



Critiquing the ethics review process in the 2019 Nieuwoudt *et al.* study on the impact of age and education on cognitive functioning among coloured South African women

A Strode,¹ BA, LLB, PhD; W Freedman,¹ BCom, LLB, LLM; Z Essack,² PhD; H van Rooyen,^{2,3} PhD

¹ School of Law, College of Law and Management Studies, University of Kwa-Zulu Natal, Pietermaritzburg, South Africa

² Human Sciences Research Council, Pietermaritzburg, South Africa

³ MRC/Wits Developmental Pathways for Health Research Unit, Johannesburg, South Africa

Corresponding author: A Strode (strodea@ukzn.ac.za)

In April 2019, Nieuwoudt *et al.* published an article on the impact of age and education on cognitive functioning among coloured women in the Western Cape Province, South Africa (SA). The study reported that coloured women in SA have increased risk for low cognitive functioning, as a result of limited education and unhealthy lifestyles. The article was widely criticised, and the journal subsequently withdrew the piece. It was argued that the study was unethical as it perpetuated racial stereotypes through its failure to recognise the distinction between race and ethnicity when undertaking biological research on a race group. The study had received ethical approval, which raised pertinent questions about the ethics review process. This article looks at (i) the role of research ethics committees (RECs); and (ii) the normative framework within which ethics committees operate. It avers that an understanding of the ethical issues of scientific validity, fair subject selection and minimising harms must be viewed in the light of the complex social issues surrounding the construction of coloured identity in SA. The article finds that the REC should have considered this study unapprovable, because its methodology was based on racist assumptions, and its focus on one race or ethnic group posed social risks for that community. The REC ought to have interrogated why researchers were unclear in their distinction between race and ethnicity, and have been mindful of race being a social rather than a biological construct.

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In April 2019, Nieuwoudt *et al.*^[1] – all of whom were associated with the Department of Sport Science at Stellenbosch University – published an article on the impact of age and education on cognitive functioning among coloured women in the Western Cape Province, South Africa (SA).^[1] The study found that coloured women in SA have ‘increased risk for low cognitive functioning as they present with limited education and unhealthy lifestyle behaviours.’^[1]

Although the article itself does not state that it was granted ethics approval, the broader study from which it emanated was approved by Stellenbosch University’s Ethics Committee for Human Research,^[2] and the article itself was peer reviewed. Despite complying with these processes, the ethical credibility and scientific validity of the study were called into question shortly after publication. These criticisms, which first appeared on social media, arose out of both the flawed methodology adopted by the researchers and the racial stereotypes embedded in and perpetuated by the study write-up.^[3-5] As a result of these and other criticisms, the article was retracted by the journal editors in May 2019, although it remains online ‘to maintain the scholarly record.’^[6]

The fact that the study was granted ethical approval by the Stellenbosch Ethics Committee for Human Research raises pertinent questions about the efficacy of the ethics review process in this instance. Two of the key criticisms were that the study had a flawed

methodology, and that it resulted in social harm – both of these are ethical issues. SA national ethical guidelines require health research to be scientifically valid, and to maximise benefits and minimise harms to participants.^[7] This leads to the question posed in the present article (and raised by others such as the Psychological Society of SA (PsySSA)^[4]): did the Stellenbosch Ethics Committee for Human Research fail to protect the rights and promote the welfare of participants by granting this study ethical approval?

This question can only be answered by looking at: (i) the role of research ethics committees (RECs); and (ii) the normative framework within which ethics committees operate. Critically important to an understanding of the ethical issues of scientific validity, fair subject selection and minimising harms raised above are the complex issues surrounding the construction of coloured identity during the colonial and apartheid eras, which gives rise to contemporary perceptions of race in SA.

We begin this article by exploring the issue of race through the use of poetry. Following this, we set out the ethicolegal framework governing ethics review of health research in SA. We describe some of the relevant norms established in national ethics guidelines,^[7] and then apply these principles to the question of the efficacy of the ethics of the Nieuwoudt *et al.* study.^[1] Before we turn to discuss these issues, however, it must be noted that the application submitted

by Nieuwoudt *et al.* to Stellenbosch University's Ethics Committee for Human Research has not been made public. The arguments presented in this article, therefore, are based on the assumption that the study and the resulting article were consistent with the submission made in the ethics application.

