



## Racial profiling in medical research: What are we measuring?

Bassett<sup>1</sup> relates the story – probably apocryphal – of the American visitor to Haiti who, upon meeting Jean-Paul Duvalier, the legendary (if notorious) dictator popularly known as Papa Doc, asked him ‘So, how many whites live in your country?’ ‘Why, in Haiti, nearly everyone is white,’ Papa Doc replied confidently. Astonished, the visitor enquired ‘But how do you define white?’ The iron-fisted ruler thought for a moment, and then asked ‘How do you define black in the US?’ The American proceeded to explain the ‘one drop rule’ whereby anyone with black ancestry within four generations was classified as black. ‘Well, we use the same definition,’ Papa Doc retorted (many Haitians can trace white ancestry within four generations).

The story aptly illustrates the soft underbelly of ‘racial’ classification based on ancestry or physical attributes, something with which we in South Africa became all too familiar during the era of apartheid with its Population Registration Act (PRA) and other similar legislation. Sadly, our current population census forms and other public and private registrations still require South Africans to indicate their ‘race’ by ticking one of 4 boxes (the bureaucrats have determined that there are only 4 ‘races’ in the country). In the US, a country with a similar history of social and statutory racism, the census form provides for 5 ‘race’ categories, which are listed as white; black or African American; Eskimo and Native American; Hawaiian and Pacific Islander; and Asian. But, in a strange and telling twist, the respondent is allowed to tick more than one box.

The rationale given for continuing to collect statistics by ‘race’ in South Africa is so that post-apartheid transformation can be monitored, the theory being that such race-based vigilance will facilitate the redress of past deprivations. Plausible as this may sound, and while one may have some sympathy for the state’s dilemma, the practice runs the real risk of entrenching a ‘race’-based mindset and ‘race’-based attitudes. People are more likely to perceive the obligation to declare one’s ‘race’ on a form as an affirmation of the validity of ‘race’ classification than as a means to erase it. In the sophisticated world of the 21st century, one would think that there was room for ‘thinking outside the box’ to devise other means for monitoring and ensuring social inclusiveness. Countries such as the Netherlands that do not require citizens to declare their ‘race’ are able to generate equally credible statistics.

It is paradoxical for a society that seeks to erase ‘race’ consciousness and stereotyping, simultaneously to oblige its citizens to state their ‘race’ in official documents. The

international community would not tolerate a Germany that required Jews to declare their ethnicity in official enumerations as a vehicle for redressing the Nazi excesses of the past. Ellison has written extensively on post-apartheid ‘race’ classification in medical research, and asserts that the practice ‘legitimizes discrimination and reinforces a racially structured view of society’<sup>2</sup>. Stolley observes in respect of the official use of racial classification in the US: ‘[I]n an attempt to redress the oppression of the past and the denial of civil and economic justice ... [t]he good intentions of the government have led to a perpetuation of unscientific racial categories and contributed to the confusion about race, genetics, and culture as contributors to past and present conditions’<sup>3</sup>.

### Race-based research reinforces racial stereotyping

In the days of apartheid, it was almost routine practice for South African clinical researchers to set the research question and conduct the analysis of the findings in a format that rhymed with the ‘race’ categories in the PRA. This often generated reams of tabulations on the manifestations of the condition under study among whites, coloureds, Indians and the Bantu (or however black Africans were then called) without an accompanying hypothesis of what was being measured. To be sure, some researchers used race classification quite consciously as a device to show up the ill effects of apartheid on the health of the disenfranchised groups, and thus to tighten the screws for change. More often than not, however, race classification in research simply represented a mindless, knee-jerk compliance with the prevailing sociopolitical mindset.

The winds of change of the 1990s inspired a new editorial policy at the *SAMJ* not to publish papers making unwarranted reference to ‘race’. The policy evoked some anxiety and debate among activist epidemiologists who viewed the continued use of ‘race’-based analysis as still necessary to highlight residual health and health care inequities, and as a mechanism to monitor and press for post-apartheid redress.

