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Blood and stories: how genomics is rewriting race, medicine and human history

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ABSTRACT In 2003 Howard University announced its intention to create a databank of the DNA of African Americans, most of whom were patients in their medical centre. Proponents of the decision invoked the routine exclusion of African Americans from research that would give them access to the most up-to-date medical technologies and treatments. They argued that this databank would rectify such exclusions. Opponents argued that such a move tacitly affirmed the biological (genetic) basis of race that had long fuelled racism as well as that the potential costs were not worth the uncertain benefits. Howard University's controversial decision emerges from research in genomic medicine that has added new urgency to the question of the relationship between science and racism. This relationship is the topic of Wald's essay. Scientific disagreements over the relative usefulness of 'race' as a classification in genomic medical research have been obscured by charges of racism and political correctness. The question takes us to the assumptions of population genomics that inform the medical research, and Wald turns to the Human Genome Diversity Project, the new Genographics Project and the 2003 film *Journey of Man* to consider how racism typically inheres not in the intentions of researchers, but in the language, images and stories through which scientists, journalists and the public inevitably interpret information. Wald demonstrates the importance of understanding those stories as inseparable from scientific and medical research. Her central argument is that if we understand the power of the stories we can better understand the debates surrounding race and genomic medicine, which, in turn, can help us make better ethical and policy decisions and be useful in the practices of science and medicine.

KEYWORDS genetics, Genographics Project, genomics, Human Genome Diversity Project, *Journey of Man*, race, racism

In the last week of May 2003 the National Human Genome Center (NHGC) of Howard University announced a plan to create a databank of the DNA

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of individuals of African descent. The *New York Times* called it 'the nation's largest repository of DNA from African-Americans', and explained that its creation was motivated by a history of racial discrimination in the United States that found expression in disparities of health care. 'We want to make sure', noted the dean of the medical school, Floyd J. Malveaux, that 'as genetics move forward, as information is collected, as data is being mined, that we are part of that process'.[1] With biotechnology widely hailed as the harbinger of a medical revolution, researchers at Howard wanted to ensure that the black population in the United States would have full access to the most up-to-date health care. They viewed the databank, which was projected to house, in five years, DNA samples from 25,000 African-descended individuals, collected mainly from patients at hospitals and clinics associated with Howard's medical school, as crucial to that inclusion. No one involved in the decision was unaware of the risks of such a databank, but its proponents believed that the nation's history of anti-black discrimination and glaring disparities in health care made the countervailing danger of African-American exclusion from the benefits of genomic research more urgent. Arthur L. Holden, president of the First Genetic Trust, a Chicago company chosen to help create the databank, insisted that the only controversial decision would be the refusal to pursue the collection of data.[2]

Critics of the decision conceded the potential usefulness of the information, but worried that it could be misleading and wondered if the benefits were really worth the possible consequences. Genomic research that rested on racial classifications risked reanimating an inaccurate understanding of the biological basis of racial difference, which has been central to racist thought for centuries, as well as underscoring the genetic causes of racially based health disparities at the expense of social and environmental explanations. One of the most prominent critics of the decision, sociologist Troy Duster, expressed concern about other uses of the information collected in such a databank besides medical research and treatment, including forensic racial profiling.[3] The Howard researchers proposed the databank against the backdrop of research concerning the role of genes in disease susceptibility and drug responses, and the development of a drug called BiDil, the first medication to be marketed specifically to a racial group. This research drew its urgency from genomic medicine, but its evidence from the findings of population genomics. As genomic research has become increasingly central to the practice of cutting-edge medicine, debate has centred on whether or not racial classifications offer useful medical information and, if so, with what consequences.

1 Andrew Pollack, 'DNA of Blacks to be gathered to fight illness', *New York Times*, 27 May 2003, A1.

2 Ibid.

3 Malcolm Ritter, 'As role of race in research questioned, a DNA databank proposed for Blacks', *Associated Press*, 19 July 2003.

Many scientists have resisted yielding to what they see as social pressures, insisting on the integrity of scientific enquiry and believing that a better understanding of the science will countermand its appropriation for racist arguments. Racism, they insist, in what has become a refrain, is a social problem that has nothing to do with the practice of science. With equal conviction, cultural critics maintain that social assumptions and biases infuse scientific concepts, paradigms and practices; racism is therefore not the result of poorly understood science but is often reproduced unwittingly and against researchers' best intentions. Stuart Hall, for example, cautions 'against extrapolating a common and universal structure to racism' that obscures 'how thoroughly racism is reorganized and rearticulated with the relations of new modes of production'.[4] The idea of 'articulation' in this context conjoins the two primary meanings of the term: the expression of ideas and the formation of connections through flexible joints. With a legacy in Marxist and ideological criticism, the term expresses the structural relationship among disparate things or ideas—for example, labour relations, race and ethnicity, and access to health care—as they are formulated and enacted through specific social practices. Genomic research produces information. Racism is articulated within that information (which is a *product*) through conventions of representation: familiar words and phrases, stock images, plotlines, interpretations and even the classifications that organize research. The archive of those images and expressions as well as the range of discussions about the research, from the scientific and medical literature to the mainstream media and popular culture, comprise the 'stories' of race and genomic medicine. These stories function as a kind of technology: they act instrumentally on the world, making information comprehensible and meaningful, and they constitute as well as produce a body of knowledge.

To understand how genomic research can reproduce racism, it is necessary to understand how racism is articulated through that research as it is practised in the context of particular social formations. The articulation is produced through stories of race and genomic research, which take many forms as they make their way from the scientific community to the general public. Stories about the research reach public consciousness through such controversial decisions as the NHGC databank as well as through the discoveries and innovations emerging from the labs of pharmaceutical companies, universities and federal institutions. Accounts of genomic research offer exciting promises, ranging from new explanations (and treatments) for some of the most feared medical problems, from cancer to avian flu, to new ways of understanding (and managing) human behaviour. They also capture the public imagination with claims of new discoveries that offer insight into the mysteries of human origins and human history, and the

4 Stuart Hall, 'Race, articulation, and societies structured in dominance', in Philomena Essed and David Theo Goldberg (eds), *Race Critical Theories* (Oxford: Blackwell 2002), 38–68 (57).

genealogies of individuals as well as groups. The claims and promises fuse in the stories of genomic research broadcast in the mainstream media, and they in turn influence policy and funding decisions and help to shape future research. These stories are fundamental in the production of scientific and medical knowledge and, therefore, as I argue in what follows, attention to them needs to be incorporated into scientific and medical research.

Race and genomic variation

Less than two weeks prior to the public announcement of the databank, the NHGC hosted a workshop, 'Human Genome Variation and ''Race''', to address the connections among race and ethnicity, genomic research and human health and medicine. Sponsors of the workshop included the Office of Science of the US Department of Energy, the Irving Harris Foundation, the National Human Genome Research Institute of the National Institutes of Health, and Howard University;[5] selected papers were published in a 2004 supplementary issue of *Nature Genetics*. In their introductory commentary on the volume, Charmaine D. M. Royal and Georgia M. Dunston, both of the NHGC, noted an apparent 'consensus that ''race,'' whether imposed or self-identified, is a weak surrogate for various genetic and nongenetic factors in correlations with health status'.[6] Yet, that 'consensus' belies the diverse claims in the volume.

There is consensus that 'race' has a wide array of definitions, and that it is a complicated term, but the contributors to the special issue show a range of opinions not only about whether, but about when and how 'race' can be a useful category of analysis in medical research. Sarah A. Tishkoff and Kenneth K. Kidd, for example, affirm both that 'knowledge of ancestry can be important clinically and in design of biomedical research studies' and that the 'emerging picture is that populations do, generally, cluster by broad geographic regions that correspond with racial classification'.[7] Joanna L. Mountain and Neil Risch understand 'racial and ethnic categories [as] ... proxies for a wide range of factors, potentially genetic and nongenetic'. While their concern with the potential misuse of genomic information makes them wary of using racial classifications in genomic research, they maintain that 'an individual's racial or ethnic affiliation will continue to be valuable

5 Ari Patrinos, '''Race'' and the human genome' (Sponsor's Foreword), *Nature Genetics*, vol. 36, no. 11s (Supplement), November 2004, S1–S2 (S1).

6 Charmaine D. M. Royal and Georgia M. Dunston, 'Changing the paradigm from ''race'' to human genome variation', *Nature Genetics*, vol. 36, no. 11s (Supplement), November 2004, S5–S7 (S7).

7 Sarah A. Tishkoff and Kenneth K. Kidd, 'Implications of biogeography of human populations for ''race'' and medicine', *Nature Genetics*, vol. 36, no. 11s (Supplement), November 2004, S21–S27 (S25–S26).

information in the context of epidemiological research'.[8] Francis S. Collins, by contrast, insists that the weak definitions of 'race' and 'ethnicity' make them 'flawed surrogates for multiple environmental and genetic factors in disease causation, including ancestral geographic origins, socioeconomic status, education and access to health care'. Accordingly, he urges that research 'move beyond these weak and imperfect proxy relationships to define the more proximate factors that influence health care'.[9] Significantly, several of these contributors have taken different positions on this issue either before or since the special issue.[10] The scientific study of race is clearly a vexed topic.[11]

While the contributors do not share a common view of the desired role of race and ethnicity in genomic medical research, they do share a common commitment to the effort to understand the usefulness of genomic research for the health care of individuals and populations, and a concern about the potential misapprehension and misuse of the information that this research generates. The well-known history of atrocities and abuse associated with scientific experimentation generally and, in the twentieth century, of genetics (eugenics) particularly makes race and, more specifically, racism central to this concern. A better understanding of the relationship between racism and the scientific study of 'race' could help to clarify both the problem of the misuse of information and the best way to address it.

