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# ANTHROPOLOGICAL INSIGHTS INTO THE USE OF RACE/ETHNICITY TO EXPLORE GENETIC CONTRIBUTIONS TO DISPARITIES IN HEALTH

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**Summary.** Anthropological insights into the use of race/ethnicity to explore genetic contributions to disparities in health were developed using in-depth qualitative interviews with editorial staff from nineteen genetics journals, focusing on the methodological and conceptual mechanisms required to make race/ethnicity a genetic variable. As such, these analyses explore how and why race/ethnicity comes to be used in the context of genetic research, set against the background of continuing critiques from anthropology and related human sciences that focus on the social construction, structural correlates and limited genetic validity of racial/ethnic categories. The analyses demonstrate how these critiques have failed to engage geneticists, and how geneticists use a range of essentially cultural devices to protect and separate their use of race/ethnicity as a genetic construct from its use as a societal and social science resource. Given its multidisciplinary, biosocial nature and the cultural gaze of its ethnographic methodologies, anthropology is well placed to explore the cultural separation of science and society, and of natural and social science disciplines. Anthropological insights into the use of race/ethnicity to explore disparities in health suggest that moving beyond genetic explanations of innate difference might benefit from a more even-handed critique of how both the natural and social sciences tend to essentialize selective elements of race/ethnicity. Drawing on the example of HIV/AIDS, this paper demonstrates how public health has been undermined by the use of race/ethnicity as an analytical variable, both as a cipher for innate genetic differences in susceptibility and response to treatment, and in its use to identify 'core groups' at greater risk of becoming infected and infecting others. Clearly, a tendency for biological reductionism can place many biomedical issues beyond the scope of public health interventions, while socio-cultural essentialization has tended to stigmatize 'unhealthy behaviours' and the communities where these are more prevalent.

## Introduction

### *Genetic explanations for racial and ethnic disparities in health*

Although ‘race’ and ‘ethnicity’ are often defined or interpreted as measuring different (biological vs social) aspects of group identity (Sankar, 2003), this paper accepts that both are social constructions and both are associated with a range of biological *and* social variables (Oppenheimer, 2001). For this reason they are often used interchangeably and debates about what each of them mean distract attention from their common role in stereotyping social groups (through biological reductionism and cultural essentialism). For this reason, and given the focus of the analyses that follow, the term ‘race/ethnicity’ has been adopted throughout to avoid drawing any unnecessary distinctions between the two.

The idea that population classifications based on race and/or ethnicity accurately describe innate genetic differences responsible for disparities in health (as well as intelligence and behaviour), has been repeatedly discredited over the past 50 years (UNESCO, 1950, 1951). The American Anthropological Association (AAA) has played a prominent role in reiterating this critique, pointing out that race ‘distorts our ideas about human differences and group behavior,’ (AAA, 1998). In turn, the AAA statement concludes, somewhat optimistically, that ‘scientists today find that reliance on such folk beliefs about human differences in research has led to countless errors’.

Anthropologists, from both the socio-cultural and biological/physical schools, are in a particularly good position to re-assess the state of the debate concerning the use of race/ethnicity as a genetic variable in biomedical research and its impact on public health. First, through in-depth ethnographic analyses, they can provide the ‘thick description’ (Geertz, 1973) required to understand how race/ethnicity is used and conceptualized by geneticists and biomedical researchers and how their findings are translated into public health programmes. Second, they are well placed to examine the relationship between genetic and socio-cultural interpretations of race/ethnicity and related constructs and categories. In fact, existing critiques of race/ethnicity as a genetic construct and category developed out of both anthropological schools. Research by biological/physical anthropologists helped establish that race/ethnicity fails to account for the full extent of human biological variation, and that racial/ethnic categories are likely to be imprecise tools for use within biological or genetic research. Instead, human phenotypic and genetic variation is felt to be more accurately described in terms of independent traits distributed along discordant gradients or ‘clines’, rather than as discrete packets of concordant traits (Bamshad *et al.*, 2004). Beyond these biological concerns, anthropological critiques from the socio-cultural school focus on the social construction of race/ethnicity and place greater emphasis upon how race/ethnicity emerged historically and has been associated with inequalities in power due to colonialism, slavery and discrimination. As such, this view of race/ethnicity sees disparities in health and related biological characteristics as the consequences of hierarchical socio-cultural and political practices rather than the result of innate genetic differences.

Similar arguments have formed the basis for many critiques of race/ethnicity as a scientific variable. Nonetheless, race/ethnicity remains a key social determinant of health and social well-being, and even those working towards a ‘colour-blind’ future

recognize the importance of using race/ethnicity to monitor, expose and tackle the causes of these disparities (Krieger *et al.*, 1999; Krieger, 2004). An important aspect of this work involves determining what role, if any, genetic differences play in such disparities. This is a sensitive issue, since the use of racial/ethnic categories in genetic and biomedical research appears to recognize these categories as scientifically and genetically meaningful – in direct contradiction to the social constructionist critique of race/ethnicity. This is further complicated by the adoption of extreme interpretations of race/ethnicity: as biologically ‘meaningless’ or as a legitimate genetic construct. Neither of these extremes places race/ethnicity beyond debate, and neither help to deal with the social *and* biological consequences of racial/ethnic classification (Bamshad *et al.*, 2004). Nonetheless, the political capital to be had from overplaying the appeal of ‘colour-blind’ and ‘colour-conscious’ paradigms is often hard to resist.

