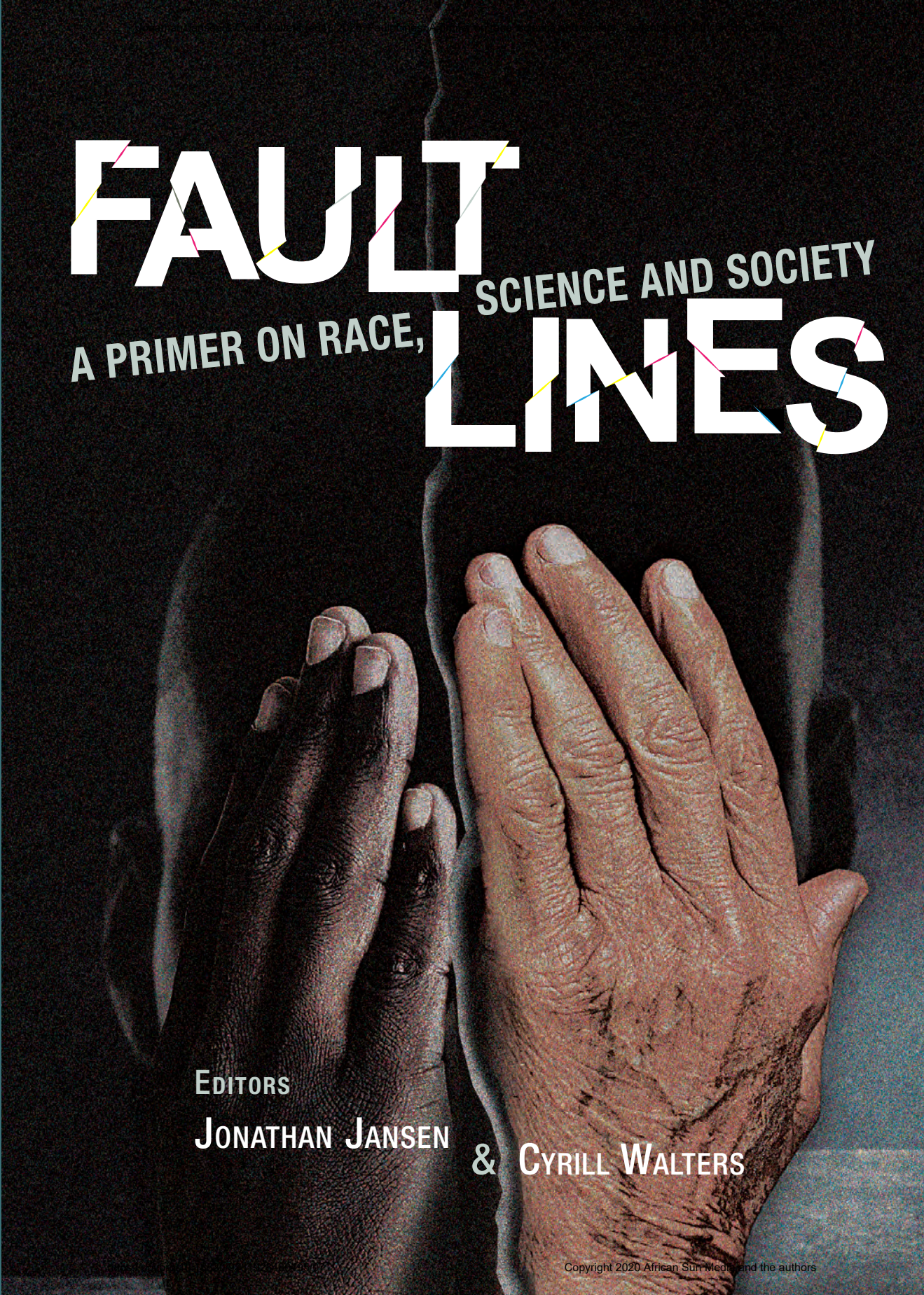
FAULT LINES

A PRIMER ON RACE, SCIENCE AND SOCIETY



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07

Race and Health

Dilemmas of the South African health researcher

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Introduction

We begin this chapter by discussing responses by members of our team to comments on articles submitted to major international journals focusing on health research. Recently, when one of our manuscripts was close to being accepted, the editors asked the author team to change its use of the term "coloured" to "mixed race". Shortly after this, another journal asked us to change the term "coloured" to "people of diverse origin". Some years ago, we were asked by a journal published in the USA to change our use of "coloured" by describing our (South African) research participants as "African American"! Lastly, when a reviewer read a manuscript we wrote about the Mamre Community Health Project, a project in a South African community where most inhabitants identify as "coloured", we were asked to expand on the rituals and practices of what the reviewer called "the Mamre". In this particular case, the implication was that there was an African tribe called "the Mamre" similar in nature, we assume, to "the Nuer", a "tribe" described by Evans-Pritchard[1] in the middle of the twentieth century.

