

THE INFORMATIONALIZATION OF RACE:
COMMUNICATION TECHNOLOGIES AND GENOMICS IN THE
INFORMATION AGE

by

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Table of Contents

Acknowledgements	ii
Abstract	viii
Chapter 1: Introduction	1
Research Questions and Rationale	7
Methodology	11
Makeup of Interviewees	14
Makeup and Analysis of Textual Data	15
Chapter Overview	16
A Brief Introduction to the HapMap Project and Genomics	18
Chapter 2: The Informationalization of Race: Communication Technologies and the New Conditions of Racialization	25
Race, Racialization, and Colorblindness	25
From Race Relations to Racial Projects and Racialization	27
Beyond Black and White: Racial Triangulation	33
The New Racial Order: Colorblindness	35
Central Frames of Colorblindness	39
The Information Age and New Media Technologies	43
Race and Technology	54
The Information Society, Critical Race, and Science and Technology Studies	57
The Informationalization of Race	62
Conclusion	67
Chapter 3: Technogenomics: The Digital Shaping of Biology and the Rise of the Database	69
From Analytics to Synthetics, From Wet to Dry Labs: Biology Becomes an Information Science	73
Data Mining the Code of Human Life	83
Databases, dbSNP, and the DNA Banking System	85
HapMap Databases and the Turn to Difference	91
The Role of the Internet in Networking Knowledge Production, Open Access to Data, and Informed Consent	96
Networking and Distribution	96
Genome data as a public good: Democratizing the data through the public domain	102
Techno-consent and community engagement	106
Conclusion	110

Chapter 4: The Legal and Institutional Formation of Biotechnology and Genomics, 1977-2004	112
The Legal Signal for the Commercialization of Biotechnology:	
<i>Diamond vs. Chakrabarty</i>	116
Deregulating University-Industrial Relations	118
Conflict of Interest Policies in biomedical and Science Journals	120
Color Consciousness in a Time of Colorblindness: OMB Directive 15, NIH Revitalization Act of 1993, and Editorial Policies on Race and Ethnicity	123
OMB Directive 15	125
The NIH Revitalization Act of 1993	131
Editorial Policies on Race and Ethnicity (EPRE), 1991-2004	134
Conclusion	146
 Chapter 5: Discursive Formations of the Informationalization of Race: Race Talk in Genomics and the HapMap Project	149
Definitions of Race in Genomics	157
Planetary Humanism	161
Out of Africa: The Single Origin Story	162
We are All 99.9% the Same	164
The Within/Between Debate	165
Does Race Exist?	166
De-Racializing the Genome: From Proxy to Precision	172
Strategic Essentialism	177
Colorblind Talk in Genomics	181
The Turn to Racial Realism	185
“I am a Racial Profiling Doctor”	186
Misinterpretation of the Data	189
Conclusion	191
 Chapter 6: Conclusion	194
Race and the Work of Information in the Age of the Digital Database	199
The Informationalization of Race: A Cultural Theory of Technology and Identity	204
 Bibliography	207
 Appendices	
Appendix A: Models of Racial Discourse	233
Appendix B: Code for Interviews	234

ABSTRACT

As a mode of representation, a structuring device, and as a biological category, race is undergoing a significant transformation in the digital age. This dissertation shows how a new form of racialization is being produced through developments and innovations in communication technologies. Increasingly, racial knowledge is being constructed from seemingly neutral and unrelated pieces of information, which are collected, sorted, analyzed, and accessed through two key technologies: databases and the Internet. I call this interaction between technology and identity the *informationalization of race*. Race as information develops from race as the body and race as culture. To understand how this new formation is emerging through the social shaping of new media technologies in a specific institutional setting, I conduct organizational, political economic, and discourse analyses of the next Human Genome Project, the HapMap Project. Advances in human genomics has recently re-invigorated scientific research into the relationship between race and biology. Where the HGP concluded that humanity is similar at the genetic level, the HapMap Project began by looking for differences between racialized groups. The findings from the HapMap project have been promised to help in developing pharmaceuticals that can target common diseases, such as cancer. However, this development also opens the door to old biological conceptions of race and a new phase of the biopolitics where biology, technology, and information converge on the human body.

Chapter 1

Introduction

Something is happening to race.

(Fausto-Sterling 2003:1)

In our time – at the end of the twentieth century – the crisis of race in America is still raging... In this age of globalization, with its impressive scientific and technological innovations in information, communication, and applied biology, a focus on the lingering effects of racism seems outdated and antiquated. The global cultural bazaar of entertainment and enjoyment, the global shopping mall of advertising and marketing, the global workplace of blue-collar and white-collar employment, and the global financial network of computerized transactions and megacorporate mergers appear to render any talk about race irrelevant.

(Gates and West 1997:68)

Three independent processes emerged in the 1970s that would converge on the most microscopic level of human life: one social, one technological, and one scientific.

The Civil Rights Movement challenged and changed fundamental assumptions about the organization of society and the meaning of identity. The protests and acts of civil disobedience of the 1960s that characterized the movement fought for and won political participation for African Americans and other minorities with the signing of the Voting Rights Act of 1965. Along with this landmark legislation, the Civil Rights Act, the Fair Housing Act of 1968, and the Supreme Court's 1967 ruling on *Loving v. Virginia*, which ruled anti-miscegenation laws unconstitutional, ushered in a new era of social organization. The movement for racial equality shifted from issues of political participation to issues of access to education, workplace discrimination, and representation in the 1970s. The focus for action shifted to other social structures, such as busing programs and affirmative action, and culture, such as changing the

portrayal of blacks and Asians in the media, in an effort to further challenge systemic racism. The end of the civil rights movement signaled a shift, but not an end, in the organization of race and expression of racism in society. The prevailing racial paradigm began to change from a society structured in dominance and Jim Crow to an ideology of colorblindness. While the first process attacked an old social system, the other two sought to build something new.

The second trend that emerged in the 1970s was the creation of a new technological paradigm in information and communication technologies that was the cumulation of a number of technological discoveries that were independent but fed back and built on one another. The key technologies were the microprocessor, the microcomputer, telecommunications, and software, each clustering with another. Advances in each technology made possible further advances in others. For example, the microcomputer was made possible by the microprocessor. The computer also relied on developments in telecommunications to facilitate its networks, making them more powerful and flexible. Many of the individual developments are all parts of computing and digital technology that we largely take for granted today. When this new communication system came into existence through the diffusion of computers and information networks in all levels of business, government, education, and the home, its shaping and diffusion was dependent on the cultural, political, and economic historical context. These new technologies and their diffusion and contribution to the organization of society are to the information age like electricity was to the industrial revolution.

Advancements in genetic engineering instigated the third process. Equally as revolutionary, it has parallels with the new information technology paradigm as it took place in similar locations, such as the Silicon Valley, Maryland, the research triangle in North Carolina, and the Boston/Cambridge area. The discovery of recombinant DNA (rDNA) technology in 1973 transformed the biological sciences from an analytical to a synthetic science and began the material development of genetic engineering (Krimsky 1999). This began the shift to molecular genetics and genomics that was aided by the use of computers to analyze sequence data (Galambos and Sturchio 1998; Mackenzie 2003). Scientists could see and conceptualize the human body in new ways and begin to map and manipulate the very building blocks of life. These three different trajectories have been converging in the last fifteen years and are productive of a new model for constructing racial difference.

The relationship between identity and technology is transforming at a time when a new understanding of the racial order is pervasive in society. Scholars began referring to the change from overt racism of the Jim Crow fashion to coded and covert forms of racial inequality as the new racism (Barker 1982). More recently, the concepts of color blindness (Wellman 2003), “laissez faire” (Bobo et al 1997), and color blind racism (Bonilla Silva 2001) have been used to characterize the cultural and structural changes in the racial system since the 1970s. This dissertation extends the arguments made by Bonilla Silva (2003), Gray (2005), and Collins (2005) and suggests that the ideology of color blindness has converged with the changing organization of society due to globalization, the emergence of the information

society, and the evolution and diffusion of ICTs. This convergence is productive of a new form of racialization. Race is being re-constructed around codes that do not necessarily depend on the epidermal body or culture, the traditional markers of racial difference. Instead, the social construction of race is becoming a process where information is the material by which social, economic, and political meaning is worked on. Racial identity, meanings, and structures are being created in terms of information collected, stored, analyzed, and distributed through the use and shaping of communication technologies. I want to suggest that the new interaction between culture and technology in the making of racial identity can be understood as the *informationalization of race*.

Informational processes have been integrated across commercial, governmental, and personal spheres of society. When society undergoes fundamental changes, deep-seated aspects of its structure like race and racism require examination. This is especially needed when the rhetoric of change, typical of the information age, is so widely heralded as progress for all. Future studies need to assess the ways in which traditional social institutions that have a history of discrimination, such as insurance and law enforcement, have adapted to the current historical context and identify new and emerging areas, such as online business. This dissertation examines the specific mechanisms and manifestations of the informationalization of race in the production of scientific and medical knowledge and its applications through an analysis of the technological, institutional, and cultural changes in human genomics.

Media scholars have argued since the 1970s that the media's relationship to power is not one of a reflective representation (Hall 1980; Morley 1980), but a constitutive element of social institutions and cultural practices. Rather than being accurate or inaccurate portrayals of the social world, the media plays an integral role in the making of social life. In a similar vein, information and communication technologies are not neutral conduits of scientific 'discoveries' and economic practices. Their stories frame our perceptions and actions. ICTs are embedded in our everyday lives and societal institutions and their contributions need to be understood as directly contributing to how we know, organize, and act in the world. While scientists argue over the accuracy or inaccuracy of scientific data, which is the outcome of computational routines, we might back up and examine how those outcomes stitch together cultural assumptions, molecular particles, microprocessed bits and bytes, and historical context. The informationalization of race is indicative of larger developments in the formation of the information society where qualitative and quantitative changes in the management, organization, and manipulation of information have been taking place since the 1970s. This is in no small part to the new technological paradigm that began in the 70s with the development of communication technologies.

My task in this dissertation is not to determine the veracity of scientists' assessment of the structure and function of the genome or whether or not 'race' exists at the molecular level. These sorts of assessments are not the domain of the social researcher. This is similar to the media scholar who is not in the business of assessing whether or not the images the media constructs are true or not true, but

how they constitute cultural frameworks for interpreting the social world, enabling and constraining human action, and allocating society's resources. Genomic science is constructing representations of the human body, race, and the natural versus the social. My aim is to explain how ideas about race and the genome are produced, circulated, and (dis)agreed upon. Claims such as "We have the structure but no meaning yet" (Lander in Marturano 2003:208) of the blueprint of life, the human genome, do not take into account the cultural power of genetics. Even scientific knowledge of the genome is *a priori* as scientists engage in framing the nature of their work in the early stages. Knowledge about the significance of the human genome pre-dated the first draft. The genome as an object of knowledge was constituted in early discussions about what possibilities its 'discovery' could hold. Whether by convincing the U.S. government to grant funds or attracting venture capitalists to invest in Celera, the competing private firm in the Human Genome Project, stories about the value of genome research had to be deployed. These stories are imbued with cultural, scientific, and economic meaning. In US society, where the gene has become a powerful (global) icon, genetic explanations for phenomena as disparate as cancer and men's proclivity to cheat on their partners have come to occupy a primary position in the popular imagination as well as scientific facts (Lee 2003; Nelkin and Lindee 1995). The twentieth century has already begun to look like the century of the genome.

In order to understand how the genome and race are being articulated we need to examine the technological, regulatory, and discursive infrastructures that enable and constrain genomics. Through the domain of science and the case of

genomics and the HapMap project, I argue that the informationalization of race is the result of the convergence of these three elements: the role of technology in the re-organization of biology, the legal and institutional development of human genomics and biotechnology, and discursive formations of genomics and race. Taken together, a new picture of racialization in this century emerges. At the heart of this shift is the new technological paradigm that includes innovations in databases, data mining, and the Internet, the industrialization of scientific research, and the dominant racial paradigm, color blindness. The construction of difference is produced from the shaping of new communication technologies in the network age.

