# Race and Ethnicity: Responsible Use from Epidemiological and Public Health Perspectives

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**R** ace and ethnicity are closely related, contentious concepts that have been abused and misinterpreted through history, but have a vast potential for good, at least in the health sciences. This article is not intending to elaborate on the conceptual foundations of race and ethnicity; I have addressed that elsewhere<sup>1</sup> and summarized my stance in the glossary reprinted below in the Appendix. The terminology used here follows the glossary. Assuming that the conceptual foundations of my stance are reasonable, the questions addressed here focus on public health and its primary health science, epidemiology, in a European context. The questions are simple ones:

- 1. In epidemiology and public health what are we trying to achieve when we use the concepts of race and ethnicity?
- 2. What would we lose by rejecting these concepts?
- 3. If we do not reject them, how do we put the concepts into operation to help achieve our goals?
- 4. What practical actions can result from the application of these concepts in order to improve the health and well-being of populations?

# Immigration, Race and Ethnicity, and the Burden of History

The key to understanding the role of ethnicity and race in multiethnic societies, at least in Europe, is immigration. Immigration mixes people from diverse places and with diverse cultures and, of course, with diversity of physical appearance. The Oxford Dictionary of Current English defines immigrant as "one who immigrates; descendant of recent (especially coloured) immigrants."2 The words in parentheses are of the utmost importance, and underline the linkage of race and ethnicity to migration. Populations that are physically different from the population majority, whether in terms of biology (e.g., facial features) or culture (e.g., wearing a burqua), are destined to be seen as immigrants and minorities. This is reflected in the persistence of illogical terminology such as "second-" or "third-generation" immigrant. The field of immigrant health is usually focused on minorities, and in the case of Europe and North America, this means non-white people. This may be to the disadvantage of white subpopulations who

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Divergence of Disease rates in two populations (theoretical)



are themselves disadvantaged; the highest all-cause mortality rates in England and Wales, for example, are in Scottish and Irish immigrants.<sup>3</sup>

Non-white immigrants in particular tend to live on the margins of society, occupying the poorly-paid jobs, the lower quality housing, and a lower social status. This is particularly true in the early years of migration, but may persist over long periods. Arguably, African-Americans are still shrugging off the disadvantages of the legacy of their immigration in the era of slavery. The key potential contribution of race and ethnicity in epidemiology and public health is to point to actions that can help these minority populations directly, and contribute to the well-being of the whole population indirectly. To accomplish this, awareness of the harm done by the concept of race in the past is essential. Race has been used to justify slavery and colonialism, abet eugenics, contribute to the controversy over the I.Q. of human subpopulations, underpin harmful medical research, and promote genocide as in Nazi Germany, to list just some of the harms. This historical burden of abuse now lies heavily on the shoulders of those who advocate the active use of race or ethnicity to promote the well-being of populations and the creation of harmonious, dynamic, multi-ethnic societies.

### The Need to Study Differences – The Fuel of Epidemiology

The starting point for my views is a frank acknowledgement of some important differences among human subpopulations against a background of substantial similarity. In the field of epidemiology, the scientific study of the patterns of diseases and their causes in populations, differences are pivotal. The strategy of epidemiology is to measure and compare disease patterns across times, places, and types of people. When there are differences, the reasons for those differences are sought using a wide range of research methods. This strategy is illustrated by Figure 1, showing the hypothetical pattern formed by the rate of disease over time. In one population (dotted black line) the rate is rising, while in the other (solid red line) the rate is falling. Why is this so? The pattern could be a data artifact or product of random variation. If neither, it may be caused by forces that actually alter the occurrence of disease. These forces could be external (e.g., bacteria or air pollution) or internal (e.g., genetic factors or personality).

