

Use of Race in Pediatric Clinical Practice Guidelines A Systematic Review

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IMPORTANCE National clinical practice guidelines (CPGs) guide medical practice. The use of race in CPGs has the potential to positively or negatively affect structural racism and health inequities.

OBJECTIVE To review the use of race in published pediatric CPGs.

EVIDENCE REVIEW A literature search of PubMed, Medscape, Emergency Care Research Institute Guidelines Trust, and MetaLib.gov was performed for English-language clinical guidelines addressing patients younger than 19 years of age from January 1, 2016, to April 30, 2021. The study team systematically identified and evaluated all articles that used race and ethnicity terms and then used a critical race theory framework to classify each use according to the potential to either positively or negatively affect structural racism and racial inequities in health care.

FINDINGS Of 414 identified pediatric clinical practice guidelines, 126 (30%) met criteria for full review because of the use of race or ethnicity terms and 288 (70%) did not use race or ethnicity terms. The use of a race term occurred 175 times in either background, clinical recommendations, or future directions. A use of race with a potential negative effect occurred 87 times (49.7%) across 73 CPGs and a positive effect 50 times (28.6%) across 45 CPGs.

CONCLUSIONS AND RELEVANCE In this systematic review of US-based pediatric CPGs, race was frequently used in ways that could negatively affect health care inequities. Many opportunities exist for national medical organizations to improve the use of race in CPGs to positively affect health care, particularly for racial and ethnic minoritized communities.

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Clinical practice guidelines (CPGs) are a common way to synthesize and disseminate best practice for some of the most common health care problems. As of 2011, there were more than 3700 guidelines from 36 countries.¹ Widely used CPGs are typically developed by organizations, such as specialty societies, advocacy groups, and federal and local agencies. When appropriately developed, CPGs can translate the complexity of scientific research findings into recommendations for clinical practice and lead to improvements in health care quality and outcomes. However, CPGs can have negative consequences on health if they are not intentionally developed to address health inequities of socially and racially marginalized communities.

Medicine has a long history of ascribing blame to the biology and genetics of racial and ethnic minoritized populations for observed differences, rather than fully acknowledging that race is a social-political construction and project, and it is society's treatment of these individuals that is a more likely culprit for the observed differences. Racism, not race, is intertwined with many barriers to good health, such as poverty, access to health care, the quality of care received, and the lived experience of racism. Health care is currently reckoning with the long-entrenched

legacy of systemic racism and the use of racialized medicine. There is a need for meaningful solutions to address these longstanding racial inequities in health care.²⁻⁴

Recently, many professional organizations have acknowledged their contribution to health inequities and have stated their commitment to address them. For example, 20 Obstetrics and Gynecology organizations published a joint statement for collective action to address racism in their practice.⁵ The American Academy of Pediatrics recently published a statement on the role of racism and childhood.⁶ The American Medical Association also published a directive on racism as a public health epidemic.⁷ The US Centers for Disease Control followed suit by declaring racism a threat to public health⁸ while journals and researchers are altering their publishing guidelines to better discuss and represent race and racism in research.⁹ Furthermore, policy makers, physicians, and critical race theory (CRT) scholars are reexamining diagnostic tools that use race as a factor in establishing diagnostic and treatment thresholds, like the glomerular filtration rate.¹⁰ However, the use of race more broadly in medical societies' clinical practice recommendations remains unknown and may represent another opportunity to address the systemic problem.