Complexities of race, identity and colouredness in contemporary SA

Although racial discrimination in SA may be traced back to the arrival of the Dutch colonialists at the Cape in 1652, the legal classification of every South African as black, white, coloured or Indian (the 'four-race silo') dates back to the apartheid era (1948 - 1994), and in particular to the enactment of the Population Registration Act No. 30 of 1950.^[8] Significantly, the coloured racial category stemmed from apartheid's collapsing of all mixed-race persons (those not white, black or Indian) into one homogeneous racial and ethnic category despite their diverse backgrounds.^[9] All South Africans were classified into one of the four race groups, and these classifications determined how resources were allocated, where people lived, where they went to school and who they could marry or have sex with.^[10]

Unsurprisingly, these racial classifications and their pernicious effects continue to shape everyday life in SA. This is evident from the need to identify your racial category on almost every form you complete, to everyday social interactions where individuals continue to see each other first and foremost in terms of physical characteristics and attributes linked to race.^[11-13] Race thinking plays a significant role in the construction of imagined communities of otherness, providing the tools for making sense of social relations, actions and events.^[14]

One of the consequences of this system of racial classification was the construction of a coloured identity. Defining coloured identity is complex, and it has been referred to as 'a dynamic and fluid identity belonging to a specific group in SA, most often attributed to persons popularly perceived as being of mixed racial and ethnic descent who, over time and due to specific historical, cultural, social and other factors, have undergone various changes in their perceptions of their identity as Coloured people.'^[9] This constructed identity, however, contained a number of negative and racist stereotypes, many of which persist today.^[9] As the poems below, by Heidi van Rooyen,^[15] illustrate, one of these stereotypes was that coloureds were considered to be 'impure' and of mixed blood as their existence arose out 'forbidden' sexual relations between colonial settlers and indigenous inhabitants.

The Left Overs

a coloured:
someone who's not black
not white
and also not Indian.
a non-person.
those remaining
after the nations were sorted out.
the left overs

Apart from being stereotyped as impure, coloureds were also believed to carry a number of inbred characteristics tainted with negativity, deviance and illegitimacy.

God's step-children

No matter how respectable
you become
or your achievements,
the taint of that original sin
remains entrenched.
You'll be reminded
how early colonists
plucked vagrant coloured women off the beach
tossed them in their kitchens as slaves
and fucked them like beasts
to produce
you—
a half-caste
bastard.
Morally weak,
defective
lacking in endurance
prone to dishonesty
licentiousness and drink
you are –
God's step-children.

Today, colouredness is sometimes viewed as synonymous with gangsterism, criminality and violence, thus deepening prejudice about the group. As these poems indicate, stereotypes of coloured people suggest a set of 'inherent' characteristics that essentialise what it means to be coloured – they offer a view of the self, seen through the eyes of the other, but also reflect a partially internalised sense of stigmatisation and shame of belonging to a socially repudiated identity category. This framing of race historically and today is important in ethical deliberations about the fair selection of research participants, and the potential for research findings to reinforce such stereotypes, thereby creating social harms.

The ethicolegal framework regulating health research in SA

All health research in SA is governed by the National Health Act (NHA) No. 61 of 2003,^[16] which prescribes that health research ('knowledge production' in a range of health fields including biology, psychology or social processes and human technology) must obtain local ethics approval from institutional RECs.^[16-18] The national ethical guidelines concur on the requirement for institutional ethics review.^[7] Furthermore, the guidelines require RECs to act independently and to objectively assess research protocols.^[7]

The NHA^[16] describes a dual mandate for RECs (s73(2)). Firstly, they must review research to establish whether the study will 'promote health, contribute to the prevention of communicable or non-communicable diseases or disability, or result in cures for communicable or non-communicable diseases.'^[16] Secondly, they must grant approval for research that meets the 'ethical standards of that committee.'^[16] The national ethical guidelines state that the overarching role of RECs is to protect the rights and promote the welfare of research participants.^[7]

The national ethical guidelines identify several normative factors for consideration in ethical deliberations. Of relevance to this article is scientific validity, that is, that the selected study design and

methodology should be sound and scientifically valid.^[7] Also, there is an ethical obligation to minimise harm.^[7]

Although the national ethical guidelines do not directly address the issue of race, they recommend that ethical review ought to be situated within a contextual analysis of the factors that may affect vulnerability, or affect the way the study is implemented.^[7]

Discussion

In recent decades, there has been a shift towards recognising the important role of RECs in protecting research participants.^[18] In tandem, there has been a shift from informed consent as the primary mechanism for protecting research participants to ensuring that an ethics committee deliberates on a range of ethical considerations and approves the study before any potential volunteer is approached to provide consent to participation.^[18] This signifies a move towards a broader public policy approach where participants may only enrol in research found to be scientifically valid and ethically acceptable.