Epidemiologists search for such differences. Diseases vary greatly by a number of variables such as age, sex, and occupation. It is well known, for example, that heart disease is more common in older people than in younger, and in men than women. It so happens that diseases also vary hugely by racial and ethnic group, however defined. In differentiating human populations' health status, race and ethnicity are among the most helpful concepts. This is hardly surprising, as the concepts imply differences in environmental exposures over evolutionary, generational, life course, and recent timescales. Exposures over evolutionary timescales result in genetic differences causing differences in a limited range of fixed characteristics. These varying exposures lead, inevitably, to inequalities in health status. Those aspects of race and ethnicity (such as skin color and dress) that may stimulate prejudice and discrimination also lead to inequalities in the quality of, and access to, health care. In societies that foster justice and equality, strategies to tackle such inequalities are needed. These strategies need to be based on data that quantify the inequalities, set targets for achievement, and monitor progress to the agreed goals. As a simple example of what would be lost without race and ethnicity data, reflect on the following problem. Smoking is the foremost controllable causal factor for an array of deadly and disabling diseases including cancers and cardiovascular diseases. Smoking is a socially patterned habit, and the interventions required to prevent people from starting and to get them to give up this noxious behavior must be tailored to the needs of the specific population. Do smoking habits vary by ethnic or racial group? By how much? Are the differences enough to matter? These are important questions. How can they be answered if race and ethnicity are abandoned?

To illustrate the importance of these categories, Table 1 gives sample data from a cross-sectional study done in the 1990's in the city of Newcastle-Upon-Tyne, England. Those data show massive differences among ethnic groups and between men and women in the minority populations, but not between European-origin white men and women. The way ethnic groups are defined clearly matters. For South Asian men combined the presence of smoking is virtually identical to that for European men. No doubt some of the subgroups within the category "European" also differ, but no data were collected on those subgroups to permit examination of such potential variations. Ethnic differences turn out to be of paramount importance. It is hard to imagine how we can develop effective public health responses without such data. There are other important questions that require ethnic-specific data as well before we can proceed to action, such as data on the cross-cultural validity of self-reports; on the beliefs,

#### Table I

Newcastle Heart Project Data on Current Self-Reported Smoking Prevalence in Indian, Pakistani, Bangladeshi, South Asian, and European populations (%)

	Indian	Pakistani	Bangladeshi	South Asian groups combined	European
Men	14	32	57	33	33
Women	I	5	2	3	31

The extract of data is created from large tables published in:

R.S. Bhopal, N. Unwin N. M.White, et al, "Heterogeneity of Coronary Heart Disease Risk Factors in Indian, Pakistani, Bangladeshi and European Origin Populations: Cross Sectional Study," *BMJ* 319 (1999): 215-220

attitudes, and social conventions that underpin variations in the incidence of smoking; and on the effectiveness of public health programs.

### Weaknesses of Race and Ethnicity as Epidemiological Variables and the Challenge of Creating Classifications

As epidemiological variables, race and ethnicity are problematic. A great deal of conceptual and practical work needs to be done if their full potential value is to be realized. I have written with Peter Senior on the attributes of a sound epidemiological variable.<sup>4</sup> Ethnicity and race are superb at differentiating populations by health status and identifying factors that influence health status. However, race and ethnicity are complex, difficult to measure, prone to ambiguity, and vulnerable to ethnocentricity. Here I will focus on the challenges of operationalizing the concepts of race and ethnicity by developing appropriate classifications.

The primary use of the concepts of race and ethnicity in epidemiology and public health is to subdivide the population. To achieve this requires a set of categories that comprise a classification of populations. The most important of these classifications are those created for censuses. Researchers and practitioners, including those in public health, have tended to rely on classifications created for the census, even though those classifications were created for administrative purposes, not designed or validated for research purposes. This is a problem made all the worse because scientists' use of classifications is often interpreted as endorsement. Scientists should become involved in the development of classifications and not be merely endusers. Whether they are using the census classifications or others, scientists should make explicit the race and ethnicity categories they are using and address the validity, value, and interpretation of those categories. The importance of doing this is demonstrated by the early

> findings of a study of census classifications by Taslin Rahemtulla and myself (in a study that is yet unpublished). The study is examining the development of census classifications in ten countries, including the United Kingdom and the United States, with an emphasis on race and ethnicity and attention to related variables such as place of birth and nationality. Some of the insights from this project are outlined below.

