

# Editorial Role in Promoting Valid Use of Concepts and Terminology in Race and Ethnicity Research

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## Abstract

The scientific literature in the field of race, ethnicity, and health has been weakened by the diverse, sometimes idiosyncratic, use of concepts, definitions, and terms. Journal editors are in a unique position to help raise standards. Our 1994 survey of 38 editors of medical journals based in the United Kingdom (28 respondents, 74%) showed that although few journals had policies on ethnicity and health, most recognized the problems, nearly one-third (32%) intended to alter policy, and most welcomed guidance. A follow-up survey of the 38 editors (21 responses, 55%) in 1996 showed that only two had formulated a specific policy. Although most editors showed a general interest in the issue, clearly it was not given high priority. Twelve editors wanted the debate to be continued and several wanted authoritative guidance. A similar survey in the United States in which 23 of 29 editors responded (79%) showed that most editors agreed with Public Health Service recommendations on race and ethnicity research and one-fourth had discussed issues with coeditors, editorial boards, or reviewers; but only seven editors had explicit poli-

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cies. On the basis of our three surveys, we propose that the strategy of leaving each journal to find its own solutions is not sufficient. Researchers, editors, statisticians, and other interested groups, including those representing ethnic minorities, need to work together.

## Introduction

The concepts of race and ethnicity have long intrigued scientists in the life and health sciences and remain central to modern epidemiology and health-services research. By systematically analyzing differences and similarities in the health status of populations grouped by racial or ethnic category, researchers can potentially spark new hypotheses on the determinants of disease, test hypotheses, refine health-care policy and plans, and provide guidance on diagnosis, therapy, and prognosis.<sup>1-5</sup> This huge potential has not, however, been achieved, and considerable debate is under way in the United Kingdom<sup>6-13</sup> and the United States<sup>1,2,14-32</sup> on the scientific meaning and value of the concepts of race and ethnicity and on the appropriate labels for populations so classified. As Donald and Rattansi say, “‘race’ and identity are inherently contestable social and political categories.”<sup>33</sup> Many of the limitations of scientific knowledge about racial and ethnic disparities in health are associated with poor conceptualization of variables used for measuring race and ethnicity,<sup>2,4,5,14,22,28,29,33-35</sup> illogical or crude classifications,<sup>11,21,25,26</sup> imprecise terminology,<sup>9,13-15,17</sup> and other methodologic weaknesses. Because journal editors serve as guardians of quality in research publication,<sup>12,34</sup> their participation in the debate seems essential.

This paper is based on the proposition that editors and referees, as the natural

guardians of the quality of research publications, have a responsibility to help researchers find solutions to these problems. Our aims are to summarize the issues that are the basis of discussion among researchers in race, ethnicity, and health; to highlight the need for joint action by editors and researchers; to summarize two published research studies on the actual and potential role of editors; to present an unpublished follow-up study of UK editors; and to make recommendations.

## Summary of the Issues

Race and ethnicity are prominent in the US and UK public-health and medical-science literature.<sup>4,6,10,19,28,29,34,36</sup> Inequalities in morbidity and mortality among racial and ethnic minority populations and unequal provision and use of health services are problems calling for more research effort. The scientific basis of ethnicity- and race-based research needs to be strengthened urgently.

Ethnicity and race are multidimensional and fluid concepts that change with time.<sup>1,4,5,29,34,37</sup> Indeed, ethnic descriptors and self-reported ethnicity can change over time or between observers. Hence, there is an absolute need for explicit definitions; unless there is common understanding, the reader may be misled. Authors should clarify whether they are using race and ethnicity as markers of biologic or social-cultural differences between populations. They should also explain their labeling of populations. Today, for example, the US reader may assume that a study of “Asians” is on the Far Eastern populations (Chinese or Japanese), whereas the British reader may infer that “Asians” are from the Indian subcontinent.<sup>9</sup> Similar problems of definition and interpretation apply to the terms *Latino* and *Hispanic*,<sup>17</sup> *black*,<sup>38</sup> and *white*.<sup>13</sup> Populations

of Northern European origin are variably referred to as *white*, *Caucasian*, *European*, and, more rarely, *occidental* or *Europid*.<sup>13</sup> At present, terms used to describe a person's ethnicity are not only inconsistent but sometimes nonsensical, for example, the coining of the term Urdu to denote an ethnic group speaking Urdu.<sup>39</sup> Furthermore, a clear definition of what is meant by *ethnicity* in publications is often lacking. For example, Williams found that researchers defined *race* or *ethnicity* in only 13% of published studies that used these concepts in *Health Services Research* in 1966-1990.<sup>36</sup> There is an increasing need for a discussion on terminology by responsible journals if a consensus is to be reached and confusion and misrepresentation are to be avoided.