Since that time, however, other peer-reviewed international journals have adopted a similar editorial policy. Wikipedia<sup>4</sup> records that ‘In February, 2001, the editors of the medical journal *Archives of Pediatrics and Adolescent Medicine* asked authors to no longer use “race” as an explanatory variable and not to use obsolescent terms. Some other peer-reviewed journals, such as the *New England Journal of Medicine* and the *American Journal of Public Health*, have made similar endeavours.’ In their 2001 editorial, the editors of *Archives of Pediatrics and Adolescent Medicine* elaborated that ‘race and



ethnicity should not be used as explanatory variables, when the underlying constructs are variables that can, and should, be measured directly (e.g., educational level of subjects, household income of the families, single vs 2-parent households, employment of parents, owning vs renting one's home, and other measures of socioeconomic status)<sup>5</sup>. More often than not, 'race' serves as a proxy or surrogate for the real causes of ill-health. Invoking ethnicity as a health determinant without further elaboration 'leads to sloppy thinking about causation and confuses social, political, and cultural determinants with unproved genetic factors'.<sup>3</sup>

### Only one human race

From its very origins dating back to Carolus Linnaeus' *Systema naturae* in the 1700s (which classified the world population into *Europeus albus*: ingenuous, sanguine, governed by law; *Americanus rubescus*: happy with their lot, governed by custom; *Asiaticus ludridus*: melancholy, governed by opinion; *Afer niger*: crafty, lazy, governed by the will of the master), the 'race' doctrine has been inseparably linked to notions of superiority of one group over others. PAC founder Robert Sobukwe was probably the first South African to hold that there was only one human race (a position clearly lost to many of his subsequent followers), and used the now fashionable catchphrase of 'non-racism' at a time when most progressives still championed a 'multi-racial' society. He was right. According to biological evidence, genetically distinct human races do not exist. The species *Homo sapiens* consists of a single population, and in a recent *SAMJ* editorial,<sup>6</sup> Kirsch suggests, somewhat tongue-in-cheek but not without some circumstantial evidence, that every human being is African. Human beings share 99.9% of their DNA in common, and there are probably a greater number of genetic variations among the Zulu than between the Zulu and Indian South Africans, for one example.

It is of course true that there has been a clustering of variant alleles, phenotypes, and polymorphisms<sup>7</sup> among sections of the human population that have lived together, bred together and shared the same culture and language over centuries in relative isolation in geographically dispersed regions and sub-continent of the world. Gene pooling has given rise to increased susceptibility to certain rare Mendelian disorders among such groups as the Amish, the Ashkenazi Jews, the French Canadians, and the Afrikaners. The higher frequencies and patterns of the relevant genes 'result from historical events such as population bottlenecks and founder effects that affect the ways in which genetic features are distributed

in subsequent generations'.<sup>8</sup> This does not render these social population groups biologically distinct 'races', nor are these disorders limited exclusively to them.

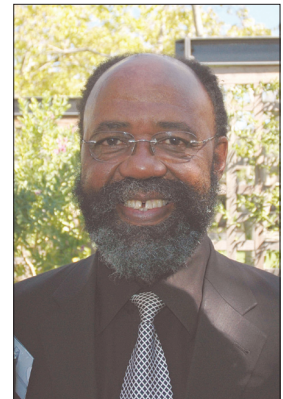
### Health inequalities are rooted in our society, not in our genes

The point of this editorial is not to deny the reality of ethnicity, understood here to refer to social formations based on shared culture, values, language, descent, religion or other commonality, and which can be fluid and open-ended, so that one can be Ethiopian, African, and Jewish all at the same time. Nor is it to deny the reality of external differences based on skin colour or other physical characteristics.

In unequal societies with a history of institutionalised racism, particular health and medical problems have a particular prevalence in ethnic groups that are longstanding victims of material deprivation and health care inequities. In this context, research into health disparities of social groups that are victims of discrimination is both legitimate and important. However, the researcher should be quite clear as to what is being measured. The research should not lead to 'social and economic variables [being] mixed up with, and confused with genetic determinants'<sup>3</sup> in the mind of the researcher, and should not lead to the misperception that being black (for example) – rather than poverty, limited education, poor housing, lack of sanitation, poor nutrition and other deprivations – is the 'explanation' for ill health.

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