> The British census goes back to 1841 and questions on country of birth and/or nationality have been asked in each one. Although the authority to include questions on race or ethnicity has been in place for more than eighty years, the first direct question (on ethnicity) was included in 1991. The question was developed after ex-

### Table 2

# Names Used for African-Origin Populations in the U.S. Census

<b>Census Year</b>	Terms used
1850, 1860, 1870, 1880, 1890	Black
1900, 1910, 1920, 1930, 1940	No options
1950, 1960 1970 1980, 1990	Negro Negro or Black Black or Negro
2000	Black, African American, Negro

With acknowledgement to Taslin Rahemtulla.

tensive public consultation, some of it contentious. The U.S. census first took place in 1790 and a question on race was included. Our current study has examined U.S. censuses from 1850 on. In 1870 "Chinese" and "Indian" (the latter referring to American Indians, although not so specified) were added to the pre-existing white, black, and mulatto categories. It was not until 1970 that questions were asked on what tribe of American Indians the respondent belonged to, and on Hispanic/Latino ethnicity. Clearly, the inclusion of race and ethnicity in the census and the specific classifications used are time- and country-specific. Change over time is shown in Table 2, listing the varying terms used in the United States since 1850 to describe Africanorigin populations.

Agyemang and colleagues have examined terms used to describe African populations in health research.<sup>5</sup> Some of these are shown in Table 3. There is a clear evolution from terms that are based on the biological concept of race, as a blanket term for a massive population group, to terms that acknowledge geographical and ethnic specificity. More scholarly analysis of the terms used to describe populations from various ethnic groups is needed, particularly to draw out lessons. Agyemang and colleagues advise that we should use classifications that reveal the heterogeneity within populations currently dichotomised as black and white. This will require careful descriptions of the populations under consideration including ancestral origins, culture, and social, demographic, and economic circumstances. For example, the words "African-origin," or for short, "African," are a suitable prefix for more specific population designations such as "African Kenyan" as opposed to "Indian Kenyan" or "European-origin Kenyan." These ethnic labels need to be defined by the authors using them.

If ethnic group terminology is to be more universal than it has been, then there needs to be greater effort to achieve consensus and much more involvement of those using terms in generating a rational vocabulary. The preliminary findings of our census project show that at any point in time a variety of classifications are in place, that major conceptual shifts do take place but are infrequent, that most changes are incremental, and that most ethnic and racial classifications are better suited for policy and planning than scientific purposes. The last is an unsurprising conclusion since these classifications have often been designed to meet political and social policy purposes, not scientific ones.

### Other Challenges: Labels and Methodology, Genetic Analysis and Evidence-Based Practice

Researchers need to be aware that racial and ethnic categories are labels that are a first step to gaining potentially important information. However, some labels may mislead rather than help, possibly because their meaning is unclear or the populations are not described clearly. The example of the label "Asian" has been scrutinized by several scholars, including me.<sup>6</sup> The label is understood differently in the United States (where it is interpreted as referring mainly to Far Eastern populations) than the United Kingdom (where it is interpreted as referring mainly to Indian Subcontinental peoples). The heterogeneity of "Asian" populations is too great to allow meaningful public health policies or epidemiological insights.

#### Table 3

# Analysis of Terms Currently Used to describe African-Origin Populations

- I. **Negro (Negroid)** Defined populations by physical features in the distant past. Considered inappropriate and derogatory. Abandon.
- 2. **Black** Describes heterogeneous populations. It may signify all non-White minority populations. Use with caution.
- 3. Black African Signifies sub-continental origin. Avoid if possible.
- 4. **African Caribbean** Often inaccurate as it is not restricted to those from the Caribbean islands, otherwise good.
- 5. African American Extremely heterogeneous as used.
- 6. African Describes heterogeneous populations. This term is currently the preferred prefix for more specific categories, such as African Nigerian, African Kenyan. Use on its own should be avoided.