CRT is a sociological framework that can be used to examine the use of race, policy, power, and distribution of resources. In medicine, it provides a structure to evaluate the use of race in the biomedical context.¹¹⁻¹³ CRT helps us understand the effect of environmental factors, specifically racism, on observed differences in outcomes for racially marginalized groups, compared with majority groups (non-Hispanic White). Simultaneously, CRT provides us the language and analysis to evaluate the use of race in clinical recommendations. There are 2 key tenets in CRT that are useful when investigating CPGs: (1) critiquing the notion of race as a biological factor or a biological plausibility for conclusions in research, as CRT tells us that race is a sociopolitical construct and not a biological or physiological one and (2) the need to critique biological racial essentialism and embrace intersectional identities. That is, race is a confounder and not an effect modifier with respect to health outcomes. Racial categories in of themselves are not directly linked to health outcomes; they are social and political identities that only make up one element of an individual's identity, yet medicine makes sweeping conclusions based on this particular variable. Our intersection of social identities tells us not how our biology functions, but how society treats an individual based on the totality of their identity (race, gender, sex, sexual orientation, etc).

As many national organizations seek ways to address structural racism and overcome health inequities, it is important to understand the way in which they use race in CPGs, particularly for vulnerable populations, such as children. We therefore performed a systematic review to describe the use of race in pediatric clinical practice guidelines and used CRT to evaluate the potential for positive and negative effect on structural racism and health care inequities.

Methods

Search Strategy

We adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) for all aspects of this study and analysis (Figure).¹⁴ We consulted with 2 University of Washington Health Sciences librarians (T.J.) to assist with identifying databases and resources in which to search. The databases selected included PubMed, Medscape, and Emergency Care Research Institute (ECRI), a guidelines database developed to replace the discontinued Agency for Healthcare Research and Quality National Guidelines Clearinghouse. These databases were searched for pediatric guidelines published from January 1, 2016, to March 31, 2020. These data were analyzed May 2020 through September 2020 and the search was updated November 2020 through February 2021. Our inclusion criteria included the PubMed search string incorporated Canadian Agency for Drugs and Technologies in Health's guidelines filter,¹⁵ a version of a validated pediatrics filter¹⁶ updated to reflect PubMed's algorithm changes to limit results to articles addressing patients younger than 19 years, and the population was limited to the US. Medscape's Clinical Practice Guidelines was searched using its pediatrics filter and the ECRI Guidelines Trust was searched using its adolescent medicine, pediatrics, and neonatal filters. Guidelines that did not include the US were excluded manually. Initially, 974 articles were identified, and citations imported into EndNote: 564 from PubMed, 63 from Medscape, and 355 from ECRI. After removing 155 publications that included populations outside the US and dupli-

Key Points

Question How is race used in pediatric clinical practice guidelines?

Findings In this systematic review including 126 pediatric clinical practice guidelines, race was frequently used in pediatric clinical practice guidelines in a way that could negatively affect health care inequities.

Meaning The use of race in pediatric national guidelines should be improved to prevent the perpetuation of racial inequity and health care inequities.

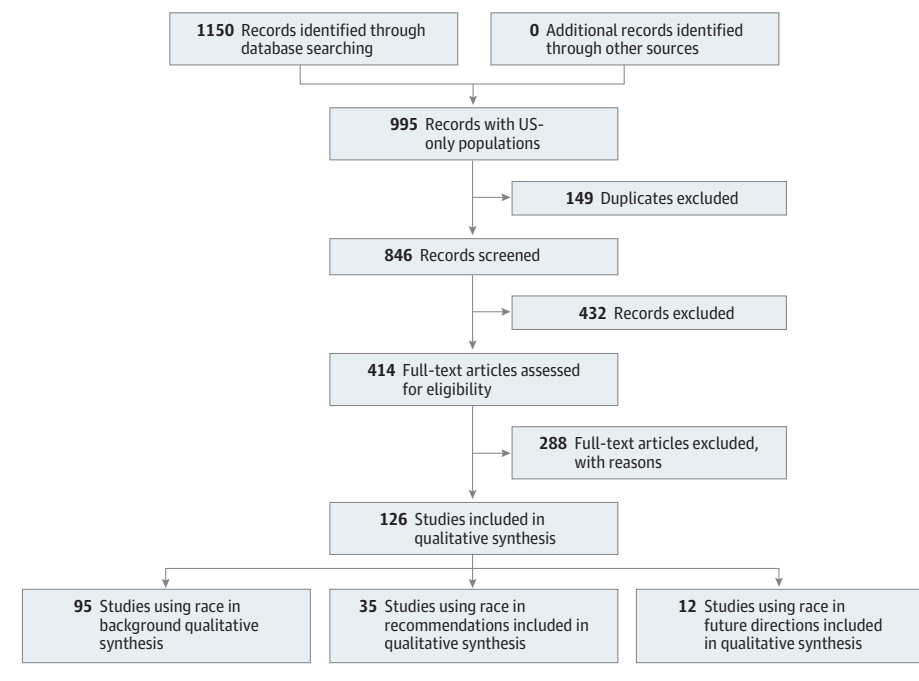
cate publications, we were left with 692 abstracts to screen. The search was updated to capture guidelines issued between April 1, 2020, and April 30, 2021, resulting in an additional 154 articles to be screened. Overall, there was a total of 846 titles and abstracts screened.