Many of the contributors to the special issue, as well as other researchers working in this area, have sought to circumvent the problems raised by 'race' and 'ethnicity' by substituting 'ancestry' and 'population'. Royal and Dunston, for example, follow their rejection of 'race' as a surrogate with the observation that, as we commence this 'new era in molecular medicine, [it] remains to be determined how increasing knowledge of genetic variation in populations will

8 Joanna L. Mountain and Neil Risch, 'Assessing genetic contributions to phenotypic differences among ''racial'' and ''ethnic'' groups', *Nature Genetics*, vol. 36, no. 11s (Supplement), November 2004, S48–S53 (S52).

9 Francis S. Collins, 'What we do and don't know about ''race,'' ''ethnicity,'' genetics and health at the dawn of the genome era', *Nature Genetics*, vol. 36, no. 11s (Supplement), November 2004, S13–S15 (S13).

10 The difference is most likely a matter of emphasis or even context. Neil Risch, for example, had taken a stronger position on the value of 'race' as a surrogate in a 2002 piece in *Genome Biology* that I will discuss later in this essay. And Francis Collins is depicted, in a piece in the *New York Times Magazine* that appeared in October 2004, as advocating, at least in a limited way, the use of 'race' as a surrogate; see Robin Marantz Henig, 'The genome in black and white (and gray)', *New York Times Magazine*, 10 October 2004, 46–51.

11 For a summary of the field, see Race, Ethnicity and Genetics Working Group, 'The use of racial, ethnic, and ancestral categories in human genetics research', *American Journal of Human Genetics*, vol. 77, no. 4, October 2005, 519–32, and Celeste Condit, 'How culture and science make race ''genetic'' ', *Literature and Medicine*, special issue on 'Genomics and the Arts' (forthcoming). For a discussion of how racism structures the debate itself, see especially Alys Eve Weinbaum, 'Coda: gene/alogies for a new millennium', in *Wayward Reproductions: Genealogies of Race and Nation in Trans-Atlantic Modern Thought* (Durham, NC: Duke University Press 2004), 227–46.

change prevailing paradigms of human health and identity'.[12] Researchers consistently express the hope that the science itself will solve the problem of racism both by showing the common origins and genomic similarities of the human species and by demonstrating the history and mechanisms of human difference. Tishkoff and Kidd insist on the biomedical importance of 'the global distribution of genetic variation' but 'emphasize that the existence of differences, however small, should not be a basis for discrimination'.[13] Yet, as Lisa Gannett has shown, the substitution of 'population' for 'race' dates back to the early work on population genetics in the mid-twentieth century;[14] the concept of 'population' that was articulated in this work, especially by Theodosius Dobzhansky, the founder of the field, absorbed and transformed but did not replace the problematic concept of 'race'.[15] The legacy is evident in

12 Royal and Dunston, 'Changing the paradigm from ''race'' to human genome variation', S7.

13 Tishkoff and Kidd, 'Implications of biogeography of human populations for ''race'' and medicine', S26.

14 Lisa Gannett, 'Racism and human genome diversity research: the ethical limits of ''population thinking'' ', *Philosophy of Science*, vol. 68 (Supplement), September 2001, S479–S492.

15 Of particular note is the debate between Dobzhansky and Frank B. Livingstone published as 'On the non-existence of human races' in *Current Anthropology*, vol. 3, no. 3, June 1962, 279–81. Here Livingstone proposed that 'race' be abandoned as a term to describe living populations of human beings on the grounds that biological variation among populations 'does not conform to the discrete packages labeled races' (279). 'Race', he argued, is inaccurate, failing both to correspond to genetic variation and to offer a sufficient explanation for that variation. He was particularly interested in the incompatibility between race and natural selection. Livingstone advocated the substitution of 'clines' for 'races', where 'clines' named gradients of genetic variations among groups that resulted from a variety of factors. Dobzhansky rejected Livingstone's premises, arguing for the biological basis of racial differences and locating the problem of defining 'race' in its status as 'a category of biological classification. . . . Discovery of races is a biological problem', he explained, while 'naming races is a nomenclatorial problem' (280). Livingstone, in turn, argued both for the inconsistency of Dobzhansky's definitions of 'race' and for the insupportability of his methodology. 'No science can divorce its concepts, definitions, and theories so completely from its subject matter', he contended, 'so that Dobzhansky's dichotomy between biological and nomenclatorial problems is impossible' (280). Despite radical disagreement over the biology of 'race', however, Dobzhansky and Livingstone shared an interest in avoiding both its ambiguities and its dangers by substituting an alternative nomenclature. I have reproduced this debate here both because of its historical importance and because the terms of this disagreement have (strikingly) continued into the present. Carleton S. Coon's *The Origins of Races* (New York: Alfred A. Knopf 1962) was also an important source in the dissemination of the concept of 'clines'. Like Livingstone and Dobzhansky, he drew on Julian S. Huxley's 'Clines: an auxiliary taxonomic principle', *Nature*, vol. 142, 1938, 219–20. Gianfranco Biondi and Olga Rickards offer a history of the debate in 'The scientific fallacy of the biological concept of race', *Mankind Quarterly*, vol. 42, no. 4, Summer 2002, 355–88. The critical responses to their essay in the same issue of the journal exemplify how the terms of Dobzhansky and Livingstone's debate are being reproduced.

Tishkoff and Kidd's observation about the correspondence of the broad geographical regions that constitute 'populations' and conventional racial classifications.[16]

The solution is not to excise the concept of 'race'. As the seven NHGC authors note in their collaborative piece for the special issue, the

> absence of 'races' does not mean the absence of racism, or the structured inequality based on operationalized prejudice used to deprive people who are deemed to be fundamentally biologically different of social and economic justice. The 'no biological race' position does not exclude the idea that racism is a problem that needs to be addressed.[17]

Duster, perhaps the foremost theorist of race and genomics, is similarly critical of the consortium of scientists who issued the 'Revised UNESCO Statement on Race' in 1995 for their effort to address the problem of racism by declaring 'race' to be a scientifically invalid concept. Racial and ethnic classifications, for Duster, are too deeply 'embedded in the routine collection and analysis of data (from oncology to epidemiology, from hematology to social anthropology, from genetics to sociology)' to be profitably excluded from scientific study.[18] He proposes instead that the study of scientific conceptions of 'race' begins with an understanding of the 'complex interplay of social and biological realities with ideology and myth'.[19] Scientific knowledge, in other words, is invariably situated in social and cultural contexts and must be understood in those terms.

'Race' and 'ethnicity' may or may not be appropriate surrogates for the study of genetic and non-genetic health issues, but they are very much surrogates in the contributions to the special issue as well as other scientific discussions on the topic for a variety of questions concerning the many uses of genomic information. The language of promise and the considerable investments of time and resources have made it difficult to pose questions about the equity, expenditure and distribution that accompany the genomic turn in medicine. The history of racism makes race an especially pressing and visible example of the abuse of scientific information. Racism is not only a problem in its own right, but also a catch-all for the social and cultural

16 I make a similar point about the substitution of 'population' for 'race' in Priscilla Wald, 'Future perfect: genes, grammar and geography', *New Literary History*, vol. 4, no. 31, Autumn 2000, 681–708.

17 S. O. Y. Keita, R. A. Kittles, C. D. M. Royal, G. E. Bonney, P. Furbert-Harris, G. M. Dunston and C. N. Rotimi, 'Conceptualizing human variation', *Nature Genetics*, vol. 36, no. 11s (Supplement), November 2004, S17–S20 (S16).

18 Troy Duster, 'Buried alive: the concept of race in science', in Alan H. Goodman, Deborah Heath and M. Susan Lindee (eds), *Genetic Nature/Culture: Anthropology and Science beyond the Two-Culture Divide* (Berkeley and London: University of California Press 2003), 258–77 (258).

19 Ibid., 259.

inequities that emerge in, and may be exacerbated by, accounts of genomic research.

Race and genomic medicine

Despite disagreements among researchers about how useful 'race' and 'ethnicity' may be as surrogates for genetic and non-genetic health factors, those accounts register an urgency that reinforces a hierarchy of knowledge in which social and cultural enquiry is often cast as naive or even obstructionist. The NHGC's justification for the databank, for example, conveys faith in a medical revolution from which individuals of African descent risk exclusion if they do not take the immediate action represented by the databank. The refusal of a biological basis for 'race' among some of the early population geneticists surfaces in these accounts as evidence of the intrinsic anti-racism of the field. In particular, Richard Lewontin's 1972 article, in which he published the results of a study that demonstrated that genomic variation was significantly greater within than between racial groups, has become the touchstone for discussions of genomic variation. Lewontin declared human 'racial classification ... to be of virtually no genetic or taxonomic significance' and the essay, in which he concluded that 'no justification can be offered for its continuance', is invoked consistently to illustrate the incompatibility of responsible scientific investigation and racism.[20] Against these claims, reports of medical research insist nonetheless that racial and ethnic distinctions offer information that is too important to ignore.