Given this mandate, the present article seeks to address the following questions: did the Stellenbosch University Ethics Committee for Human Research fulfil its statutory mandate? Did it protect the rights of research participants and promote their welfare through ensuring that the study was both relevant and ethical? These two issues are intertwined with the considerations of race.

The study by Nieuwoudt *et al.*^[1] does appear to be addressing what the authors suggested was a significant health issue for women, namely age-related cognitive decline. The authors justifiably argued that given increased life expectancy, it was important to understand this phenomenon.^[1] However, we question whether the study would promote the cognitive health of women generally, as it focused on a single socially constructed race group, in one geographic location. Further, we contend that this should have been considered during ethical deliberations. The authors advance three reasons for enrolling only coloured women into the study. First, they quote earlier research by Peltzer and Phaswana-Mafuya^[19] that found lower cognitive function scores among black African and coloured participants.^[1] Second, they suggest that there has been limited further research into this finding among coloured persons, and that this makes it difficult to advocate for improved services to them.^[1] Third, although they concede that the term coloured is a 'product of the apartheid era', they suggest that this population group is in terms of a class analysis considered a homogenous group, and thus knowledge may be generalised within the group.^[1]

These rationales do not explain why women of other races living in the same community exposed to the same environmental conditions were excluded from study participation. The literature included in the article makes it clear that environmental and lifestyle factors are significant contributors to cognitive decline.^[1] It is unlikely that the target community only consisted of coloureds, and this indicates that the researchers and the REC did not adequately consider the ethical principle of justice and fair selection of study participants. Given concerns around research exploitation of historically disadvantaged groups,^[20] it is pertinent that RECs carefully consider the rationales for excluding other race groups from research. Furthermore, we argue that the ethics committee erred in finding the study relevant, as in our post-apartheid era the SA Constitution^[21] provides that 'everyone' has a right to access healthcare services. How could any results of the study inform the development of state services when the information

cannot be generalised, for a number of reasons, particularly that the researchers only enrolled a small number of participants from a single race group living in one community into the study. This is especially problematic as they draw conclusions about all coloured women in SA based on only 60 women in the Western Cape.

Beside being socially valuable and relevant, it is clear that to be ethical, research must be scientifically valid, and participants must be protected.^[7,22] The study has been criticised as methodologically flawed,^[4] and its scientific design based on 'racist ideological underpinnings'.^[3] Furthermore, the write-up of the study findings evokes stereotypical views about coloureds that resulted in social harm to the participants – reinforcing negative stereotypes of coloured people as lazy.^[9] The focus on women only reifies sexist stereotypes that women are cognitively deficient compared with men.^[23] Both criticisms are underpinned by unarticulated racial (and sexist) stereotypes. Racial stereotypes are constructed perceptions that all members of the same race group (or ethnicity) share certain characteristics, which are typically negative.^[24] We agree with other commentators who observed that the Nieuwoudt *et al.*^[1] study displayed several scientific and methodological flaws. For example, the sample size was too limited to draw generalisable conclusions, the sampling approach was convenience rather than random probability sampling and the research instruments were not validated for use in SA.^[4]

In addition to these flaws, we argue that the failure of the REC to address the issue of race further undermined the scientific validity of its results. Where race is an element of the research question or a factor that may lead to vulnerability, this ought to fall within the ambit of the ethical deliberations. Ethical research is research that is mindful of contextual factors that may impact on the vulnerability of research participants.^[7] We argue that a contextual approach to ethics, and ethical review, requires a recognition of our social context, and this includes concerns about race and identity, particularly when these form part of the research question or may impact on the way the research is to be conducted. In this instance, it appears that the researchers and the REC failed to recognise the interplay between race, ethnicity, identity and vulnerability. For example, the researchers' methodology included asking women who were not familiar with computers to complete an electronic IQ-based assessment. This raises serious questions about the scientific reliability of such an approach, and demonstrates a failure to understand the context of the community being researched. In the study, instead of recognising the context and defining the study group as historically and socioeconomically disadvantaged, with poorer access to education, and linking experiences of poverty and educational attainment with cognitive dysfunction, the authors erroneously linked 'biological' race with cognitive impairment. This heightened participants' vulnerability, as it contributed to the further stigmatisation of coloured women as cognitively impaired. Research that uncritically uses 'race' as a variable to explain behaviours or outcomes runs the risk of perpetuating racial (and gender) stereotypes,^[23,25] and therefore social harms, through resultant stigma and discrimination. Furthermore, such findings may irresponsibly reinforce highly controversial (and discredited) race science research that argues that race (genetics) and intelligence are related.^[26,27]