Meanwhile, race/ethnicity is routinely used within epidemiological, genetic and related biomedical research as if it were both a ‘natural’ bio-genetic category and a valid scientific risk factor for a number of specific ‘racial/ethnic diseases’ – despite the contested nature of race/ethnicity and a lack of consensus on: what this means; whether it is a useful analytical variable; and (if so) how it should be operationalized. This use of race/ethnicity as an accepted and integral part of biomedical research exerts a powerful influence over public health practice – both directly, in terms of prevention (using race/ethnicity to target screening for genetic ‘disorders’: e.g. Bubb & Matthews, 2004) and treatment (such as the development of separate guidelines and therapies for different racial/ethnic groups; e.g. Williams *et al.*, 2004; Taylor *et al.*, 2004), and indirectly, in terms of the readiness to view racial/ethnic health disparities as innate and beyond the scope of public health interventions (e.g. Krieger, 2004). More generally, biomedical researchers and many of the public health programmes underpinned by their research seem prone to take the genetic model as the dominant line of enquiry when explaining racial/ethnic disparities in health. This model then has a dual impact on public health: first, its dominance encourages solutions that follow the path of developing specific treatment programmes for different racial/ethnic groups; and, second, the model masks any social and structural factors responsible for racial/ethnic disparities in health which might otherwise be amenable to interventions operating across *all* such groups.

At the White House conference in June 2000 marking the completion of the first draft of the human genome (Briefing Room, 2000) President Clinton proclaimed that this had proved that ‘all human beings, regardless of race, are more than 99.9 percent the same’. He predicted that the Human Genome Project would ‘revolutionise the diagnosis, prevention and treatment of most, if not all, human diseases’. Such was the fundamental belief in the Project that President Clinton likened the study of DNA to ‘learning the language in which God created life’. President Clinton’s speech appeared to signify the end of race as a biomedical category. His confident assertions were re-iterated by Craig Venter, President and Chief Scientific Officer of the Celera Genomics Corporation, who stated that ‘in the five Celera genomes, there is no way to tell one ethnicity from another. Society and medicine treats us all as members of populations, where as individuals we are all unique, and population statistics do not apply.’ So why, in 2005, is there still such controversy surrounding the use of

racial/ethnic categories in genetic and biomedical research? Anthropology offers us a way of answering this question – conceptualizing race/ethnicity as a ‘social construct’ that varies across different cultural contexts and cannot be assumed to have universally accepted meanings be these genetic, phenotypic, cultural or structural. As such race/ethnicity continues to be relevant in a range of contexts and to a range of constituencies – including those biomedical researchers who view race/ethnicity as a useful bio-genetic tool.

*Anthropological critiques of race as a genetic construct and category*

In *Human Types*, Raymond Firth (1956) wrote: ‘It is common to attribute ways of life and thought which we do not fully understand to racial differences.’ Firth was highly critical of arguments concerning racial mixture and felt that ‘discussions regarding the intermixture of a number of hypothetical pure stocks is unprofitable, and there is no direct evidence whatever for the existence of “pure” racial populations’. Likewise, when Frank B. Livingstone wrote his chapter *On the Nonexistence of Human Races* in 1964, he criticized the utility of the race concept for explaining genetic variability, arguing that ‘if a population is X per cent Negro in one characteristic it must be X per cent in all characteristics for this [racial explanation of difference] to be an adequate explanation’. In fact, as Livingstone explained, genetic traits can often be *discordant* and ‘if two genes vary discordantly, the races set up on the basis of one do not describe the variability in the other’.

However, the social reality of race can make it difficult to see past what Feldman *et al.* (2003) have called the ‘iconic [phenotypic] features of race’. In *Why Genes Don’t Count (for Racial Differences in Health)* Alan Goodman (2000) wrote of his own university experiences in which a physical anthropology professor had surprised him, along with many of his fellow students, by declaring that ‘although race is still real, it is not biologically based; rather, it is social with biological consequences’. Goodman came to understand how the social nature of race meant one could change racial identity, depending on the social context. As such, the same person might label themselves, or come to be labelled, ‘black’, ‘African’, ‘West Indian’ or ‘Jamaican’ within different contexts in which these labels imply different, context-specific, meanings. Goodman’s paper also recalled the valuable social lesson of how ‘scientific ideas [such as race/ethnicity] can endure and be made to seem real if they have social and political-economic utility’. This point echoed the AAA statement on race which had emphasized how race is the product of social and historical forces rather than being the result of biological, and ultimately genetic, factors. Indeed, the AAA statement had highlighted associations between race, slavery, colonialism and Nazism and had pointed out how, in the past, ‘leaders among European-Americans fabricated the cultural/behavioral characteristics associated with each “race”, linking superior traits with Europeans and negative and inferior ones to blacks and Indians’. As such, anthropologists, from both the socio-cultural and biological/physical schools, have been instrumental in recasting those aspects of traditional Eurocentric ideology, which regarded racial groups as unalterable sub-species, in a new socio-political light. In the process they have sought to deconstruct what passed for bio-scientific ‘reasoning’, and have shown how this masks the social and political

foundations of race and can make defining race as a bio-genetic category a largely futile exercise.

The rebuttal of race as a biologically meaningful concept has led some to question its very existence. However, in *Buried Alive: The Concept of Race in Science* Troy Duster argued that just because race/ethnicity is not, genetically or biologically, a 'true' category, does not mean it cannot have real biological effects derived from its social relevance (Duster, 2003). His argument is that while geneticists and biological anthropologists (such as Lewontin, 1972; and Barbujani *et al.*, 1997) have demonstrated that race/ethnicity is neither unambiguous nor helpful as a genetic category – since very little genetic variance is attributable to race/ethnicity – this finding is really only important to geneticists. Duster proposed that instead of choosing only one of these two perspectives – race as biological or race as social – researchers need to recognize it as a biosocial construct, denying neither its biological nor its social attributes. He argued that the AAA statement on race is useful but 'gives the impression that the biological meanings that scientists attribute to any phenotypical variation by race are refutable by biological facts, while the social meanings that lay persons give to race are either errors or mere social constructions not themselves capable of affecting biochemical, neurophysiological, and cellular aspects of our bodies that, in turn, can be studied scientifically'.