Two reviewers (E.G.L. and J.S.T.) reviewed all abstracts in a blinded fashion for inclusion and an article was excluded if both reviewers felt the article did not address patients younger than 19 years, did not provide clinical recommendations, or made recommendations for patients living outside the US. Any disagreements were automatically included for the full-text review. Next, we used 2 methods to identify articles that used race. The 414 remaining articles were uploaded into Rayyan¹⁷ and each full-text article was blindly and manually reviewed for the use of race by at least 2 reviewers (C.A.G., L.K., E.G.L., J.S.T., S.C.). In addition, we programmed an electronic search tool of full-text articles to identify all articles that used any of the following race or ethnicity terms from the list of National Institutes of Health–designated US disparity populations¹⁸ or from any term that referenced race or ethnicity that was identified in the manual review: African American, Alaska Native, Asian, Black, Caucasian, Chinese, Eskimo, ethnic, ethnicity, European, Filipino, Hispanic, Indian, Korean, Latino, Latin American, Mexican, minority, minority group, Native American, Pacific Islander, race, racial, Vietnamese, and White. All disagreements were unblinded and discussed as a group until agreement was reached.

Analysis

Each occurrence of race use was abstracted into Microsoft Excel (2020; Microsoft Corp) and also highlighted in the PDF (to maintain appropriate context) for further analysis. An expert in CRT (E.G.L.) guided the team on the categorization and assessment of CRT with a focus on 2 main tenets: (1) critiquing race being used as a genetic and biological marker and (2) examining racial essentialism to better embrace an understanding of intersectionality. First, each occurrence was qualitatively analyzed and categorized by the reviewers as to whether the statement was intended to provide (1) background and epidemiological information, (2) clinical recommendations, or (3) recommendations or gaps for future directions. Then the reviewers further qualitatively analyzed and categorized the use as having potential to (1) positively affect health inequities, (2) negatively affect health inequities or perpetuate structural racism, and (3) neutral or indeterminant. The use of race that was not clearly positive or negative in its potential effect on overcoming health inequities were placed into the indeterminant or neutral category. This category included many instances of vague or unclear

Figure. PRISMA Flow Diagram



statements, or that left open many interpretations for a positive, neutral, or negative effect. The use of race with a potential negative effect included themes of (1) normalizing the majority group (centering whiteness), (2) conflating race as a biological risk factor, (3) conflating race with negative stereotype (eg, dietary preferences and poverty), (4), conflating race, ethnicity, and genetic risk, and (5) establishing testing or treating thresholds or using racial coefficients.^{19,20} The use of race with a potential positive effect included (1) using race to describe health disparity, (2) using race used to describe inclusivity, (3) establishing representative committee structures, (4) recommending cultural humility, and (5) describing geographic risk (instead of race-based risk). Statements that were categorized with more than one potential effect (ie, both positive and negative) were included in both categories. A selection of excerpts from articles were tabulated to provide examples of each theme and to understand the context. To train reviewers to accurately apply the CRT framework and identify the themes for potentially positive, negative, or neutral effect, each author initially evaluated the same set of 20 articles and then discussed them as a group. All categorizations were performed by 2 independent reviews initially, reviewed by the authors, and any disagreements were discussed among reviewers until agreement was reached.