Research Questions and Rationale

The dissertation examines the role of communication technologies in the management and manipulation of information and how the process of sorting people is productive of social identities and, specifically, new modes of racialization. The technologist, policy, and market proposition has been that the information revolution will liberate society from discrimination. Instead, this dissertation argues that there is occurring a deepening of social practice in terms of the material and symbolic construction of racial difference and racism. Increasingly, scholars have been urged by the rapid and escalating development and innovation of new information and communication technologies to examine how social processes and actors shape them for the purposes of individual expression, community building, political participation, social control, and resistance. By far, the technology literature tends to address critical questions of social power along the lines of Jurgen Habermas (1962,

1989), Howard Rheingold (1994), and Robert Putnam (2000). While these authors address issues of the public sphere, community, and civic participation their work, which represents the mainstream of academic and public discussions, technology scholars who follow their arguments tend to ignore how the social shaping and use of communication technologies enables and constrains racial and gendered identity. This is not to say that race is entirely absent. Racial equality in terms of access to the Internet has been an important concern in discussions of the digital divide (Mack 2001; Servon 2002). Still, these perspectives seldom examine the impact of technologies and ICTs in particular on the nature of a racialized social system and the ways in which minority communities in turn shape its development, diffusion, cultural meaning, and utilize technology in everyday and acts of resistance. When Latino high school students walked out of their schools in Los Angeles during the spring of 2006 in protest of anti-immigration laws, (almost) everyone was surprised that they organized and coordinated across the city using MySpace.com.

There is an expanding body of literature on technology and cyberspace that situates race as its object of inquiry (Gray 2005; Hammonds 1997; Ignacio 2005; Jenkins 2002; Kolko et al 2000; Nakamura 2002). This emerging body of work tends to follow a cultural and media studies approach which examines both theoretically and empirically the construction of cultural meaning through representation and signifying practices in the media and through the use and shaping of new media technologies. Using this approach as a starting point, I ask the following research questions regarding the relationship between the shaping of communication technologies and racial identity. How is the management and manipulation of data in

the information society producing new formations of racial difference and reproducing old notions of racial identity? What impacts have developments in new information and communication technologies have on racialization? How is race being constructed in terms of information, instead of the traditional markers of phenotype, culture, and nation?

A key site where the relationship between technology and identity can be observed is the biomedical sciences and the biotechnology industry. There are others, such as the insurance industry, law enforcement, and marketing and consumer profiling. The informationalization of racial identity represents new trends in the manipulation and management of information that cut across sectors and is a broad social process that emerges from the rise of the information society, developments in information and communication technologies, and the shifting politics of racial identity and social inequality. This dissertation will focus, however, on the specific mechanisms, processes, and observations, and their meaning in genomic research through a case study of what is being described as the next Human Genome Project, the HapMap Project. There is wide agreement that there have been concurrent biological and electronic revolutions since the 1970s (Capra 2002; McGuigan 1999). Focusing on genomics in general and, in particular, the HapMap Project allows for the extrapolation of a general trend from the political economy and cultural frameworks that structure the convergence between these two revolutions. As mentioned above, information and communication technologies are central tools for scientific research into the genetic origins of disease and developing pharmaceutical treatments. One of the most salient social categories for scientific research and the

most controversial is race. From the development of race drugs to the Human Genome Project, across medical, scientific, and pharmaceutical journals, debates have been raging on how to use race in scientific and medical research. The following questions stem from the notion that knowledge production can be analyzed through two important facets, political economic and socio-cultural processes. How does genetic research in the biotechnology industry construct race in terms of information, rather than biology, culture, or nation? What is the role of information and communication technologies in genetic research? What have been the economic and regulatory changes that have facilitated convergence between the electronic revolution and the genetic revolution, especially in terms of industrial and academic relations? How do particular industry structures and new technologies enable scientific and medical research? How do different actors in the biotechnology industry view the place of race in genetic research? What happens to race when population identification moves from phenotype to genotype?

The HapMap Project is significant for a number of reasons. First, unlike the Human Genome Project, it focuses on differences between racial groups. While there are a number of population groups that could have been compared by HapMap, the DNA samples were taken from people with ancestry from Europe, Asia, and Africa. These three countries code for the so-called base races of humanity in traditional taxonomy and social understandings of race. Second, the members of the HapMap represent three developments in scientific research: collaboration between an inclusion of an Ethical, Legal, and Social Implications group (ELSI) made up of a consortium of scientists, social scientists, bioethicists, legal scholars, and

representatives from non-governmental organizations (NGOs) to set the guidelines for overall ethical concerns and community engagement; the globalization of scientific research in terms of cooperation between nation-states; collaboration between entrepreneurs, academics, and public servants. Third, HapMap shows how information and communication technologies are becoming central to knowledge production in the information economy. Without the Internet, databases, and datamining technologies, the international research sites would not be able to communicate effectively and efficiently with one another and download samples to a centralized data repository, as well as map and analyze the sequence data. It is widely accepted that genomics, the comprehensive study of genes, would be impossible without ICTs. The HapMap project is an important site to understand how such technologies are being shaped for social and scientific uses and the meanings they produce. Finally, there has been an increasing interaction between the biological revolution and the information and electronic revolution. The HapMap project is a current example of this convergence not only in terms of man-made technology meeting biology to produce knowledge and products, the techno-sphere and the bio-sphere, and computer scientists meeting biological scientists, but of the adoption of theories and techniques of biological science from computer science. As this dissertation will show, HapMap is an information science.

Methodology

I employ the concept of the informationalization of race to highlight how information and communication technologies are being developed and utilized in the

sorting of racial difference. Theoretically, this dissertation brings together scholarship on the information age, science and technology studies, and critical race. Understanding the relationship between technology and identity means making links between technological, institutional, and cultural change. This approach borrows methodologically from Stephen Small's (1999) concept of racialization and Stuart Hall et al's "circuit of culture" (1997). Stephen Small's article "The contours of racialization" attempts to conceptualize race as dynamic and relational process. Small argues that race needs to be understood in terms of its historical transformation in both cultural representation and institutional structures. Both the image and the institution organization are central to understanding the reproduction and contestation of social inequality.

Stuart Hall and a team of scholars authored a six-book series entitled *Doing Cultural Studies* as a course reader at the Open University in the UK. Released in 1997, the series aims to study a cultural artifact from five perspectives in what they referred to as a circuit of culture. The circuit of culture brings together a number of different approaches that had been emerging out of British cultural studies in its development over the preceding two to three decades. Each book focused on one of the five points of culture: representation, identity, production, consumption, and regulation. This approach also attempts to intervene in the internal debate within cultural studies about the relationship between culture and political economy and the debates between political economy and cultural studies about the merits of either approach for the study of communication and media (Garnham 1995, Grossberg 1995, Mosco 1996, Murdock 1995). Political economy foregrounds the production of

media industries and messages while cultural studies usually begins with the point of reception or decoding as an object of analysis. Admittedly, these are both gross generalizations of both political economy and cultural studies, especially the latter. Similar to Small, Hall et al offers a broad conceptualization of the study of culture that incorporates both culture and economy. Also, the series is concerned with the emergence of new technologies and how they are being produced and incorporated into cultural practices.

There are many different kinds of sources this dissertation draws on, including semi-structured interviews of HapMap participants and scientists working in the biotechnology industry, policy documents, scientific and biomedical journal articles, and documents from the HapMap Project, the National Human Genome Research Institute, and the National Institutes of Health, as well as a host of Internet documents and websites. Due to the multi-site nature of the HapMap project and the renewed interest in race as a category for biomedical research across medicine and science, data collection for this dissertation is a process of following the object (Marcus 1995). Interviews follow the international locations of the project. Anthropologist George Marcus suggests that when the “thing traced is within the realm of discourses and modes of thought, then the circulation of signs, symbols, and metaphors guides the design” of the research (Marcus 1995: 108). Thus, textual and documentary analysis traces discussions about race, genomics, and health across various journals and across different fields within the biomedical sciences. Also, I pay particular attention to a select number of major journals in the fields of science, medicine, and genomics.

Makeup of Interviewees

Interview research allows for an in-depth understanding of the issues involved in the development and application of genomic technologies. Interviews are able to gain a detailed description of the scientific process and the production of scientific knowledge of race (e.g. the use of such categories and the creation of them), the role of communication technologies in genomic research, and applications for such knowledge. A total of 26 interviews with members of the HapMap Project were conducted from May to October in 2005. Subjects were recruited by letter, followed by Email, and then telephone. They included geneticists, lawyers, anthropologists, bioethicists, doctors, bioinformaticians, project managers, biologists, directors of NGOs, pharmacologists, and senior scientists for a leading biotechnology company. This configuration of professions is increasingly common on international genome projects and big science, in general. Since HapMap is a global project, interviewees for this research were located in Canada, Japan, Thailand, the UK, and the United States. Because of the high cost of travel almost all of the interviews were conducted by telephone and ranged in time from 30 minutes to 1.5 hours. They were all recorded on a digital format and transcribed.

The interviews were semi-structured containing three sections on technology, university-industrial relations, and race. The initial research design focused on the themes of technology, genomics, and race. However, my approach developed a recursive relationship between the data and the research questions. The format included both structured questions and allowed for conversation to emerge when

necessary. While each interview created new ways of looking at the questions, I stayed with the original format as much as possible, augmenting and clarifying questions as new information became available. Each interview was a process of refinement as well as continuity. Even though questions were of a professional nature and deemed low risk to the subjects, interviewees were guaranteed anonymity. Since the topic of race and genomics has become a controversial issue, I hoped that concealing their identity would allow these professionals to express their personal views more readily. However, statements are not attributed to single individuals but seen as representative of general themes. Descriptors of the individuals' positions were included to contextualize the responses without making them identifiable.

Makeup and Analysis of Textual Data

Primary textual data was collected from key biomedical and scientific journals such as *Science*, *Nature*, *Nature Genetics*, *Genomics*, *Genome Biology*, the *Journal of the American Medical Association*, and the *New England Journal of Medicine*. While the focus of the textual analysis was on these particular journals, I traced important themes across other journals according to discussion threads identified by authors that travel across various journals in the domains of science, medicine, biotechnology, and public health. The major journals have been identified in terms of standing in the fields of science, genetics, genomics, and medicine and also impact. "Impact" refers to the amount of citations that articles from a specified journal occur in other journals. There are a number of ranking systems that conduct such measurements across the social and natural sciences. Scientific journals are all

available online which makes for an efficient data collection process. Primarily, the perspectives, editorials, and opinion articles in these journals are where the debates about the role and nature of race take place in each of the above fields. Overall there were two levels of reading the data (Mason 1996). The literal level consists of the content and substance of the articles, the 'face value' of the literature. The interpretive level consists of what the implicit norms and values of the discourses. This version is a blend of what I observed and what exists in the secondary literature.

Chapter Overview

In Chapter Two, I trace the three areas of scholarship that this dissertation draws from: critical race, information society, and science and technology studies. This chapter highlights the current literature on racialization, technology, and science by focusing on the relationships between race, the information society, and new communication technologies. This chapter explores the new conditions and mechanisms of racial structuring and representation in society. Central mechanisms of change and continuity are innovations in new communication technologies, the rise of the information age, and the dominance of a color-blind, racial ideology. To this end, I suggest that a new formation of race is emerging called the informationalization of race. Then I explain the theory of the informationalization of race and situate it at the confluence of the three areas how it contributes to them. The chapter ends by introducing the case study on which this dissertation is based, genomics and the HapMap project, and how biology has become an information science.

Chapter Three returns to the third process outlined in the introduction, the biological revolution. Since the discovery of recombinant DNA in the early 1970s, biology has grown from the public and academic labs to a burgeoning biotechnology industry. This shift has largely been due to innovations in information and communication technologies and the incorporation of computing technologies and computing methods into the toolkit of biology. A new type of biology based on computational techniques has emerged and joined the wet labs of experimental biology. I describe how biology has incorporated theoretical and practical aspects of computing to become an informational science. Genome projects such as the Human Genome Project and the International HapMap Project have not only incorporated these technological and scientific transformations, but also motivated them. Many scholars acknowledge the central role of computing power and software in the rise of genomics. I explore the role of two equally important technologies that serve more than simply instrumental purposes in sequencing DNA, databases and the Internet.

