EPISTEMOLOGICAL AND ETHICAL CONSIDERATIONS

Uses and Abuses of the Concept of Race in the Genomics of Sport Performance

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Outline of talk

1. The reification of the concept of race in sports genomics
2. The unfulfilled HGP promise and the post-genomics re-inscription of the scientific concept of race
3. The epistemic disutility of the concept: an example from concussion research
4. Ethical aspects of the use of race in sports genomics
5. Latest developments, and call for action
The reification of the concept of race in sport genomics
Examples from concussion research

Black collegiate-athletes found to have lower concussion symptom knowledge than White counterparts


How did we get here?

Didn’t we say...?
The unfulfilled promise of the HGP to put an end to the scientific concept of race

- The completion of the HGP had showed that the genetic differences within a population were much higher than the genetic differences between populations, confirming previous studies from Lewontin (1972) and Luca Cavalli-Sforza (1997)

- At the White House ceremony announcing the completion of the 1st draft of the human genome, Craig Venter, and NIH Director Francis Collins announced that ‘The concept of race has no genetic or scientific basis’

June 26th, 2000 White House ceremony announcing the completion of the 1st draft of the human genome project
For the 1st time, this article showed that populations were more genetically diverse than previously thought, as most genetic variation in *Homo Sapiens* is contained within populations.

The 1972 article by Lewontin was the 1st of many calls in the following years to *abandon the use of the term ‘race’ in the human species.*

Most of the variability between human beings can be explained in terms of differences within a population (however defined), not between populations.
With the advent of genome sequencing, Lewontin’s findings were confirmed in 1997 by Guido Barbujani and Luca Cavalli-Sforza who published in *PNAS* an article with a very similar title, and concluded that:

- There is **no significant genetic discontinuity** between any so-called racial groups which could provide a biological basis for **any racial classifications** in the human species.
- ‘**The burden of proof is now on the supporters of a biological basis for human racial classification**’. 
In a praiseworthy example of an intellectual collaboration between a geneticist and a philosopher of biology, Guido Barbujani and Massimo Pigliucci have argued that:

‘The analysis of large genomic datasets is showing why it proved impossible to find an agreement on the main biological groups of humankind. Among nearly 250,000 polymorphic genome sites, no single-nucleotide polymorphism was found at which a fixed difference would distinguish any pair of continental populations’

However... a ‘post-genomic’ surprise?

There is substantial evidence that developments in several fields of inquiry and practice related to molecular genetics e.g. pharmacogenomics, clinical genetics, personalized medicine, forensic science, as well as sport genomics, have served to re-inscribe race as a biological category.

The post-genomics age has witnessed a ‘surprising’ re-inscription of biological discourses of race.
How did this happen?
Why didn’t genomics fulfil its promise of eliminating the concept of ‘race’ from scientific discourse?

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The National Institutes of Health (NIH), in an *effort to ensure inclusivity* and diversity of populations in genomics data, is requiring the use of ‘race’ in their studies.

What this means is that scientists funded by the NIH are mandated to include race based on US Census categories.

Not only a US-problem.... Also the European Commission and the UN, among others, issue recommendations for their member states’ census or other data collection efforts to *include race* in their research projects.
The post-genomics reinscription of the concept of race

• Neil Risch at University of California San Francisco is a strong supporter the biological concept of race in the US.
• Risch argues that each continent is home to a race, and claims that they could demonstrate the validity of racial self-categorisation ‘from an objective perspective’.
• He also a supporter of ‘race medicine’ and argues that race can serve as a useful heuristic to determine differences in treatment responses or disease prevalence.

While Risch’s claims have been discredited by several scholars within the scientific community, he remains in a position of credibility and his views continue to influence the outside world.
Yudell has referred to this reification of race in genomics as the ‘paradox of the 21st century’ where self-reported racial identity remains ‘an essential variable used at all stages of genetic research’.

Taking race out of human genetics

Engaging a century-long debate about the role of race in science

By Michael Yudell,1* Dorothy Roberts,2 Rob DeSalle,3 Sarah Tishkoff

In the wake of the sequencing of the human genome in the early 2000s, genome pioneers and social scientists alike called for an end to the use of race concept in biological research. Some have argued that relevant genetic information can be seen at the racial level (7) and that race is the best proxy we have for examining human genetic diversity (8, 9). Others have concluded that race is neither a relevant nor accurate way to understand or map human on racism (i.e., some race (i.e., supposed position) in the ethnic ‘effects’ (authors to distinguish racial categories...
Today’s scientists using the concept of race in genomics claim that their focus on ‘genetic clusters’ has excised the political aspects of race from their research, and that they are using the term in a neutral way as a proxy for other variables.

*Can we have a ‘neutral’ scientific racial discourse?*
A ‘neutral’ scientific racial discourse?

In his 2017 book, Marks, anthropologist at UNC, reflects that the scientific community willingly, if not deliberately, facilitates the perpetuation of societal racism when it fails to aggressively challenge and refute the arguments about a ‘biological’ concept of race.

It is not possible to have a neutral discourse about the ‘biological’ concept of race.
I agree with Dorothy Roberts at the University of Pennsylvania:

“What these scientists remarkably fail to acknowledge is that their own acceptance of racial category influences the decision to inscribe genetic clusters into genomics research itself”.