Like ourselves, PsySSA found it surprising that the ethics committee did not highlight the issue of race, given our context – a historical narrative in which science was used to promote the political ideology of white supremacy.^[4] Furthermore, coloured women, as a study

group, do not exist from a biological or scientific perspective.^[23,27] They are a population group that exist as a result of our history: they exist as a politically constructed group who suffered a particular and unique form of racial discrimination. The poems set out above describe this social disadvantage. In our opinion, it is ethically and scientifically valid to study the impact that this unique form of discrimination has had on the economic, physical, psychological and social development of coloured women. Such research, however, must proceed from the basis that they are a politically constructed group, and that race is not a biological fact.^[23] Using this approach, we argue that it would be ethical to study coloured women (or constructions of race more broadly), and the consequences that our historical legacy and ongoing racial stereotyping have had on their cognitive development or other outcomes.

This leads to the question of whether the approach of the researchers and the REC was based on an unarticulated stereotype of coloured persons.^[23] We argue that delineating the study group on a biological basis was racist. This approach accepted the colonial and apartheid argument that there is such a thing as a coloured race, and that they are biologically inferior to other races, especially whites – they are the left overs – God’s step-children. Furthermore, in their use of race to explain low cognitive function, the authors unscientifically reproduced politically constructed racial groupings and stereotypes, ‘thereby perpetuating stigma, discrimination, and racism’^[23]

Conclusion

In conclusion, we argue that the Stellenbosch Ethics Committee for Human Research should have considered this study unapprovable, as its methodology was based on racist assumptions, and its focus on a single race group posed a social risk for that community. Furthermore, the methodological flaws of the study introduced scientific bias, and it should also have not been approved on those grounds.

The ethics committee ought to have interrogated researchers’ use of race as a variable. Limiting enrolment to participants who self-identified as coloured was scientifically invalid, as there was no biological basis for such an approach. Nor was there a control group against which to compare study findings. In this instance, researchers were wanting to study a biological phenomenon (cognitive functioning) in a population that does not exist from a biological perspective – a point both Nieuwoudt *et al.*^[1] and the REC failed to recognise. Furthermore, the researchers and the REC did not consider the complicated history of racial stereotyping regarding colouredness, and this resulted in social harm to the participants. Concepts of coloureds as being of mixed race and therefore deviant, as well as cognitively deficient and lazy, were perpetuated by this study. Some commentators have raised concerns about ethics creep, specifically, that the review process falsely absolves researchers of their ethical responsibility, which is instead shifted to RECs.^[27] We agree that the onus is on researchers to clearly consider these issues, but consider that it is the mandate of RECs to ensure participants’ protection and promote their welfare.

RECs must pay attention to protocols in which race is an element of the research question, or where the participants are to be limited to a particular race or ethnic group. This underscores the common practice that researchers submit for REC review their rationales for excluding race groups or genders for a particular study. Researchers

and REC members must be mindful of race being a social rather than a biological construct. This is not to say that one could never research biological phenomena from a sociopolitical perspective, which may involve particular race groups. In the latter instance, the difference would be that one could, for example, study the sociopolitical impact of our colonial and apartheid past on the health of a given group.

We recommend that RECs should critically examine:

- (i) the rationale for the study of a particular race, ethnic or gender group;
- (ii) the nature of the study, i.e. whether it is biological or social in nature, and whether membership of a racial or ethnic group is required to answer the research questions, and likewise whether the study requires persons to be a particular sex. This may require asking the researchers to explain how they define the group under study, and how this is linked to answering the research questions;
- (iii) the scientific validity of focusing on one or more particular racial, ethnic or gender groups to the exclusion of others;
- (iv) the relevance and validity of research tools and measures in the SA context; and
- (v) the potential for social or other harms that may directly or indirectly occur due to the focus on a particular racial or ethnic group. In particular, they should interrogate whether there are any underlying group stereotypes (either explicitly or, more importantly, implicitly) that may be perpetuated by the study, and efforts of the researchers to offset these.

Dedication. This article is dedicated to Prof. Brenda Grant, who passed away on 23 May 2019. Brenda, who was classified as coloured during the apartheid era, touched all of our lives in multiple ways. Perhaps her most outstanding quality, however, was her ability to recognise the role race continues to play in all of our lives, while also being able to look beyond it.

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