Chapter Four turns from technological innovation to regulatory transformations that organizes and shapes scientific, ethical, and legal process that genome projects operate within. From 1977 to 2004, key legal and institutional changes took place that enabled and constrained the biotechnology industry and scientific research, both in and outside of academia. Since the Bayh-Dole Act of 1980, a series of government policies deregulated the relationships between commerce and universities with the aim of making the US a world leader in biotechnology. This produced a climate where some scientists became weary of research submitted to journals that was increasingly being funded by corporate

interests. Journal editorials, comments, and letters to the editor become forums for discussing conflict of interest policies. Finally, another set of institutional changes also occurred in the same journals as well as government organizations such as the National Institutes of Health that were aimed at the inclusion and treatment of ethnic and racial minorities in biomedical and scientific research.

In the Chapter Five, I examine the role of cultural and scientific discourse in genomics. While scientific research is built on a position of neutrality from the object of study, it is impossible to study race without common sense understandings of racial difference ‘infecting’ the purity of science. Scientific discourse is embedded in cultural assumptions about the nature of race and social order. I argue that four discursive frames characterize the informationalization of race and examine their relationship to discursive formations of race, genomics, and health in scientific race talk.

A Brief Introduction to the HapMap Project and Genomics

The HapMap Project is a \$130 million venture to find variation in the human genome that is linked to disease. The project was initiated by the National Human Genome Research Institute (NHGRI) of the National Institutes of Health (NIH) and began with a planning meeting held in Washington, D.C. in the summer of 2001. The two-day conference featured panels and discussions about the scientific, ethical, and legal issues involved in a study that would span four continents, link up major research centers in the world, and draw on subjects from identified communities. The project launched in 2002 and Phase I was completed in 2005. Phase II has been

underway and consists of further mapping and sequencing work being performed on the original four populations. Sample collection of Phase III, expanding on the original four population groups, is currently in progress. Even though it was billed as the next Human Genome Project, it has not received the same type of fanfare and media hype as the competing human genome projects, which jointly completed a draft of the human genome in 2001. Where the HGP featured competition, HapMap is a collaborative venture that spans academic disciplines and international borders including participants from Canada, China, Nigeria, Japan, the United Kingdom, and the United States. The press conference for the HGP took place at the White House, announced by President Clinton with co-heads of the two groups, Craig Venter of Celera and Francis Collins, and a satellite linkup with British Prime Minister Tony Blair in London. Recently, Phase I of the project was completed, culminating with an online database that is open to anyone who wants to make use of the data. The completion of the first phase was marked by publication of the findings in the journal *Nature* (International HapMap Consortium 2005) and a simultaneous press conference featuring NIH Director Francis Collins and the various chairs of the project's sub-committees.¹ Only Collins led the proceedings, without President George Bush. While it was hardly a media event, the impact of HapMap findings for racial identity could prove to be far more profound than the Human Genome Project's findings that humanity is 99.9 percent the same at the genetic level.

The International HapMap Project is described by organizers as the next step in understanding genetic differences in human populations. Through the information

¹ The press conference can be streamed at <http://www.genome.gov/17015416>.

gained in this project, scientists hope to determine the “common patterns of DNA sequence variation in the human genome” which will “allow the discovery of sequence variants that affect common disease, will facilitate development of diagnostic tools, and will enhance our ability to choose targets for therapeutic intervention” (Ibid; see also Deloukas 2004; Lee 2003; Rotimi 2004). The change to cataloguing haplotype blocks and linkage disequilibrium in the search for ancestral differences is a key development in genetics in the last five years that has been made possible by advances in computing. Scholars argue and initial interviewees from the HapMap project unanimously agree that there could be no new genetics without computing science. One of the most significant challenges in the Human Genome Project was the computational analysis of massive sets of data. Developments in communication technologies have made possible genetic technologies faster and cheaper, such as high through put, and data sharing through the Internet. In this regard, HapMap has built on the technological innovations of the Human Genome Project. HapMap has also built on the social failings of the Human Genome Diversity Project (HGDP).

Led by renowned geneticist Luca Cavalli-Sforza, the HGDP sought to map differences between human population groups globally. However, the HGDP works on the old model of population groups from nineteenth century notion of populations (Reardon 2005). The U.S. model has shifted to admixture of populations, which includes North American genetic technologies such as ancestry-informative markers (AIMs), which give clues to one’s ethnic background. HapMap raises key issues in regards to methodology in academic and commercial research into human

populations. What are the techniques used by academics and pharmaceutical researchers in identifying the populations before they conduct the research and what is the rationale? Usually the debates about the history of anthropological genetics are cited as the justification for choosing one possible sample population over another. This was certainly the justification used for the for the HapMap project. Interviews with the members of HapMap concerning the creation of the project show how their discussions built on the issues of sampling and community politics from the Human Genome Diversity Project. While the scientists heading the HGDP were well intentioned in their pursuit to explore the diversity of the human species, their efforts were met with controversy and opposition from many groups, especially indigenous organizations from around the world. In her seminal history of the project, Jenny Reardon (2005) asks how the scientists working on the project who have been advocates and leaders of efforts against the legacy of scientific racism could be charged with racism and their effort dubbed the Vampire Project. Apparently the scientists involved were unaware of the socio-political context in which their work would be situated. The members of the HapMap Project are not able to claim such ignorance. HapMap is a revision of the early failings of the Human Genome Diversity Project (HGDP). One of the outstanding issues is the choice of two Asian populations and only one African one. The rationale runs contrary to what is known about anthropological genetics.

The HapMap consortium collected samples from “populations with ancestry from parts of Africa, Asia, and Europe” (International HapMap Consortium 2003:789). While project organizers deliberately decided to refer to the sample

groups in terms of populations and not racial groups, the initial groups do match a traditional American taxonomy of race. When the National Human Genome Research Institute (NHGRI) of the National Institutes of Health (NIH) decided to build databases and a haplotype map the scientists involved decided that the groups would be labeled according to geographical rather than racial signifiers: CEU for the population from Utah, CHB from Beijing, China, JPT from Tokyo Japan, and YRI for the Yoruba from Nigeria.

Beginning with the initial planning meeting held in Washington, D.C., in July 2001, the planning discussions focused on ethical issues in terms of group participation and the implications of the project for race and ethnicity. Attendees included social scientists, bioethicists, legal scholars, as well as representatives from Native American groups and the NGO, Indigenous Peoples Council on Biocolonialism. Sociologist Troy Duster, a leading critic of the social implications of new genetics on health and law enforcement, led one of the sessions entitled, “Ethical and social issues relating to the inclusion of identified populations in a haplotype map project.” He discussed the issues of inclusion and exclusion of certain groups, eliminating versus retaining ethnic group names to describe the data, and the risks of the project conveying meaning to race/ethnicity (HapMap). A session on the ethical and social issues of consent and inclusion of identifiable populations by a panel of experts followed. Learning from the challenges of the HGDP, members of HapMap seemed well aware from the beginning of the socio-political world in which their efforts would be situated.

But while largely scorning conventional racial categories, population geneticists and researchers equipped with new genotyping tools are increasingly identifying patterns of genetic variants, particularly single-nucleotide polymorphisms (SNPs), that are prevalent among specific populations. Researchers have found that SNPs, variations of a single nucleotide at a particular spot on a chromosome, tend to occur in blocks called haplotypes. (Rotman 2005)

The fact that racial and ethnic categories were on the table in a serious manner is largely the result of the public nature of the NIH, the structure of the funding for the Human Genome Project, and advocacy groups protesting the Human Genome Diversity Project. Since the HGP was a federal project, (“biological and social scientists, health care professionals, historians, legal scholars, and others”) bioethicists and social scientists, pushed for the creation of a sub-group to be primarily focused on ethical issues. The result was the inception of the Ethical, Legal, and Social Implications program (ELSI) as an institutionalized subsection of the NIH’s National Human Genome Research Institute (NHGRI), headed by Francis Collins, the director of the public Human Genome Project. ELSI receives 5 percent of the total federal funding allocated to the NHGRI. It was this type of funding and feedback from scholars and professionals outside of the scientific community that stopped the HGP short of going all out on race. In terms of the HapMap project, ELSI members were crucial in ensuring that the markers included in the HapMap database were not racially coded, but, rather, were sorted in terms of the population group’s geographical location (Interview 1013; www.hapmap.org). Differences in responses to this issue by scientists and non-scientists clearly show how the naming originated from ELSI members. While the scientists and bioethicists seem to agree on trying to avoid the discrimination and racism of the past in regards to science and

race, some respondents clearly viewed ELSI's insistence on the specifics of language used to code the population groups, such as CEPH for the sample from Utah and JPT for the sample from Japan, as simply semantics. There was the sense that issues such as the type of language used up time in meetings that could have been better spent on other, more scientific or technical, matters. One of the most important contributions of ELSI is putting race on the table for discussion and the implementation of protocols for community engagement and consent. While the ethical parameters of scientific research have previously been the domain of scientists, in recent years social scientists, legal scholars, and bioethicists have been included in scientific research.

Chapter 2

The Informationalization of Race:

Communication technologies and the New Conditions of Racialization

Race, Racialization, and Colorblindness

Social constructionists of race have delineated the nature of race into two, main ontological phases, which overlap and are interdependent of one another: race as biology and race as culture. In both paradigms, racial identity is constructed by locating social hierarchy in bio-cultural markers of group identity and behavior. In the race as biology paradigm, racial groups are identified according to a collection of physical phenotypes, such as skin colour, hair texture, shape of eyes and nose (Banton 1998; Jordan 1974; Miles 1989). These epidermal markers have been socially understood to indicate biologically determined group characteristics and have also set the political limits of inclusion to national citizenship and access to material resources. Scholars have located the origins of the biologizing of race in the nineteenth century by scientists and population geneticists, such as Francis Galton, working from Darwin's evolutionary model (Foucault 1978; Gould 1996).

In the race as culture paradigm, racial difference is constructed from cultural material (language, practices, and behaviors), often understood as ethnicity, rather than the body. This development has been referred to as the culturalization of race (Razack 1998) or the new racism (Barker 1982), which signifies the shift in discourse from biological classification to cultural codes, yet the practice of racism remains quite similar:

In its modern form, overt racism, which rests on the notion of biologically based inferiority, coexists with a more covert practice of domination encoded in the assumption of cultural or acquired inferiority. (Razack 1998:60)

Group characteristics continue to be ascribed based on the symbolics of the body, yet the real differences between groups are no longer biological (although there are still some social scientists who pursue this belief) but rather ethnic or cultural. Racial signification and positioning in public discourse is rearticulated in cultural terms, “talk about a group’s culture often serves to disguise what are fundamentally racial claims” (Kim 1999:117). A minority group may not be biologically inferior, however, they are set apart through their perceived ‘difference’ from the dominant, white culture. Not better or worse, but different. Still, the Other is juxtaposed and left on the margins of social inclusion. Against conservative narratives of racial progress, Kim argues that the move to culturally coded racial discourse has in fact stabilized White privilege in the post-civil rights era.

It is precisely because it has been revamped in nonracial language that the field of racial positions functions so effectively to reinforce White privilege today. Representing a cultural explanation for group inequalities, the field of racial positions implies that American society is substantially colorblind and that the American Dream is still viable. (Kim 1999:117)

Bio-race does not seem to be present in current public discourse about group differences, however culture is deployed in a similar manner, homogenous, dislocated from history, and static, and containing an implicit association to group position in the social order: “a fixed property of social groups, [rather than] “something intrinsically fluid, changing, unstable, and dynamic” (Gilroy 2000:266). White supervisors and co-workers in the context of the workplace may explain the

behavior of a minority person who is facing racism as a “cultural thing.” What the former group may interpret as a ‘bad attitude’ could simply be a person of color standing up for himself in the face of individual and institutional discrimination.