Results

Overall

We identified 414 pediatric CPGs for full review, of which 126 (30%) from 40 national organizations met study inclusion because of the use race or ethnicity terms. A total of 288 (70%) were excluded as they did not use a race or ethnicity term. *Race* was used 175 times across the 126 CPGs. Seventy-three CPGs (57.9%) used race or eth-

nicity 87 times (49.7%) in a manner that could exacerbate health inequities, whereas 45 CPGs (35.7%) used race 50 times (28.6%) with potential for a positive effect. Only 12 CPGs used race to discuss recommendations or gaps for future research. **Table 1** provides a summary of CPGs and categorical breakdown.

Background and Epidemiology

Potential Negative Effect

Most of the 126 CPGs (95 CPGs [75.4%]) used race at least once to describe background or epidemiological information (126 occurrences [72.0%]) and they did so disproportionately in a way that could exacerbate inequities. A person's race was commonly suggested as a risk factor for disease pathology. For example, "A variety of factors associated with earlier menopause, including current smoking, substance abuse, African American race, lower socioeconomic level, and low relative body weight..."²¹ Race was also conflated with culture while perpetuating negative stereotypes, the Infectious Diseases Society of America Clinical Practice Guidelines for the Diagnosis and Management of Infectious Diarrhea states, "Higher risk groups in the United States include young African American and Asian children, especially during winter months...the higher rates among African American children had been attributable to cross-contamination within the home during preparation of chitterlings, a seasonal dish prepared from pig intestines..."²² Additional excerpts found in eTable 1 in the [Supplement](#).

Potential Positive Effect

Potentially positive uses of race occurred 31 times. For example, the American Academy of Pediatrics reports, "focusing on disparities and understanding the cultural needs of a given population will aid in boosting immunization coverage rates."²³ eTable 2 in the [Supplement](#) illustrates additional excerpts.

Indeterminant or Neutral Effect

Race or ethnicity was used in 28 CPGs. There were many instances where epidemiological racial data were used without a clear rationale or context for inclusion. For example, the American Academy of Pediatrics published, "Although the majority of new HIV infections among youth occur among gay and bisexual males, female youth in the United States continue to remain vulnerable, with certain ethnic groups at higher risk than others. In 2010, black youth accounted for an estimated 57% of all new HIV infections in youth in the United States, followed by Hispanic/Latino (20%) and white (20%) youth (both male and female)."²⁴ eTable 3 in the [Supplement](#) illustrates additional quotes of indeterminant use of race in background and epidemiology section of CPGs.

Clinical Recommendations

Potential Negative Effect

Race or ethnicity was used in 35 CPGs with 37 occurrences, mostly by recommending that race be used to establish a testing or treatment threshold, including using race as a coefficient in a calculation. For example, there were 5 influenza CPGs that recommended a lower threshold for immunization or chemoprophylaxis for American Indian or Alaska Native children without providing any evidence to support the recommendation. In fact, one study made this recommendation despite stating, "these disparities might be attributable in part to the higher prevalence of underlying medical conditions or disparities in medical care among these racial/ethnic groups. A more recent case-control study of risk factors for death from 2009 pandemic influenza that adjusted for factors such as pre-existing medical conditions, barriers to health care access, and delayed receipt of antivirals found that American Indian/Alaska Native status was not independently associated with death."²⁵ Additionally, CPGs from endocrine societies frequently used race and ethnicity to establish norms for obesity (body mass index and adiposity), diabetes, and short stature.²⁶⁻²⁸

Potential Positive Effect

At least 12 CPGs used race or ethnicity to overcome inequities. For example, the American College for Obstetrics and Gynecology stated, "when engaging in shared decision making regarding contraceptive use, obstetrician-gynecologists should be aware of and address their own biases, work to empower patients, and strive for equitable outcomes for all patients regardless of age, race or ethnicity, class, or socioeconomic status."²⁹ eTable 4 in the [Supplement](#) includes additional excerpts of race used in clinical recommendations.