The mainstream media have reproduced this formulation as actively as the specialist literature. A July 2003 *Washington Post* piece on the controversial role of race in clinical drug trials offers a typical example. Drawing on a simplified explanation of Lewontin's point, the author explains that

> recent advances in genetic mapping have all but dismissed race as a biological construct. Race accounts for only a tiny amount of the 0.1 percent genetic variation between one human and [an]other. That means that someone who is considered black, for instance, might have more genes in common with someone who is white rather than someone who is also black.

The explanation is immediately followed by a qualification. 'Yet, on the other hand', notes the writer, 'science also has shown that certain groups share inherited traits, and often similar ailments'.[21] Medicine emerges subtly in

20 Richard C. Lewontin, 'The apportionment of human diversity', *Evolutionary Biology*, vol. 6, 1972, 381–98 (397).

21 Ariana Eunjung Cha, 'Race plays role in new drug trials: treatment by genetic origin, ethnicity divides medical profession', *Washington Post*, 28 July 2003, A01.

this formulation as the compelling reason for bringing a biological construction of race back into consideration. Population genomics has all but disproved the biological existence of race, *yet* the correlation between race and health makes the biological underpinnings too important to ignore.

Much of the publicity surrounding the issue resulted, as in the *Washington Post* piece, from reports of a drug produced by NitroMed Inc., a biotech company, to treat heart failure in Blacks. Scientists had founded NitroMed in the mid-1990s to develop nitric oxide-based therapies to treat heart failure. The company acquired the rights to BiDil after the Food and Drug Administration (FDA) had already declined to approve the drug in the absence of an appropriate study; however, a reorganization of the data according to race led to a race-specific study and, eventually, to the long-sought patent.[22] In 2005 BiDil became the first drug marketed specifically to a racial or ethnic group.[23] The research that led to the development and approval of the drug exemplifies the scientific controversy. Critics argue that the race-based study was driven by circumstances that were extraneous to scientific research, that the ambiguous statistics do not justify the claim that the drug is more effective for individuals of African descent, and that the publicity surrounding these findings is irresponsible and market-driven.[24] Whatever its motivation, the publicity certainly invigorated public discussions about the medical relevance of racial and ethnic ancestry.

BiDil, however, did not inaugurate these debates. A *New York Times* piece about the publication of a scientific article on the use of self-identified race and ethnicity as classifications in genomic medical research in a 2002 issue of *Genome Biology* shows the newsworthiness of the topic, independent of specific pharmaceutical developments.[25] The scientific article, 'Categorization of Humans in Biomedical Research: Genes, Race and Disease',[26] presents the response of Stanford population geneticist Neil Risch *et al*. to James F. Wilson *et al.*'s argument for race-blind genomic research.[27] Wilson *et al.* had concluded, in the words of Howard McLeod in an accompanying

22 Pamela Sankar and Jonathan Kahn, 'BiDil: race medicine or race marketing?', *Health Affairs*, Web Exclusive, 11 October 2005.

23 An article in the *New York Times Magazine* in October 2005 helped to publicize both BiDil and the surrounding debate; see Henig, 'The genome in black and white (and gray)'.

24 Sankar and Kahn, 'BiDil'; Jonathan Kahn, 'Getting the numbers right: statistical mischief and racial profiling in heart failure research', *Perspectives in Biology and Medicine*, vol. 46, no. 4, 2003, 473–83.

25 Nicholas Wade, 'Race is seen as real guide to track roots of disease', *New York Times*, 30 July 2002, F1.

26 Neil Risch, Esteban Burchard, Elad Ziv and Hua Tang, 'Categorization of humans in biomedical research: genes, race and disease', *Genome Biology*, vol. 3, no. 7, July 2002, 1–12.

27 James F. Wilson, Michael E. Weale, Alice C. Smith, Fiona Gratix, Benjamin Fletcher, Mark G. Thomas, Neil Bradman and David B. Goldstein, 'Population genetic structure of variable drug response', *Nature Genetics*, vol. 29, no. 3, November 2001, 265–9.

commentary, that 'clusters identified by genotyping . . . are far more robust than those identified using geographic and ethnic labels',[28] that, in other words, data from the race-blind study of genetic markers associated with disease yield more useful information than data classified by self-identified race and ethnicity. Risch *et al.* took issue both with Wilson *et al*.'s study and with editorials in scientific publications that drew on it to argue against racial and ethnic classification in genomic medical research. Risch *et al.* disagreed particularly with two positions: the insistence that there is 'no biological basis for race', and the advocacy of 'a ''race-neutral'' approach' to research in genomic medicine.[29] They maintain, by contrast, that 'from both an objective and scientific (genetic and epidemiologic) perspective there is great validity in racial/ethnic self-categorizations, both from the research and public policy points of view'.[30] Their article, however, does not fully support this conclusion. While Risch *et al*. argue persuasively for the epidemiological usefulness of self-identified race and ethnicity, they do not convincingly present the genetic basis of their claim.

Their argument turns on—and begins to unravel around—the definition of 'biological', for which they offer two possibilities. 'If biological is defined as genetic', they contend, 'then . . . a decade or more of population genetics research has documented genetic, and therefore biological, differentiation among the races'.[31] As I have noted, however, there is considerable disagreement among scientists about what the research has documented. Unlike many population geneticists, Risch *et al.* assert that 'two Caucasians are more similar to each other genetically than a Caucasian and an Asian'.[32] To support this claim, they draw on studies in population genomics that, they argue, 'have recapitulated the classical definition of races based on continental ancestry—namely African, Caucasian (European and Middle East), Asian, Pacific Islander (for example, Australian, New Guinean and Melanesian), and Native American' and note that, 'for the purpose of this article, [they] define racial groups on the basis of primary continent of origin . . . (with some modifications . . .)'.[33] This argument reproduces rather than resolves the ambiguity associated with the relationship of ancestry to race. As many of the participants in the NHGC symposium so forcefully insist, there is no 'classical definition' of 'races'.

'*Self-identified* race and ethnicity' further begs the question of the relationship between biology and culture. As has been widely reported in the mainstream media, the increasing popularity of DNA testing for ancestry

28 Howard L. McLeod, 'Pharmacogenetics: more than skin deep', *Nature Genetics*, vol. 29, no. 3, November 2001, 247–8 (247).
29 Risch *et al*., 'Categorization of humans in biomedical research: genes, race and disease', 1.
30 Ibid.
31 Ibid., 4.
32 Ibid., 5.
33 Ibid., 3.

has shown that many people are surprised by the results of such tests.[34] Researchers have offered such unanticipated results, in fact, as evidence of how population genomics can dispel the myths of racism by demonstrating how interconnected the human population really is. Self-identification does not necessarily yield the most 'objective and scientific' information about one's genomic profile.

Genomic information is notoriously difficult to interpret even by researchers in the field. The frequency of alleles that mark genetic drift—the the rate of genetic changes resulting from mutations, or divergent alleles, in relatively inbred populations—tells where and when there was a divergence within a group. Those alleles are used to mark ancestry. But, as Michael J. Bamshad and Steve E. Olson note, 'how groups are divided depends on which genes are examined; simplistically put, you might fit into one group based on your skin-color genes but another based on a different characteristic'.[35] The DNA that yields information about one's ancestry—typically mitochondrial and Y-chromosome DNA—in fact tells only part of the story of genetic ancestry. The complexity of nuclear DNA does not yield sufficiently clear information to complete it. Moreover, as Jay Kaufman has pointed out, Risch *et al.*'s study relies on the dismissal of 'intermediate groups', such as 'Hispanic Americans', whom Risch *et al*. acknowledge could 'aggregate genetically with Caucasians, Native Americans, African Americans or form their own cluster' and are therefore 'not easily classified',[36] but the size of those groups attenuates their claims.[37] They are too large to be dismissed as an exception. Intermixture is increasingly the rule.

The other definition of 'biology' Risch *et al.* offer is more compelling, but not genetic. If 'biological is defined by susceptibility to, and natural history of, a chronic disease, then again numerous studies over past decades have documented biological differences among the races'.[38] This definition does not distinguish between environmental and genetic *causes* of the racial and

34 *Nightline*, the American nightly news programme, for example, featured a man who had lived fifty years defining himself as 'black' only to learn, through an ancestry test performed recreationally by DNAPrint Genomics, that his DNA revealed Indo-European, East Asian and American Indian, but no African, roots. Once again, that lineage reflects a focus on particular markers, and does not tell the whole story of genetic inheritance, although such qualifications do not typically reach the general public. Moreover, that particularization of a genetic lineage countermands the claim that 'we are all African under the skin'.

35 Michael J. Bamshad and Steve E. Olson, 'Does race exist?', *Scientific American*, vol. 289, no. 6, December 2003, 78–85 (78).

36 Risch *et al.*, 'Categorization of humans in biomedical research', 6–7.

37 Jay Kaufman, 'Race and genomic medicine: false premises, false promises', paper given at a symposium on race and genomics, Duke University, Durham, NC, 3 March 2005.

38 Risch *et al.*, 'Categorization of humans in biomedical research', 4.

ethnic differences that are evident in medical *outcomes*. The persuasive argument here is that self-identified race and ethnicity supply relevant information in the epidemiological study of disease and drug response: they are relevant variables in the study of health outcomes.