Scholars of race have investigated the role of institutions in re-producing race and racism such as the law (Crenshaw 1993, 1995; Crenshaw and Peller 1993; Williams 1991), policing (Chan and Mirchandani 2002; Hall, Critcher, Jefferson, Clarke, and Roberts 1978; Holdaway 1996), education (Lopez 2002; Razack 1998), and the media (Cottle 2000; Dyer 1997; Entman and Rojecki 2000; Gray 2000; Hall 1980, 1981, 1992; Hunt 1997, 1999). The turn to popular culture, especially in cultural studies, has been productive for understanding how racialization is negotiated in everyday life (Fiske 1996; Hall 1996; Hooks 1992; Spiegel 2001). Recently, there has been a call to understand the role of whiteness (Morrison 1992). Scholars have responded by tracing the historical process of European ethnic groups becoming white (Ignatiev 1995; Jacobson 1998), the relationship between race and class (Roediger 1999), and how popular cultural forms, such as black face minstrelsy, were sites of constructing racial identification through difference (Lott 1993; Rogin 1996). The above scholarship widely covers how racial difference is constructed and operates to re-produce social inequality. The next section explores major theories of race that largely underpin the above domain studies.

From Race Relations to Racial Projects and Racialization

One of the most influential and widely cited theories of the process of racial construction is Omi and Winant’s (1994) theory of *racial formation process*. They

argue for an anti-essentialist conceptualization of race and offer a theory for studying the meaning of race and racism. They define racial formation as "the sociohistorical process by which racial categories are created, inhabited, transformed, and destroyed" (55). Their theory situates race as "an unstable and "decentered" complex of social meanings constantly being transformed by political struggle" (Ibid). Central to their analysis are two ontological conditions that the authors recognize in their theory. The first condition is the primacy they give to race as a social phenomenon and the second concerns the relationship between cultural representation and social structure.

Omi and Winant argue that race is not reducible to other social phenomena, such as class or market forces. While race operates in articulation with other forms of difference, such as gender and sexuality, its formation does not lie at the intersection of other, primary social processes and institutions. Race is an autonomous aspect of society rather than an anomaly within it or an epiphenomenon. A theoretical position that recognizes race as a social phenomenon rather than an epiphenomenal one seeks to,

...avoid both the utopian framework which sees race as an illusion we can somehow "get beyond," and also the essentialist formulation which sees race as something objective and fixed, a biological datum. Thus we should think of race as an element of social structure rather than as an irregularity within it; we should see race as a dimension of human representation rather than an illusion. (55)

Often the manifestations of race are studied in institutional settings, such as the law, education, and labor (Smith 1995) or in terms of its cultural representations, such as in the media (Collins 2005; Gray 2005; Hall 1992). Race is understood as part of the

organization of society into different strata, or subgroups, or as identities mapped and inscribed onto or representing different types of human bodies. Structural analyses measure levels of racial discrimination in institutional settings, but are unable to describe how differences forms of racial difference emerge, diffuse, and transform through symbols and cultural practices. On the other hand, approaches that treat racism as systems of signification cannot make sense of disparities in health or enrolments of visible minorities in higher education. Racial formation process acknowledges the importance of both methods of analysis. Race is a case of both structuring and signifying where the two inform and construct one another. We create our social structures out of the way we understand the world and our actions are enabled and constrained by our social structures. The ontological perspectives of the primacy of race and the link between social structure and cultural representation lay the groundwork for Omi and Winant's theoretical approach, racial formation process.

The authors elaborate on racial formation process in two ways. Firstly, racial formation is "a process of historically situated *projects* in which human bodies and social structures are represented and organized" (Ibid). Secondly, racial formation is linked to the evolution of hegemony. Here, hegemony is understood as the manner in which society is organized and ruled through consent rather than coercion. The authors believe that a whole scope of social problems involving race, such as sexism and other forms of difference, inequality, and oppression and their relationship to race, can be understood through their approach.

Ideologically, racial projects do the work of making the links between social structure and cultural representation.

A racial project is simultaneously an interpretation, representation, or explanation of racial dynamics, and an effort to reorganize and redistribute resources along particular racial lines. Racial projects connect what race means in a particular discursive practice and the ways in which both social structures and everyday experiences are racially *organized* [emphasis in original] based upon that meaning. (56)

The idea of racial projects helps to broaden the scope of race and racism and the question of rule. Instead of restricting the conceptualization of inequality to the domination of one group over another, racial projects spread the struggle of rule over a network of power relations. Projects act as the "building blocks not just of racial formation, but of hegemony in general" (68).

Racial formation has been taken up by a number of scholars of whiteness (see Frankenberg 1993; Jacobson 1998; Lipsitz 1998; Roediger 1999). In *Whiteness of a Different Color* (1998), Jacobson explains how different European groups became white through three great racial projects of U.S. immigration history. Entrance into whiteness was intimately bound to changing notions of citizenship, naturalization laws, and white ethnic consolidation. Roediger (1999), in his study of nineteenth century working class culture, shows how racial formation and class formation were "bound to penetrate each other at every turn," but not reduced to one another, and that "the pleasures of whiteness could function as a 'wage' of white workers" (20, 8, 13). Similarly, Lisa Lowe (1996) links class formation to racial formation, as well as gender formation, in the history of Asian immigrants and Asian Americans. Like Jacobson, she argues that a key site is the law and the construction of citizenship.

The law and relations of production have a recursive relationship as the former “must be understood as *both* an ideological and a repressive state apparatus, as both symptomatic and determining of the relations of production” (14). Lowe builds on the relationship between structure and agency in racial formation by showing how the law worked both discursively and institutionally. For Lowe, the process of racialization was intimately tied to class and gender formation of Chinese laborers, the state legal apparatus, and the wages of whiteness.

Racialization is another widely used concept used to analyze race. This term is often discussed in place of or in conjunction with racial formation. Similar to racial formation, racialization argues that race is not a category, but a process imbued with power. Part of the problem with dealing with race or race relations is getting away from the idea that race is something tangible, static, natural. A race relations paradigm continues to force the terms of discussion and analysis into the framework of a pre-existing phenomena; there are biological races and they engage (or do not) in relations with one another and racial conflict is the outcome of races (or ethnic groups) in contact (Small 1999:48). Stuart Hall reminds us of the deconstructionist position, which he refers to as a post-modern mantra: “race is indeed a sociohistorical concept, not a transhistorical discourse grounded in biology” (Hall 1998:190). Racial formation makes a progressive analytical step towards thinking race as a social, cultural, political and economic operation that is contingent on place and time, geography and history. Robert Miles (1989) uses racialization to refer to those,

instances where social relations between people have been structured by the signification of human biological characteristics in such a way as to define and construct differentiated social collectivities. The characteristics signified vary historically and, although they have usually been visible somatic features, other non-visible (alleged and real) biological features have also been signified. The concept therefore refers to a process of categorisation, a representational process of defining Other (usually, but not exclusively) somatically. (75)

The process of signification in racialization is a dialectical one where the definition of the Other involves the definition of the Self. Miles uses racialization to refer to instances where the discourse of race is linked to biological traits, which is largely a process of signification. Where his analysis falls short though is in linking ideology to social structures and cultural practices or forms of racism that are not dependent on typologies of race (Anthias 1992:11). Small (1999) makes this correction through a reconceptualization of race and race relations in terms of the process of racialization in a manner akin to Omi and Winant's racial formation.

Like Miles, Small's definition breaks with static and biological notions of race. However, Small favors a social, contextual, and relational concept that forces an interrogation of the everyday practices of people, the signifying of social meaning, and institutional practices. In short, he proposes an investigation of "economics, politics, power; and to the ways in which structures, images and ideologies operate to sustain inequality and injustice" (Small, 1999:49; see also Cottle 1992:4). Similar to racial formation, racialization enables the tracing of the emergence and dynamic nature of the concept and action of race in social institutions and cultural representation: in the law, in movies, in slavery, in politics, in the work place, in schools, in sexuality, in gender, and in cyberspace, for example.

Beyond Black and White: Racial triangulation

In recent years, there has been a call for discussions of race to go beyond the black-white binary that has defined racial discourse in American history. Many scholars have found inquiries into the nature of race and society solely from the experiences of whites and blacks to be limiting for social analysis. This leaves out a myriad of other relations in American history, such as the experiences of Asians, or Latinos have not been pursued. In a post-Civil Rights era that is increasingly being defined by the presence of immigration from the global south a bipolar lens is becoming increasingly limited. This hides many of the complexities of racial formation in America in terms of the relationship between the dominant and minority populations as well as between minority groups. Omi and Winant's racial formation and Smalls' racialization framework have both been attempts to move beyond the black/white binary. Claire Kim critiques racial formation as a "different trajectories approach" (1999:105). While racial formation is an open-ended, variable process that focuses on the different histories of Latinos, Native Americans, Asians, and other groups, and formations of racism, it tends to situate each group in isolation from one another. Each group's experience with the racialization process is not simply in binary relation to the dominant culture, but in *relation* to each other.

Kim seeks to foreground the intimate connections between the different groups and the relational nature of group identities through *racial triangulation*. Kim (1999) argues that minorities are set in triangulation with one another and the dominant white group. For example, Kawai (2005) argues that Asian identity has

historically been located between the dialectic of the yellow peril and model minority. Employing racial triangulation, Kawai explains how white constructs of Asians and African Americans are related to one another in representation and in history. Kawai reveals where the term the model minority may have first entered public discourse. Two separate articles in the mainstream media have been credited with the emergence of the model minority myth, one in the beginning the 1966 in the *New York Times* and the other at the end the same year in *U.S. World News and Report*. Both described Chinese and Japanese groups as exemplary minority success stories (Kawai 2005:113). The implicit assumption in creating a model minority is that other minorities are not working hard without assistance to pull themselves up by their own bootstraps. Both articles defined African Americans as a problem minority. It was no accident that the two articles constructing the model minority were published in the middle of the 1960s when African Americans were working hard through organization and protest to progress their place in American society. Of course, to mainstream media outlets such as the *Times* and *World Report*, protest is viewed as complaint and African Americans are looking for a hand out. While Asian Americans are located above African Americans in terms of their perceived work ethic, they are triangulated and subordinated to Whites as an unassimilable Other in American society. Often, especially in media texts, there is little distinction between Asians and Asian Americans (Kawai 2005).

The New Racial Order: Colorblindness

Racial triangulation operates through the post-civil rights claim that America has moved from a society structured in racial dominance to a colorblind society. The color-blind racial structure attributes differential standings of minorities to market forces, naturally occurring phenomena, and cultural variations between groups (Bonilla-Silva 2003:2). In his racialized social system framework, Bonilla-Silva argues that race and the process of racialization are structural parts of society and the rational actions of individuals, not simply reducible to individual attitudes and irrational behavior. Bonilla-Silva's framework draws on Omi and Winant's theory of racial formation (1994). Like Bonilla-Silva, they argue that race and the conditions of racism are historically contingent and depend on social, political, and economic context.

Bonilla-Silva (2001) suggests that the civil rights movement marked a shift in the racial structure of society from Jim Crow racism to color-blind racism. In the former phase, blacks and other minorities were considered inferior to whites because of their biological and moral inferiority. Where biology and social construction demarcated a fairly clear line between proponents of racial ideology and progressive politics, the former became much more out of fashion after the civil rights movement. In the aftermath of social protests from 1955-1965, overt forms of racism became much less socially acceptable and the structures of society such as the law, economics, and higher education became the next sites of struggle. The advancements of the 1960s and the feelings of social and political progress that

culminated in the Voting Rights Act of 1965 were sharply contrasted with the economic problems of the 1970s.

There has been a political and ideological flip in the politics of the civil rights era in the US. Concepts of social and political equality where everyone is created and treated equally was based on the notion of sameness, of a common humanity.

However, one of the routes to equality for African-Americans and other minority groups was the enactment of color-conscious policies, such as school busing and affirmative action. Most people on the left or right would not espouse racial ideologies of superiority and inferiority based on the assumption of biological difference, at least, in an overt manner.

