Introduction

Race and Genetics in a Genomic Age

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One specific, unified message accompanied the official announcement of the completion of the Human Genome Project: human beings are essentially the same. Human genetic sequences are 99.9% identical; of the 0.1% of the human genome that varies from person to person, only 3% to 10% of that variation is associated with geographic ancestry (Feldman and Lewontin, this volume). This message was nothing new—for decades, the finding that there is greater genetic variability "within groups" than "between groups" had generally been accepted as evidence that the human species is not divided into discrete races. Geneticists publicly interpreted these results as disproving a biological race concept and voiced their hopes that such scientific findings might help deflate racism. Throughout the second half of the 20th century, most historians, social scientists, and race theorists followed suit, affording biology little status in theories of human difference (Fredrickson, 2002). With the advent of the Human Genome Project, race scholar Paul Gilroy (2000) was even inspired to imagine a future in which race would become obsolete as attention shifted from the body politics of skin color, hair texture, and eye shape to the molecular-level biopolitics of the gene. Contrary to these expectations and hopes, post-genomic science has revived the idea of racial categories as proxies for biological differences. In a recent series of papers, population geneticists argue that the genome holds the key to medically and forensically significant biological differences among human racial and ethnic populations. Increasingly, genetic variation among human populations—races, ethnicities, nationalities—is an object of keen biomedical interest.

Revisiting Race in a Genomic Age documents two years of intensive interdisciplinary conversations on race and genetics at Stanford University. From 2003 to 2005, the workshop "Revisiting Race in the Context of Emerging

Genetic Technologies" hosted a series of discussions that examined how race is revisioned through the lens of emerging genetic findings. Recognizing that the dynamic social meanings of race and the rapidly changing reach of genetic technology outpace the resources of any single discipline or observer, the workshop provided a forum for structured interdisciplinary dialogue. Population geneticists, philosophers, physicians, sociologists, psychologists, historians, legal scholars, and anthropologists shared their research and worked to generate new vantage points from which to interpret and analyze human genomic research on race. The workshop took up a range of questions, including the following:

- Does the global pattern of human genetic variation uncovered by emerging DNA technologies correspond to racial categories as traditionally understood?
- How will understandings of race change as more precise, complete, and predictive genomic information becomes available in the future?
- What ways of describing, categorizing, and communicating about samples collected in the course of human population genetic studies minimize reification of racial categories?
- How might genetic analysis of race, including commercially available genetic ancestry tests, affect notions of personal identity and understandings of social group membership?
- In light of health policy goals to eliminate race-based health disparities, what social harms and benefits arise, or might arise, from research linking racial ancestry with genetic information?
- What are the conceptual tools and interdisciplinary arrangements necessary to interpret emerging genomic research on race?

In 2006, workshop participants returned to Stanford to discuss individual papers in preparation for this volume. In the spirit of interdisciplinary dialogue, humanists, social scientists, and natural scientists were assigned to critically discuss a paper from outside of their field. The chapters in this volume represent the outcome of this three-year experiment in interdisciplinary exchange and register the approaches, questions, and issues that surfaced in the course of this intensive survey of new research on race and genetics.

Why Revisit Race and Genetics Today?

"Race Is Seen as a Real Guide to Track Disease" announced a 2002 *New York Times* article, reporting on a new paper by Risch, Burchard, Ziv, and Tang in

Genome Biology. In that paper, Risch and colleagues argued that genetic differences among populations cluster into five major groups corresponding to a "classical definition of races based on continental ancestry" and boldly made the case for the "validity of racial/ethnic self-categorization" in genetic epidemiology research (2002). In challenging the seemingly unified chorus among scholars and scientists that race is not rooted in human genes, the paper was a pivotal event in redirecting the emerging discourse on race and genetics. It was followed eight months later by a *New England Journal of Medicine* paper (Burchard et al., 2003) that not only advocated the use of race in human genetics research but framed its necessity in terms of the public policy goal of mitigating health disparities among racially identified populations.

The vigorous reassertion of the coupling of race and genes, once seen as antiquated, accompanies the shift of human genetic variation research into the genomic age. The new research revives old debates and polarities over the existence of a biological basis for race. But the new genetic race concept is importantly different than its predecessors; so too is the context of the debate. Race in a genomic age raises new and challenging social, political, and ethical concerns, and, we believe, new opportunities for dialogue. Four distinctive developments distinguish the current debate over race and genetics from its predecessors.