Future Directions

Only 12 CPGs used race to discuss opportunities for ongoing research and discussed gaps in clinical practice and disparities. For example, the US Preventive Services Task Force recommendation statement on Behavioral Counseling to Prevent Skin Cancer stated, "studies regarding the effectiveness of counseling persons without a fair skin type are lacking. These cohorts should include populations with diverse skin colors and should include adolescents, young adults, and preschool-aged children and their parents."³⁰ Another example from the US Preventive Services Task Force recommended statement on Primary Care Interventions for Prevention and Cessation of Tobacco Use in Children and Adolescents states "More

Table 1. Included Clinical Practice Guidelines by Categories

Category	No.
Positively impact health inequities	
No. (%)	45 (35.7)
Race used to describe health disparity	18
Race used to describe inclusivity	7
Establishing representative committee structures	2
Recommending cultural humility	14
Describing geographic risk	4
Negatively impact health inequities or perpetuate structural racism	
No. (%)	73 (57.9)
Normalizing the majority group (centering whiteness)	15
Conflating race as a biological risk factor	23
Conflating race with negative stereotype	8
Conflates race, ethnicity, and genetic risk	7
Establishing testing or treating thresholds or using racial coefficients	20

research is also needed on interventions tailored specifically to prevent initiation of use and promote cessation of other types of tobacco and interventions tailored to subpopulations with elevated tobacco use rates (such as African American youth, Native American/Alaska Native youth, LGBTQ youth, and youth with mental illness)." See [Table 2](#)³⁰⁻³³ for additional examples.

Discussion

In this systematic review of pediatric clinical practice guidelines, we found that 288 of 414 of CPGs (70%) did not mention race, representing a potential missed opportunity for medical organizations to be proactive in addressing health care inequities. We also found that when race or ethnicity is used, 57% of the time it is used in a way that could exacerbate or have negative effects on inequities.

This study demonstrates many opportunities for national organizations to use CPGs to positively address racism in medicine. Of all CPGs, only 15.1% appear to do so with potential for a positive effect. Although we do not know the race and ethnicity data available to CPG developers, we believe that there is ample opportunity for leaders of organizations to prioritize this work and for developers to better describe inequities and make recommendations toward practice change, similar to the recent publication by the US Preventive Services Task Force providing strategies to mitigate the influence of racism in its recommendations.³⁴ For example, 4 leading cancer organizations state, "racial and ethnic disparities in health care contribute significantly to this problem in the United States. Patients with cancer who are members of racial/ethnic minorities experience disproportionately from comorbidities, experience more substantial obstacles to receiving care, are more likely to be uninsured, and are at greater risk of receiving care of poor quality than other Americans. Awareness of these disparities in access to care should be considered in the context of this clinical practice guideline, and health care providers should strive to deliver the highest level of cancer care to these vulnerable populations."³⁵

Even if the use of race in some of the CPGs were not clearly inappropriate, falling in the indeterminant category, the interpretations of