The absurdity of the last two of these examples is obvious, and the requests were therefore easy to resist. In the case of both of the other examples, however, with articles close to acceptance in prestigious journals, we simply complied with what the editors wanted. This was despite the fact that all the authors agreed that technically

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all people are "mixed race" and "of diverse origin". In the event, we queried the editor suggestions in both cases and argued for our use of the word "coloured" as a category with social meaning in South Africa, a category which does not map onto scientifically justifiable "racial" or "origin" categories, but one which may have profound implications for how one is positioned socially.

These examples from our own research highlight what we suspect is a central issue for many health researchers in South Africa. Most of us are not social scientists and are not centrally concerned with the politics of labelling and identity. Instead, we are interested in health matters and in questions of how to improve health. In reflecting on the debacle of the Sport Science article that sparked the controversy which ultimately led to this book, we have no doubt that there is a debate to be had about racism, implicit or explicit, in health research. But there is also a narrative about researchers directing their energies to improving health, not on thinking about and discussing complex social issues. There may also be a story, we suggest, of simple naïvety about social issues which have important bearing on health and health research.

Explaining the influence of race on health and disease

It is incontrovertible that race has profound implications for health and illness, but what are we to make of claims that racial differences or disparities in health are related to biological differences amongst race groups? A book, published under the auspices of the American Anthropological Association, titled *Race: Are We So Different?* offers an in-depth account of current scientific thinking on "race-as-biology" that is helpful for our understanding of the link between race and health.[2] The authors begin by acknowledging the reality and necessity of human biological variation and continue by making the case that race provides a poor explanation for such biological variation or difference. A number of arguments are offered in support of this view:

1. **Human variation is continuous.** Genetics (allele frequencies) tend to vary gradually, and there is no consistent means of using this information to determine where one race begins and another ends. This reality fits poorly with the idea of race as fixed and unchanging human types. Evolution, rather than race, say the authors, therefore provides the better explanation for human variability;
2. **Human biological variation involves a number of traits which vary independently.** While skin colour, for example, may correlate with a few other phenotypic traits, such as hair and eye colour, there is no evidence that it influences mental abilities, behaviour or disease risk;

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3. **Genetic variation within races far exceeds the variation between them.** This means that two individuals who self-identify as "white" may be more genetically different from one another than from someone who self-identifies as "black"; and
4. **There is no method of consistently classifying humans by race.** If groups cannot be defined in a reliable and consistent fashion, it is not possible to make generalisations about them.

Given these limitations to the use of race as an explanation for biological (genetic) difference, how might we account for the observed health differences/disparities across so-called race groups? Why do people of colour, for example, experience worse health throughout the life course and die at younger ages than whites? The most likely reason is that people from different race groups often experience different and unequal social conditions, related to socioeconomic status, educational attainment, nutrition, housing, psychosocial stress, and quality of care. These socially mediated factors, acting directly or in interaction with genetic factors, can lead to health disparities between race groups. It should, at the same time, be kept in mind that peoples' social experiences, even within one race group, can vary widely, causing substantial within-group health differences.

It further needs to be mentioned that there are instances where causative alleles (genetic risks) do cluster within socially defined racial or ethnic groups (or subgroups), which can contribute to disease incidence varying by race/ethnicity.[3] This phenomenon is most commonly encountered in monogenic diseases. Examples include sickle cell anaemia (previously considered to be a disease of black people) in those people whose ancestors lived in malarial areas, Tay-Sachs disease amongst Ashkenazi Jews and cystic fibrosis in people of Northern European descent. Such effects are much less likely to be seen in common diseases, for example, hypertension, diabetes and cancer, where causation is much more complex. For these diseases, numerous genetic variants interact and usually combine with environmental factors to determine disease risk, and the relative contribution of genetic factors to disease incidence is typically small.