Risch *et al.* in fact most insistently invoke race in order to introduce social or environmental factors into an analysis of health outcomes. Citing Wilson *et al.*'s conclusion that race-blind genotyping yields more useful medical information than classification by self-identified 'geographic and ethnic labels', they argue that genetic clustering will 'actually create and/or exacerbate problems associated with genetic inferences based on racial differences'.[39] The reason, they explain, is that genetic clustering risks reducing the explanation for medical outcomes to genomics, failing to take 'environmental risk factors' into account. In other words, self-identified race and ethnicity provide the social and environmental contexts that modify genomic information. This assertion is consistent with the claim that self-identified race and ethnicity are relevant to epidemiological research because those classifications can offer important information about social and environmental risk factors, but not necessarily with the assertion that they have a genetic *basis*.

The public story

Science writer Nicholas Wade found Risch *et al.*'s argument sufficiently important to feature it in the *New York Times.* The image of Risch that he paints in this article is of a heroic scientist who is determined to place research above politics, and strike out against a dangerous political correctness. Thus is the public story created. Quoted in support of Risch's argument, prominent geneticist Stephen O'Brien notes that the effort to invalidate 'race' as a biological concept 'comes from honest and brilliant people who are not population geneticists'.[40] The piece does not explain that it is also population geneticists who most strongly (if not consistently) insist on removing 'race' as a biological category and distinguishing it from 'population'. O'Brien goes on to affirm the sincerity of 'those honest and brilliant people' but remarks:

> What is happening here is that Neil and his colleagues have decided the pendulum of political correctness has taken the field in a direction that will hurt epidemiological assessment of disease in the very minorities the defenders of political correctness wish to protect.[41]

39 Ibid., 7.
40 Quoted in Wade, 'Race is seen as real guide to track roots of disease'.
41 Quoted in ibid.

The charge of 'political correctness' obfuscates the terms of the scientific debate. While Wade includes quotations from population geneticists who argue that race-neutral research yields 'more accurate' information, the piece features Risch, who 'has plunged into an arena where many fear to tread', and gives him the last word.[42] The article concludes with his pronouncement: 'We need to value our diversity rather than fear it. . . . Ignoring our differences, even if with the best of intentions, will ultimately lead to the disservice of those who are in the minority.'[43] Wade depicts Risch's opponents, by contrast, as offering not an alternative scientific perspective, but a 'race-side-stepping proposal'.[44]

Pointing an accusatory finger at 'political correctness' not only deflects the scientific dispute, but also ignores the medical importance of the social consequences of racism, measured in health outcomes. Drawing a stark contrast between medical science and social concerns, a distinction that Risch *et al.*'s article itself troubles, that accusation renders social concerns suspect except as they provide epidemiologically useful information. Neither Wade nor Risch *et al*. address what constitutes epidemiologically useful information. Risch *et al.* dismiss potential abuses of genomic information (such as those that fuel racism) as unscientific, arguing

> that identifying genetic differences between races and ethnic groups, be they for random genetic markers, genes that lead to disease susceptibility or variation in drug response, is scientifically appropriate. What is not scientific is a value system attached to any such findings.[45]

But this assertion presumes that science and medicine can be divorced from their social contexts and that information circulates in value-neutral terms. History does not support that presumption, and calling racism 'not scientific' does not address the value system or alleviate the problems—including health outcomes—associated with it.

The social and epidemiological causes of differential health outcomes are exactly the problems that Risch *et al.* most persuasively offer to justify their retention of the categories of 'race' and 'ethnicity'. This suggests an epidemiological (rather than politically correct) reason to consider racism, which includes the potential abuses of the genomic information that emerge from racial and ethnic classifications. If, as Risch *et al.* suggest, race and ethnicity might be factors in medical outcomes (hence, their relevance to

42 Ibid. In fact, as I have noted, the thorny question of 'race' has been a topic of concern for population geneticists since the inception of the field (see note 15). And the accusation of political pandering has obscured the scientific disagreement from the outset.

43 Quoted in ibid.

44 Ibid.

45 Risch *et al.*, 'Categorization of humans in biomedical research', 11.

epidemiology), then why should the potential medical consequences of retaining them not also be part of this 'scientific' or, in Risch *et al.*'s words, 'objective' analysis? Calling on the language of 'science' and 'objectivity', Risch *et al.* seem effectively to have set the terms according to which the medical impact of racism is a factor only in epidemiological assessment and not in the analysis of health inequities. *Racism*, it seems, as much as race, affects health outcomes; potentially racist uses of racially classified genetic data could have such outcomes and therefore should be factored into these debates *as medically relevant* and not dismissed as 'politically correct'.

Taking racism into account does not mean refusing to collect and classify data in medical research according to race and ethnicity. On the contrary, those classifications provide important epidemiological information, as Risch *et al.* maintain, about the impact of social and environmental factors—including socio-economic inequities and cultural biases—on the health of individuals and groups. As Troy Duster argues, the way to 'recognize, engage, and clarify the complexity of the interaction between *any* taxonomies of race and biological, neurophysiological, society, and health outcomes' is to consider 'how science studies deploy the concept of race'.[46] The story of how biotechnology is revolutionizing medicine has put genomic research very much into public consciousness and has made genetic explanations of health disparities among individuals and especially groups the 'default position'.[47] Distinguishing between genomic and social and environmental factors in disease susceptibility and drug response is notoriously difficult, especially since, as Keita *et al*. note, 'some environmental influences can be so subtle and occur so early in life as to be missed . . . '.[48] Yet, that distinction determines how researchers and practitioners understand and address the problem of health disparities. 'Race' and 'ethnicity' are very different as surrogates for genomics and for social and environmental factors in the assessment of health outcomes, which is why the larger stories in which the research is embedded are scientifically and medically as well as socially relevant.

Neither Wade nor Risch *et al.* address the complexity of the information that is emerging from population genomics. The markers currently associated with genomic ancestry, as I have noted, tell only a small part of the story both of an individual's genealogy and of the fluidity of populations over time. The category of 'mixed-race' individuals is growing exponentially as are the number of markers that researchers are discovering. 'Populations' are overlapping and variable. Genotypes and phenotypes, moreover, are often at odds, leading to mischaracterization by 'self-identifying' individuals as well as researchers. Skin pigmentation, for example, results from geographical factors that do not necessarily correlate to genomic similarity,

46 Duster, 'Buried alive', 259.
47 Keita *et al.*, 'Conceptualizing human variation', S19.
48 Ibid.

and different alleles can be responsible for common medical conditions. The medical annals tell tragic stories of misdiagnoses of sickle cell disease or cystic fibrosis because the patient's 'race' did not conform to assumptions about the genetic dispositions of the disease, and popular media in the form of television series have picked up on these stories.[49] Classifications can affect the interpretation of the data. The statistical difference that ostensibly appeared when the BiDil research data were classified by race, for example, could lead to assumptions that would result in a doctor's prescribing the drug when it would be ineffective or failing to prescribe it when it would be useful.

Concern about the racist consequences attendant on race-based genomic research seems to have made some inroads even among the staunchest advocates of the research. The position that Mountain and Risch take evinces a departure from, or at least modification of, Risch *et al.*'s claims in the earlier article. Noting that 'our lack of understanding of the etiology of many complex traits means that racial and ethnic labels remain useful in epidemiological and clinical settings', Mountain and Risch recognize 'the potential for furthering racism by discussing race and genetics together in a scientific context', and therefore 'might seek to eliminate the use of racial categories in these contexts'.[50] Yet, their reasoning suggests a capitulation to the very 'side-stepping' of which Risch is critical in Wade's article rather than the kind of structural analysis that Duster advocates. Mountain and Risch follow their claim with the assertion that 'current health disparities' and the assumption 'that our society values the goal of understanding the underlying basis of those disparities' justify 'the continued use of labels in epidemiological research and clinical practice . . . '[51] Their endnotes send the reader to Risch *et al.*'s earlier 'Categorization of Humans in Biomedical Research' as well as to a concurring piece, E. G. Burchard *et al.*'s 'The Importance of Race and Ethnic Background in Biomedical Research and Clinical Practice'.[52] The nature of the research itself does not seem to be in question.

49 The television series *Chicago Hope*, for example, included an episode about a white woman who was dismissed by medical staff as crazy when she insisted she was suffering from sickle cell disease, but who, when she was finally tested, turned out to be correct. Richard S. Garcia has publicized a similar case of misdiagnosis in 'The misuse of race in medical diagnosis', *Chronicle of Higher Education*, 9 May 2003, B15. See also Lynn B. Jorde and Stephen P. Wooding, 'Genetic variation, classification and ''race'' ', *Nature Genetics*, vol. 36, no. 11s (Supplement), November 2004, S28–S33.

50 Mountain and Risch, 'Assessing genetic contributions to phenotypic differences among ''racial'' and ''ethnic'' groups', S52.

51 Ibid.

52 Esteban González Burchard, Elad Ziv, Natasha Coyle, Scarlett Lin Gomez, Hua Tang, Andrew J. Karter, Joanna L. Mountain, Eliseo J. Pérez-Stable, Dean Sheppard and Neil Risch, 'The importance of race and ethnic background in biomedical research and clinical practice', *New England Journal of Medicine*, vol. 348, no. 12, March 2003, 1170–5.

