parameters used, descriptions of population samples involved, the limitations of inferences, and a consideration of social, ethical, legal or economic issues raised by the research.

Checklist on race and ethnicity for context-specific application

Drawing on the preceding materials, we adapted a previously published checklist for use by researchers and research ethics committees. It had originally been intended for the editorial review of manuscripts submitted for journal publication.^[20] Two of the original 21 items were not suitable as these were checklist instructions and not criteria. Neither were suitable for adaptation to items concerning requirements for publishing a manuscript. Three of the original 21 items were editorially merged with others that had the same focus. This adapted and rather plain checklist can hardly be exhaustive on this rather complex issue. Nonetheless, it contains crucial aspects that may assist researchers in justifying references to race or ethnicity in their study.

Consider for each of the questions whether the question applies to a specific study

1. Is there an adequate justification for focusing attention on race and/or ethnicity in the study (e.g. may the geographical location or geography-associated factors be more apt than race)?
2. Will the study allow for valid racial or ethnic comparisons? For example, a study population defined as a single race or ethnicity does not allow for comparisons using its own data, and comparisons with other studies must ensure that race or ethnicity is truly the defining feature rather than, say, geographical or geography-related factors.
3. Was the focus/framing of the research in racial or ethnic terms informed by those individuals or groups who are participants in the research?
4. Are key concepts of ethnicity, race or related concepts adequately explained and justified?
5. Have the researchers used terminology consistently and appropriately?

6. Have the researchers carefully addressed the appropriateness and limitations of the racial or ethnic categories used for the topic under investigation?

7. Are there sufficient details and justification for how such categories were assigned?

8. If the focus on race or ethnicity is warranted in the study, are participants properly informed of this in the informed consent document?

9. If the focus on race or ethnicity is warranted, is the sampling strategy accounting for this in ways that ensure representativeness, and that comparisons are valid and reliable?

10. Do the proposed analyses exercise appropriate caution in claims about causal links between race and/or ethnicity and experiences/outcomes? (For example, in quantitative analyses, do the researchers avoid interpreting statistical associations as explanations/causal effects?)

11. If the focus on race or ethnicity is warranted, do the researchers address confounding influences on, or alternative explanations for, race or ethnicity data?

12. If the focus on race or ethnicity is warranted, do the researchers adequately engage with internal diversity within racial and/or ethnic groups?

13. If the focus on race or ethnicity is warranted, do the researchers address potential stereotyping, stigmatising or pathologising of certain racial or ethnic groups or populations?

14. If the focus on race or ethnicity is warranted in a qualitative study, do the researchers address adequate reflexivity in the research (e.g. acknowledging the researchers' own social position(s) and any assumptions and limitations of the methods used) as well as the transferability of the findings to other research and practice contexts and limits to this transferability?

Conclusion

In deliberations about race as a variable and in defining a study population in health research, justification is required for the sake of scientific and societal accountability. To this end, we have presented reasons and a checklist for researchers and research ethics committees by which race should not be confused with ethnicity nor ancestry, and terms should be used appropriately rather than using proxies for, or statistical correlates of, race. We welcome constructive commentary on this working document in a collaborative effort to ensure scientific rigour and in recognition of the equal dignity of people regardless of their race or ethnicity, as stipulated in the very first section of the Constitution of SA, 1996.

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