Concepts related to race

Two concepts related to race that are regularly conflated with race in the health literature deserve special mention: ethnicity and ancestry.[4] Ethnicity is often used interchangeably or in combination with race (as race/ethnicity). Ethnic categories are used to group people according to their shared cultural heritage, language, social practice, traditions, and geopolitical considerations. As with race, there is no universal

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agreement on how ethnic groups should be defined, and no clear principles for their application in research or practice, which similarly limits the value of ethnicity as an explanatory variable for health differences.

Ancestry refers to the geographical origins of a person's recent biological ancestors, as reflected in the DNA inherited from those ancestors. Genetic ancestry is inferred by comparing an individual's genotype to global reference populations, using ancestry informative markers (AIMs). Unlike race or ethnicity, which is concerned with how a person fits into a particular group, genetic ancestry focuses on how an individual's history has unfolded – essentially, how his or her ancestors moved and mated. Someone's self-identified or assigned race or ethnicity may therefore differ considerably from data computed using AIMs, and may also reflect multiple ancestral origins. "Genetic ancestry" is generally regarded as more useful term for describing human diversity.

As methods used to decipher genetic/genomic information advance and computational capacity improves, and the integration of genetic information with data on the environmental, social and economic drivers of health and disease becomes more widespread, personalised medicine will emerge as a more effective and efficient approach to managing disease.[5] This development will help shift practice away from the use of race as a marker of disease risk and promote the adoption of more direct and reliable measures at the level of the individual. For now, the ubiquitous and controversial practice of relying on concepts of race and ethnicity to explain health differences will, however, persist. This may have important social consequences, and not just for research. For example, Tsai et al.[6] reported that race was used as an unexplained, definitive category in the teaching of medical students in the USA, and that essentialist and misleading ideas about race were being reproduced through this education. The same is true of the training of health professionals in many other countries.

International debates about the use of racial terminology in health research

Anguish about how and when or if to use the concept of race in medical research and education is not unique to South Africa. For example, in 2017, the *American Journal of Bioethics* published an article titled "Now Is the Time for a Postracial Medicine: Biomedical Research, the National Institutes of Health, and the Perpetuation of Scientific Racism".[7] We do not have the space here to review the many responses both in the issue in which the article appeared and elsewhere, but these provide useful contextual readings for anyone considering race issues in health-related research. Recently, Gutin[8] has joined a global chorus of researchers and scientists calling for health scientists and practitioners to develop a more sophisticated

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understanding of race in health research and practice. Our own contribution in this chapter is more modest: we provide a snapshot of health research published by the Faculty of Medicine and Health Sciences (FMHS) at Stellenbosch University. Three of the authors of this chapter are associated with that faculty, and the fourth author is employed at Stellenbosch University and regularly collaborates with colleagues at the FMHS.

Investigating the use of race in health research at Stellenbosch University

We believed that if as an institution we were serious about addressing the problems associated with the publication of the Sport Science article on "colored women", it would be important to understand the context of that article. An important part of that context is the landscape of health-related research published at Stellenbosch University (SU). We, therefore, became interested in looking at how the concept of "race" was being used by researchers at the FMHS. This led to our decision to conduct a mini-review of articles published over a one-year period (2018) by researchers based at the Faculty. We aimed to determine how often the concept of "race" was used in research and to explore why and how racial categories were used. Additionally, we examined the extent to which use of the race concept conformed to previous international guidance on the use and reporting of race in biomedical research.[9]

We plan to report the detail of our review elsewhere, but for purposes of this chapter, we note, probably not surprisingly, that there was striking heterogeneity in terms used for "racial categories" across the 15 relevant articles we identified (see Table 7.1), and in almost none of these articles was the use of the categories discussed in any detail. It is simply not clear, in most cases, what the authors understood by the categories they were using.

It is possible that the sheer number of unexplained terms used in the articles may in itself reflect conflicts and confusions regarding what may be the "appropriate" terms to use, and it may also reflect not the researchers' own preferences, but suggestions and requirements from journal editors, as we ourselves have experienced.

We noted a general conflation of concepts of ancestry, ethnicity and race. Race was commonly presented as a stable category and a risk factor for various health outcomes. In some articles, a distinction was made between the supposed "homogeneity" of the black or white racial groups, as against the "mixed" nature of the coloured group. This distinction, in terms of genetic variation, is not justified. Here, we see a clear conflation between ideas of genetic diversity and aspects of social categorisation.

