

# Racism, Ethnicity, Health and Society

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Advanced article

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Online posting date: 15<sup>th</sup> March 2012

**Racialised thinking about human diversity underlies some infamous medical and scientific abuses, although in some cases the form of discrimination is cloaked in the language of ethnicity. A central dilemma of measuring equity along the lines of ethnicity is that categories of difference are inevitably reinforced. Although measuring iniquity may facilitate its redress, it may also reify and reinforce categories which are the basis of discrimination. The role of historical manifestations of racism in the case of rickets and sickle cell disease are discussed. The compounding of racialised disadvantage with other forms of marginalisation is discussed in terms of individual and institutional discrimination with regard to the origins of the HeLa cell line.**

## Terminology: Race and Ethnicity

Race and ethnicity are often used as synonyms to refer to difference between groups of people. Race tends to be used for difference that can be read from appearance, and is assumed to concern phenotype or physical difference with a biological basis. Ethnicity is used to refer to those aspects of shared group identity that are cultural, such as language, religion, marriage patterns, dress and food. The assignment of race categories by observers contrasts with the greater emphasis on the self-assignment of ethnic categories. It is sometimes assumed that ethnic groups are simply subdivisions of the broader racial groupings with the (problematic) implication that biological differentiation can never be overwritten by cultural demarcation.

The ongoing development of the meaning of race and ethnicity is location-specific and can be understood in relation to that place's history of migration, slavery and empire (Bradby and Nazroo, 2010). In the US race and ethnic group are both defined for census purposes, whereas only ethnic group has an official status in the UK. Elsewhere in Europe there has been a longstanding resistance to collecting data on ethnic group in health settings, which is

eLS subject area: Bioethics & Philosophy

### How to cite:

Bradby, Hannah (March 2012) Racism, Ethnicity, Health and Society.  
In: eLS. John Wiley & Sons, Ltd: Chichester.  
DOI: 10.1002/9780470015902.a0005660.pub2

only recently shifting and so official terminology is still emergent.

In genetic terms it is widely agreed that there is no such thing as race: humanity cannot be divided into distinct groups on the basis of the genetic variation that corresponds to the typologies defined by race scientists. Humans are a fairly homogenous species in terms of genetic variation (Jones, 1981), with approximately 85% of identified human genetic variation accounted for by differences between individuals and only 7% due to differences between the so-called races (Lewontin, 1993). Although these differences can be useful in tracing human evolutionary history (see: *Peopling of India: Insights from Genetics* by Partha P Majumder and *Genetic Isolates and Behavioral Gene Searches* by Carlos N Pato, Kim M Schindler and Michele T Pato), two individuals who share a skin colour, hair and nose type that would place them in a single racialised category may be no more similar in genetic terms than two individuals from different racialised groups. This seemingly simple point, which is largely undisputed in scientific discussion, underlies misunderstandings of the nature of differences between ethnic groups in many discourses. **See also:** [Genetic Isolates and Behavioral Gene Searches](#); [Peopling of India: Insights from Genetics](#)

The consensus over the nonexistence of a genetic basis for categorising humanity into discontinuous races has led commentators to suggest that the term 'race' has no place in scientific vocabulary. To utilise the term race is to perpetuate and confirm a notion that was conceived as part of a racist and sexist scientific project and which has been utilised in research that has denigrated and exterminated groups defined as inferior. Presumed inferiority in the hierarchy of races has underpinned attempts to exterminate complete groups (such as the Jews and the Roma in the holocaust) and to prevent or hinder the reproduction of others. **See also:** [Nazi Movement and Eugenics](#); [Nazi Scientists](#)

Eugenics and racism were embedded in scientific thinking until after the Second World War, when the scale of the holocaust was acknowledged publicly and the consequences of a racist categorisation of humanity and a strong eugenic science became apparent. Eugenics as a science was largely abandoned, but racist practice in science was not. For example, in 1932 in Macon County, Alabama, the infamous Tuskegee syphilis experiment was started in which public health service physicians withheld treatment from infected men and observed the course of the

disease. All of the infected men were Black, and by 1972 over 100 had died despite the widespread availability of penicillin as an effective treatment by 1946. The deaths associated with medical research in the Tuskegee experiment suggest that despite the public documentation of the horror of the holocaust, science is not immune from the prejudices that justify discrimination elsewhere in society. Racism constructs certain categories of people as inferior and, in extreme cases, as unworthy of preservation. Although the study was well known through American medical circles and had been subject to ethical review, it was discontinued as a consequence of a journalistic exposé rather than pressure from the medical profession.