African American politics of the post-civil rights era sees to be between a rock and a hard place. Racial segregation as the legal mechanism for racial oppression has been struck down and the racial ideologies that justified it have been forcefully challenged. Few would offer biological explanations for African American joblessness, poor school performance, higher rates of pregnancy out of wedlock, and higher rates of incarceration. But the changing legal climate and the muting of racial theories rooted in biology neither means that new forms of racism are absent nor that cultural arguments are replacing biology as the reason given for African American disadvantage. (Collins 2004:45)

As overt forms of racism and racial intolerance became socially unacceptable in the 1980s, at least in everyday public discourse, seeing and acknowledging race was deemed a negative action. Many white people adopted a liberal racial consciousness, rooted in making race invisible. One of the discursive techniques of whiteness became, "I don't see people's color of skin. I treat everyone the same." According to this ideology, the denial of racial identity will itself produce an absence of racism.

However, four hundred years of racial domination and colonization of the body, in representation, material practices, legal policies, government regulation, and policing cannot and has not been undone in a couple of decades.

In the context of a colorblind society, diversity is celebrated along with color-neutral policies. The language and practice of exclusion has been replaced by the discourse of inclusion without considerations to “special interests.” For example, college admissions that once systematically discriminated against women and racial minorities now openly encourage such applicants. However, the color-conscious measures that were products of the Civil Rights Movement to ensure diversity of access to education and the workplace have been challenged across the U.S.

Affirmative action programs have been struck down in some states, notably in the University of California system, through Proposition 209 in 1996. The politics that lead the Civil Rights Movement, equality through sameness and color-conscious policies, now are being seen as regressive. Proponents of a color-blind society argue that color-conscious policies have outlived their usage and are now responsible for reverse discrimination. In the 2003 gubernatorial elections, Proposition 54 sought to bar any government agency or government funded organization from categorizing people or collecting any statistics on the basis of race or skin color. Originating from the Racial Privacy Initiative, conservative UC Regent Ward Connerly attempted to continue from his success with Proposition 209, where affirmative-action policies were struck down in the University of California system. The color-blind racial structure attributes differential standings of minorities to market forces, naturally

occurring phenomena, and cultural variations between groups (Bonilla-Silva 2003:2). The new language of race is couched in terms of neutral codes that do not directly reference the overt racist terms of the past.

Kim (1999, 2000) and others argue that the claim of race neutrality is fundamentally ideological, as minorities still remain in subordinate positions in the racial structure in terms of material conditions and civic participation. Against the claims of racial uplift (Wilson 1987), racism continues to structure society institutionally and in people's everyday experiences. Smith (1995) takes on claims such as William Julius Wilson's that racism is declining in significance and any disparities between racial groups are the result of historical racisms and, increasingly, class. Through an array of empirical sources, including legal cases and forty years of survey data, Smith demonstrates how racism continues to persist in American society at the micro and macro levels of everyday life and institutions and across the domains of health, housing, education, consumer services, and employment. More recently, Hurricane Katrina uncovered much more than dirt and soil. When the storm was over, the aftermath of displaced people whose homes has been destroyed revealed the deep legacy of slavery, the remnants of Jim Crow, and the unfinished work of the second reconstruction. The news and Internet media fed images of structural poverty and social exclusion straight into people's homes around the globe. The sheer coverage of African Americans in plight may be unmatched since the civil rights movement.²

² Evidence of media bias was also on display on Yahoo.com. Now known as the "two photo controversy,"² captions beneath a pair of photographs of people wading

Central Frames of Colorblindness

Bonilla-Silva (2003) identifies a number of central discursive frames of color blindness. He argues that Jim Crow racism is characterized by ideological assumptions about biology and morals while the new racism constructs different in terms of culture and markets. Through an analysis of two sets of survey and interview data from a Midwest college and Detroit, he finds four frames that white respondents used when talking about race. Bonilla-Silva refers to them as abstract liberalism, naturalization, cultural racism, and minimization of racism (27-30).

Abstract liberalism explains racial matters by using discourse associated with political and economic liberalism. Race talk is relegated to abstractions about social policies being achieved without being forced and people's decisions should be left up to individual choice. Whites who used a naturalization frame tended to explain away racial situations by seeing them as natural and almost biological. For example, this position would suggest that when minorities cluster together or whites choose to

through flood water with food described the African Americans in one of the photos as looters and Whites in the other as simply as "finding" food. For discussions about the "two photo controversy" and the photos themselves go to [Media Awareness Network](#) and [Snopes.com](#). The latter website includes quotes from the news agencies, AP and AFP, and the photographers, Dave Martin and Chris Graythen about what they witnessed before taking the pictures. Both photographers state their choices of captions as facts, what they saw. Hall (1980) suggests that it is not due to individual racism that the media operates in a manner that reproduces racial stereotypes. Removing individual racists would change the practices and conventions of news reporting and photography no more than removing individual stockbrokers from Wall Street would disrupt capitalism. Regardless of whether or not the photographers believe looting was taking place does not change the impact of Yahoo's posting of the two pictures. Yahoo's editorial choice reveals the uncritical manner in which human suffering can be framed in racialized terms.

date or associate with other whites is natural. People just like to be with their own. Racial associations are seen as nonracial because they are grounded in some instinctive urge for sameness. Bonilla-Silva's conception of cultural racism is consistent with the above discussions of the culturalization of race. Seeming patterns among groups have become cultural rather than biological, such as differing emphases on education and educational attainment according to race.

The minimization of racism fosters the belief that prejudice only exists if you look for it. Those who point out social inequality whether through observation (no one 'experiences' macro social processes such as the digital divide) or lived experience, the micro level at which most public discourse on race takes place.

Black.White is a television reality show that examines racism purely at this level. The show aired on Fox's FX Network in early 2006 and was billed as an "experiment" where two families, one black and one white, "switched" races through makeup and prosthetics. They lived together in a house in Los Angeles' San Fernando Valley for a couple of months and shared experiences of each others' "new" race. One of the show's characters is Bruno, the white father. When he becomes black, he has trouble seeing racism at all, even when he and his wife go to a country and western bar and are the only black people, or any people of color for that matter, in the bar. In one scene, Carmen, his wife, is asked for a credit card by the bartender to finish making a cup of coffee while she goes to ask Bruno a question in another part of the bar. Carmen relates her experience to Bruno on the the ride home from the bar and expresses surprise at the bartender's request for a deposit and the obvious sense of distrust. Bruno does not believe that his experiences as a black man are any different

than his as being white. The other father, Brian, becomes increasingly annoyed at Bruno's lack of acknowledgement of racism. Bruno responds to Brian's ascertain that he only sees what he wants to see by saying, "And you don't see what you don't want to see." The implication being that Brian frames out colorblindness from his life perspective. Kim (2006) refers to Bruno as a "racism-denier." Bruno does not deny that racism exists, only that it does not exist in his life world. I would call this the *third-person effect of racism*.

The third-person effect (Davison 1983; Perloff 2002) refers to the notion that the media does have an impact on individual behavior, but not to oneself. The third-person effect "is an individual's perception that a message will exert a stronger impact on others than on the self" (Perloff 2002:490). A message has less effect on me or you than on them. In terms of the every day lived experience of race, Bruno has trouble seeing what Brian sees. This is more in line with Bonilla-Silva's minimization of racism, a central frame of colorblindness. For Bruno, racism is not the central factor in his experience as a black man and he states that it is for Brian. Like many whites who embrace colorblindness, it is not social inequality that reproduces race and racism, but minorities who focus on it. Racism is something of the past and not part of the present social structure. The third-person effect of racism is based on the premise that individual choice and perspective is more powerful than macro social forces and that one's outlook, and the aggregation of different individuals' outlooks, can shape that phenomenon. An online response to Kim's article on the show on the journal *Flow*'s website is a typical framing,

The black family seemed to have a chip on their shoulders. I had to agree with Bruno about people being treated according to their attitude they give off. If you always think that everything negative that happens to you is because [sic] of your race, guess what? you'll always [sic] be finding things you can turn into racism. I know there is racism out there, but what people need to understand is it's becoming less and less all the time. And if they would not pass their negative beliefs on to their children, eventually it would just about disappear [sic]. But we have to let go and not always [sic] think every thing white people do is done in malice. Every time they don't [sic] get waited on right [sic] away at a store, ect [sic]. Guess what? I'm [sic] white, and sometimes I don't [sic] feel like I get treated fair at all. Let's all grow up and quite playing the worn out race card.

Similar to Bruno, this respondent does not deny that racism exists; such a position would seem irrational in light of what the popular imagination understands about the history of the United States. However, the white power structure is not implicated in this statement at all. One could assume from this comment that well-meaning whites are the ones who are working to diminish racial inequality and it is minorities that continue to perpetuate it because of the “chip on their shoulders.” The focus here is on the individual and racism as an individual attitude, rather than as the result of the racial structure of society. Brown et al (2003) argue that writers such as Dinesh D’Souza (1995) and Shelby Steele (1999) perpetuate colorblind ideology by claiming that progress has been made since the 1950s in addressing racial justice and that racism is a thing of the past. Contemporary inequalities are not due to white racism, but inactivity on the part of minorities, and that minority leaders keep racial fervor alive so they can benefit from government programs (Brown et al 2003:6-7). They do not suggest that racial discrimination has disappeared, but that discourse about race should.

The Information Age and New Media Technologies

Contemporary discussions of information largely begin with Shannon and Weaver's (1949) theory of information as an orienting point and an important convergence between computing science and telecommunications that would have a critical impact on culture and commerce (Lyon 2005). Since then information has become a ubiquitous symbol for changes in the structure of advanced capitalist societies. It marks the rise of the information age which has its beginnings in the 1960s and 1970s and has been fueled by social movements, such as the civil rights and feminist movements, the restructuring of capitalism, and the new technological paradigm, such as the innovation and development of new communication technologies. The literature on the information society is varied and voluminous. Webster (1999) usefully separates scholars into those who endorse social change and those who emphasize continuity. The former consists of theories of postindustrialism, postmodernism, flexible specialization, the control revolution, and the informational mode of development. According to Webster, these theorists, such as Daniel Bell, Jean Baudrillard, and James Beniger, the old, modern, industrial society has given way to a new one. Neo-Marxism, regulation theory, flexible accumulation, national state and violence, and the public sphere characterize those theorists who focus on the continuities in society, such as Herbert Schiller, David Harvey, Anthony Giddens, and Jurgen Habermas, usually in terms of the re-production of the social order (Webster 1999:139). While the two camps, "information society theorists" and "informatization thinkers" (Ibid.), differ in their perspectives on the nature of society and, within the camps, can be oppositional in the information age's central

characteristics and mechanisms, they both acknowledge that information has a special place in late capitalist societies that requires close attention.

Only during the twentieth century did information become central to the social, political and economic organization of life and only late in that century did information become inextricably linked with technology...In today's globalizing world the newer sense of information as coded, commodified and computer-compatible is in the ascendancy. (Lyon 2005:223)

The two camps have differing perspective on change and continuity. This dissertation will consider both the changes in technological and informational infrastructures as well as the continuities in how technologies are deployed in a racial system.

While minority groups fought to build on the gains of the civil rights movement in the classrooms, offices, and studio back lots of 1970s America, entrepreneurs were developing new innovations in computer technology in the labs of Silicon Valley that would provide the technological infrastructure for the information age. It is no stretch to say that a number of key discoveries together ushered in a new technological paradigm. The new technological paradigm was not the result of a social context such as the restructuring of capitalism or the arms race in the 1970s (Schiller 1999). Rather, it was the result of a number of technological discoveries that were independent but fed back and built on one another. The key technologies were the microprocessor, the microcomputer, telecommunications, and software, each clustering with another. Advances in each technology made possible further advances in others. Thus, the new paradigm was not initially produced by sociological design, but by a number of technological innovations and inventions.