Mountain and Risch, like most of the other participants in the NHGC symposium, concede the complexity of the information that emerges from population genomics, although the participants vary in the emphasis they put on that complexity. Royal and Dunston, in fact, call attention to the 'scientific focus of the inaugural meeting in the *Human Genome Variation and "Race"* series'—and therefore to the special issue that it spawned—and concede that a 'substantial portion of the ongoing dialog on this issue has been devoted to the glaring medical and societal implications, often glossing over the ambiguous science that underlies many of these implications'.[53] The information that emerges from population genomics about the 'meaning' of human genomic variation and its relevance to the practice of medicine is central to an understanding of how race and racism articulate to genomic research. Population genomics supplies the information and categories—and, in effect, constitutes the underlying story—of 'race' and genomic medicine. That story needs to be part of the discussion.

The genomic story of human diversity

If medicine brings urgency to the question of the biological basis of race, human history brings drama and scope. Retelling the story of human migrations is in fact the chief aim of the field of population genomics, even if medicine offers the most fertile ground for the application of its insights. As one of the most prominent figures in the field, Luigi Luca Cavalli-Sforza, explains, population genomics offers a way to resolve the chaos of cultural definitions: 'human populations', he observes, 'are hard to define in a way that is both rigorous and useful because human beings group themselves in a bewildering array of sets, some of them overlapping, all of them in a state of flux'.[54] In his view, population genomics can sort out the categories and replace social chaos with scientific order; it can, that is, tell a more orderly story about genomic information.

Population geneticists chart the movements and migrations of people by measuring genetic drift. The frequency of alleles can offer information about when a group branched off from the 'family tree'. Allelic frequency is like a photograph of a population, fixing it in—and defining it by—a particular moment in time. Over long periods of time, populations are fluid, as early population geneticists sought to acknowledge with the concept of 'clines', or gradual shifts between populations. DNA, as Bamshad and Olson observe,[55] records a person's membership in any number of populations, which vary

53 Royal and Dunston, 'Changing the paradigm from "race" to human genome variation', S6.

54 Luigi Luca Cavalli-Sforza, 'Genes, peoples and languages', *Scientific American*, vol. 265, November 1991, 104–11 (104).

55 Bamshad and Olson, 'Does race exist?'.

according to the source of the DNA and the markers that are under consideration. The account of a person's 'ancestry' marks a decision to begin his or her descent at a particular historic and geographic point and on the basis of selected information. The technologies used to chronicle human migration can equally generate a picture of distinct biological populations. The same data can yield—have yielded—different stories. Yet, the concept of a (genetic) diaspora suggests that a fixed conception of the group can transcend the historical and geographical particularities. There is an inherent tension in population genomics between the fluidity of the concept of a population that population geneticists characteristically underscore, and the methodology and models of the discipline that seem designed to discover its fixity. Genomic information emerges, and is interpreted, through that tension.

The social categories, moreover, have been tenacious. While populations may not conform exactly to contemporary racial taxonomies, they reflect the evolution of human differences that more or less map on to the familiar categories, not only in popular discussions but, as several of the contributions to the NHGC symposium published in the special issue of *Nature Genetics* attest, in many scientific accounts as well. The story makes all the difference. The contradictions are evident in the urgent claim with which the editors preface the special issue that 'unless we discuss human genome variation, we will all miss the emerging story of who we are and where we come from'.[56] Although they explicitly advocate abandoning 'race' in favour of 'human genome variation', they do not consider how 'genome variation' has itself posed thorny questions about classification. The formulation implicit in '*the* emerging story' eludes the multiple (and contested) stories that are in fact emerging from the data. There are, that is, many stories about human migration and variation that could be supported by the scientific research as well as by data in other fields. This statement, moreover, presumes a coherent 'we' and defers the question of who has the authority to write its history. The stories about genomic information influence what is seen and, conversely, what is not seen. They have material consequences, since they affect funding, policy and even research and health outcomes. The contest over the emerging stories is therefore medically as well as socially relevant.

That contest was at the heart of the controversies surrounding the Human Genome Diversity Project (HGDP), which grew out of the critique, issued by Cavalli-Sforza and others, of the homogeneity of the Human Genome Project (HGP). He and his colleagues were—and remain—determined, as he explains in the April 2005 issue of *Nature Genetics*, to provide 'a resource that is aimed at promoting worldwide research on human genetic diversity, with the ultimate goal of understanding how and when patterns of diversity

56 'The unexamined population' (Editorial), *Nature Genetics*, vol. 36, no. 11s (Supplement), November 2004, S3. The claim can be read as a tacit defence of the field of (human) population genomics, in which human genome variation has always been the central focus.

were formed'.[57] The goals of the HGDP were articulated and shaped in a series of symposia in the early 1990s that addressed the scientific, ethical and anthropological issues involved in chronicling the history of human migration by collecting and studying the DNA of isolated population groups worldwide.[58] From the outset, the project reflected an overriding interest in reconstructing a more accurate history of genetic diversity and human migration patterns and the conviction that the DNA of relatively isolated—'indigenous'—populations contained the most pertinent, and most easily studied, information. The contention that these populations were on the verge of cultural (and biological) extinction lent urgency to the project. While its proponents cited the medical benefits of the information that would be gathered, those benefits were not foremost in the original justification for the research.[59]

Cavalli-Sforza and his colleagues were surprised to encounter charges of racism as the project increasingly gained public notice. Objections from indigenous groups worldwide to the assumptions and nature of the research as well as to its feared consequences—what they termed 'biocolonialism'—helped to halt work on the project. From the perspective of a decade, Cavalli-Sforza summarizes the objections he encountered as 'the fear that indigenous people might be exploited by the use of their DNA for commercial purposes (''bio-piracy'')' and the anxiety 'expressed', as he puts it, 'by naïve observers' that the data generated by the HGDP would fuel ' ''scientific racism'' ... despite the fact that half a century of research into human variation has supported the opposite point of view—that there is no scientific basis for racism'.[60] The planning document for the HGDP included among the list of practical applications for the research that it would 'help to combat the widespread popular fear and ignorance of human genetics and [would] make a significant contribution to the elimination of racism'.[61] The scientists involved in the project believed that understanding the nature of human genomic variation was the best way to see the unity of the human species. From their point of view, they had only good intentions, but

57 Luigi Luca Cavalli-Sforza, 'The Human Genome Diversity Project: past, present and future', *Nature Genetics*, vol. 6, April 2005, 333–40 (333).

58 Ibid.

59 I have written about the response to the HGDP in Wald, 'Future perfect'. The most extensive treatment of the history and critique of the project is Jenny Reardon, *Race to the Finish: Identity and Governance in an Age of Genomics* (Princeton, NJ and Oxford: Princeton University Press 2004). See also Jonathan Marks, ' ''We're going to tell these people who they really are'': science and relatedness', in Sarah Franklin and Susan McKinnon (eds), *Relative Values: Reconfiguring Kinship Studies* (Durham, NC: Duke University Press 2001), 355–83 and, for a discussion of the arbitrariness of genomic classification, Jonathan Marks, *What It Means to Be 98% Chimpanzee: Apes, People, and Their Genes* (Berkeley: University of California Press 2002).

60 Cavalli-Sforza, 'The Human Genome Diversity Project', 333.

61 Quoted in Steve E. Olson, 'The genetic archaeology of race', *Atlantic Monthly*, vol. 287, no. 4, April 2001, 69–74, 76, 78–80 (73).

Cavalli-Sforza's current understanding of the problem manifests the same logic that leads researchers to 'side-step' race in their medical studies; he locates the problem in the difficulties surrounding the question of 'race' and fails to address the concerns articulated by the critics of the project. He simply declares racism (as opposed to race) to be scientifically baseless. Even Steve Olson, in an *Atlantic Monthly* piece about the conflict that is sympathetic to Cavalli-Sforza, concedes that, for his belief that 'if people understood genetics, they couldn't possibly be racists', Cavalli-Sforza 'must certainly be judged naïve'.[62]

The most sustained critique of the work has come from the Indigenous Peoples Council on Biocolonialism (IPCB), which emerged from indigenous opposition to the HGDP.[63] More complex than Cavalli-Sforza's summary suggests, the IPCB's charges address the inscription of his proposed genomic research in the social and economic inequities that reflect centuries of colonization in which resources, defined broadly to include human labour and human being, were exploited and populations were oppressed often to the point of annihilation. That exploitation can take many forms and even has a history relevant to genomic research, as exemplified in the case of the Hagahai. In 1984 the Hagahai people of Papua New Guinea requested medical assistance for the many diseases that were afflicting them. An anthropologist who made contact with the group took blood samples for diagnostic purposes, but when medical researchers discovered unusual immunological properties in the blood of many Hagahai, they used the samples for research and even patented a cell line derived from the DNA of one man. While the controversial patent was withdrawn, the cell line established from his DNA remains available for research purposes. The case raises questions that are relevant to the HGDP in terms both of motivation and of control over the information: who is conducting the research and for what ends? To what uses will the resulting information be put? Who will profit? These questions involve more than money. They express the unequal relationship between the groups: the group in power not only determines how the information will be used, but also the kinds of stories that will be told about it and the material consequences they will generate.

62 Ibid., 80.

63 The earliest organizational opposition came from the Rural Advancement Foundation International (RAFI), a Canadian-based group that had previously concentrated on corporations' exploitation of developing world farmers (Olson, 'The genetic archaeology of race'). Objections to the HGDP and its subsequent incarnations have varied, ranging from a specific critique of the nature of the project to broad-based opposition to genomic research and biotechnology generally in all of their forms. Cavalli-Sforza does not distinguish among the objections, dismissing them all with the explanation: 'There are some people who hate biology. . . . Or they hate humanity' (quoted in Meredith F. Small, 'First soldier of the gene wars', *Archaeology*, vol. 59, no. 3, May 2006, 46–51 (51)). My own concern in this essay is with the specific critique of the biocolonialism of the HGDP and its offshoots.

