

Statement by UpToDate sent September 23, 2022

We thank the authors for studying this important subject and are pleased to offer some points of clarification.

The authors conclude that some of the content examined “...often inappropriately link[s] Black race to genetics or clinical phenotype without considering socio-structural variables or the health effects of structural racism – thus perpetuating a false narrative that race is inherently biological.” Further, that “UpToDate articles may also promote unequal treatment by recommending race-based clinical practices. Such racial essentialism risks exacerbating racialized health inequities.”

UpToDate is committed to providing evidence-based content that is accurate, comprehensive, and transparent. Our editorial process involves multiple levels of peer review and daily updating that includes regular review of the published biomedical literature as well as other sources of evidence. We continuously strive to improve, and one of our many efforts involves working with our contributors to eliminate bias. We have specifically stressed the importance of having our contributors examine any mention of race/ethnicity and either remove it if it is irrelevant or add language addressing the societal factors and health care disparities that may account for any observed differences. In fact, most of the topic areas from January to March 2020 the authors used as examples had already been revised as part of our ongoing work to address racism in medicine.

The paper defined ten thematic codes with 21 text samples from UpToDate to illustrate their definitions. Based on these codes, they categorized 208 pre-selected UpToDate topics (all contained either “Black” or “African American”). The authors concluded that “biologization of race” was the most common issue.

We disagree with some of the authors’ assessments. They imply that every one of their defined codes describes a negative aspect of the content. However, in our review of these text examples, we believe that some were applied to appropriate and clinically relevant content.

As examples:

- **Genetics + race/ethnicity** – The authors define this code as follows: “when members of particular racial or ethnic groups are described as having allele frequencies or single nucleotide polymorphisms (SNPs) relative to members of other racial or ethnic groups.” We recognize that race is primarily a social construct and that genetics should never be used to explain race or assumed to apply to all members of a self-defined racial/ethnic group. However, certain genetic variants are clustered within larger racial/ethnic groups and recognizing these associations can be a valuable aspect of medical care.

We are assuming that the authors are objecting to content that states that certain alleles appear to increase the risk of a disorder *and* are more prevalent in a certain racial/ethnic group, rather than simply saying that the allele is a risk factor for the disorder. The example cited was a discussion of the APOL1 variants in certain types of chronic kidney disease. However, these variants are found *exclusively* in individuals with African ancestry, are common in African American patients, and are associated with poor outcomes. This information is helpful since improved outcomes may result if the clinician can identify patients in whom close monitoring

and detailed attention to treatment may be required, as genetic testing is not routinely available or feasible.

- **Black populations understudied** – The authors apply this code to the following settings: *"when a lack of research studying a specific disease condition or clinical phenomenon in Black or African American patients is described."* The authors of some UpToDate topics point out that Black (and other) populations are understudied. This is very useful information and serves to remind readers of health disparities in research and trial design. In addition, trials that have specifically been performed on African American populations, particularly when perceived differences in populations are unproven, are valuable. In other words, this is not a negative feature of our content as implied by the study.
- **Social/structural context** – The authors define this code as applicable when discussions regarding racism, structural violence, social inequality, social determinants of health, environmental factors, etc. **are provided** to contextualize racial disparities. Two examples from our content were cited. As above, we view such discussions as positive, but they were cited in the paper as a negative feature.
- **Skin pigment** – The authors apply this code to text *"when race is more specifically discussed in terms of variation in skin pigmentation."* UpToDate authors point out when a specific type of skin lesion, especially one involving redness, is more difficult to appreciate on darkly pigmented skin, and we have been adding more images of various disorders on highly pigmented skin to improve diagnosis. This is helpful and serves to rectify health disparities, as underdiagnosis of various skin disorders in people with more pigmented skin is a recognized problem. This was highlighted in a recent study evaluating different rheumatologic images, which reported that UpToDate had a higher percentage of images depicting important findings on highly pigmented skin than any of the other resources examined [Strait, *et. al.*]. In addition, discussing associations between skin pigmentation and specific disorders is medically correct and clinically appropriate in some cases (eg, vitamin D deficiency).

In summary, we thank Cerdana, *et. al.* for raising these important issues. The editorial staff at UpToDate, together with our expert contributors, strive to deliver the most useful, transparent, and unbiased content possible. We will continue to do so. We believe that some of the examples flagged by the authors were clinically relevant and presented for the very appropriate purposes of correcting underdiagnosis and identifying social determinants of health that contribute to health disparities.

We have spearheaded an initiative across the Health division at Wolters Kluwer to create a guide to language used in our products that embodies the values of diversity, equity, and inclusion. The mission of UpToDate is to help clinicians deliver the best care possible, anywhere in the world. We want those reading our content to feel that it applies to them and the patients they are caring for and we remain committed to achieving this goal.

Reference

Strait A, Graf J, Margaretten M, *et al.* Race, Ethnicity, and Disparities in Rheumatology Educational Materials. *Arthritis Care Res (Hoboken)* 2022; 74: 1416-1420.