When the new systems came into existence, however, their shaping and diffusion was dependent on the cultural, political, and economic historical context. Put another way, the development of technologies is never separated from the social realm. For example, Webster (1999) argues that “research and development decisions express priorities, and these value judgments, particular types of technologies are produced” (143). Social values are always imprinted on technologies, such as bridges in New York being designed at a certain height so that buses traveling from poor and black neighborhoods are prevented from going to the beaches (Winner 1986), or the social status of luxury cars. While technology is shaped by the values of society and its implementation, it is also embodies society’s aspirations for a better future.

Utopian visions of the new technological developments of the 1990s argued that innovations such as the Internet would be democratizing and lead us into a more equitable and less discriminatory society. This position contends that the constraining effects of identity, such as racism, can be overcome by the diffusion and integration of information and communication technologies (ICTs) into society. However, this dissertation will argue that, instead of freeing us from discrimination and social inequality, ICTs may be deepening our relationship to racial identity. ICTs are not neutral tools in the struggle over racial terrain; their development and deployment is intimately involved in the shaping the contours of racialization, not only in local, national contexts, but globally. We are witnessing a “shift or transformation in the scale of human social organization that links distance communities and expands the reach of power relations across the world’s major regions and continents” (Held and McGrew 2000:4). While discussions about

globalization have well explored its economic, cultural, and political impacts, the globalization of scientific research has not received the same amount of attention. Innovations in communication technologies have provided the material and informational infrastructure for collaborations across national boundaries. Held and McGrew describe this aspect of globalization as “a growing magnitude or intensity of global flows” (2000:3). Cooperation between scientists from different countries is not a new phenomenon, however, technologies such as the Internet have made the archiving, transfer of data, interpersonal communication, and collaborating on papers much more feasible. The key technology that provides the informational infrastructure for this communication is the database.

Unlike the more visible forms of new media technologies such as the mobile phone laptop computers, and the iPod, or ‘invisible’ delivery systems such as wi-fi or the web, the database is a central innovation in the information economy (Elmer 2004:55; See also Cubitt 2000; Loro 1995; Manovich 1999; Poster 1991). Databases play a pivotal role in the process of sorting and storing data, networking information, and constructing knowledge. For some, databases enable a “networked “multilogue” between marketers, consumers, and products” (Loro 1995:55). Consumers can feedback into the system of product development and sales and become producers. At the same time, consumer feedback is usually accompanied by giving personal information as part of filling out a comment form, becoming part of an online service, or having one’s club cards swiped with every purchase. While companies are finding out what people like, they are also learning who they are. Knowing your clientele takes on new meaning with the modern database. Gone are the days of

rolodexes. Consumer profiles have become products themselves. Simple query searches for sorting information have given way to complex techniques of “knowledge discovery in databases” (KDD) or “data mining” (DM).

Data mining was initially developed by Usama Fayyad as a technique of searching databases at General Motors to find latent defects company products in the early 1990s (Zarsky 2003). According to Fayyad, "there were hundreds of millions of records-no human being could go through it all" (Waldrop 2001:online). The result of Fayyad's work at GM and the pattern recognition algorithm he created became the subject of his doctoral dissertation in 1991. Fayyad's work with GM is often cited as the birth of KDD. In the short span of a few years, data mining is now an integral method used in KDD or Knowledge Discovery in Databases. This technique has proliferated across disparate domains in society as molecular biology, the war on terror, and the National Basketball Association. Data mining can be used to map the human genome, predict terrorist attacks, or assist basketball coaches in assessing game data. An NBA coach commented that data mining is like having another coach on the team (Bhandari 1997). Giving data mining human abilities may not be far off as programs are made up of artificial intelligence, neural networks, and sophisticated algorithms. Data mining identifies patterns in databases of information. The technique can search within a given set of parameters and variables given by the user or it can “discover” hidden patterns and relationships between the data and make predictions (Zarsky 2003). In short, they can do what they are told by following a scripted narrative or become storytellers on their own. Internet companies such as Amazon use databases and KDD along with “recommender

programs” to offer customers additional buying options based on their purchases and other customers who have purchases similar items. This combination of technologies has also lead to “price customization,” where different buyers are offered different discounts or coupons based on their profiles and purchasing histories (Turow 2005).

The database as a communicative form breaks down the traditional transmission model of producer and user by using customer feedback mechanisms. Manovich (1999) calls the database “a new symbolic form of the computer age” (81). Like the novel and the cinema that came before, the database is “a new way to structure our experience of ourselves and the world” (Ibid). One of the main characteristics of the information age is the seemingly infinite array of texts and images that litter the sensual landscape in both the material world of our everyday experiences and the ever-expanding virtual world of the Internet. The Internet is the ultimate expression of database linking and feedback where consumers are producers. With its hypertext architecture, there is no linear path through the web. The linear narratives of old media forms are shattered in the “anti-narrative logic” of the web (Manovich 1999:82). The overall narratives are evolving with each user’s input. With discussion boards, chat rooms, and comment boxes, user feedback constantly pushes the discursive possibilities and actual boundaries of Internet websites. Manovich argues that the multiple and potential paths of a database are in contrast to the linearity of the narrative in old media. Users create “hyper-narratives” (87). Castells argues that it is not the centrality of knowledge and information that characterizes the current technological revolution, “but the application of such knowledge and information to knowledge generation and information

processing/communication devices, in a cumulative feedback loop between innovation and the uses of innovation” (Castells 2000:31). In this system, those who use technology and those who do things to technology become the same. Put another way, readers become writers and contribute their own nodes to a network of stories in an open-ended narrative (Landow 1992; See also Elmer 2004). For example, Wakeford (2000) suggests that browsing the Internet is also an act of production as there are multiple pathways within a website and also through the vast digital network of the web. Some argue, however, that databases are actually passive forms when compared to surfing the web (Elmer 2001:56). Customers merely input their data or it is done for them and they are disconnected from the production and articulation of the information. In terms of marketing databases, this may be true. The role of consumers is one of strictly inputting one’s details. This perspective points to the agency of the consumer, and not the nature of the database itself. Data has to be generated. Again, taking from the Internet, images have to be produced, audio and video recorded, web pages authored, and algorithms written. Data indexing has become a new profession. While databases and the Internet have opened up new possibilities for consumer participation, many have been warning about the increased surveillance capabilities of new technologies.

Databases have been key technologies in the increasing surveillance of society. From law enforcement to insurance to marketing, databases are used to sort, compare, rank, include, and exclude people based on any number of categorical variables and demographic data. This type of data management has been central to the modern practice of the management of societies and the process of normalization.

A central technique in the concurrent homogenization and individualization of society is data mining. Oscar Gandy (2002) calls the use of data mining the “panoptic sort” and suggests that data knowledge discovery in databases is the latest technology of surveillance. One of the central purposes of information infrastructures is for surveillance (Lyon 2002, 2003). Surveillance can include government records of citizens, DNA databanks, customer information collected and shared by companies, and employers monitoring employees. Different technologies are utilized to make up the information infrastructures such as CCTV, biometrics, and DNA. Biometrics is a technology of the present as it archives parts of the body previously collected from. CCTV is a technology of the present as it watches and records people and events as they happen. DNA is becoming a technology of the future with the focus on the predictive possibilities of people’s genetic code. Foucault (1978) has shown how surveillance was a central technique in the management of populations. Surveillance has increasingly become dependent on digitized information infrastructures “which simultaneously made them even less visible and even more powerful, and also produced some specific kinds of coding” (Lyon 2002:245). Dataveillance is the use of database technologies for surveillance of a population (Elmer 2004:75; See also Gandy 1993; Garfinkel 2000; Poster 1990). Again, the networking of databases strengthens the use of digital technology for knowing a population for the purposes of risk management and commercial exploitation. Companies and government have been developing sophisticated data mining techniques to analyze and create knowledge about consumers and citizens alike.

With information becoming central to the operation of businesses and organizations, data mining is increasingly being implemented in the everyday operations and cultures of many sectors. One of the primary areas of attention from scholars, policy makers, and consumers is marketing. Companies employ data mining to analyze data collected from customers' profiles and purchasing activities. Customers' are ranked and sorted according to a number of variables including the amount of money they spend at any particular website or their history with a company. Recently, Joe Turow (2005) recalled a discussion that took place in one of his classes called "Spam and Society." A number of the students asserted that they knew of instances where airline websites were charging new customers lower prices than returning customers. In 2000, Amazon.com was in the news for consumer profiling when it offered the same DVD to different customers at different prices. This sort of "price customization" is made possible through the commercial practice of tracking customers. Companies collect a number of different types of information (demographics, geographic location, shopping history, etc.) to try to identify and target the "best" customers. The others are relegated to lesser services, such when financial institutions score their clients and use friendlier scripts for the more desirable ones at their call centers or by excluding them from certain promotions or coupons (Turow 2005).

The emerging phenomenon of consumer sorting through multiple data points has also been referred to as *weblining* (See Chung and Grimes 2005; Gandy 2002; Stepanek 2000). The term plays on the concept "redlining," where, historically, racially segregated communities were cut off from banking and business insurance

services. In the late 1990s, as companies began to utilize the web to gather various sorts of information on customers for marketing and targeting, companies also used identity data such as race, gender, and class as sorting variables. Companies that sell marketing data would include such categories amongst others. For example, *Business Week* reported that Acxiom, a data brokerage firm, offered a service called Info Based Ethnicity System that could match someone's ethnic group against education, housing, and income (Stepanek 2000). Other, more innocuous forms of data mining are based on customers' purchasing history.

Recommender programs utilize data mining to offer products to registered return customers. The algorithms are based on individual choices and total customer purchases. For example, if I go to Amazon.com and sign in or simply browse the website from my home or office computer, which Amazon already recognizes me through cookies on my hard drive, a number of suggestions will be waiting for me. For example, after I purchased *Database Nation*, by Simon Garfinkel, Amazon 'noticed' that a number of other customers who purchased the same book also purchased Oscar Gandy's *The Panopticon Sort*. And there are a number of other books as well for me to peruse. The recommendations are always changing whenever I re-enter the site. Also, Amazon will send me an email alerting me to new releases based on my past purchases. For example, just today they 'noticed' that Graeme Meikle purchasers (*Future Active: Media Activism and the Internet*) are also Charlie Gere purchasers. Gere's *Art, Time, and Technology* comes out in paperback in a couple weeks and would I like to pre-order a copy?

Wal-Mart executives temporarily shut down their recommender program at the beginning of 2006 when it created a PR nightmare. Shortly after the new year, customers received emails with links to suggested movies. One of the DVDs on offer was a *Planet of the Apes* box set, which was linked to the main website at www.walmart.com. When customers looked up “Similar Items” at the *Planet of the Apes* page, they found all of the films offered were about African Americans, including civil rights leader Martin Luther King, Jr. Walmart reacted quickly, shutting down the “item mapping” program, and manually linking the box set to other DVD sets of *Friends*, *Everybody Loves Raymond*, and *Star Wars* (Kabel 2006). Part of the damage control strategy of Wal-Mart was to frame this occurrence as a “malfunction” and list a few other “random” matches that also occurred. Spokeswoman Mona Williams said that the company was “heartsick,” “horrificed,” and “deeply sorry.” Zarsky (2003) argues that automation of data mining should mitigate discrimination. When individuals make decisions in situations of surveillance, such as in the monitoring of a CCTV, they rely on cultural frames to make their decisions, a case of the “unequal gaze.”

By using KDD, the entire process is carried out via computer algorithms that present the final result without being manually focused on one group or another by a human eye or arm and after taking into account *all* available information. When applying data mining, the results of database analysis are balanced, displaying patterns drawn from the population in general that were chosen according to objective criteria and not subjectively driven. (Zarsky 2003:28)

Through clustering, rather than hypothesis-based classification, decisions are made by a computer based on several different types of variables. However, the Wal-Mart example shows how the information that goes into the choices of what clusters to

create is derived from socially produced sets of information. Data mining is dependent on social categories and cultural practices. Any neutrality needs to be encoded into the program first.