A solution to problems of nomenclature is not yet in sight. Writing in support of the *British Medical Journal (BMJ)* guidelines, McKenzie and Crowcroft recommended that authors describe the population under study accurately and fully and that the rationale for the descriptions be explained in the methods section even if this means that the terminology used is complex.<sup>11</sup> The *BMJ* guidelines recognize that a single internationally agreed-on classification of ethnic groups is not achievable at present. Description, then, is a compromise in the absence of agreed-on definitions.

Government agencies in the United States and the United Kingdom have played a key role in developing ethnic and racial classification systems used by researchers. The US Office of Management and Budget (OMB), in issuing its Directive 15, "Race and Ethnic Standards for Federal Statistics and Administrative Reporting", in 1977, cautioned that "these classifications should not be interpreted as being scientific or anthropological in nature."<sup>40</sup> During a review of Directive 15 that was initiated in 1993, Representative Thomas C Sawyer, chairman of the House Subcommittee on Census, Statistics, and Postal Personnel, said, "we have developed categories that, in the view of many, have become misleading over time. . . . As a result, we create an illusion of specificity, an illusion of precision where it may not exist. . . . We don't want

## Box 1. Themes of Comments by UK Editors with Illustrative Examples<sup>a,b</sup>

### *Importance of issue*

"This is a good example of the slack or imprecise use of language which scientific journals should try to discourage."

### *Context of past discussions*

"In drawing up a guide to house style."

### *Need for guidance*

"We need positive advice on approach to nomenclature. This is an important issue which should be addressed by the Vancouver Group of Editors."

### *Intentions regarding discussions, policy, and instructions to authors*

"Not so much an unwritten policy as an implicit set of standards which would automatically come into play if I felt inappropriate terminology was coming into play."

### *Difficulties of categorization*

"Ethnic groups should be defined as accurately as possible even if the terminology is cumbersome. However, problems will still exist. For example, how do you define a second-generation son of an 'Asian' millionaire from Uganda?"

<sup>a</sup>For a fuller set of comments, see reference 12.

<sup>b</sup>Comments in the boxes have been edited when necessary for clarity.

our standards of measurement to distort the intricacies of ethnic identity."<sup>35</sup> In 1997 the review process resulted in several changes in federal racial and ethnic categories and data-collection procedures, such as subdivision of the "Asian or Pacific Islander" category and acceptance of multiple responses to questions on self-identification of race. But the classification is still not grounded in scientific understanding of race and ethnicity.

The weaknesses of using nonscientific classification for the purposes of science have been repeatedly demonstrated. For example, Hahn and others have demonstrated bias in estimates due to racial and ethnic misclassification,<sup>20,21,22,26</sup> Weissman challenged the use of racial or ethnic classification without scientific justification in clinical pharmacology publications,<sup>18</sup> and Huth has advised against the use of racial or ethnic descriptors in clinical case reports "unless a fact represented by that term was crucial to decisions in the case."<sup>27</sup> Historical<sup>1</sup> and contemporary reviewers<sup>5,34</sup> point to the need for action.

## **The Need for Joint Action by Editors and Researchers**

Osborne and Feit<sup>34</sup> have urged that editors of medical journals be accountable for the consequences of their editorial policies for medical decision-making arising from the research they publish on race and ethnicity.

Over 500 journals adhere to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals" issued by the International Committee of Medical Journal Editors (ICMJE). These define standards on many aspects of research quality and terminology. The fifth edition of the "Uniform Requirements", released in 1997, includes only the following cautionary but nonspecific guidance on race and ethnicity: "The definition and relevance of race and ethnicity are ambiguous. Authors should be particularly careful about using these categories."<sup>41</sup> That is a recognition of a problem but not a solution.