Despite arguments for the nonexistence of race as a clear-cut genetic category and evidence of the abuse of racialised categories in research and clinical settings, the persistence of race categories is remarkable. The enduring appeal of race is worth some consideration, since it goes against various expert opinion and progressive initiative. The idea of race has persisted in both scientific and popular discourse in various forms, suggesting that this is an ontological, rather than just a terminological issue.

Although racialised categories for Black people have largely fallen out of usage, the ongoing and widespread use of the term Caucasian, usually as a synonym for White or 'of Northern European origins' in scientific papers is notable. Caucasian is a term coined by Blumenbach when he was engaged in a project of measuring skull volumes to demonstrate racial hierarchy. People from the Caucasus were deemed to have the biggest brain volume and therefore represented the purest form of 'the most beautiful race of men' (quoted in Jones, 1994). Current use of the term probably does not imply that authors believe White brains to be superior to non-White brains, but nonetheless 'Caucasian' has widespread currency, without ever being defined: its meaning is implied. The term 'Caucasian' apparently confers scientific respectability on the category 'White' despite its lack of geographical, historical or social merit as a descriptor of populations of northern European descent. An institutional inability or unwillingness to think through the implications of using such terminology is part of its persistence.

Discredited racist and eugenicist science may imply that the vocabulary of race should be jettisoned, but the continuing existence of racism means that race has a social reality that cannot be ignored. The effects of racism on health inequalities show the measurable power of discrimination in terms of morbidity and mortality (see *Ethnic Inequalities in Health* by James Y Nazroo). The rise of the use of the hybrid term 'race/ethnicity' in the US, following a trend already established elsewhere in the anglophone world, suggests a recognition of the unsatisfactory nature of 'race' categories but an unwillingness to abandon racialised categories. **See also:** [Ethnic Inequalities in Health](#)

Yet even without reference to race, categories based on ethnic or cultural difference have regularly been used as an euphemism for a form of difference that is immutable and essential. The term ethnic (without reference to majority or

minority) is regularly used to mean alien and/or exotic as in 'ethnic food' or 'ethnic clothes'. Widespread agreement that, in theory, ethnicity refers to a shared cultural or religious identity has not prevented the term from picking up baggage from racialised thinking. The slippage between the vocabulary of race and that of ethnicity suggests a reluctance or inability to conceptualise human diversity without recourse to essentialism. The hybrid term 'race/ethnicity' underlines the reluctance to jettison a dimension of essential difference related to biological inheritance when apparently referring to cultural difference. The seemingly compelling nature of racial categories on our collective imaginations in both popular and official discourse.

In both research (see 'Race', IQ and Genes by Michael Carson and Jon Beckwith) and clinical settings (Gamete Donation and 'Race' Giuliana Fuscaldo) race continues to be a potent category for interpreting human difference in the world. The dimension of physical appearance referred to as race, is highly salient in techniques of assisted reproduction involving donated gametes: people want their children to resemble them physically. When this expectation is violated, strong feelings are aroused, as explored in the literature on so-called transracial adoption and the intemperate commentary that accompanied the implantation of 'White' gametes in a 'Black' woman. **See also:** [Gamete Donation and 'Race'](#); 'Race', IQ and Genes

The imposition by health professionals of crude racialised categories is clearly inappropriate and has become increasingly rare. However the interpenetration of the market with racialised identity politics complicates the politics of race in healthcare beyond simple stereotyping and discrimination. The example of BiDil illustrates this complexity. BiDil is the trade name for a combination of drugs, marketed specifically for African-Americans. The disproportionately high mortality from heart disease among African-Americans is widely attributed to social and economic causes and yet this health inequality is used as a marketing pitch by pharmaceutical companies.

BiDil as a combination drug was only tested among self-identified African-Americans, so any benefit to other groups remains unexplored (Kahn, 2007). The maker of BiDil solicited support from Community and Black advocacy groups to promote BiDil as a pharmaceutical that offered some restitutive justice to the African American community (Rusert and Royal, 2011). This apparently cynical exploitation of racialised politics for marketing a combination of drugs that are already available in separate doses, has the effect of reinforcing the idea of immutable racial categories with the authoritative gloss of bioscience.

Lending scientific authority to the notion that humanity can be divided into clear-cut racial groupings that are relevant to a differential incidence of disease is the description of geographically structured genetic clusters which are, in some cases, reported as mapping onto major self-identified ethnic/racial groups. The ground-work making it possible to interpret the complexities of human genetic variation in terms of discrete populations that can

be measured and compared has been attributed to the work of social anthropologists and linguists of the 1930s and 1940s (Braun and Hammonds, 2008). In Africa, this work resulted in discrete populations being named and logged in international atlases and databases, permitting their use in large-scale population genetic studies and subsequently the more recent reinvigoration of the search for measurable difference. The argument that races and tribes (on which their more recent descendants 'racial/ethnic' groups are based) were socially constructed, does not negate the existence of genetic variation, but does demonstrate how the assertion of the existence of bounded entities became self-fulfilling (Braun and Hammonds, 2008). If racialised population groupings were referred to as geographic or continental ancestry groups, would it impede the essentialist interpretation of complex diversity?