Race and Technology

An increase of interest in the social sciences and humanities into the social impacts of technology, especially the Internet, and the information society in the past two decades has accelerated along with innovations and transformations of the technology. Traditional questions about the nature of society, the relationship of the individual to social action, and social inequality have been transposed and reinterpreted for the new social conditions arising from globalization and the information age (Rasmussen 2000). Barry Wellman outlines three “ages” of Internet studies (2004). In the early 1990s, a euphoric interest in a new technology that was just making its way out of the universities turned into the dotcom boom of the mid-1990s. Wellman situates the beginning of the second age in 1998 when government, industry, and academia began to undertake systematic studies to move discourse and knowledge from praise to description. As the Internet grew and the dotcom bubble burst, the diffusion of the technology moved it from a plaything of computed scientists to a utility of the masses. Volleys between utopian and dystopian visions of the computer age abounded. Presently, the third age of the Internet involves much deeper analysis than standard social scientific data could produce in Age II, “with more focused, theoretically-driven projects” (Wellman 2004:127).

During the latter part of Age II, a small but growing interest in the interaction between race and technology emerged from parts of new media studies, cultural studies, and sociology. Evelyn Hammonds (1997) examined new computer programs that could ‘morph’ people from one race into another in Michael Jackson’s “Black or White” video and software used to create SimEve, a virtual woman made up of an amalgam of a number of facial features of different racialized groups. Rather than deconstructing biological notions of race, she argued that these “new technologies of race” in fact reinforced centuries old stereotypes of racial difference and cultural anxieties of miscegenation. Ideologies of bio-race were translated into the seemingly neutral space of the digital. Kolko, Nakamura, and Rodman (2000) build on the oppositional stance taken by Hammonds that race is neither biological nor genetic and bring together a number of authors who examine how race is articulated in cyberspace and new uses of information and communication technologies in online community formation. In spite of utopian visions of fluid online identities, the editors argue, “race matters no less in cyberspace than it does “IRL” (in real life)” (4). Herman Gray (2005) dedicates the last section of his recent book to the possibilities of cyberspace as a site for black cultural production of a critical counterknowledge. Gray’s work has long been concerned with the articulation of cultural representation and social structures in the realm of analogue (jazz), cable (television), and, now, digital (Internet) space. He argues that popular cultural forms are now translated, mediated, and transformed into commercial forms in the hypertext space of the Internet. African American groups such as the Afrofuturists, a movement made up of a loose collection of artists, musicians,

writers, and critics, utilize the global networked architecture of cyberspace to stitch together and create anew cultural production in the Black Atlantic.

Scattered across the vast geographies of the black diaspora, the only way to piece together the puzzle of black life and imagination is by way of the (re) assembly of the cultural equivalent of the Human Genome Project, a sort of sound archive in which the traces of a black presence can be recut, remixed, and reassembled not as the original but as something new. This is the work of the Afrofuturist. The digital information and communication technologies that make possible the storage, retrieval, production, reproduction, and manipulation of black soundings are their most important tools. (164)

As mentioned above, scholarship on new media, the Internet, and race is only beginning to emerge and, surprisingly, quite slowly. Lisa Nakamura's *Cybertypes* (2002) is the first full-length book study of race and technology. She refers to the transcoding of offline racial ideology and racism online as "cybertyping." Through an analysis of MUDs and MOOs, she found that cultural stereotypes of racial difference were reproduced in the chatrooms. While the Internet allowed for fluid performances of gender and race, usually in the form of identity tourism where users could 'act' a different gendered or racialized identity, participation often occurred through stereotypes. White people passing as black, for example, tended to "try on" and perform what they perceive to be signs of blackness, often relying on caricatures.

Scholarship on race and technology to date has extended issues central to cultural and media studies. In this regard, the Internet is studied in a manner similar to old media research. The traditional producer-message-audience model has been modified to fit new media, primarily the Internet. As discussed above, users are understood to be producers and audiences at the same time. While old media models tended to be linear in form, with variations in limited feedback mechanisms, the new

media model is an interactive network. Content remains a central object of study as identity formation shifts from social currents both on and off line. This loose connection of scholarship between race and technology tends to engage with popular forms and uses of new media, such as the Internet and mobile phones. However, the same technologies that appear on the surface of the information age and the ones that under gird it, such as databases, are ubiquitous across social institutions and private industries. The social shaping of new media beyond popular culture could provide crucial insight into the role of technology in identity formation. This type of research has been the domain of sociology and some aspects of anthropology, especially the work associated with STS. In turn, cultural and new media approaches could be utilized in such a study to bring a focus institutional power, and the social construction of racial identity.

The Information Society, Critical Race, and Science and Technology Studies

Scholarship on the information society examines changes in technology and its impact on society well, but does not tend to engage questions of race and racism. Cultural studies and critical race theory has identified many mechanisms in representation, theorizing the nature of race and the shifting racial order, whether in the media, popular culture, or the law, that make up racialized identities. However, this body of work has not paid particular attention to emerging mechanisms shaped by new technologies and the information society. As Leger (2005) has pointed out, there is a disjuncture between the cultural studies of science and medicine and science and technology studies (STS) in regards to the object of investigation. The

former is interested in the representation and production of medical and scientific knowledge (Treichler 1999; Treichler, Cartwright, & Penley 1998; Haraway 1997) while the latter places priorities on the production of scientific knowledge in labs, clinics, or the field (Rapp 1999; Rabinow, 1996; Latour 1999; Pickering 1995; Latour & Woolgar 1990; Fujimura 1996). This dissertation is concerned with both foci: How scientific knowledge produces and represents race through the shaping of new communication technologies.

In studying how science and scientists construct racial knowledge one may see an alternative in STS to a cultural studies approach that largely focuses on representation in media and popular culture. However, while STS has developed a critique since the 1970s of the construction of knowledge in scientific settings, essentially unveiling the black box of science, and the social construction of technology, race has largely been absent. M'Charek has noted that while studies of gender and technology have become well established in STS, there is a virtual absence of studies about race and technology (2005:165). A survey of a leading journal in STS, *Science, Technology and Human Values*, shows only a handful of articles on race since 1999.³ The last meeting of the largest STS association, the Society for the Social Study of Science, in 2005 still designates a "race" panel, a special session rather than an object of study in the fabric of STS.⁴ A recent survey

³ STHV articles and abstracts are only available online from 1999 onwards.

⁴ The 2005 program for the SSSS conference held in Pasadena, California, shows only two panels that deal specifically with race or racialization. One panel is simply titled "Race" (the race panel) and the other, "Race, Genetics and Diseases: Questions of Evidence, Questions of Consequence". The 2006 program to be held in Vancouver, Canada, was not available at the time of writing this dissertation.

text on STS by Bauchpies et al (2006) only mentions race a few times in their discussion of the field. Race is treated in an “add-and-mix” fashion and is usually sandwiched in a manner typical to STS, “gender, race, and class.” Apparently, in the decades of STS research, there is not enough material on race, science, and technology to warrant a full chapter discussion. This seems odd considering the work of Haraway (1989, 1997), Harding (1998), and Hammonds (1997), for example. One of the defining characteristics of cultural studies since the late 1970s has been its focus on race along with other identities of difference, class, gender, and sexuality. What critical race theory has failed to address is the staying power of race as an organizational concept in society, the lived experience of everyday people and a fundamental classification of knowledge in biomedical science. As Fausto-Sterling emphasizes, race is a “concept that refuses to die” (2003:2). The trouble quotes have gone up and come down and race is still with us, no matter how much social construction, deconstruction, historical materialism, and postmodernism has been thrown at it.

Scholarship on science, race, and society has investigated the relationship between racial ideology and scientific knowledge in terms of eugenics and race (Duster 2003a; Gilman 1985; Gilman 1988; Haraway 1997; Holtzman 1999; Kevles 1985; McLaren 1990; Paul 1998; Van Dijck 1998), intelligence (Gould 1996; Lewontin, Rose, and Kamin 1984), and the ownership of human DNA (Nelkin and Andrews 2003; Nelkin and Tancredi 1989; Poudrier 2003). Recent scholarship focusing on forensic science and DNA racial profiling (Cho and Sankar 2004; Duster

2003b; Ossorio and Duster 2005; Sachs 2003), pharmacogenomics and BiDil (Duster 2003a; Kahn 2003, 2004; Lee 2003; Lee, Mountain, & Koenig 2001), and genome projects (Duster 2005; Reardon 2005) has examined the reemergence of race as a biological category in biomedical research and the implications of this process for health, identity, and society. However, crucial emerging questions need to be answered about how current trends in DNA research are utilizing communication technologies and old conceptions of race to produce new types of racial knowledge in the socio-political contexts of the information society and the dominant racial ideology of color-blindness. Paul Gilroy (2000) suggests that new scientific technologies are “prosthethically extending sight into nano-scales and can be linked to the impact of digital processing and other allied approaches to the body that allow it to be seen and understood in new ways, principally as code and information... skin, bone, and blood are no longer the primary referents of racial discourse” (44, 48; See also Nelkin and Tancredi 1989:15). Race is being constructed in terms of genetic information, rather than the traditional markers of skin, culture, or nation. The new genetic research is bypassing the skin in its search for the truth of who we are at the molecular level. Digital imaging is re-imagining the body as code and information, rather than flesh and blood.

The boundaries of “race” have now moved across the threshold of the skin. They are cellular and molecular, not dermal. If “race” is to endure, it will be in a new form, estranged from the scales respectively associated with political anatomy and epidermalization. (Gilroy 2000:47)

Gilroy refers to the process of constructing race at the genetic level as the molecularization of race (See also Fullwiley forthcoming). While discoveries are

being made to cure before untreatable diseases, the interaction between culture, technology, and science in genomic research has opened up old questions about the biological validity of race, the role of race in science, and science's role in the construction of race. Instead of finding evidence that we are all indeed the same beneath the skin, genomic research is attempting to discover new (and not so new) differences based on old assumptions (Duster 2003a:146). Both Gilroy (2000) and Duster (2003a) point to the relationship between the knowledge of genetic research and the technologies that make the body, below the skin, able to be seen.

Genomic research is only in the beginning stages and the social uses and consequences of this new 'truth' of the human body are in their infancies. Recent developments in DNA research concerning the biological basis of human differentiation shows that new scientific technologies are envisioning the body as genetic code, rather than skin, hair, and facial features. Race is being constructed in terms of information, rather than the traditional markers of skin, culture, or nation. Genomic research of identified population groups is producing scientific, medical, and forensic knowledge about variation between groups and how genetic variation may contribute to differential behavior. Each of the above research traditions has their own approach to the study of race, technology, science, and society. Separately, however, they miss a crucial new trend that is emerging with the impact of new communication technologies on the social construction of racial identity.

The informationalization of Race

A new emerging process of racial signification is characterized by the creation and deployment of informational codes that do not make reference to phenotypic notions of race (color of skin, shape of eyes, texture of skin), culture, or national identity, the traditional markers of racial difference. Instead, the social construction of race is becoming a process where information is the material by which social, economic, and political meaning is worked on. I call this phenomenon the informationalization of race. Race as culture emerged from race as biology and race as information comes from both. Social organization, symbolic flows, and human action are produced racially without reference to biology or culture. The informationalization of race is *not* replacing its reference to ethnicity or skin colour. It is moving alongside them while continuing to use them as points of signification. Meaning and action in social, political, juridical, scientific, and other institutional contexts is still overly dependent on skin colour and cultural and national markers. While race is by no means finished with phenotypes or culture, it is not always reliant on them either.

What distinguishes race as information from other modes of racialization is the transformation of society due to globalization, the new economy, and ICTs. Racial identity, meanings, and structures are being created in terms of information collected, stored, and analyzed through the use and shaping of communication technologies.⁵ Of particular interest are innovations in computing, databases, data

⁵ Information and communication technologies is an umbrella term that refers to recently developing forms of electronic communication, including computers, microprocessors, databases, digital imaging systems, the Internet, wireless telephony, satellites, fax machines, and fiber optics. They are intentionally separated from

mining, and the Internet. I take the position that new communication technologies increasingly make up central systems in which racial meanings are created, transformed, and destroyed, to borrow from Omi and Winant, and social action is enabled and constrained. This networked system is not simply a delivery tool for ideas and meanings, its very structure and scope, both hypertext and globally linked, is productive of new mechanisms of racialization. Whereas traditional conceptions of race have been formed around points of culture or biology, modern procedures of collection, classification, storage, and processing of information are having racial outcomes. Instead of examining representation in television, film, and news, the concept of informationalization of race focuses on the discourses produced in the hypertext communication environments of computers, databases, knowledge discovery in databases (KDD) or data mining, and the Internet. Before we can look at the technology, however, the term “informationalization” requires some elaboration.