The concerns raised by the IPCB are both cultural and socio-economic. Exploitation of resources, they argue, is not limited to financial profit. They also underscore a fundamental clash in world-view between Euroamerica and indigenous cultures that includes differences in spiritual beliefs and in the understanding of property. While it is not only across cultures that some of the practices associated with genomic research might constitute 'a violation of . . . cultural and ethical mandates',[64] Euroamerican scientists are less likely to understand the nature of those beliefs held by indigenous communities. And a difference in the conception of property complicates the consent that is requisite for research conducted on human subjects.[65] The IPCB maintains that 'the protocols, rooted in Euro-american thought, [that] assume that the individual has the right to sell or give away anything that is their own . . . is in conflict with indigenous notions of group rights'.[66] Certain kinds of knowledge may not be alienable in all cultures, or may belong to the group rather than to an individual. Differing conceptions of property are part of the particularly vexed history of Euroamerican and indigenous relations, since they were used to justify Euroamerican dispossession and colonization of indigenous peoples in the New World. The issue is especially relevant and pressing in genomic research, which is primarily concerned with information about the group rather than about individuals.

Critiques of the project have also questioned the motivation for expending resources on data collection—cell lines for a genomic museum—rather than on other kinds of aid to groups that might address the problems they face, as in the case of the Hagahai. The individualized health care that is the goal of genomic medicine is considerably more relevant for the health problems of Euroamericans than for many of the indigenous populations studied by the HGDP, in which people are dying from treatable diseases such as malaria and measles. The research itself, in so far as it widens the information and technology gaps between wealthy and impoverished nations and communities, can contribute to the social and economic inequities that have created the conditions that threaten the existence of these groups in the first place. The ostensible inevitability of tribal extinction with which the HGDP justified their research, for example, obscures the social and political causes of the problems faced by indigenous peoples—the worldwide inequities and their environmental expressions—that are not inevitable. The language of inevitability, in other words, can cloud the analyses of the problem and forestall the possibility of social change.

64 IPCB, 'Indigenous people, genes and genetics: what indigenous people should know about biocolonialism. A primer and a resource guide', June 2000, available on the IPCB website at www.ipcb.org/publications/primers/htmls/ipgg.html (viewed 21 July 2006).

65 Reardon, *Race to the Finish*.

66 IPCB, 'Indigenous people, genes and genetics'.

Cavalli-Sforza and his colleagues do not see how the revolutionary promise of biotechnology, and in particular population genomics, can exacerbate the racism, poverty and other structural inequities that they hope their research will help to abolish. One problem is that they do not acknowledge the impact of the stories through which their research is articulated. As a result, they continue unwittingly to reproduce the problems. Although they lost their federal funding and were forced to abandon the HGDP, it has been reincarnated, with funding from the National Geographic Society, IBM and the Waitt Family Foundation, in the Genographic Project, which was announced in April 2005, the same month in which Cavalli-Sforza's piece on the HGDP appeared in *Nature Genetics*. There have been some changes that register the effort to profit from the critiques—notably, the concerted attempt to involve representatives of indigenous communities more fully in the research project—but the basic contours and storyline of the project remain the same. Cavalli-Sforza, who chairs the advisory board of the new project,[67] continues to defend the HGDP, insisting that it was unfairly criticized and misunderstood, and other public relations ventures attest to an intention to market the present project more effectively to the general public.

Human history and the drama of genomic research

Among the most successful public outreach ventures is a documentary film, *Journey of Man: The Story of the Human Species*, directed by Clive Maltby and hosted by Spencer Wells, a former postdoctoral student of Cavalli-Sforza. The film, which premièred on PBS in January 2003, dramatizes the project of chronicling human history through genomic research. Wells offers rudimentary science lessons in which he explains how he and his colleagues have deduced human migration routes based on the frequency of genetic markers found in Y-chromosome DNA—hence the journey of *man*—as he follows the migratory routes that he posits. National Geographic meets the HGDP in this film, which features Wells's trip around the globe and his meetings with the members of indigenous groups whose DNA forms the basis of the study. In *The Journey of Man: A Genetic Odyssey*, a book published in 2002 as a companion to the documentary, Wells concedes that 'science can sometimes run roughshod over cultural beliefs' and offers his 'hope that this book might be a small step towards changing the field [of population genomics] into what it really is—a collaborative effort between people around the world who are interested in their shared history'.[68] Wells works to dramatize that collaboration in the documentary, but the language, images and

67 Small, 'First soldier of the gene wars', 51.

68 Spencer Wells, *The Journey of Man: A Genetic Odyssey* (Princeton, NJ: Princeton University Press 2002), xvi.

narrative of the film tell a story that in fact exemplifies the concerns of the anti-biocolonialism movement. *Journey of Man* demonstrates how unexamined assumptions can surface in the story through which genomic information is interpreted and presented.

The language of discovery dominates the film. The advertising copy on the DVD captures the tone in its summary of the film:

> There was a time—not so long ago—when the human species numbered only a few thousand and their world was a single continent: Africa. Then something happened. A small group left their African homeland on a journey into an unknown, hostile world. Against impossible odds, these extraordinary explorers not only survived but went on to conquer the earth. Their story can finally be told through the science of genetics.

It identifies Wells as 'part of a team that has been re-writing history. He has been disentangling this epic story from evidence all people carry with them—in their DNA—inherited from those ancient travelers'. Wells *disentangles* rather than *writes* that story, which means that he discovers a story that is already there. Early in the film, he pricks his finger, and the camera moves in for an extreme close-up of a drop of his blood, as Wells describes its content as 'the greatest history book ever written'. The story that Wells is telling is written in the blood and 'discovered' in Cavalli-Sforza's lab. Wells acknowledges neither that he is telling one among many possible stories about the data, nor that the Y-chromosome offers only a partial record of ancestry. He is not telling—and cannot tell—the whole story of human migration.

Wells consistently reiterates an explicit message of human connection, but a familiar developmental hierarchy pervades the language and images. The story he tells begins with the heroism and conceptual sophistication of the first group of modern human beings who left Africa. He explains that the audience of the film descends from them, while his story begins with 'the few survivors they left behind, the San Bushmen'. The visual and narrative features of the film implicitly construct the San as the relics from whom the rest of humanity has evolved, although Wells does not explain that the genomic data cannot definitively confirm that claim. The film freezes the San in genomic time, depicting them as the most direct biological link to—the 'brothers and sisters' of—the original people who made the journey, while 'we' (the audience) are the 'distant cousins' of both. By the end of the initial scene, Wells has begun to refer to the San as 'our living ancestors'. A visual refrain that punctuates the film underscores their role. With each new stage in the journey, Wells invites the viewer to 'walk in the footsteps of our ancestors'. The phrase is accompanied by the superimposed image of 'primitive' people, whose dress and bearing, as they have been established by the film, identify them as San. The monochromatic images are

elongated and distorted; the focus projects these diaphanous, spectral figures walking across beaches and deserts out of—and into—a mythic past.

Implicit in the image is the inevitability of their extinction: the ancestors must move on, leaving only the traces of their DNA in the genomes of their descendants and the laboratories of the HGDP in its subsequent incarnations. Modernization and cultural intermingling is recast in the film as a biological extinction that justifies the project as it underscores the impending extinction of the San people. 'Their numbers are dwindling', Wells intones. 'Soon they could be gone entirely. We came none too soon.' The proleptic nostalgia—nostalgia, that is, for a time that is not yet past—certifies as it laments their passing. Their way of life consigns them to a different—and a distant—time. One of the men in the scene thanks Wells for the information that he brings but, as the film makes clear, that information is only evidence of their inscription in a story for which they form the backdrop and in which their passing into myth seems almost to require their departure from the present. Their disappearance is intrinsic to the story that has already been written—literally—in blood.

While the collaboration that Wells espouses depends on a respectful integration of world-views, the film continually recasts indigenous and western knowledge as a distinction between story and science, and genomic knowledge emerges at the top of a hierarchy, as a corrective to the current wisdom of both indigenous tradition and archaeological evidence. Following 'the genetic trail' from Africa to Australia, Wells respectfully demonstrates the information that archaeology can reveal, but he shows its limitations when archaeology can offer no insight into how human beings first got to Australia. Next he turns to the oral culture of the Australian aboriginal songlines to see if there is any evidence of a migration, but the journey they describe does not originate in Africa. Only genomic information can definitively (as he represents it) chronicle human migration routes and tell the story of human history.