The *BMJ* has published guidelines on the use of ethnic, racial, and cultural terms

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in research. Authors are asked to describe accurately the populations studied and to explain the logic of any racial or ethnic categories used.<sup>11,42</sup> Examples of descriptive terms cited in the *BMJ* are “self assigned as black Caribbean (Office of Population Censuses and Surveys category)” and “UK born individuals of Indian ancestry.”<sup>42</sup> Consistent editorial guidelines pertaining to writing on race and ethnicity, however, have not yet been achieved, and there is no evidence that the *BMJ* guidelines have been effective.

In 1993 the US Centers for Disease Control and Prevention (CDC) and Agency for Toxic Substances and Disease Registry (ATSDR) published recommendations for conceptualizing, measuring, and using race and ethnicity data.<sup>43,44</sup> CDC has adopted an in-house policy on reporting of race and ethnicity in *Morbidity and Mortality Weekly Report (MMWR)* on the basis of the CDC-ATSDR recommendations. This, together with the *BMJ* actions, is an important indication that editors are recognizing the need for action.

### Summary of Two Published Research Studies on the Actual and Potential Role of Editors

UK Study (baseline)<sup>12</sup>

To ascertain British medical-journal editors' views on terminology in ethnicity and health, Bhopal and colleagues developed a two-page self-completion postal questionnaire that focused on policy on terminology in relation to ethnic minorities and on whether the issue was important enough for editorial actions.<sup>12</sup> In 1994 the questionnaire was sent to editors of 38 medical journals based in the United Kingdom, and 28 responded (74% response rate). Of the 28 journals, 10 (36%) had considered the issue of terminology in relation to ethnic minorities, one (4%) had a written policy, and five (18%) had an agreed-on but unwritten policy. However, 23 (82%) agreed that the issue of terminology was important for ethnicity and health research, 16 (57%) felt it important enough for the editorial board to discuss, nine (32%) thought it needed to be in a

### Box 2. Representative Comments from US Editors' Survey Respondents<sup>c</sup>

“Race and ethnic identification are not used unless scientifically relevant. These issues are discussed and reported if their epidemiologic relevance can be established.”

“Good science, ethically conducted.”

“When racial or ethnic group assignment is a categorical selection variable or a categorical outcome variable, we expect authors to explain their group assignment criteria and the means of application of those criteria.”

“We encourage submissions dealing with issues of race and ethnicity and from minority authors.”

“We wish to encourage both ethnicity-specific analyses and analyses stratified by ethnicity—and to have sample sizes that are sufficiently large to make such analyses meaningful.”

<sup>c</sup>For additional comments by US editors, see reference 32.

written editorial policy, and nine (32%) thought that a policy should be included in instructions to authors. The qualitative findings are summarized in Box 1.

This study showed that few British journals had devoted time and energy to debating and clarifying policy on terminology in relation to ethnicity and health research, and only one had a written policy. However, most editors believed it to be an important matter and understood the difficulty of achieving precise terms, and several committed themselves to take action. Only one comment was of a negative nature: that the debate on terminology was driven by “political correctness”.

Bhopal and colleagues recommended widespread debate, involving editors, on the issue of terminology in relation to ethnicity.<sup>12</sup> They called on the ICMJE or the World Association of Medical Editors to facilitate the development of authoritative guidance.<sup>12</sup>

US Study<sup>32</sup>

In 1994 a sample of 29 US journals likely to receive articles on the health of people described by ethnic group was selected from the “Public Health” and “Medicine, General and Internal” headings in the 1994 Science Citation Index and the

“Public Health” and “Health Policy and Services” headings in the 1994 Social Sciences Citation Index of the JCR Journal Citation Reports.<sup>45,46</sup> A postal questionnaire covered the following:

- Editorial policies, written or unwritten, regarding race and ethnicity terminology and research.
- Editors' familiarity with OMB Directive 15 (which was under review at the time of the survey).
- The frequency with which four problems emphasized by Senior and Bhopal<sup>5</sup> occurred in manuscripts related to race and ethnicity.
- Editors' level of agreement with CDC-ATSDR recommendations on the use of race and ethnicity in public-health surveillance.<sup>43,44</sup>
- Opinions of MMWR's policy of asking authors to specify their rationale, methods, and limitations in studies of race and ethnicity.
- Editors' practices and plans related to editorial policies on race and ethnicity.