With acknowledgement to Charles Agyemang: these points were made in C.Agyemang, R. S. Bhopal and M. Bruijneels, "Negro, Black, Black African, Caribbean, African American or What? Labelling African Origin Populations in the Health Arena in the 21st Century," *Journal of Epidemiology and Community Health*. 59 (2005):1014-1018.

### Table 4

### Challenges for Ethnicity and Health Research

I. Inclusion of minorities in research

- 2. Clarification of the purpose of the research
- 3. Definitions of concepts relating to ethnicity and race
- 4. Definition and precision of terms, and ethnic/racial classifications
- 5. Recognition of heterogeneity within ethnic minority groups
- 6. Identification of representative populations
- 7. Ensuring comparability of populations that are to be compared; requiring socio-economic data over the life-course
- 8. Accurate measurement of the denominators and numerators in calculating rates
- Ensuring the quality of data, particularly in cross-cultural comparisons
- 10. Maximizing completeness of data collection
- II.Avoiding misinterpretation of differences that are due to confounding variables
- 12. Proper interpretation of associations as causal or non-causal
- 13. Maximizing validity and generalizability of the research
- 14. Presentation of research to achieve benefits for the population studied, avoiding stigmatization and racism
- 15. Stimulating appropriate policy and service activity to follow the research
- 16. Pinpointing genetic bases of genetic hypotheses
- 17. Integrating the research with law, policy, and service action

This table is a modified version of a list I have previously published.<sup>18</sup>

This issue of terminology is only one of a number of challenges facing ethnicity, race, and health research. Some of the others are listed in Table 4. Most have been discussed by myself or colleagues in other publications,<sup>7</sup> and the research community has been rising to the challenge. Here I wish to touch on four issues that are likely to become highly important and contentious – inclusion of and consultation with populations in research, devising cross-culturally valid methodology, analyzing genetics, and creating evidence-based policy and interventions. These topics all deserve more attention in the future.

Research methods in the health sciences involve specifying a research question (or aim or hypothesis) and gathering the data in the most convenient and least costly way. Priorities are largely set by the research community itself, rarely in consultation with populations in need of public health research and interventions. This approach has created inequity: most health research has been done in rich countries, although most disease occurs in poor ones. This means that public health research focuses mostly on European-origin populations, with Japanese populations being the main exception, in the last fifty years. Moreover, the research effort has, in relative terms, neglected women and ethnic minority groups. This inequity has been tackled directly in the United States with a legal requirement to justify the exclusion of populations.<sup>8</sup> No such requirement is in place in Europe. Globally these historical inequities will not be redressed without purposeful and massive redistribution of research expertise and resources.

Why are researchers generally neglectful of racial and ethnic minority groups? The answer is complex, but one factor is that such research attentive to racial and ethnic groups is difficult and much more costly. Among the scientific challenges of research including minorities is assuring comparability of data across cultures, ethnic groups, and racial groups. The principles for ensuring cross-cultural comparability of self-report data were reviewed by Hunt and Bhopal.<sup>9</sup> Experience shows that putting those principles into practice is extremely difficult. Cross-cultural comparability is less of a problem in biomedical research that does not depend on self-report. Nonetheless, we need to keep an open mind as to whether biological norms are valid across ethnic and racial groups, be those norms of weight, height, or biochemical values such as blood pressure, two-hour glucose as a marker of diabetes, or red cell counts. How to assure inter-group comparability of data and establish valid norms will matter as we strive to interpret the avalanche of genetic research that is under way and planned on everything from behavioral characteristics to drug response.

The post-World War II consensus that genetics and biology make only a modest contribution to racial variations in human health, though probably correct, will be severely tested. Interpreting genetic data requires examination of the interplay of genetic and environmental factors. For ethnicity and health researchers there will be a number of crucial questions, including these: Has the postulated genetic basis for variation, say in a disease such as diabetes, been demonstrated by pinpointing the genetic variations responsible? Have environmental explanations for the disease variation been considered? If environmental explanations have been set aside, is the quality of the measurements made well enough to instil confidence in the results? Finally, in what ways do the environmental and genetic factors interact to create the disease variation? Ethnicity and health researchers will be compelled to perform genetic analysis, attempting to tease apart the relative roles of genetics and environment.