A drive to adopt the language of ethnicity, as a means of avoiding the essentialist implications of race, which skeptical scare marks around 'race' cannot eliminate, has perhaps promoted the rise of the ethnic/race hybrid. Ethnicity, if defined as the real or probable, or in some cases mythical, common origins of the people with visions of a shared destiny that are manifested in terms of the ideal or actual language, religion, work, diet or family patterns of those people (Bradby, 1995) is a characteristic of groups and individuals that is contingent, labile, hybridising and complex. As with any complex theoretical concept that is subject to empirical research, a measurable proxy must be identified that will inevitably encapsulate rather less of this contingent, negotiated complexity. The particular difficulty with operationalising ethnicity as a research variable is the existence of the commonsense notion of race that is often assumed to be easily measurable by any observer. As Megyesi *et al.* (2011), among others, point out racial/ethnic differences are cited with increasing regularity and genetic causes implied to underlie their existence. These authors' review addresses bone density and points to the lack of consistency or clarity in the definition of race or ethnicity and the lack of attention to genetic data. These objections to the use of ethnic and racial variables could equally apply to other areas of bioscience.

The difficulty of using a proxy for a theoretically complex variable in quantitative analysis is the apparently irresistible temptation to suspend knowledge of the limitations of data and to read meaning directly from the categories around which statistics are constructed. Thus, a category such as 'Chinese' or 'Punjabi' becomes reified, and, particularly where gender and/or socio-economic status have been controlled for statistically, the cause of any ethnic disadvantage shown in the data is sought in what it means to be, for instance Chinese or Punjabi. Either the genetics of people from the Punjab or from China or a feature of their culture is nominated as an explanation for a measurable health deficit (Bradby and Nazroo, 2010).

Attention to terminology is thus more than just a matter of avoiding the offence of individual sensibilities. Particularly in the field of genetics, precision and clarity in defining the dimension of human difference that is under

consideration are crucial. The danger of research and practice informed by models of human diversity that are based on racialised categorisations, whether expressed in terms of race or ethnicity, is that they invite essentialist interpretation.

## Racialised Thinking in Research and Practice

### Sickle cell and racism in the United States

When a screening programme for sickle cell anaemia was introduced in 1972 in the United States, the genetic basis of the disease was well-established, including an understanding of the environmental conditions that lead the recessive gene responsible for the condition in the homozygous state to increase in frequency in regions where malaria is endemic. The screening programme was initially welcomed by Americans of African descent as a means of addressing a long-neglected health problem, but it soon became clear that its effects on people's life chances were going to be largely negative. Sufferers (homozygotes) and carriers (heterozygotes) of the sickle cell condition were identified and treated in a way that has been described as both stigmatising and punitive (Duster, 1990). For example, being a carrier of the trait resulted in termination of employment, increased insurance premiums and delay in adoption proceedings.

Although irrational and morally unacceptable, discrimination against those with the disease is predictable and tends to be justified in terms of the greater burden of supporting an individual who may have a greater than average need of healthcare. Regardless of whether this justification is acceptable for those who are homozygous for the sickle cell gene, it does not apply to heterozygotes because there are no symptoms or health penalties associated with carrying a single copy of the gene. Indeed, it confers some health benefits in those areas where malaria is endemic. In seeking to explain the punitive and stigmatising aspects of this screening programme, the role of racism cannot be ignored. When the screening programme was instigated, the legal segregation of people of African Americans in public life was very recent history. The systematic exclusion of people from, for example, particular institutions of learning on the basis of their skin colour and hair type rested on an assumption of inferiority in various respects: intellectual, moral and cultural. Evidence of a faulty gene, even if it was only a single copy of a recessive gene, in the context of a long history of presumed inferiority of 'African racial stock', reinforced and perpetuated existing racist discrimination.

### Rickets and racism in Britain

In the nineteenth century, rickets was prevalent among British inner city dwellers living and working in squalid conditions. The observation that many of the sufferers were

Irish (labour migrants to the developing industrial centres) led a contemporary commentator to propose that the propensity to rickets and to red hair were linked and could be attributed to the poor quality of the Irish racial stock (Cooper, 1984).