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We do not attribute any ill intention to this conflation, but it does speak to the overlay of unsubstantiated "race science" thinking – a legacy from imperial and apartheid views of races – in current health science research. The colonial and apartheid category of "coloured" was constituted precisely as a boundary-breaking condition constituted largely through the breach of miscegenation taboos. As Posel[10] notes, it is the "coloured" label that was defined in the Population Registration Act as "a person who is not a white person nor a native", which creates a particular challenge for common-sense or naïve understandings, as it violates the neatness of supposedly "pure" categories. Given this, it is probably not surprising that the article that sparked this book was one dealing not with other "racial" categories, but with the category of "coloured", the constitution of which implies a breaking of boundaries, and hence a taboo.

TABLE 7.1: Terms used for referring to apartheid era and other racial categories

Black	White	Coloured	Indian
▪ Black African ▪ Black ▪ Bantu ▪ Black Xhosa-speaking ▪ Black Xhosa African ▪ African ▪ Black African descents (black population) ▪ Native Africans ▪ Xhosa	▪ White ▪ European ▪ Caucasian ▪ European descents (white population)	▪ Mixed ancestry ▪ Mixed ▪ Coloured ▪ South African Coloured ▪ Khoisan ▪ Coloured, Mixed ancestry ▪ Admixed ▪ Mixed descents (coloured population) ▪ Mixed population ▪ Mixed race	▪ Indian ▪ Asian

Discussion

It is clear that as health researchers, we cannot and should not be taking "racial" categories for granted – we should not be skipping over the challenge of engaging with complexity. Following international and local guidelines, we suggest the following.

The reason for using race or ethnicity should be specified

Whenever researchers use race in research, they should provide clear justification for doing so. The use of terms such as race or ethnicity without explanation can reinforce the impression that these are natural means of grouping people,[11] or that

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group differences are genetically determined, with little or no influence from social and environmental factors.[12] Such practice also creates the idea of certain race/ethnic groups being genetically "at-risk", which can reinforce racial stereotypes.[13]

Almost half of the studies we reviewed failed to state the purpose for using race as a variable, and in cases where authors did provide reasons, the majority expressed interest in studying race as a biological variable (a proxy for genetic risk), which is not feasible in the absence of actual genetic evidence. Furthermore, we found no studies where the intention was to evaluate race as a marker for socially mediated forces, and none that specifically focused on racial or ethnic discrimination or structural racism as potential drivers of health disparities.[14]

Racial categories should be described and justified

Racial categories are often broad and overlapping and can have ambiguous or contradictory meanings amongst researchers, research participants, and the general public.[15] The International Committee of Medical Journal Editors has recommended the following:

> Authors should define how they determined race or ethnicity and justify their relevance. Authors should use neutral, precise, and respectful language to describe study participants and avoid the use of terminology that might stigmatize participants.[16]

We found that authors sometimes used a variety of labels in referring to a particular race group in different parts of the same article. In addition, multiple terms for the same racial/ethnic group were often used across studies. This lack of uniformity makes interpretation of the reported findings challenging. We further noted the adoption of the term "Caucasian". The history of the origins of this term is instructive.[17] Introduced in 1795 by the naturalist Johann Blumenbach, it was originally used in reference to a skull found in the Caucuses Mountains (between the Black and Caspian Seas) that was used by Blumenbach to exemplify his "superior race", which later came to be synonymous with the "white race". The continued use of the term "Caucasian" is problematic, because it lacks meaning (most white people do not have their origins in the Caucasus; there is no Caucasoid language or culture, etc.) and also because it is offensive, given its links to ideas of white supremacy.

Our review further found that in most studies, investigators either did not state how race was determined or indicated that self-reporting had been used. Racial or ethnic self-identification presents a number of challenges, which should be acknowledged, such as the fact that identities are complex and multi-layered. People may, for example, resent the imposition of a particular race category and choose another, or

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they may identify with more than one group. Self-identity can also evolve across time or place, along with the changing social or political meanings associated with a particular classification.[18]

All relevant variables should be considered in the analyses

Most health problems arise from the social conditions in which people live and work, from their genetic make-up and from interactions between the two. In addition, racism and other forms of discrimination mediated through psychosocial stress, poor healthcare access and differential quality of care can have profound effects on health disparities. Researchers assessing differences in health attributes or disease risks amongst groups defined by race, ethnicity or ancestry should therefore exercise care in attributing racial differences to genetic factors without considering all relevant sociocultural and environmental factors. While a number of the studies in our sample gave some attention to confounding variables, very few of these variables were considered or adjusted for in the analyses. In particular, socioeconomic and educational factors received scant attention, and the word "racism" did not feature in any of the 15 studies.