Of the 29 questionnaires sent, 23 (79%) were returned. Nearly three-fourths of the responding journals had no relevant policies. The only editor who had written editorial policies did not attach them as requested. Box 2 summarizes the unwrit-

ten policies as described by six respondents. Editors were concerned about the clarity, consistency, and acceptability of ethnic or racial terms to readers. The style of one journal was to use *ethnic group* rather than *race*. One reported that variations in terminology introduced by authors are accepted as long as the terms are internally consistent and conform with the terminology used to gather baseline data.

Of the 23 respondents, nine (39%) had heard of OMB Directive 15 and two (9%) had read it.

Measurement problems in relation to ethnicity were noted by five respondents (22%) and inappropriate aggregation of heterogeneous populations by four (17%), but none perceived frequent problems with unclear rationale or ethnocentric bias in manuscripts.

When presented with CDC-ATSDR guidelines on the use of race and ethnicity in public-health surveillance, editors indicated a high level of agreement except with the recommendation to “conduct analyses to document the effects of racism”. Only three editors were aware of the MMWR editorial policy on race and ethnicity, but 10 thought that such a policy would be appropriate for their own journals. One editor thought the policy “excessive”. Several did not believe a formal policy was necessary, and some had reservations about treating this issue differently from other concerns.

Few of the issues raised had been topics of discussion with coeditors, editorial boards, or reviewers. Four editors stated that they had plans to prepare policies on these issues. Among editors without definite plans, several indicated that they felt a need to think about the issues and would be willing to be involved in discussions.

### Summary of Unpublished Follow-up of Baseline UK Survey

The target sample was the 38 editors of the medical journals selected in the 1994 survey.<sup>12</sup> A two-page self-completion postal questionnaire, a letter of explanation, a copy of the paper summarizing the first study,<sup>12</sup> and a stamped return envelope

### Box 3. Themes of Comments by UK Editors on Why a Written Policy Was Not Required

#### *Practical difficulties*

“There are too many ethnic groups to include.”

“There is a limit to the number of requirements we can impose on authors.”

#### *Responsibility of editors, referees, and authors*

“We leave this to the referees and subeditors. The terminology varies and is too difficult to include in a specific policy. We expect authors to define terms used in their papers.”

“Referees and editors of this journal ensure appropriate definition of study populations and their ethnic origins.”

#### *Individual approach*

“Each paper, and the details included in it, should, I think, be viewed on its own merits. Legislating a general rule does not seem helpful to me.”

“Need to address the specification of ethnic groups on an ad hoc basis.”

#### *Problem of definition*

“The issues of race and ethnicity are very important but are extremely difficult to define. The definition of race, for example, means that even a very small group of people are entitled to define themselves.”

“There are different practices and implications of different terminology in different countries.”

#### *Ethics*

“We have a society statement of ethics which should cover this.”

were sent in 1996, 18 months after the initial survey. Five editors who were successors to those previously surveyed were included. The questionnaire asked

- whether there had been any change in editorial policy or the journal's instructions to authors on the issue of terminology in ethnicity and health studies since completion of the first questionnaire
- whether the journal had a written policy on terminology
- how editors would like the discussion on editorial policy on terminology for ethnicity and health studies to be taken forward. Comments were invited.

Because questionnaires were anonymous, a reminder was sent to all participants 6 weeks later. A letter was then sent to ask why some editors had decided not to respond. Of the 38 editors, 21 (55%) responded; 19 (50%) completed the questionnaire and two wrote a letter. Of eight editors who informed us why they had not responded to the questionnaire, six cited lack of time.

Three editors reported some change

since 1994. One editor reported a change in “the way we think especially about the term ‘Asian’”, one reported a change in instructions to authors advising them on appropriate language, and one reported adding a written policy on terminology for ethnicity and health studies. Of three editors who thought that a written policy was required, two had plans to prepare one. The third remarked: “I would like to see one developed which I would then consider incorporating. Our journal has few papers of this kind, so we prefer to wait for a policy to be developed by more knowledgeable experts.”