By the late twentieth century rickets had been identified as a disease that results from vitamin D deficiency. Labour migrants from south Asia were, like the Irish nearly two centuries earlier, attracted by employment opportunities in British cities. Having been all but completely eradicated among the general population with the introduction of fortified foods, rickets reappeared among people of south Asian origin. The shock of a nineteenth-century disease of poverty appearing in an industrialised nation in the twentieth century was contained by labelling it 'Asian rickets'. The transfer of the descriptor 'Asian' from the sufferers to the disease implied that its origins lay with the people themselves. In this case, race was not straightforwardly seen as causing the disease, but rather cultural practices such as diet and clothing were held to deprive Asians of adequate vitamin D (Donovan, 1984). However, the importance of skin colour as an indicator of inferiority is seen, despite the mainly cultural causes identified for rickets, in the way that the greater pigmentation of Asian compared with northern European skin was blamed for an inability to synthesise vitamin D in the British climate.

The preponderance of cultural over biological features identified as causing rickets means that it might be included in what came to be called the 'new racism'. However, there is very little novelty in the effect of identifying 'Asian' rickets as essentially different from the non-Asian variety and therefore people of south Asian origin themselves as essentially different from other Britons.

## Henrietta Lacks and HeLa Cells

Public health responses to haemoglobinopathy and rickets were discriminatory in ways that depended on earlier forms of racism and also re-created them in contemporary form. The way in which our quotidian experience is inextricably linked with historic cultural forms is common-place in the humanities, but more routinely ignored in bioscience. The story of Henrietta Lacks (1920–1951), whose cervical cancer cells were removed without her consent in 1951, and have been successfully grown in laboratories across the world ever since, illustrates how historic forms of racism are inextricably linked with the ongoing disadvantage of marginalised groups and with bioscience's success and the related profits of the biotech industry.

Henrietta Lacks, descended from slaves and having worked as a tobacco farmer and later in a steel mill, died of metastasised cervical cancer, aged 31, leaving five children. The unusual vigour with which Lacks' cells grew *in vitro* gave rise to a cell line named 'HeLa' which has been used to research numerous diseases, including the development of the polio vaccine. It is estimated that 50 million tonnes of HeLa cells have been grown since Lacks' death and their

use has been acknowledged in at least 60 000 scientific papers. The enormous contribution of the HeLa cell line to scientific progress has been contrasted with the poverty in which Lacks and her family lived, including her painful death in the only public hospital that treated Blacks and her burial in an unmarked grave. The researcher who first grew Lacks' cells in the lab did not make money from the cell line, but it has subsequently been marketed worldwide and yet her descendants cannot afford health insurance (Skloot, 2010).

The HeLa cell line and the Lacks family's story shows that racism operates at an institutional level. Henrietta Lacks' treatment options in 1951 were limited because she was Black, not necessarily or only because an individual clinician was racist. Lacks' descendants have not prospered and some cannot afford health insurance and so maybe denied access to the diagnostic and therapeutic benefits that her cells have helped to develop. The family's deprivation is not because they are Black, although this is part of the cause of both their marginalisation and of the ease with which cells were removed from Lacks' body and subsequently subject to research without her consent/of her family's knowledge.

## Is racism an inevitable effect of measuring diversity?

Ethnicity is a complex, contingent and labile characteristic, unlike race, which was, at least in its crude form, conceptualised as essential and immutable. The challenge of understanding the bewildering ethnic and cultural diversity of humanity and operationalising such a complex concept in research around health has often been sidestepped by falling back on the cruder, familiar, racialised categories, although these might be referred to using the vocabulary of ethnicity. Discrimination operates institutionally as well as at the level of the individual and can use the language of race, ethnicity and/or culture.

Some countries have been extremely wary about gathering data regarding ethnic categories because of the danger of reinforcing racialised groups who are subject to discrimination. However, without documentation of iniquity, it cannot be addressed through policy intervention. The classification of ethnic diversity for use in national censuses and other population surveys in various countries and the merit in retaining comparability with existing data, means that broad classifications are unlikely to disappear in the near future. Equally, the dangers of reproducing and reinforcing racialised distinctions continue to be a concern.

The best general advice in operationalising a measure of diversity is to avoid any assumption that observed difference is due to biological difference and to relate the rationale for any ethnic categorisations to the research question under investigation with great care and precision. Although such conceptual work is difficult given the complexity of the social and economic variables, the dangers of avoiding it are considerable. **See also:** [Ethnic Inequalities in Health; Ethnicity and Disease](#)

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## Web Links

- Center for Genetics and Society. <http://www.geneticsandsociety.org/>