### *Aims and objectives*

It is therefore from a biosocial, anthropological perspective that the analyses which follow explore the use of race/ethnicity as a genetic construct and category, and the consequences this has for public health. These analyses do not set out to deny either the genetic or the social interpretations of race/ethnicity, but instead examine the former in order to explore their relationship with the latter. The aims of the analyses are: first, to understand how and why geneticists view race/ethnicity as a valid genetic variable; second, to determine how geneticists address anthropological critiques of race/ethnicity as an unreliable marker of genetic variation and a culturally contingent social construct; and third, to place geneticists' use of race/ethnicity within the cultural context of genetic research. The paper concludes by assessing how anthropological insights might support geneticists conducting legitimate research into the genetic causes (and correlates) of racial/ethnic inequalities in health, without reifying race/ethnicity as a genetically determined construct (or category), and without undermining the development of public health services to address the socio-political causes of racial/ethnic inequalities in health.

### **Methods**

Socio-cultural anthropology's ability to explore the symbolic and material meanings of natural entities and cultural artefacts within different social contexts forms the framework within which the following analyses are situated. Twenty-two semi-structured interviews were conducted (by GTHE) with geneticists working on the editorial boards of the nineteen most highly-cited genetics journals that routinely publish articles using race/ethnicity (see Ellison & Rees Jones, 2002; Fig. 1, p. 266).

Given the geographical distribution of these journals' editorial offices (thirteen in the US, four in the UK and two elsewhere in Europe), only one of the interviews took place face-to-face and the remainder were conducted by telephone. Consent was obtained from each interviewee to tape-record their interview, following an assurance that their interview would be analysed anonymously. These recordings were later transcribed to facilitate analysis and the extraction of verbatim quotes to illustrate the key themes that emerged.

The interviews lasted between 50 and 120 minutes and covered four broad areas using a flexible topic guide containing a range of questions and prompts prepared following informal discussions with both geneticists and anthropologists. These four areas examined: (i) the nomenclature, classification and measurement techniques used to operationalize race/ethnicity in genetic research; (ii) interviewees' views regarding the reliability and validity of race/ethnicity as a genetic and socio-cultural variable; (iii) the principal explanations offered for racial/ethnic variation in the distribution and penetrance of genetic traits; and (iv) possible options for strengthening the use of race/ethnicity in genetic research (including editorial guidelines and interdisciplinary collaboration). Discourse analysis was used (Wetherall *et al.*, 2001) to explore all four of these areas, whilst paying particular attention to the second and third.

In the absence of visual cues for sustaining dialogue the telephone interviews sought to generate free-flowing conversation between interviewee and interviewer. In this way the interviewees were encouraged to explore avenues of personal interest, experience and expertise rather than being restricted to issues on the topic guide. This approach helped to focus the data collected on each interviewee's particular experience as a researcher, editor and member of both scientific and non-scientific communities. Crucially, interviewees were encouraged to situate themselves within a wider socio-cultural framework that looks to science to provide 'objectively constructed' truths yet attaches a variety of meanings to race/ethnicity.

## Results

### *Endorsing a genetic meaning for race/ethnicity*

The geneticists interviewed experienced race/ethnicity both as a nebulous social classification and as an effective scientific tool (for exploring those aspects of genetic variation that differ between different population groups). These somewhat contradictory experiences stemmed from a fundamental belief in the value of scientific findings as factual 'givens', tempered by a recognition that race/ethnicity is a socially and politically sensitive issue.

*Transforming social constructs into genetic categories.* When interviewees were asked how race/ethnicity should be measured, several shared the view 'that any kind of racial or ethnic definition is not precise'. This inherent lack of precision also affected their confidence in race/ethnicity as a marker for genetic difference. Interviewees explained that they felt it was 'clear that there isn't always a clear correspondence, certainly at the individual level, between self-identification, labels of ethnicity, group membership, and broader patterns of genetic group'. The interviewees certainly recognized the inherent

subjectivity of self-assigned racial/ethnic categories, but felt that geneticists were ill-equipped to question the veracity of such classifications. As one interviewee put it, 'I'm not an anthropologist, so I just accept what they tell me. I think the reality is a severe miss [i.e. inaccurately captures their *true* race/ethnicity].' Re-affirming the differences between geneticists and anthropologists in this way seems to place the capacity (if not the responsibility) for improving the classification of race/ethnicity firmly with anthropologists and other human scientists. This stance would also seem to leave geneticists free to continue their work without having to concern themselves unduly with classificatory problems outside of their control. Under these circumstances, it is not surprising that most interviewees emphasized how the inaccuracy of self-assigned race/ethnicity undermined its association with genetic variation: 'self-perception of group membership or ethnicity may or may not correspond with what some genetic analysis says'. Meanwhile, the absence of a clear correspondence between race/ethnicity and genetic variation was also felt to reflect, and to be compounded by, population mixing. Again, this was partly an issue of measurement, as one interviewee explained: 'I fully recognize that any kind of racial or ethnic definition is not precise, and that's particularly relevant in the type of culture that we have, particularly in this country, which is a melting pot of races.' 'Mixing' also had a perceived impact on the genetic heterogeneity of different groups: 'we know that there is no such thing as a pure bred 'black', 'white' or 'Hispanic' in this country [the United States], probably...'