Fifteen editors thought that a written policy was not required (and two did not know), for the following reasons: practical difficulties (six); the responsibility should be left to editors, referees, and authors (three); individual approach needed (three); difficulties in definitions (two); and ethical guidelines cover this matter (one). Examples of editors' comments are presented in Box 3.

Editors' opinions on how to take the

*Editorial Roles continued*

debate forward were mixed. Four indicated a lack of interest: Two did not care, one thought that the debate should be dropped, and another was neutral. Twelve editors made comments supporting more debate. One thought that the debate should be “constantly on the agenda” but could not easily see a solution as “most/many people are not respectful of other people’s cultures”. One editor thought that the debate should involve continued discussion, two suggested that the issue be discussed at a European Association of Science Editors conference, and three wanted further debates in journals. Another editor proposed a study of inappropriate language in medical studies. However, one editor cautioned, “Raise awareness, but leave editors to apply careful judgment.” Two editors wanted the debate to culminate in a consensus with “an agreed definition of ethnic populations and a definite policy to be adopted by the relevant journals”.

Six editors (32%) made additional comments; one considered ethnicity to be a minor difference among human beings and wondered “why minor differences attract attention. Would it not be better to educate people to understand?” One supported our recommendation<sup>12</sup> that the issue be addressed by the ICMJE, and one called for publications on this subject in high-ranking journals because “it is the authors you need to get to think about these issues.”

Our 1994 survey found that 16 editors (57%) felt the issue of terminology in ethnicity and health research warranted discussion by the editorial board and nine editors (32%) thought the issue needed incorporation into written policy and/or instructions to authors. Two years later, two of the 19 editors (11%) who completed the questionnaire reported a change in editorial policy, although neither reported a written policy, and only one reported a change in instructions to authors. In fact, 14 editors (74%) now thought that a written policy was not required.

The response rate for this follow-up survey (55%) was lower than that for the first one (74%). The lower response and the lack of policy-related action either indicate that the issue is not a top priority for many

journals or highlight how controversial and difficult it is to address.

### Conclusion and Recommendations

Lively debate has focused the attention of researchers and government agencies on the problem of imprecise use of ethnicity and race in research and has led to recommendations on pertinent research and practice issues.<sup>18,24,27,43,44</sup> The debate addresses deep scientific questions about the nature of race and ethnicity research. Journals that aim for the highest scientific standards should be especially concerned with their treatment of these concepts and variables, which have been misunderstood, distorted, and even abused in the biologic, medical, and social sciences.<sup>1,2,4,5,10,16,30,34</sup> Unless scientific publications define race and ethnicity with greater precision, are based on a rational classification of groups, and fully describe the nature of populations studied, their findings cannot be compared across time or place. Without comparability generalization is impossible, in which case the work is of minimal scientific value (although it may have local application).

We urge journal editors to participate in debates on the nature, value, and presentation of race and ethnicity research. Editors’ involvement would enhance the scientific quality of published research on race and ethnicity and stimulate researchers to sharpen their definitions and methods. Journal editors should seek involvement in future reviews of race and ethnicity and through them engage the scientific community. The resulting discussions among editorial staff and advisory boards would aid the implementation of consistent policy within and between journals.

Editors’ organizations have accepted and acted on the authority to develop guidance on style. The ICMJE has acknowledged the lack of clarity and the need for heightened awareness regarding race and ethnicity.<sup>42</sup> Such a warning without specific guidance may add to authors’ confusion without resolving the need for coherence and consistency. The recent *BMJ* publication of “Ethnicity, Race, and Culture: Guidelines for Research, Audit, and Publication”,<sup>42</sup> which reflects a

great deal of scientific debate, is an excellent starting point for clarifying the “Uniform Requirements for Manuscripts Submitted to Biomedical Journals”.

On the basis of our three surveys in the United Kingdom and the United States, we suggest that the strategy of leaving each journal to find its own solutions is not sufficient. A multidisciplinary group incorporating researchers, editors, statisticians, epidemiologists, and other interested groups, including those representing ethnic minorities, should work together and share the task of taking this forward.

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