Finally, researchers will be pressed for data to guide policy and practice. Presently, there is a remarkable paucity of data on the effectiveness of interventions for health improvement by ethnic or racial group. The assumption is usually made – and often with good reason – that what works in one ethnic group probably works in another. This general principle is more likely to be sustainable for interventions that are pharmacological (*e.g.*, statins), rather than social (*e.g.*, tobacco cessation programs). We see, however, in the example of Bidil, discussed elsewhere in this symposium, that even this principle is going to be challenged as ethnopharmacology ad-

vances.<sup>10</sup> It is likely, therefore, that the imperative for evidence-based policy and practice is going to demand empirical data by ethnic or racial group – a formidable requirement for multi-ethnic nations. In the next section I consider how the United Kingdom, and within that country, Scotland, is responding to the challenges of a multi-ethnic society.

# Legislative and Policy Drivers for Taking Public Health Action – UK / Scotland's Approach

While it would be naïve to portray the United Kingdom as a paragon of virtue, at least the country has not in recent history created laws and institutions that explicitly endorse racial inequality as has been the case in South Africa under apartheid, Germany under the Nazis, and the United States in the era of segregation, for example. To counter pervasive racial discrimination that imposed barriers to employment, housing, and social contact ("no colored" signs in bars, for example) the Race Relations Act 1971 outlawed such actions. The racist murder in London in 1997 of a British-born teenager, Stephen Lawrence, followed by an inadequate police response, led to the MacPherson Inquiry<sup>11</sup> that spurred the Race Relations (Amendment) Act of 2000.<sup>12</sup> This Act has required a major shift in the way public bodies approach racial discrimination in employment and the provision of services. The Act places a duty on public bodies to actively promote racial equality. The Commission for Racial Equality is the lead body monitoring the implementation of the Act.<sup>13</sup> Among the principal outputs from public bodies are Race Equality Schemes, comprised of detailed action plans and then regular progress reports. This legislation virtually mandates ethnic monitoring of both employment practices and service delivery. It also requires action in response to epidemiological demonstrations of health inequalities.

In Scotland, the Executive Health Department, in collaboration with academics and health service professionals, has similarly created and is implementing a wide-ranging policy called Fair for All.<sup>14</sup> This policy requires National Health Service staff to meet the health and health care needs of ethnic minority communities. Among the many outcomes of this policy is the 2002 creation of the National Resource Centre for Ethnic Minority Health.<sup>15</sup> The Centre started its work by focusing on policy implementation, training, information, and mental health. The Scottish Health Service

With legislation and policy in place that promote equality and well-being, epidemiological data can be generated and used to advance public health.

> has responded enthusiastically, though goals are always difficult to achieve in the light of resource and expertise limitations, as well as competing priorities. Nonetheless, the principles and processes established by the Fair for All policy are worthy of wider application, for example to combat inequalities in services for the disabled, the elderly, and those of non-heterosexual orientation.

> With legislation and policy in place that promote equality and well-being, epidemiological data can be generated and used to advance public health.<sup>16</sup> Scotland has funded work to generate such data both retrospectively and prospectively. Certainly, the risk of harm from studying racial and ethnic differences is reduced in this environment.

## **Recommendations for Using Racial and Ethnic Categories in Epidemiology and Public Health** Eight recommendations flow from my analysis:

- 1. The goal of improving the health and well-being of minority groups and therefore the population as a whole is central to the responsible use of the racial and ethnic categories.
- 2. When that goal is embraced politically and socially, it is irresponsible not to acquire and use race and ethnicity data to tackle the nation's need to improve health in both absolute and relative terms.
- 3. The way race and ethnicity are operationalized needs to be subtler and more flexible than hitherto. The way categories and classifications are created, and resultant data summarized, analyzed, and interpreted depends on the purpose and context. Usually, though not always, the greatest value will come from analyzing the heterogeneity of the populations under study.
- 4. Ethnocentrism, the tendency to perceive and interpret from the standpoint of one's own culture, is a hindrance to epidemiology and public health. Ethnocentrism usually means comparing the health of minority populations to that of the standard or norm in the majority, usually the white population. Public health advances are more likely to come from setting the standard for each disease or health problem using that ethnic group within the society under consideration that has the most favorable profile (for example,

for coronary heart disease this will often be the Chinese, while for stroke it will often be the white population).