Despite recognizing and acknowledging these methodological weaknesses, the interviewees were keen to point out that people 'grouped into a particular race or ethnicity will share certain genetically measurable markers'. The consistency of results demonstrating genetic differences between racial/ethnic groups was therefore felt to overcome the classificatory problems facing race/ethnicity: one interviewee argued that 'the [genetic] differences we [researchers] are measuring between different ethnicities are greater than the error that we are incurring in not classifying certain people correctly'; while another pointed out that although 'these [population groups] are self-described and poorly defined by anyone's standard ... you still see grouping together at the genetic level'. Clearly, the interviewees shared the view that racial/ethnic categories are 'very useful handles on population differences, and for some alleles, these are very strongly different between some types of groups', and found it 'interesting because you find certain alleles are very common in one group and not in another'. As such they were seen as useful markers for both allelic frequencies of specific genetic traits and potential 'modifying' genes, and for the Mendelian 'disorders' and complex multi-factorial conditions underlying population differences in health. Indeed, they felt confident that race/ethnicity could be made useful for research into the genetic causation of disease even though they acknowledged that race/ethnicity was not a genetic category in itself and that only a few diseases are strongly associated with discrete racial/ethnic groups. The self-evident logic of this approach led one interviewee to point out that 'there's no reason why you should use them [race and ethnicity] at all in a genetic study, unless you assume that [i.e. that they are genetically different]'. In other words, if geneticists felt that race/ethnicity did not capture a useful amount of genetic difference, or were unable to demonstrate that race/ethnicity could operationalize this difference, there would be little point in using race/ethnicity as if it did.

*A role for 'mixed' and 'isolated' populations.* The view that race/ethnicity is a useful genetic variable also influenced the way interviewees understood and operationalized 'mixed' and 'isolated' populations. As we have seen, the interviewees recognized that racial/ethnic groups were unlikely to be 'pure bred'. Nonetheless, aspirations for 'purity' informed the way 'mixed' and 'isolated' populations were conceptualized. 'Mixed' populations were often described as those 'who have multiple ancestries or something of that nature'. In this sense, the term 'mixed' appealed to folk beliefs of past racial/ethnic purity, when ancestral populations were separated and developed distinct biological (and social) differences over time. 'Mixing' therefore appeals to the notion of race/ethnicity as a marker for ancestral states that reflect the natural consequences of racial/ethnic separation. This approach offers a way of accommodating the inherent weaknesses of using race/ethnicity for genetic research in 'mixed' populations by drawing on a particular strand of evolutionary theory, and a belief that there was a time when something approaching 'pure' racial/ethnic populations existed. From this perspective, even modest genetic differences between contemporary racial/ethnic groups, which geneticists acknowledge to be unreliably classified and 'mixed', can be taken as evidence of more pronounced historical/evolutionary differences. Thus one interviewee felt that there was 'very good evidence that these major population groupings have some biologic meaning – and it is still no surprise that the major populations have been partially isolated for a long time'. This rationalization of the level of genetic difference found in crudely classified and mixed populations was strengthened by the more extensive differences observed from selective sampling of 'isolated' populations. One interviewee explained why geneticists are keen to gather genetic data from these sorts of populations: 'there are known regions that are geographically, and may be genetically, isolated for historical reasons ... so certain populations ... are studied just because they're known to be genetically isolated and tend to be a fairly homogeneous ethnic group'. Thus the validity of race/ethnicity as a genetic variable was rationalized by reference to populations whose geographical or social isolation results in identifiable genetic differences, and to less distinct groups viewed as mixtures of hitherto distinct, ancestral populations.

*A symbolic role for key Mendelian disorders: Tay-Sachs and sickle cell anaemia.* Just as the genetic consequences of being a 'mixed' or 'isolated' population were reframed to justify the utility of race/ethnicity as a genetic variable, so Mendelian disorders were used to emphasize the relevance of genetic differences to broader racial/ethnic disparities in health. In particular, the view that race/ethnicity was useful for genetic research relevant to public health was routinely supported by reference to Tay-Sachs disease and sickle cell anaemia, which are more prevalent amongst the Ashkenazi Jewish population and those of West African descent, respectively. In emphasizing that 'there are some populations – like the Jewish population – who have very characteristically high frequencies of this or that disease' interviewees drew on the notion of population-specific diseases, and on the principal interest of geneticists: the genetic components of *all* disease. This was evident in the contrast one interviewee drew between epidemiology and genetics: 'I think epidemiology journals tend to take a viewpoint of the environment causing disease ... [while] geneticists tend to take almost the opposite view' – one in which genetic causation is the principal focus. The

potential benefits of adopting such a focus were justified by one interviewee who noted that ‘the incidence of Tay Sachs disease has only a few cases a year now – they have successfully applied genetic screening within the population’. In other words, the scientific rationale for using race/ethnicity as a genetic variable was strengthened by suggesting that this had genuine benefits for public health. However, just as the interviewees juxtaposed their views of ‘mixed’ and ‘isolated’ populations to situate the practical utility of race/ethnicity as a research variable within the real world, so they qualified the utility of Mendelian disorders as models for understanding racial/ethnic disparities in common complex diseases: ‘The findings from such populations [associated with Mendelian disorders] are certainly helpful, but as far as understanding common disease that affects lots of people, it’s difficult to extrapolate.’ Nonetheless, these cautionary asides were set within the context of a preoccupation with the genetic determinants of all diseases, including complex diseases, and a belief that more genetic aetiologies would eventually be found. For this reason, racial/ethnic disparities in health were implicitly assumed to reflect inherent genetic differences.