A low angle shot of Wells looming in the Australian desert embodies the perspective of the film. Where Wells means to enact collaboration, he consistently displays the explanatory superiority of his methods and his information, as in his interaction with Greg Inibla Goodbye Singh, 'an aboriginal artist from Queensland'. Singh's refusal to accept DNA evidence about his ancestors' African origins over the information in the songlines occasions Wells's performance of his sensitivity to the indigenous concerns and respect for an indigenous world-view. 'It's complicated to explain', Wells begins, simply and off camera. The focus remains on Singh as Wells explains that what he would like Singh 'to think about the DNA stories we're telling is that they are that: they are DNA stories. That's our version as Europeans of how the world was populated and where we all trace back to. That's our story line.' The camera begins to pan right as Wells slowly comes into view, continuing his explanation: 'We use science to tell us about that because we don't have the sense of direct continuity our ancestors didn't

pass down as stories.' Wells works hard in this scene to show his respect for Singh's tradition and even uses the analogy between the songlines and the DNA stories—which he calls the resurrection of 'a global songline' in his book[69]—to articulate his hope for collaboration. But his garbled diction betrays his discomfort with his explanation. To Singh he concedes: 'We've lost [the ancestral stories] and we have to go out and find them, and we use science, which is a European way of looking at the world, to do that.' Although he moves rhetorically towards an acknowledgement that his interpretation is one way of telling the story of descent, the film continually distinguishes between 'science' and 'story'. Singh's traditional *stories* lead him to question Wells's assertion that Australians originated in Africa, but Wells's *science* has established the truth of the claim.

While Wells speaks, the camera is still. He is shot in profile, looking, presumably, at Singh and framed by a large rock, some trees and a halo of light. Wells has already established the mystical pull of the land in a conversation with Roy Kennedy, a descendant of the Mungo people, whose affective knowledge makes the desolate site of an archaeological dig feel, in Wells's words, 'like home'. Kennedy confirms his deeply felt connection with the land, as the film displays the preparation and enactment of what is depicted as a traditional ceremony. In the terms of the film, Kennedy's sense of connection to a particular place is inscribed within the world-view of a backward-looking, ritualistic and static culture and implicitly distinguished from the mobility that characterizes western modernity. Although less forceful than Singh, Kennedy, too, insists on his belief that his ancestors are 'from here'.

Considering the critique of the IPCB, the interchange with Singh is crucial. 'You guys don't need that', explains Wells, referring to his research. 'You've got your own stories.' Singh readily assents, as Wells nods sympathetically. A cut to a close-up of Singh, who again strongly affirms his belief in the aboriginal oral tradition, displays his resistance. Wells responds, lamenting, over a cut to a shot of the ocean that dissolves into lab notes: 'This really isn't going very well. Tradition rarely sits well with cutting-edge science.' Relegating the songlines to 'tradition', he contrasts them with the certainty of science, which has established the pattern of migration. The remaining question is the routes human beings took when they left Africa.

'Let's go see if we can make history', Wells proposes, leaving the aborigines to their time warp and heading to India to find the 'elusive Australian marker' through which he claims that he can chronicle the route Africans took to Australia. He calls this marker—an allele present in Australians, but not in Africans—the 'missing link', a term he misleadingly transfers to the individual who carries the allele. Wells significantly over-simplifies the science of this claim, passing over other possible explanations

69 Ibid.

for the presence of the allele; his subsequent discovery of the 'missing link'—visually displayed by the face of the man who carries the allele—suggests that population genomics is rewriting the narrative not only of human migration, but also of human evolution.[70] These discoveries, in other words, constitute a scientific revolution.

Multiple migrations require Wells to choose how he will narrate simultaneous or overlapping migration events, but the language of discovery obscures those choices. Wells consistently reminds viewers that he is following the trail dictated by research, and he does not acknowledge the choices involved in researchers' interpretations of the data or in filmmakers' sense of the drama of the story. One such choice is evident when Wells introduces his own genealogy. At this point, his narration manifests the temporal tangle of population genomics, in which the language of relationality (the *family of man*) oscillates between connection and distinction. While 'we' are all descended from the San, Wells's *own* ancestors, he explains, are from Northern Europe. 'The story gets a little more personal here', he confesses, standing in a forest in France. The shift to the 'personal' brings a change in temporal focus. From the story of a connection to a distant past in Africa, it has become a story about a rupture from that past: the discrete population from which Wells descends *begins* in Northern Europe. Ironically, the personal connection to place brings him rhetorically closer to the point of view expressed by Kennedy and Singh, who insist on the origins of *their* ancestry in Australia. As Wells explains, his

70 Craig Venter makes a similar implicit claim in his recent project that retraces Darwin's routes while doing wide-scale genomic sampling of the flora and fauna. I am grateful to Robert Cook-Deegan for his timely and succinct explanation of the possibilities that Wells does not allow, including the possible mobility of the ancestors from whom the individual inherited the allele, the uncertainties of ancestry (unknown liaisons in more recent history between individuals of different ancestry), even new and coincidental mutations. The story Wells tells, in other words, is one among a range of possibilities. A scene in the film that features Wells's meeting with another of his 'missing links', this one from Central Asia, demonstrates the slipperiness of the language. Wells reports his discovery of an 'ancient marker'—or 'spelling mistake'—that chronicles the ancestry of Europeans in Central Asia, which he calls 'the nursery of mankind'. The term 'missing link' superimposes one kind of evolutionary narrative on to another and turns the man in question—not just his ancestor—into the missing link. The use of language in this scene is misleading for viewers unfamiliar with the science. 'Missing link' suggests a prior stage of evolution in common parlance. Wells potentially creates further confusion when he refers to the man as a 'genetic giant in history', as though the accident of his genetic lineage is an achievement. The information his blood gives to the researchers makes him special, and Wells congratulates him repeatedly on his 'very important blood'. Nor does Wells correct him when, in response to his explanation of the 'meaning' of this marker, the man smiles, thanks him and observes, 'that means my blood is pure'. No one with even a passing familiarity with the language of eugenics could fail to hear a chilling resonance in the discussion of the purity of blood, and it is surprising that Wells chose to leave the comment in the film without any correction or explanation.

ancestors represent a small branch of the tree. While not inconsistent, the alternative temporalities represent two different ways of telling the story of descent. The narration literally *makes* the difference, and Wells unwittingly slips back and forth between them.

With the move to Northern Europe, the film becomes increasingly self-conscious about the science of 'race' and phenotypic distinction. The scene initiates the greatest concentration of scientific 'experts', talking heads who detail the climatological changes that probably motivated the migrations and explain the evolutionary selection behind the mutations that resulted in a change of skin colour and body type. Against a black-and-white (mythic) background in which a dark-skinned 'native' is engaged in spearfishing, Wells notes that geological changes attendant upon the Ice Age isolated this population, resulting in distinctive alterations in such features as hair colour, height and nose shape: features, in other words, that are traditionally associated with 'race'. Subtly, but deliberately, the film offers this scientific explanation of phenotypic difference in response to the charges that this research fosters racism. But the visual and narrative logic of the film undercuts those intentions, as it reaffirms a developmental narrative of ancestry.

The scientific explanations culminate in a French village where a group of men is playing boule. 'Today', intones Wells in voice-over, 'people with European ancestors, like me and these French boule players, look pretty different from our distant relatives'. A series of frames featuring representatives from several of the indigenous groups he has been tracking follows to illustrate the differences. These people, all contemporaries, become the 'distant relatives' of Wells and the French boule players in the logic of the film. The most obvious difference, of course, is skin colour—the film presumes that the audience will all see physical resemblance in the same way—and, while Wells does not use the term 'ancestor', the film has already established the visual vocabulary of a developmental hierarchy and a temporality that is summoned by the photographs of these 'primitive' peoples. During the display of this series, moreover, Wells explains the dramatic change in life skills that transpired as 'our ancestors' made the long and arduous journey to Northern Europe.

The ambiguous phrase 'our ancestors' has by now come to mean the immediate forebears of Europeans, and his invocation interpolates his presumed audience in that group. A close-up of the boule playing, a leisure activity that marks an advanced civilization, suggests a comparison with the ritual activities in which the indigenous groups depicted in the film are engaged. Once again the indigenous groups featured in the film become the living ancestors who herald human development in the West. The scene in the French village is in fact a scientific detour, and temporal forecasting, in the narrative of the film; the genetic trail follows the more 'isolated populations' of 'indigenous' groups, and Wells moves back to Central Asia

where he again picks up the genetic trail that eventually culminates in Canyon de Chelly, a sacred site of the Navajo people.

In the penultimate scene of the film, Wells stages the collaboration he has been promising throughout. The IPCB critique looms over the meeting with the representatives of 'an ancient tribe', the Navajo. A conciliatory Wells concedes that he 'wanted to tell them about the genetic trail that had led [him] to them, but [he] soon learned that they had migration stories of their own'. Letty, the one woman in the scene, and the only female 'indigenous' interlocutor in the film, greets him with the assurance that 'we are glad to share our *information* about our place here'. She stresses the word 'information', and it is repeated several times in the scene. But Wells's chief interlocutor is Phil Bluehouse, whose advocacy of a return to Navajo traditions in issues ranging from Navajo law enforcement and medicine to environmental restoration has made him both a celebrity and a logical representative in the Navajo community. Bluehouse picks up the challenge that Greg Singh, the Australian aboriginal artist, had also issued, when he questions Wells's use of the word 'myth'. 'Why do you call something that a people tell you a myth as opposed to an experience that they had and relive . . . over and over?', he asks. *Myth*, he explains, is a 'substandard event that does not have any relevance'.