First, the completion of the sequencing of the human genome in 2001 commenced the "genomic" age, instituting a shift from relatively limited gene hunting research to whole-genome analysis. Confronted with a vast pool of largely undifferentiated genomic data, researchers must then find ways to make sense of it. As many commentators have noted, much of the new genomics is non-hypothesis-driven. Researchers query the human genome seeking distinctions and patterns as leads for further research. The data derived from the human genome, like any large, multidimensional database, can be probed, inscribed, and organized in various ways. Race has rapidly become a prominent "search tool." Intensive work of this sort has resulted in the identification of slates of genetic markers common within many racial and ethnic populations. These markers may be useful for diagnostic and etiological research for genetic diseases that show different frequencies in different populations. These carefully constructed, racially inscribed sets of markers in the human genome, however, may then become a point of reference for further research, as the data are analyzed and transformed for use by specialists beyond the fields of their creators. Used uncritically and outside of context, these race-inscribed categories may become naturalized, reified, institutionalized ways of conceptualizing the human genome, with serious implications for all subsequent human genome research.

Second, academic race and genetics research is now entering the marketplace. As several contributors document in this volume, race and

genetics research increasingly occurs in a corporate context and is driven toward market applications. There is tremendous financial incentive to package "race" as a genetically underwritten commodity. Pharmacogenomics, genetic genealogy services, and forensics are prominent areas of corporate crossover for academic human population variation researchers. Academic researchers concerned to ameliorate racialist interpretations of their work, for example, by using the term "ancestry" instead of race, nonetheless slip into the language of race in their commercial work. The slippage is transparent and inevitable as human population variation research hits the marketplace. The development of proprietary databases and methods for human population variation research raises further concerns about the soundness of the scientific claims underlying this work and poses a challenge to the self-policing scientific standards of the field.

Third, with the increasing specificity and range of claims about racial ancestry made possible by genetic genealogy services, and inexpensive public access to genetic testing via the Internet, research on race and genetics now enters the politics of identity. Recreational genetics introduces new and challenging frontiers in racial identity formation; as such, it also raises distinctive bioethical questions. Testing services, like any commercial venture, sell both a product and a desire for the product. Marketing literature is laced with the discourse of racial purity and racial mixture, as well as constructs such as blood, kinship, ancestry, and homeland. The implications are as yet unclear. Genetic testing may serve to complicate notions of racial purity or to build them up. As ancestry testing becomes cheaper and more widespread, new configurations of racial and national identity may emerge. At the policy level, genetic race verification services have potentially serious implications for community concepts of kinship and nationhood. In the case of entitlements that are tied to race, such as affirmative action, genetic ancestry testing may inflame long-standing debates about eligibility and the social recognition of race as a class. In all of these areas, the technology of biological race verification will change the terms of debate and analysis.

Finally, today genetic research on race increasingly takes place in a medical context. Throughout much of the 20th century, human population variation genetics was most closely associated with anthropological efforts to reconstruct the history of human migration. This research succeeded in offering impressive corroboration for the "out of Africa" hypothesis of human colonization of the globe and demonstrated the association between time, geographical distance, and genetic variation. In a departure from this anthropological context, today the goals of "personalized medicine" and alleviation of "health disparities" drive social investment in genetic research on human population variation. Research on genetic variation among racial populations is widely pursued as a stepping stone to a future goal of therapies tailored

to individual biogenetics, or personalized medicine. Pharmacogenomics, or the search for genomic markers that may help physicians determine safe and effective drug dosage, is the first likely application of personalized medicine. As the pharmaceutical industry seeks marketable technologies to patch over an unexpected post-genomic drought in medical breakthroughs, pharmacogenomics has become a particularly attractive investment. Converging with this trend, increased government interest in alleviating health disparities, which often fall along racial lines, has also directed resources toward research on genetic differences among races. While the discourse of health disparities once focused primarily on differences in health outcomes and access to quality health care, health disparities now fuels investment in research, for instance, on the genetic causes of asthma among African Americans and Hispanics. In the pharmaceutical industry, the promise of remedying health disparities has also been used to lend a politically correct image to efforts to market drugs or genetic tests to racial subgroups. The twin emphases on redressing health disparities and individualizing health care shields race and genetics research from appearing fringe or retrogressive as it once might have. A result is new and unpredictable political alliances around race and genetics, calling attention to the need to appreciate the specificities of the political-discursive context of this research today.

Volume Overview

This volume is designed to be an accessible, comprehensive, interdisciplinary resource on contemporary human population genetic variation research in the United States. The book has four sections. Part 1 offers a general introduction to the history, methods, and key analytical concepts of race and genetics research. Part 2 focuses on race-based therapeutics and the uses of human genetic variation research in clinical practice and drug development. Part 3 treats commercial genetic ancestry tests, examining the methodologies and social implications of this technology. The final section addresses the impact of emerging race and genetics research on public policy, the media, and public discourse at large.

Part I: Concepts of Race

Part 1 provides an overview of key concepts in the race and genetics debates. These chapters introduce the intellectual history of debates around race and biology and characterize the different ways that sociologists, biologists, and philosophers conceptualize race. This opening section makes clear what is at stake in the recent resuscitation of the race and genetics debate. New research challenges old framings of the debate, stretches the boundaries and assumptions of race and ethnic studies, and forces the clarification