The use of race or ethnicity as markers of biological variation should be discouraged

Using race in health research and practice perpetuates the idea of inherent racial differences that can impact negatively on patient care in several ways.[19] First, "clinical racial profiling" can contribute to diagnoses being delayed or missed. For example, a doctor may fail to consider a diagnosis of sickle cell disease in a patient who looks or self-identifies as white, if she considers the disease to be more prevalent in black people. Second, viewing patients through a racial lens encourages evaluation of people as representatives of particular race groups, rather than as individuals. This can promote racial bias in the delivery of care. It has, for example, been documented that the erroneous belief that blacks are less likely to experience pain than whites influences the way black patients are perceived, and accounts for racial disparities in pain assessment and treatment.[20] A third way the understanding of "race-as-biology" can undermine the quality of patient care is by fostering a mind-set that undervalues the importance of the social, environmental and structural causes of disease. Thus the study of the biological costs of social factors, operating through racism and other forms of discrimination, generally tends to be neglected in health research.[21]

It needs to be emphasised that even though race and ethnicity in research can have value in tracking and addressing health disparities, they remain poor surrogates for genetic variability (as noted earlier in this chapter) and therefore their use in studying disease risk is discouraged. Ancestry, ideally estimated through direct

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measurement of genomic information, rather than self-report, offers a better way of assessing genetic susceptibility. It has been recommended that health researchers use biogeographical (genetic) "ancestry" to study the potential health effects of genetic variation, "race" to describe socially-mediated health disparities; and "ethnicity" where the interest is in evaluating such factors as traditions, lifestyle, diet and values.[22] Our review demonstrated a great deal of confusion and inconsistency in the way these terms are being used, with many instances being identified of authors using the labels interchangeably.

Conclusions

Ours was a small study, occasioned by a particular impetus. Our intention in this chapter is not to argue for representivity of the articles we reviewed, but rather to provide a partial institutional context for understanding the article that led to the outcry. It is also important for us to acknowledge that because of where we ourselves are placed, we looked at publications from only one faculty in one university – without more research, we cannot say how representative our findings may be of health research more generally in South Africa. We suspect that we would find many similar usages of terms across a range of South African universities and research institutions, but we cannot, of course, be sure of this without having the data.

Overall, the picture we saw is similar to what has been reported in the international medical literature: use of terms of convenience or shorthand terms to designate research populations, with very little engagement with what terms mean, and with the common conflation between the concepts of race, ethnicity, ancestry, or genetic variation. In all the articles we reviewed, researchers were focused on clinical and health issues of concern, and in general, mention of race or ethnicity was secondary to the primary aim of the research.

We do not believe that it is helpful to blame medical researchers for this – the patterns we see are similar to what is seen globally and reflect the limitations inherent in health sciences education, where race is often dealt with as a "black box" concept, representing presumed biological (genetic), environmental, social and cultural factors affecting health.[23] But what is key here is that we can see how health research in our own faculty is reproducing the problems identified in the local and the international literature regarding the use of these categories. As readers of the articles we reviewed, we cannot know what the thinking was on the part of researchers in their approaches to questions of reporting of race and ethnicity, and this is a question for further research. On an impressionistic basis, however, and recognising the limitations of our interpretation of motives that are not explicitly mentioned by authors, we suggest that there are two key issues which should be

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addressed in further research and training. The first of these may be the somewhat unthinking use of labels without due care to their complexity, and the second may be the wish to avoid discussion of an issue which many South African authors are well aware has been a source of great pain and injustice, but not the focus of concern of the researchers themselves. Both these responses (if we are correct that they are there) are understandable. It is clear that for South African health research to move forward in a more scholarly manner with respect to the use of racial labels in research, we need to be aware of and to implement existing international guidelines. It is also incumbent upon us, however, to consider the local context and the particular history of racial terminology and divisions in our country, and the ongoing legacy of this in our work at present.

Endnotes

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