It is not possible to have a neutral discourse about the ‘biological’ concept of race.
Let's go back to the example of concussion.
What I am talking about: a supposedly ‘neutral’ scientific racial discourse

The findings suggest a relationship between race and symptom duration, school days missed and changes in post-concussive activity. Black athletes experienced a shorter duration of symptoms (12 days compared to 21 days among white athletes) and returned to school more quickly.

These results are a starting point for future research looking at race differences, Yengo-Kahn said.

“Based on Jessica’s prior work on athletes and concussion knowledge across races, it may be that the Black athletes appear to be recovering faster, but because they are early reporting fewer symptoms and reporting earlier resolution to get back to playing sports, which they were doing prior to the concussion,” he said. “Using a more recent dataset, we have found a significant discrepancy in symptom reporting between Black and white athletes, which also supports this hypothesis.”

The findings also have great implications for future research on concussion. “If you know these groups of athletes are so different when it comes to recovery, you need to start accounting for that when you’re studying them, otherwise prior findings in heterogeneous groups of athletes may not be equally applicable,” Yengo-Kahn said.

“Even after controlling for many confounding variables, we were still able to see differences, which we were frankly expecting to see,” said senior author Scott Zuckerman, MD, MPH, assistant professor of Neurological Surgery.
It is NOT their race, but other variables (e.g. psycho-social, economic and cultural factors) that lead to under-reporting severity and duration of symptoms in black athletes!

*For example...*

**Eliminating Racial Bias and Challenges for Black Athletes With Sports-Related Concussion: The Role of Speech-Language Pathology Clinicians and Researchers**

Alaina S. Davis

https://doi.org/10.1044/2022_PERSP-21-00281
Epistemological issues in concussion research

Race and risk for adverse outcomes following (repetitive) head injuries
Recent data on active and former American football players who self-identify as black point to increased risk factors for long-term adverse neurological outcomes following repetitive head injuries. Several aspects of this standpoint warrant critical scrutiny. First, self-identified racial identity depends on several kinds of psychological, cultural and social factors not always explicitly recognised in the methodology. The observed associations between self-identified racial identities and adverse outcomes following TBI in the recent data on former football players who self-identify as black could be explained only with the psychosocial, economic and cultural factors for which self-identified race is used as a proxy.

The race variable should NOT be used in the explanation and prediction of possible risks of neurological disorders in populations and individuals after repetitive head injury.
If this weren’t enough...

What are the ethical issues associated with the reification of race in sport genomics?

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Ethical implications

1. **Stereotype threat:** Negative feedbacks of using concepts of *self-identified race* as proxies for risks of neurological outcomes reinforces racial stereotypes, and racial discrimination.

2. **Adverse Health Outcomes:** Not only stereotype threat, but: many studies show that the exposures of discrimination do have health implications directly through stress mechanisms, through effects on gene expression.

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Some good news, but ... lots of work to do!
Researchers Need to Rethink and Justify How and Why Race, Ethnicity, and Ancestry Labels Are Used in Genetics and Genomics Research, Says New Report

WASHINGTON — Researchers and scientists who utilize genetic and genomic data should rethink and justify how and why they use race, ethnicity, and ancestry labels in their work, says a new National Academies of Sciences, Engineering, and Medicine report.
STUDY CHARGE

The study sponsor, the National Institutes of Health (NIH), asked the National Academies to conduct a study to review and assess existing methodologies, benefits, and challenges in using race, ethnicity, ancestry, and other population descriptors in genomics research.² The statement of

Using Population Descriptors in Genetics and Genomics Research
A New Framework for an Evolving Field
(2023)

CONTRIBUTORS
Committee on the Use of Race, Ethnicity, and Ancestry as Population Descriptors in Genomics Research; Board on Health Sciences Policy; Committee on Population; Health and Medicine Division; Division of Behavioral and Social Sciences and Education; National Academies of Sciences, Engineering, and Medicine
Recommendation 1. Researchers should not use race as a proxy for human genetic variation. In particular, researchers should not assign genetic ancestry group labels to individuals or sets of individuals based on their race, whether self-identified or not.

Recommendation 2. When grouping people in studies of human genetic variation, researchers should avoid typological thinking, including the assumption and implication of hierarchy, homogeneity, distinct categories, or stability over time of the groups.

Recommendation 3. Researchers, as well as those who draw on their findings, should be attentive to the connotations and impacts of the terminology they use to label groups.
A concerted effort is needed

“It would be silly to think that science will somehow extricate us from a racial quagmire. Despite advances in scientific thinking on race - racism and the belief in races persist. Racism is too complicated to be eradicated by science alone”. (M. Yudell, 2014)

In the second expanded and revised edition of the book published in 1996, S. J. Gould warned specifically against the ‘particular appeal of genetic explanations’ and foresaw what was yet to come with genome sequencing.
Conclusions and action points for the community

1. It is **not** possible to have a scientifically neutral ‘racial’ discourse.

2. The race variable should **not** be used in any contexts in genomics as a proxy to predict something else (in sport: performance, injury, recovery...)

3. Sports scientists, bioethicists and philosophers of sport need to be wary of the latest reincarnation through genetics of old ideas of biologically determined inequalities, which is used to explain away social differences, and work towards implementing a race-free scientific discourse in sports genomics.
References

Thank You!

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