*Removing unwanted non-genetic correlates of race/ethnicity.* While the interviewees recognized that, as a social construct, race/ethnicity was associated with a range of social, cultural and political phenomena, their interest in race/ethnicity as a genetic variable led many to allude to a future in which racial and ethnic groups ‘are going to be defined at a genetic level’. When this was possible, they felt that the non-genetic factors associated with race/ethnicity would be something that geneticists would be able to remove by ‘stratifying to sensibly take into account of the noise, whatever that kind of noise might be’. Indeed, the geneticists interviewed were largely uninterested in the non-genetic aspects of race/ethnicity, and wanted ‘to try to strip out [everything else] and just look at the genetics’. The process of removing non-genetic ‘noise’ was felt to be ‘something which is certainly an evolving art/field’ – the use of the word ‘art’ suggesting it was a highly prized yet poorly understood and elusive technique. However, the approach that interviewees described when using race/ethnicity to explore genetic variation, clearly relied on the belief that genetically meaningful racial/ethnic categories can be detected and operationalized separate from any contamination with the social/environmental correlates and consequences of classification (including, as we have already seen, those resulting from the methodological difficulties of measuring race/ethnicity).

#### *Separating the scientific from the societal*

The apparent contradiction between the contrasting views of race/ethnicity, as a scientifically useful variable versus a fluid social construct, was sustained by a separation of the scientific from the societal in the world-view of geneticists. However, the interviewees did not discount society’s view as irrelevant or wrong, but simply as different to, and separate from, geneticists’ understanding of race/ethnicity.

*Distancing from social and political interpretations.* Several interviewees recognized that in the public’s mind there can be a strong association between genes and identity. For example, one recalled the case of a ‘woman whom claimed to have gypsy

ethnicity and wanted us to prove she was a gypsy using genetics'. Another felt 'that there's a naivety on the part of the general public that social identities are somehow concrete and long lasting' and therefore identifiable using genetics. However, this interviewee also recognized that genetic findings were likely to have a profound effect on the public, even when the findings were misinterpreted. Indeed, they felt that geneticists tended to downplay this: 'It seems to me just a kind of naivety that geneticists think that kind of [genetic] information won't be of import to individuals.' Other interviewees felt that concerns about genetics and identity were essentially beyond the realm of genetics. This reflected a desire amongst the geneticists interviewed to distance themselves from society, as one interview explained: 'One has to be careful to not become part of a political process but rather focus on communicating research findings.' Interviewees displayed a strong desire to demarcate the areas of influence and relevance for genetics, and those relevant to society (and, as we shall see, to social scientists). This was summed up neatly by the interviewee who felt it was necessary 'to make a clear distinction between the scientific interpretation of race and the social interpretation of race'. However, this same interviewee also felt that the distinction may 'get clouded quite often – get confused in the public's mind'. As such, the public's view of race/ethnicity was routinely labelled as being 'confused'. This does not mean that the general public was felt to be wrong in its interpretation of race/ethnicity *per se*, but were often wrong in their interpretation of what race/ethnicity meant genetically. As such, interviewees felt that the best qualified people to understand the genetic meaning of race/ethnicity were geneticists – not the general public.

*Distancing from racism.* Closely connected to this desire to separate what race/ethnicity meant within the context of genetics from the public understanding of race/ethnicity, was an equivalent separation of race/ethnicity (as a genetic category) from racism and ethnic discrimination (as features of social life). As one interviewee argued: 'Essentially what we are discovering is that that there is no basis for racism ... yet people decide to focus on skin colour.' By implication the conflation of race/ethnicity as a useful genetic category with racial/ethnic discrimination was again beyond the control of geneticists. Indeed, another interviewee suggested that 'even if genetic differences between populations disappeared altogether, people will still figure out some way of defining themselves'. Clearly, the interviewees felt powerless to influence public perceptions of race/ethnicity, and many separated the production of genetic data (including that disaggregated by race/ethnicity) from public misinterpretations of genetic findings – even though others recognized that this separation was 'naive' (as we saw earlier).

Nonetheless, the interviewees were all acutely aware that race was a contentious, sensitive and politicized term, which was capable of stigmatizing those who used it, regardless of the context. This was evident in the interviewees' reflections on the distinction between race and ethnicity, and which of the two they preferred. Once again, the geneticists interviewed claimed that their science had little to offer by way of explanation – even though they were often prepared to offer a qualified, 'personal' view: 'As a scientist I wouldn't really know how to tell them [race and ethnicity] apart ... but in the social context ... race has become tainted, much more so than ethnicity,

so people tend to prefer using ethnicity.’ This view was echoed by another interviewee who said that they ‘associate[d] the word race with something more confrontational than ethnic grouping, even though they are used interchangeably. That has nothing to do with science, just my personal view.’ These ‘personal views’ were in stark contrast to the stated aim of genetic science. This was neatly summed up by the interviewee who felt that what ‘most geneticists who submit papers [to their particular journal] are concerned about is how can you use the information about the genome to answer questions to do with biology’. Clearly the interviewees were at pains to demarcate their zone of influence, separating their science, but not themselves as individuals, from issues concerning the preference for either race or ethnicity as conceptually distinct entities, and the associated issues of racism and ethnic discrimination.

*Distancing from social science.* Several interviewees appeared keen to engage with social science as a way of resolving the debate concerning racial/ethnic categorization in genetics. However, what might seem, at first sight, to be a desire for interdisciplinarity, was actually limited to the potential role social scientists might play in helping genetic researchers strengthen the value of race/ethnicity as a genetic variable. For example, one interviewee felt that ‘if we can layer [on that] our knowledge about ancestry of the population, how people are related and likely to be related to each other, we can gain a lot more information, a lot more power’. Likewise, another interviewee acknowledged that ‘it really requires almost a social scientist to offer advice to the genetic epidemiology group about what are good identifiers of groups that would make them genetically homogeneous’. In other words, this interviewee was keen to draw on the expertise of social scientists, but only insofar as they contributed to the genetic research. Thus while the interviewees hoped that social science might improve the acuity of race/ethnicity as a genetic variable, they were not prepared for, nor interested in engaging with, the wider contributions social scientists might make – such as understanding the contextual contingency, or the symbolic and material meaning(s), of race/ethnicity. Instead, the wider contributions social science might offer were simply alluded to as further evidence of the difference between social and scientific meanings of race/ethnicity, and to legitimate its use as an asocial scientific variable in genetic research.