Table 2. Appropriate Use of Race in Future Directions

Clinical guideline	Organization	Year	Guideline excerpt	
Overcome disparity				
Clinical practice	Clinical Practice Guideline for Multicomponent Behavioral Treatment of Obesity and Overweight in Children and Adolescents: Current State of the Evidence and Research Needs ³¹	American Psychological Association	2018	“Additionally, it is worthwhile to note that in many cases, race and ethnicity were not reported in the participant section of the published reports. To address the significant health disparities that do exist in childhood obesity, researchers must report the race and ethnicity of their participants, consider how culturally tailored interventions may increase treatment efficacy, and describe in detail how interventions are tailored.”
	Charting the Future of Cancer Health Disparities Research: A Position Statement From the American Association for Cancer Research, the American Cancer Society, the American Society of Clinical Oncology, and the National Cancer Institute ³²	American Association of Cancer Health Disparities Research	2017	“For example, although race and ethnicity are distinct constructs, they are often conflated such that a person is identified as Hispanic without identification of his or her race. A standard set of race and ethnicity as well as sociodemographic measures should be agreed upon by the cancer health disparity research community. The cancer health disparity community should establish reporting standards for measurement variables, similar to Consolidated Standards Of Reporting Trials (CON-SORT) and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, for journal editors and peer reviewers to facilitate and standardize assessment of the quality of the data collection method when evaluating health disparity research findings for publication [...]”
	Behavioral Counseling to Prevent Skin Cancer: US Preventive Services Task Force Recommendation Statement ³⁰	US Preventive Services Task Force	2018	“In addition, studies regarding the effectiveness of counseling persons without a fair skin type are lacking. These cohorts should include populations with diverse skin colors and should include adolescents, young adults, and preschool-aged children and their parents. These studies may be used to further develop technologies and vehicles for administering relevant interventions for behavior change in the primary care setting, especially among nonwhite persons, young adults, and persons who practice indoor or outdoor tanning.”
	Guidelines for the Care of People With Spina Bifida ³³	Spina Bifida Association	2018	“Especially needed is to extend the exploration of current factors to include whether finances, ethnic identity, religion and spirituality or aging with play a role in quality of life/health-related quality of life”.

the language left much to be desired. The ambiguity was viewed as ultimately having a negative effect because it allowed for the possibility for a negative interpretation, whether or not that was the intent of the authors. For example, 1 CPG presented epidemiological racial data for unclear reason, stating, "The incidence was highest among those aged ≥ 65 years and was greater among females and whites."³⁶ This CPG was not focused on racially marginalized patients and also never contextualized or explained these data. The mention of race was out of place, unnecessary, and failed to further the science of the CPG. In this particular CPG, race was mentioned without explaining its use and the benefit of having these racial statistical data.

Why CRT Is a Necessary Framework for CPG Developers

We used 2 tenets of CRT, (1) critiquing race being used as a genetic and biological marker and (2) examining racial essentialism to better embrace an understanding of intersectionality. First, race should

not be considered risk factors for pathology. Race is sociopolitically constructed and assigned (and accepted), not biologically constructed and assigned. The definition has and will change with society. The second tenet embraces the understanding of intersectional identities. Biomedical research and CPGs should stop essentializing race as a key variable that explains all disparate health outcomes between racial groups, oftentimes normalizing the non-Hispanic White race. Race alone, as a complex social construct, will never help us completely understand the health care experience of the individual and their health needs. In fact, its use can further perpetuate the structural racism known to exist in medicine. CPGs should focus their efforts to identify and overcome the barriers (or effect modifiers) that have contributed to the marginalization of individual patients in our society, such as structural racism, access to care, and poverty. For example, when there is disparity noted in a certain racial group, we encourage authors of CPGs to explore the

barriers that individuals in that group may experience when in search of care, such as ways that systemic racism has affected their health, preferred health care languages other than English, poverty, untrustworthy health care system, and racist behaviors from physicians as they are developing and writing CPGs.^{9,37}

Limitations

This research study has several limitations. First, although we systematically and electronically surveyed the literature for CPGs containing race and/or ethnicity pertaining to US populations, it is possible that we did not identify all pediatric CPGs. Second, without a validated categorization standard, there is room for subjectivity when interpreting the CPGs using the CRT framework. At categorization,

we cannot know the intent of the writer and can only speak to our interpretation and the potential effect on patients. Additionally, although we systematically assessed the literature in a blinded fashion, we offer one interpretation of the potential effect of a CPG using a single framework.

Conclusions

In this systematic review of US-based pediatric clinical guidelines, race was frequently used in ways that could negatively affect health care inequities. All CPG developers should adopt strategies, methods, and partnerships to address racial health inequities.

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