Racial labelling in Human Genetics research in Southern Africa.

Malebo F. Malope, Jorge E.B. da Rocha, Karen J. Fieggen, as members of the SASHG Committee.

Racial labelling in South Africa is a particularly sensitive issue due to the negative connotations that arose from the Apartheid regime that attached discriminatory social imperatives to race which are still widespread across the country. Over the past few years, research articles which used inappropriate labelling were found to be deeply upsetting or discriminatory to the participants studied (a key example - Nieuwoudt et al., 2020, which was retracted).

Racial and ethnic labelling in research has been the focus of many discussions held by the Southern African Society for Human Genetics (SASHG) for over 10 years. These discussions began with an attempt to create a list of appropriate labels that would not offend, but no consensus has been reached. Moreover, this has raised a greater question: is racial labelling in research necessary, and if so, how to carry it out so that participants and the communities they represent are protected? To begin the search for an answer, we have drafted a survey to ask members of SASHG and other related genetic communities for their views and inputs into racial labelling. The remainder of this communication outlines the responses.

Results and Discussion

Our members have described that they believe that moving away from all labels in genetic research is not feasible. The majority agree that the use of "race" (Black, White, Coloured etc.) is inappropriate and outdated, and that more layered classifications such as ethnicity (Bapedi, Irish, AmaXhosa etc.) should be used. Geographical or social classifications were also recommended. Although these provide more depth, we see that these labels could also lead to stigmatisation, or discrimination. To address this, our members urged that one should avoid using any labels whenever possible, and, if it is not possible for sound scientific reasons, to make use of broader classifiers such as area or country to prevent singling out a single ethnicity or population. Other suggestions included grouping participants by defined genetic ancestry alone, and while this is a common practice in the field, care should still be taken on how "labels" by which participants are grouped are used. Table 1 below summarises some of the survey responses.

Key message: Participants MUST be involved

The respondents have strong consensus in urging that research participants must be involved in discussions of labelling to be used in the work. Participants must describe what labels they approve of, and in turn researchers should share what the main

Table 1: Summary of racial labelling survey responses

Respondents' Occupations		
Occupation	CEO- 1 Clinicians- 6 Genetic Counsellors (Including interns)- 6 Junior scientists/ researchers- 5 Postdoctoral fellow- 1 Postgraduate students- 6 Professor/Readers- 12 Senior scientists/Researchers- 13 Undergraduate student- 1	**Private industry/ Clinical: 13** **Academic: 38** **Total: 51**

Survey responses	
Question	**Responses**
Who else (other fields) do you think we should include in our racial labelling discussion?	**Social sciences**: Sociology, social workers, anthropologists, linguistics, political sciences, psychology **Humanities:** Philosophers, historians **Community engagement experts** **Public:** Community leaders of different ethnic groups, family member s, advocacy groups, **Ethics:** Human research ethics committee, medical law and bioethics, human rights lawyers, institutional review boards Multidisciplinary ethics committee (academic, religious, lay person etc.) **Health sciences:** Medicine, human biology medical geneticists, genetic counsellors, public health, physiology **Government**
Should participants be included in racial labelling discussions?	Yes: 43 (84.3%) No: 4 (7.8%) Maybe: 3 (5.9%) Unsure 1 (1.9%) **Total responses: 51 (100%)**
Could a list of accepted vs rejected labels be feasible?	Yes: 37 (72.5%) No: 8 (15.7%) Maybe: 4 (7.8)

	Unsure: 2 (3.9%) **Total responses: 51 (100%)**

research questions are. This understanding may lead to better research quality in the present, and to sustained research engagements in future.

Community leaders or representatives were highlighted as key individuals to be included in these discussions. A local leader would also help to facilitate trust and establish working relationships with participants. Research benefits of this include avoidance of self-reported race (which can be incorrect), and knowledge about the culture of the populations assessed, which may explain environmental or lifestyle factors which would otherwise be missed. It was suggested that before disseminating the results, the researcher should discuss with the participants or relevant stakeholders the use of ethnic labelling, ensuring constant informed consent.

A list of generally acceptable and unacceptable labels would be useful for researchers. Such a list is thought to be feasible, although there are numerous challenges in creating and maintaining such a list. Survey respondents advised that the list would need to be a living object that adapts with public perception and reminded that even if a label is viewed as acceptable, it must be used in a responsible manner with agreement from participants. This makes participant feedback before publishing essential and encourages a relationship of informed consent. Experts from different fields (Table 1) have been suggested to be a part of these conversations for an ethically sound outcome.

Current genetic research benefits from the obscurity of genetic nomenclature to the general public. As time progresses, genetics will become more familiar, and the implications of the findings will be understood by a wider audience. It also is important to uphold the ethical standard of non-maleficence in research. In the example of Nieuwoudt et al., 2020, the outcome clearly perpetuates stigma and unsubstantiated preconceptions about specific ethnicities or population groups, which causes harm to the participants. When reporting on complex traits, especially those which could be interpreted negatively, ensuring a full investigation into the causes and factors linked to these will allow for an accurate reflection and a more nuanced interpretation.

South Africa is a new democracy, and our relationship with the concept of "race" is still fragile. This survey and the advice provided by the wide range of respondents serves as a starting point to address the challenges of racial and other labelling in genetic research. There is still much more work needed to establish the "ground rules" to conduct research in a way in which both researchers and participants receive optimal benefit, protection, and respect. We hope to see our society, and many others in South Africa to continue these discussions and develop the procedures and guidelines to reach this goal.

If you would like to reach out to the SASHG committee with your views, understandings, or advice - please contact us at sashgmembers@gmail.com

References:

Nieuwoudt, S., Dickie, K.E., Coetsee, C., Engelbrecht, L., and Terblanche, E. (2020). RETRACTED ARTICLE: Age- and education-related effects on cognitive functioning in Colored South African women. Aging, Neuropsychol. Cogn. *27*, 321–3