This moment stages the most direct and pointed challenge to Wells that anyone has offered. Where Singh had insisted on his belief in the aboriginal story of origins, Bluehouse turns the focus on Wells, calling attention to his language and the point of view it betrays. The question asks Wells to consider stories as experiential and important to collective identity rather than simply as evidence of uninterrogated belief systems. It underscores the discrepancy between the language of 'story' and 'creation' through which Wells explains his research and the framework in which he actually understands it. But Wells does not follow through on the insight, responding, as he has throughout the film, with the explanation that he is a scientist and he relies on 'evidence'. For him, the struggle is between science and myth, and he does not consider the formative power of stories: that he, too, is a storyteller whose 'information' reflects the choices he has made in the interpretation of his data. While he politely acknowledges Bluehouse's objection that 'myth' is a dismissive term, his self-congratulatory voice-over—'I'm getting pretty good at this'—suggests that the scene is not included as a moment of introspection or collaboration, but as a demonstration of the superiority of scientific explanation. Bluehouse does not contest the science, the evidence or the conclusions of Wells's story; he challenges his language. Wells does not hear the difference, and that is precisely the problem with the film.

Bluehouse, however, accepts the explanation, and his acquiescence marks indigenous support of the project. The scene turns on his eager response to Wells's claims about the genetic lineage of North American indigenous peoples that leads from Central Asia to the Americas. 'Looking at a book

from people from Central Asia', Bluehouse quips, 'I saw my cousin Emmett and Abraham and Auntie Grandma Buggs, and I said, ''My God, I got family over there in Central Asia.''' It is Bluehouse, rather than Wells, who ultimately makes the point 'that somehow we're finally . . . acknowledging one another from the scientific realm and the traditional realm'. The ostensible response to the IPCB critique, in other words, comes in the final words of a Navajo man, who tacitly reinforces the point of the film and of the renovated diversity project.

'A desire for cultural privacy, perhaps combined with the suspicion that the scientific results may not agree with their own beliefs', acknowledges Wells in his book,

> is leading more and more indigenous groups to choose not to participate. Scientists have a responsibility to explain the relevance of their work to the people they hope to study, in order for their participation to become what it really is—a collaborative research effort. Only then we can regain some of the trust we have lost.[71]

The documentary registers the efforts of Wells and his colleagues to regain that trust by including representatives of indigenous groups, such as Bluehouse, in their research and by demonstrating their sensitivity to cultural differences. Bluehouse, in fact, has since become a representative of indigenous communities that are participating in the Genographic Project and, in that capacity, attended the public ceremony in Washington, D.C. at which the project was launched. Yet, the IPCB remains unpersuaded; in a press release issued shortly after the announcement of the project, Executive Director Debra Harry called it a 'recurrent nightmare'.[72]

Race as proxy

Journey of Man ends with the familiar anti-racist message about a 'lesson' that 'stands out from all the others. It's a lesson about relationships', Wells observes, against the backdrop of a multiracial group of young adults that resembles (and might be) a photo shoot for a Benetton ad.

> We're all literally African under the skin, brothers and sisters separated by a mere 2000 generations. Old-fashioned concepts of race are not only socially divisive, but scientifically wrong. It's only when we've fully taken this on board that we

71 Wells, *The Journey of Man*, 195.

72 Quoted in 'Indigenous peoples oppose National Geographic & IBM genetic research project that seeks indigenous peoples' DNA', IPCB press release, April 13, 2005, available at www.ipcb.org/issues/human_genetics/htmls/geno_pr.html (viewed 22 July 2006).

> can say with any conviction that the journey our ancestors launched all those years ago is complete.

Against this message, however, is the familiar language of inevitable extinction that accompanies the affirmation and urgency of the project. Fifteen years ago, Wells explains, from within a Mardi Gras crowd in Rio de Janeiro, depicting globalization and human mixture, scientists lacked the technology to conduct this research and the story could not have been told.

> But, in this era of globalization, isolated populations are being absorbed at an ever increasing rate. It's possible that by the end of the century that [*sic*] genetic signposts of our journey will have been disbursed around the globe. When this happens, the story will once again become hidden.

Globalization, in this formulation, bleeds into cultural extinction; Wells posits a temporality in which 'indigenous' becomes synonymous with ancestry, and the problems of indigenous communities are cast in terms of cultural preservation rather than racism, poverty and disease. Wells and his colleagues are evidently unaware of how this story perpetuates a particular world-view: how it expresses who and what should be valued and how they should be valued, how resources should be allocated, who will have access to those resources and for what purposes. The story Wells tells in the film is an interpretation; it registers choices about what information will be relevant in determining someone's genealogy, such as the decision to locate the origin of his specific ancestry in Northern Europe. According to the narrative of the film, western civilization has developed ineluctably, and indigenous peoples, in the inevitable and unalterable course of things, become extinct—or pass into the western audience's ancestry. So it is written in the genes. What this account obscures, as I have noted, are the social determinants of development, including the health disparities that evince not the inevitable expression of cultural and biological difference, but the impact of social and economic inequities. Wells's story is written in the language of unacknowledged power as much as genes, and it exemplifies the problem that the organizers of the Howard University symposium underscore as their motivation: that the careless rendition of the genomic story, whether told through medicine or human history, will obscure the social, political and economic sources of outcomes—including health outcomes—and thereby put them beyond investigation. It will, that is, biologize (and naturalize) outcomes that could in fact be addressed and changed.

The sincerity of the scientific refrain that racism has no scientific basis and that scientific racism can be forestalled by explaining the science to the public is apparent. But, as the story of *Journey of Man* makes clear, racism is much more complicated, and much more intricately interwoven in the language, images and stories—the representational conventions—that have

developed with centuries of oppression. The histories—or stories—embedded in our most basic communications are as complex and difficult to understand as the science. They register (and foster) assumptions that inevitably become part of genomic information, from the definition of what constitutes data and the practices through which it is collected to the narratives through which it is interpreted and applied. Health care disparities are the result of many factors, some of which can be rectified by research in genomic medicine. But the narratives that inform the science and its applications can perpetuate the very inequities they seek to address.

The stories about ancestry that emerge from population genomics can be incomplete and misleading. Yet they inform many of the assumptions through which researchers constitute self-identified race and ethnicity as proxies in the practice of genomic medicine and can therefore influence the screening, diagnosis and treatment of medical conditions. The language of urgency permeates the stories and forestalls introspection: if race and ethnicity can provide useful medical information, it is 'irresponsible' not to consider them; if indigenous populations are disappearing, we cannot waste time deliberating about the ethics of DNA sampling. The urgency obscures the disagreements surrounding the science as well as the lack of clarity concerning the motivations of the project, and it reinforces the hierarchy of knowledge. It puts the stories beyond question. It also conjoins—and recombines—the fields of medical and population genomics; the medical imperative turns the impending occlusion of the genetic trail into an apparent loss of valuable medical knowledge.[73] Yet the urgency of the two fields is in fact at odds: if population intermingling and racial admixture are becoming the norms, then how useful will self-identified race and ethnicity be as medical proxies?

Genomic stories have thus reconstituted the biological basis of race as a central question in scientific research and public discussion at the moment when, according to population geneticists, cultural and reproductive intermingling are recombining genomic profiles at unprecedented rates, hence the threatened 'disappearance' of some genetic markers. Wells calls DNA a 'global songline' and refers to his account as a 'creation story' of western science. Throughout *Journey of Man*, he seeks to replace indigenous accounts with his own migration story, which the loss of 'ancient' markers threatens to obscure: that is the story he is concerned about losing. Against the reproductive intermingling that will reshuffle the DNA of all contemporary 'races' and 'populations', *Journey of Man* could be read as a Euroamerican creation myth written against a perceived threat to the 'racial' integrity and power of (white) Euroamerica.

73 It is interesting to consider how this formulation reproduces the ecological concern that the disappearance of the rain forest will result in the loss of plants with important medical properties. 'Indigenous' DNA, in other words, becomes part of the flora and fauna of the disappearing ecosystem.

That is not, of course, the story Wells and his colleagues intend to tell, but stories, like genes, can be both inherited and mutable. The scientific and public accounts of genomic medicine and human migration risk infusing the genomic creation story with the authority of science and the history of racism. As epistemological technologies, these stories inform the collection and interpretation of data. Reintroducing the biology of race without attending fully to the history of racism is therefore as irresponsible as uncritically dismissing the research. Francis Collins calls for 'more anthropological, sociological and psychological research into how individuals and cultures conceive and internalize concepts of race and ethnicity'.[74] The 'individuals and cultures' under consideration must include the practitioners of western science, and they must consider their cultural investments in their own creation stories.[75] The enquiry needs to begin with an understanding of how the intricate interarticulation of cultural and biological identity is central to health outcomes. Incorporating analyses of these stories—and, specifically, of racism—directly into genomic research is not only ethically and politically correct, it is also good science and medicine.

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74 Collins, 'What we do and don't know about ''race,'' ''ethnicity,'' genetics and health at the dawn of the genome era', S14.

75 Collins follows this recommendation with another that calls for researchers to 'assess how the scientific community uses the concepts of race and ethnicity and attempt to remedy situations in which the use of such concepts is misleading or counterproductive' (ibid., S15). As I have been arguing throughout this essay, such an examination of vocabulary and other representational practices is crucial, but genomic researchers need to understand the problem as more than one of vocabulary and miscommunication. Cultural assumptions and biases are embedded in and perpetuated by the tools of communication, and western societies must be understood as 'cultures' with their own sets of beliefs and practices. The recent move in anthropology that has made it increasingly acceptable to do fieldwork in one's own culture marks an important turn; the laboratories of researchers, in fact, have increasingly become sites for anthropological fieldwork.