## Discussion

### *Race/ethnicity and pragmatism in genetic culture*

During the course of the interviews three separate yet inter-connected themes emerged: the pragmatic use of race/ethnicity as a rough and ready categorical scientific variable; the view that racial/ethnic groups were the residues of pure ancestral populations; and the interpretation of racial/ethnic disparities in health as evidence of substantive genetic differences between racial/ethnic groups. While interviewees accepted that the methods used to categorize race/ethnicity did not capture discrete genetic differences, these methods were viewed as good enough for dividing up the human population into groups that were useful for genetic research.

Ultimately, the limitations of classifying racial/ethnic categories were then eclipsed by the fact that genetic research seems to produce (or is *seen* to produce) consistent differences in genetic parameters between racial/ethnic groups. As such, the argument that race/ethnicity is a purely social construct which should not be useful, and should not be used, as a scientific variable in genetic research, was felt to have been disproved by the results of such research. The second theme drew on the use of race/ethnicity as a theoretical concept referring to genetically pure ancestral populations. The interviewees referred to populations 'mixing' within contemporary social environments, and the impact of this on the genetic heterogeneity of extant racial/ethnic groups. In turn they conceptualized 'mixing' as something that undermined the acuity of genetic analyses that used race/ethnicity, and explained why so many geneticists were keen to study 'isolated' populations to produce clearer genetic results. Indeed, they often appeared to accept that 'pure' racial/ethnic groups had existed (and might, in some senses, still exist), by referring to 'mixing' as something relatively recent. This was compared with a much longer period of time in the past when human populations were presumed to have lived in relative isolation. This view was supported using well-worked examples of Mendelian traits strongly associated with specific populations – particularly two examples: sickle cell anaemia and Tay-Sachs disease. These were seen to provide evidence that race/ethnicity had a genetic basis, and to further validate the use of race/ethnicity in the search for genetic patterns and their associations with disease (be they causal, protective or modifying).

In other words, the interviewees interpreted genetic findings as evidence that race/ethnicity is a useful scientific category in genetic research, and therefore something quite different to the tentative social construct described in anthropological critiques of such research. In this way, geneticists protected their interpretations of race/ethnicity from societal or 'personal' interpretations of race/ethnicity. As such, they distanced themselves from issues concerning the role of race/ethnicity in social identity and the relationship between race/ethnicity, discrimination and culture. In particular, they criticized public and media perceptions of genetic research in which the use of race/ethnicity as a genetic category was confused with race/ethnicity as a component of group or personal identity – perceptions which assumed that geneticists might be able to 'measure' or 'fix' social identities.

These findings suggest that geneticists operate within a particular cultural context. Geneticists recognize this, and can place themselves inside or outside this context when reflecting on particular issues and when stressing this or that point. And, as with all cultural groups, geneticists inevitably develop a range of shared ideas and become committed to these, defending their own interpretations of the world from their critics. The use of race/ethnicity as an operationalizable variable with demonstrable genetic correlates is one such idea – one the interviewees felt to be very different to flexible and imprecise notions of 'social identity', and one the interviewees carefully protected. There is nothing unusual in this. To the contrary, it simply reflects how those who belong to a particular culture feel they have a particular stake (or vested interest) in its cultural values and beliefs, and that these are something worth defending. Clearly, when approached through an interpretative stance, it is evident that genetics is a scientific culture that has been created through the actions and words of those within that culture.

*Race/ethnicity as tool and artefact in the culture of genetics*

Ethnographic studies of scientific research have sought to demonstrate that 'discoveries' are the products of 'local practices' (such as laboratory techniques), rather than being handed down by the data themselves (Rabinow, 1992). To this end, several ethnographers have gone into laboratories to study scientists in their 'home' environments (see, for example, Knorr-Certina, 1981; Latour & Woolgar, 1986). The semi-structured, qualitative interviews we used aimed to adopt a similar gaze, using open-ended discussions to explore: the development and use of race/ethnicity as a scientific tool; the subsequent creation of related scientific 'facts'; and the meanings of these 'facts' as cultural artefacts. In *The Anthropology of Science*, Jonathan Marks described how 'the scholarly study of [natural] science is itself situated outside of the [natural] sciences' (Marks, 1996a) and instead has become a subject for the humanities and social sciences. As the 'study of humankind', anthropology is the most appropriate social science for 'straddling the sciences and humanities' and is capable of analysing 'both the boundaries of science itself and the activities of scientists in society' (Marks, 1996b). Moreover, the division of anthropology into its constituent parts – evident in the separate schools of socio-cultural anthropology, archaeology and biological/physical anthropology – provides the discipline with a particularly keen sense of how barriers drawn between the 'natural' and the 'social' undermine our ability to understand science as a cultural activity.

Genetics has several attributes common to cultural groups, as understood by anthropologists. First, genetic culture shares a core discourse – characterized as 'genetic essentialism' by Nelkin & Lindee (1996) – which operates as a lens through which genetic traits are examined, analysed and interpreted. Quite simply, genetics aims to generate genetic facts and to ascribe genetic causation to other (phenotypic) traits. This is a legitimate aspiration and one that has the potential to bestow substantive benefits for human health in the future. However, there has been a tendency (by some scientists and some sections of the media) to jump the gun, as it were, and ascribe a genetic cause to variation across a wide range of human traits. This has caused profound social damage in the past, and continues to do so today (Kitzinger, 2005). Though risible to those who recognize the malleability of human traits, and the power of the environment to overwhelm or reverse genetic signals, Nelkin & Lindee (1996) describe how the term 'gene' is used as a cultural icon to explain not only disparities in health, but also various other social attributes – including profound philosophical and emotional concepts such as 'guilt' and 'responsibility'. They highlight how the apparent simplicity of genetics – and popular ideas that genes make us well, ill and behave in certain ways – make 'gene' both a word and a concept that is commonly misappropriated as a powerful idiom in popular language, legal cases and even comedy, *despite* its inherent complexity. In *Blood Will Tell (Won't it?)* Jonathan Marks (1994) examined the longer term history of a tendency to underpin social processes and policies by appealing to 'natural' (unexplained) products of blood lineage, and highlighted the dangers of attributing social behaviour to 'nature'. Such critiques are most keenly contested when geneticists are felt to be applying a genetic reasoning to the social attributes of race/ethnicity. As such, these critiques have formed part of the background to intense hostility to a range of different genetic projects, most notably the Human Genome Diversity Project