- 5. While politics and policies are likely to be driven by values, beliefs, and attitudes, those should be informed by valid scientific data. The results of policies should be monitored using qualitative and quantitative data to ensure that those policies are having the desired beneficial effects.
- 6. The study of race and ethnicity in health has suffered from a weak theoretical foundation. That foundation needs to be strengthened by more and better theoretical scholarship, to balance the much larger volume of empirical research using these concepts. Moreover, empirical researchers need to try to apply the theoretical principles that are being established. In recent decades there has been a substantial amount of constructive criticism of the state of the art. There is, however, little evidence that this work is successfully influencing empirical researchers.
- 7. Funding bodies and leadership organizations have a responsibility to foster the dialogue and build the structures and processes required to improve the quality of research. A starting point would be a continually updated handbook - probably web-based - on ethnicity and health research in international and national contexts. One of the earliest priorities in this endeavour should be the documentation of variations in concepts and nomenclature over time and place. Creating an internationally agreed glossary on ethnicity and race would be difficult and ambitious, but such a reference is overdue. The National Institutes of Health (NIH) could make this a priority to promote the responsible issue of race and ethnicity in research. NIH needs to work in partnership with the World Health Organization and the International Committee of Medical Journal Editors.
- 8. Most importantly, work on race, ethnicity, and health must be historically informed. There is no room for racism (or ethnicism) in science. We must endeavour to make scientific racism no more than a bad memory.

# Appendix

This extract is from my glossary.<sup>17</sup> "Ethnicity is a multifaceted quality that refers to the group to which people belong, and/or are perceived to belong, as a result of certain shared characteristics, including geographical and ancestral origins, but particularly cultural traditions and languages. The characteristics which define ethnicity are not fixed or easily measured, so ethnicity is imprecise and fluid. Ethnicity differs from race, nationality, religion and migrant status, sometimes in subtle ways, but may include facets of these other concepts.

The biological concept of race, whereby human populations were divided into sub-species mainly on the basis of visible physical characteristics, was dominant from the early nineteenth century to its decline with the defeat of the Nazis at the end of the Second World War. In retrospect, the biological concept of race was ill-defined, poorly understood and invalid and the science based on it needed sharper scientific criticism. The modern concept of race, particularly as utilized by many scholars in the United States, emphasises its social origins rather than its biological basis. In this perspective, race provides a way of defining, for social purposes, populations which look different and have different ancestral roots. It is evident, however, that even this social concept of race is ultimately based on physical and hence biological factors, though these are de-emphasised in social epidemiology as secondary, unimportant matters. The term race should be used with caution for its history is one of misuse and injustice. In the study of racism, however, the concept is central."

The definitions I gave in the glossary were:

*Ethnicity:* "The social group a person belongs to, and either identifies with or is identified with by others, as a result of a mix of cultural and other factors including language, diet, religion, ancestry, and physical textures traditionally associated with race (see Race). Increasingly, the concept is being used synonymously with race but the trend is pragmatic rather than scientific."

*Race:* "By historical and common usage the group (sub-species in traditional scientific usage) a person belongs to as a result of a mix of physical features such as skin colour and hair texture, which reflect ancestry and geographical origins, as identified by others or, increasingly, as self identified. The importance of social factors in the creation and perpetuation of racial categories has led to the concept broadening to include a common social and political heritage, making its usage similar to ethnicity. Race and ethnicity are increasingly used as synonyms causing some confusion and leading to the hybrid terms race/ethnicity (see Ethnicity)."

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- 18. Id.