(HGDP). Even though Luca Cavalli-Sforza (1991) and other leaders of the HGDP clearly stated that they did not intend to seek a genetic basis for race, fears of biological exploitation and accusations of racism caused the project to founder (Gutin, 1994; Santos, 2003).

The ability of genetic culture to adapt its shared interpretative schema to the cultural environments which surround it is essential for its cultural survival. This was evident in the ability of interviewees to debate, assimilate and reject information from other cultures in such a way that they reinforced the integrity of their own cultural beliefs. In particular, the interviewees sought to distance themselves from eugenics as this had been closely associated with the previous manifestation of genetics as a socio-political tool. They also separated the scientific from the personal in distancing themselves as scientists from debates concerning race/ethnicity as anything other than an asocial, genetic category. This is evidence of what McCann-Mortimer *et al.* (2004) have found to be commonplace for avoiding or rejecting contrary and contradictory discourses when promoting and rejecting race/ethnicity as a genetic entity. Drawing on the work of Gilbert & Mulkay (1984), McCann-Mortimer *et al.* (2004) conducted a detailed discourse analysis of scientific papers in which a range of rhetorical devices were used to make different points about the same issue. They identified what they called 'ontological gerrymandering' and demonstrated how often assurances were given that the 'facts will assert themselves'. Within science both proponents and opponents of using race as a genetic variable use what Gilbert & Mulkay (1984) have labelled the 'truth will out device'. However, as McCann-Mortimer *et al.* (2004) demonstrate, proponents of race/ethnicity as a useful variable for genetic research feel that their opponents have clouded the truth by assimilating politically correct (i.e. value-laden rather than fact-driven) arguments into their analysis. In turn their opponents feel that those wishing to highlight the validity of race/ethnicity as a genetic variable are 'motivated by racism, even within the realm of science'.

*Integrating the biological and cultural meanings of race/ethnicity: a role for anthropology?*

How might this entrenched and polarized debate be resolved? Moving beyond a dichotomized perspective of science versus society and the natural versus the social, it appears that the use of race/ethnicity has locked geneticists into a circular biosocial paradigm in which the categorization of populations is derived from popular culture and leads to genetic research that is then readily misinterpreted within society. Indeed, Richard Jenkins (1994) has argued that it may be impossible to separate 'facts' and 'values' when dealing with race/ethnicity. In his work on *Rethinking Ethnicity: Identity, Categorization and Power* he explored the relationship between external categorization and internal 'group identification', and described how the distinct qualities of external categories may become internalized under a range of different social situations. These include legal enforcement and resistance, as well as the incremental changes that occur when dominant languages and cultures overwhelm others. Jenkins argues that the categories used to divide up populations 'tell us about the categorizers – how they see themselves and their objectives – not [about] the categorized'. However, in a hierarchical social context, in which the categorizers are often more powerful, their categories

may nonetheless become internalized by those who have been categorized. In the case of genetics the power of racial/ethnic classification lies in the popular perception of genetic information as predictive fact. The internalization of racial/ethnic categories as genetic constructs is, of course, the principal reason why many human scientists are so concerned with the essentialization of race/ethnicity. Yet, it also demonstrates the fluid nature of the 'barriers' between science and society (Lindee *et al.*, 2003). While some might argue that the political context has changed since the heyday of eugenics, Epstein (2004) points out that from 'the phenotypic standpoint, and in everyday life, race retains an aura of self-evident naturalness and, to be sure, a profound political salience'. And when used as an externally imposed or objectified biomedical category, race/ethnicity can be transformed into an essentialized and internalized property that 'can sometimes change the way in which biomedicine does its work'. Thus, with more than a hint of irony, Epstein (2004) points out how the contemporary drive against the under-representation of minority (i.e. racial and ethnic) populations in biomedical research – which took off in the US and UK during the 1980s – might actually fuel a greater emphasis on differences between racial/ethnic groups.

The analyses presented here have demonstrated that different interpretations of racial/ethnic disparities in health are essentially cultural attributes of the academic disciplines involved (Chapman & Berggren, 2005). This finding suggests that a much better understanding of each discipline's cultural milieu might be required to achieve consensus on the meanings of race/ethnicity. Indeed, the analyses confirm that the anthropological critique of race/ethnicity as a genetic construct has not successfully engaged geneticists. This is quite simply because race/ethnicity means very different things to geneticists and other human scientists. Geneticists also feel under pressure from anthropologists (and other human scientists) who are critical of their work, while anthropologists (and other human scientists) become increasingly alarmed by the willingness of some geneticists to seek a genetic cause for almost any human attribute – from complex multifactorial diseases and health risk behaviours to the wider socio-cultural processes that undermine health. Might anthropology not only provide the basis for a critique of race/ethnicity as a genetic category but also offer, through its unique ethnographic insights, a greater understanding of how and why race/ethnicity is used and embedded in the culture of genetic research? The latter would assist geneticists, anthropologists and public health specialists to situate race/ethnicity as a tool for helping to understand genetic contributions to disparities in health without sustaining cultural confusion around the complex biosocial phenomena encompassed by race/ethnicity. From an anthropological perspective, the distinction geneticists (and others) draw between the scientific and the societal 'world views' of race/ethnicity is essentially a cultural act – one that other scientists have used before to justify the unrestricted pursuit of 'facts', by separating science as an objective imperative from society as morally contingent. If anthropology is to address the concerns raised by the continuing use of race/ethnicity as a scientific tool in genetics research, they will have to engage with the cultural devices geneticists use to place their use of race/ethnicity beyond reproach (at least in their own eyes). Perhaps a more even-handed critique that explored how both the social *and* natural sciences tend to essentialize selective elements of race/ethnicity might help in this respect? To accommodate *both* academic cultures might require integrating *both* interpretations to capture the combined social and

biological causes of disparities in health between racial/ethnic groups. In turn this would greatly assist public health practitioners to develop programmes that deal with the multidimensional causes of racial/ethnic health disparities, and to look beyond the technological allure and scientific authority of genetic explanations.

*Public health implications of bio-genetic interpretations of race/ethnicity*

In the meantime, what are the likely consequences for public health of this predilection for genetic explanations of racial/ethnic inequalities in disease and disease risk? First, it can lead public health to view racial/ethnic health inequalities as the products of intractable genetic differences that are not susceptible to public health interventions. Second, it may encourage the development of different public health services for different racial/ethnic groups – further stigmatizing some groups and re-enforcing notions of innate difference. And, third, it may distract attention away from analyses that explore the political economy of race/ethnicity and its role in structural violence through historical and contemporary discrimination. By way of conclusion, it is worth exploring how this bio-genetic model has impacted on a prominent public health concern – taking, as an example, the prevention and treatment of HIV/AIDS.

The search for a major breakthrough in the fight against HIV/AIDS is perhaps the most pressing public health issue of our time, with millions infected worldwide and no end in sight as the pandemic spreads through Eastern Europe and South-east Asia. It is also an issue in which race/ethnicity has played a troublesome role for a number of years, particularly in the long-standing controversy over the stigmatization of Haitians as a ‘core group’ and dominant vector of the disease in the US (Santana & Dancy, 2000; Castro & Farmer, 2005), and in the more recent furore over the use of race/ethnicity to screen blood donations for HIV in South Africa (Ellison, 2005). While these crude stereotypical practices have been criticized on scientific grounds, the notion that race/ethnicity captures a degree of genetic homogeneity (and therefore reflects different susceptibilities to disease and different responses to drug therapies) has exerted a strong influence on the interpretation of population differences in HIV prevalence and the effectiveness of treatment (e.g. Marshall, 2005; Atlas *et al.*, 2005). In the main, these interpretations tend to essentialize cultural practices thought to facilitate the transmission of HIV (Glick Schiller *et al.*, 1994) and invoke genetic explanations for population differences in immunological parameters (Atlas *et al.*, 2005) – even though the latter are subject to a range of structural and socio-cultural factors such as differences in stage at presentation for care (Boyd *et al.*, 2005). Moreover, this interpretive stance has encouraged researchers to explore racial/ethnic differences as a routine aspect of data analysis and to draw bio-genetic conclusions even when their methods preclude such analyses and their data provide a flimsy basis on which to do so.

It is therefore hardly surprising that during the course of recent trials of ‘AIDSVAX’ – a prototype HIV vaccine developed by the California-based company, VaxGen – racial/ethnic subgroup analyses were conducted that appeared to demonstrate that the vaccine worked better amongst ‘black’ participants (Jacobs, 2003; Montefiri *et al.*, 2004). For the most part, researchers were quick to apply the genetic model of racial/ethnic difference and postulate a genetic aetiology for the AIDSVAX results, and largely ignored potential structural and socio-cultural explanations. While

headlines appeared in the popular press announcing the development of a drug that might be useful for preventing HIV, if only among specific racial/ethnic groups, a number of critics raised serious scientific reservations. One of the main issues concerned the failure to include subgroup analyses *a priori* as an integral component of the trial's design. As a result the subgroup analyses were statistically underpowered: of the 5400 trial participants, just 314 were classified as 'black' and just thirteen of this group became infected (four from the treatment and nine from the placebo group). Furthermore, the trial as a whole was deemed a failure, because the vaccine did not lead to a significant reduction in infection (Abate, 2003; Russell & Abate, 2003). Under these circumstances the emphasis placed on the statistically significant subgroup analyses is likely to reflect a variety of interpretive and reporting biases that undermine the validity of the findings and cast doubt on the integrity of the researchers involved. These reservations appear, for the time being, to have put paid to the further development of AIDS VAX as a 'racial/ethnic vaccine'. However, it is clear that they have done little to dissuade researchers from using race/ethnicity to explore and invoke bio-genetic explanations (Montefiri *et al.*, 2004; Atlas *et al.*, 2005). Indeed, the successful patenting of 'BiDil' as the first 'ethnic drug' (which drew on similar subgroup analyses of results from otherwise inconclusive trials: Kahn, 2003, 2004) is testament to the potential of this approach to circumvent the structural and socio-cultural determinants of disparities in health and subvert public health in favour of bio-genetic medical therapies. Clearly, public health can be undermined by the use of race/ethnicity as a cipher for innate genetic differences in susceptibility and response to treatment, and for classifying 'core groups' at greater risk of becoming infected and infecting others. To address the combined biological and social causes of racial/ethnic disparities in health will require a more even-handed critique of how both the natural and social sciences essentialize selective elements of race/ethnicity. The analyses presented here suggest that this is likely to benefit from the unique interdisciplinary insights that anthropology has to offer (Ellison *et al.*, 2003).

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