The term “informationalization” builds on the insights of the literature on the information society that examines the shift in societies from industrial economies to services economies due to the restructuring of capitalism, the new technological paradigm, and globalization (Webster 2002). Informationalism is a “specific form of social organization in which information generation, processing, and transmission become the fundamental resources of productivity and power” (Castells 2000:21). Communications and technological systems are increasingly the sites where power is

traditional communication technologies, such as the telegraph, analog telephones, and television, as they emerged during globalization.

enacted, circulated, and contested. Whether power is nowhere and everywhere in a web of discourses (Foucault 1978) or held and exerted within the structure of the network (Rentenan 2005), different forms of media, old and new, makeup the technological, economic, political, and cultural spheres of influence. In the changing communication systems, the media plays a central role in representation and consumption (Collins 2004; Gray 2005). For example, Mackenzie (2003) questions the usefulness and point of tracking computational processing of sequence data: “Does not bioinformatics merely support the more decisive intellectual, social, political, cultural and economics events associated with contemporary biology and genetics” (316)? Mackenzie’s question points at key issues to STS and new media studies. Understanding the relationship between technology and society or science and society does not only mean looking to the practices within scientific and technological development. A sociologically informed analysis looks beyond these internal questions to the social context in which institutions operate. The turn to information in science in other domains in society expresses particular transformations in the location and production of power. The research in this dissertation examines the nature of information and its relationship to power and the ‘reality’ of the social world.

The concept of information denotes a neutral set of facts, data, or observations. When information is networked and takes on the form of an information infrastructure, such as when databases are compiled and linked or the seemingly endless pathways of the World Wide Web, it should not be treated as having a simply reflective role in the social world. Like other media forms (news,

television, film) information infrastructures do not just support cultural, political, social, and scientific processes. They play a constitutive role.

It is politically and ethically crucial to recognize the vital role of infrastructures in the 'built moral environment.' Seemingly purely technical issues like how to name things and how to store data in fact constitute much of what we have come to know as natural. (Bowker and Star 1999:326)

Technologies and the classification systems that utilize them tend to make invisible the myriad of decisions that create them.

That is, the arguments, decisions, uncertainties and processual nature of decision-making are hidden away inside a piece of technology or in a complex representation. Thus, values, opinions, and rhetoric are frozen into codes, electronic thresholds and computer applications. (Bowker and Star 1999:187; See also Garfinkel 2000)

Put another way, the seemingly descriptive representations derived from information infrastructures in fact naturalize a whole set of practices, procedures, and ideological premises.

Looked at historically, information seems basic to social life. In oral cultures, stories and ancestral anecdotes ensure that people know about reality, and some of this involves what might be called 'natural' signs to do with, say, weather or hunting. In modern, literate cultures, artificial signs proliferate, and are frequently associated with social order itself. Signs tell us of distant events, places, persons and processes. Information is relational, connecting by reference persons and things. Intelligence is assumed, as are the reality of things and contexts. But whereas information might once have thrown light on reality, or even, through instructions or recipes, contributed to the transformation of reality, once technological devices become the predominant carriers of information, the distinctions blur. (Lyon 2005:225)

The oral stories and cultural signs that have told us and continue to tell us about the social order, including the racial order, are now not only mediated but created in communication technologies but through informational codes. The informationalization of race acknowledges that race as a structuring device in society

has not diminished in importance with the information age and has continuity with modernity. While at the same time, this research seeks to examine how innovations and applications of communication technologies and the rise of information have produced new mechanisms of racialization in a post-civil rights context. There are a number of institutions where we can see the informationalization of race at work, such as law enforcement, biomedical research, insurance, and marketing. While each would have their own set of technologies for information storage, classification, and surveillance, they have increasingly employed a similar array of technologies to their own institutional needs. For example, where the microscope has been a central observational tool in the biomedical sciences, actuarial tables in insurance, and fingerprinting in law enforcement, data mining techniques and the technological infrastructure that it requires is commonly used across these different institutions. Communication technologies play a leading role in the everyday practices and organization of a range of social institutions and industries. This dissertation will develop a case study of human genomics to understand the specificities of the informationalization of race in one institutional setting. While scientists debate the accuracy or inaccuracy of scientific data, which is the outcome of computational and statistical routines, we might back up and examine how those outcomes stitch together cultural assumptions, molecular particles, microprocessed bits and bytes, and historical context.

Conclusion

This chapter has explored the theoretical terrain of the areas of race and technology and suggested how social and technological transformations have produced a new form of racial difference, the informationalization of race. The informationalization of race articulates how race is being constructed out of information and informational processes that are the product of technological developments and innovations, globalization, and colorblindness. Investigating strategic sites is central to understanding what the key mechanisms are in this process and how and where they are taking place. As I outlined above, genomics is a critical site of knowledge production of the informationalization of race. Genomics and the HapMap Project are products of the information age. This dissertation's examination of the informationalization of race in genomics is three-fold. The following chapters will examine the technological, legal and institutional, and cultural dimensions of genomics using the HapMap Project as a cases study. Technological innovations are increasingly becoming ubiquitous in the development and management of most domains of society. It is becoming difficult to discuss social organization without including the role of technology. However, technological innovation does not take place in a vacuum and needs to be understood in terms of the changing historical frameworks, especially in terms of regulatory changes in governance and the law. Equally important in this contest over the structure and meaning of genomics is culture. Discursive frameworks about race shape not only how the data is reported and knowledge is produced, but influence the questions being asked, the designs of studies, especially big science genome projects such as HapMap, and the meaning of

the human body at the molecular level. A first level of research design may pose culture as the dependent variable, viewing racial categories as being acted upon by scientific processes. However, cultural understandings of race deeply influence how the scientific process is carried out.

Chapter 3

Techno Genomics:

The Digital Shaping of Biology and the Rise of the Database

Through the 1970s, a small group of individuals began to realize that computers and sequence information were a natural marriage. Bride and groom struggled to overcome vast cultural differences. Computer scientists and molecular biologists traced their lineage through difference tribes, with vastly different norms, and only a few hardy souls could converse in both languages and command respect in both communities. The database that stored sequence data became their meeting ground.

(Cook-Deegan 1994:285)

The fact that the development of computer technology, with its demands on information theory, has occurred contemporaneously with the growth of molecular biology has not merely provide the physical technology, in instrumentation and computing power, without which the dramatic advances of the decades since the 1960s would not have been possible. It has also given the organising metaphors within which the data was analysed and theories created.

(Rose 1997:120)

The discovery of rDNA in 1973 provoked a paradigm shift in the institutional goals of biology. Instead of studying how things worked, scientists could begin to manipulate the molecular structure of organic life through the transplanting of genes. This watershed moment in the history of biology and genetics marked a change in biology from an analytical science to a synthetic one and the beginning of genetic engineering (Krimsky 1999). New organisms could be manufactured and biological products could be mass-produced. The cutting and splicing of different strands of recombinant DNA opened up infinite possibilities and the imaginations of scientists. The implications for science, society, and governance were not lost on scientists in the biomedical sciences. Foreseeing the gravity of re-producing and altering nature, a

number of scientists met at the Asilomar Center, nestled in the evergreen trees and the sea mist of the west coast of California in 1975. “Asilomar,” as it has come to be known (which means ‘refuge by the sea’), was organized by a group of scientists lead by Paul Berg, a Stanford biologist and an early leader on potential risks of rDNA, and attended by over 140 participants, mostly made up of biologists, but also some doctors and lawyers and more than a dozen journalists (Barinaga 2000). This was a particular moment in the history of biology where scientists engaged in self-governance and reflected on their social responsibilities.

The main discussions revolved around the creation of guidelines and principles for the safe handling of recombinant DNA molecules and how to contend with possible government regulation. On the one hand, scientists were worried that a dangerous bacterium could walk out of a lab on the bottom of someone’s foot. On the other, the institutional fears of the scientists were that Congress would step in to allay public fears about the unknown consequences of genetic engineering. They were concerned about how the type of social panics, as seen in response to chemicals such as lead or asbestos, would provoke the government to institute strong and inflexible regulations from without rather than from within the scientific community. Government directives would weaken the legitimacy of molecular genetics and hamper its progress, thus reducing autonomy in assessing and managing risk and a principle research method (Krimsky 1991). The key body to manage the guidelines that came out of the Asilomar conference and alleviate the concerns of government regulators and the public was the National Institutes of Health. According to one of

the co-organizers, Robert Sinsheimer, Asilomar “helped in many ways to launch the complex world of biotechnology we know today” (Quoted in Petsko 2002:1).

The world of biotechnology has indeed become a complex one. The issues that scientists discussed at Asilomar, while progressive in terms of the ethics of scientific research and self-governance, were much simpler in 1975. The academic oriented, inward thinking concerns of scientists studying and creating a technology that was just beginning to be imagined have moved outside the academy into biotechnology companies. While a number of the academics have joined the private sector, the entire discipline imagines itself beyond the university lab as the primary location of the enterprise. Genetic technologies have developed alongside and with innovations in information and communication technologies. Government bodies, activists, and corporations have dismantled the type of self-regulation that scientists were used to operating in. Issues of ethics, law, and society are no longer the sole domains of the scientific community. A few of the original attendees returned to the seaside center in 2000 to discuss the current state of genetic engineering. Only this time, the meeting was organized by internationally recognized legal scholar, Alex Capron, and included panels featuring sociologists, journalists, and activists from NGOs (Barinaga 2000). Finally, the scientific community has also been forced to incorporate cultural concerns into the core of their discussions. Previously marginalized groups such as women, gays and lesbians, and racial minorities have insisted that the scientific process become more attentive to social concerns and more inclusive of diversity both in the minting of new scientists and expanding the core of research subjects and issues outside the white male norm. Bioethicists,

advocacy groups, and scholars across the humanities and social sciences are active members of large scientific projects, especially ones that pertain to human genome research such as the HapMap Project. Biologists can no longer seek a ‘refuge by the sea.’

Genomics is an important domain in which to study the informationalization of race as it has come to embody these technological, institutional, and cultural changes. Building on the history of population genetics, physical anthropology, and molecular biology and aided by developments in communication technologies and computer science, genomics is the “comprehensive study of all genes” (Interview 1001; Interview 1022). In contrast, the traditional domain of genetics is on inherited differences in specific genes, such as from parent to child. The “omics” in genomics is to be comprehensive, while genetics focuses on individual genes. A genetic approach to studying the long strands of DNA that are the building blocks of life differs from genomics in that the objects of study are individual genes. The HapMap project will allow for an in-depth analysis of the building blocks of this dissertation and the concept of the informationalization of race, the three broad areas of change (technological, legal/institutional/cultural) that make up the substance of the next three chapters. Chapter four will map out the changing landscape of regulations that govern genome research in particular and biotechnology more generally. Chapter five will explore the culture frameworks and discourses of race that are being negotiated around genomics.

The present chapter will examine the technological changes in genome research due to the convergence of the biological revolution and the new

technological paradigm. The outline of this chapter is three-fold. First, I explore how developments in biology have interacted with innovations in computing to become an informational science. Second, I show how databases and data mining techniques have become central tools to store, search, and analyze digital DNA data in the convergence of biology and information technology. There has also been a proliferation of DNA databanks at the national and global levels. Finally, I will discuss how the Internet has changed the practice and culture of genomics through the networking of labs and scientists, the form and function of genetic data, and issues of intellectual property.

From Analytics to Synthetics, From Wet to Dry labs: Biology Becomes an Information Science

Many molecular biologists who welcomed the Human Genome Initiative undoubtedly believed that when the genome was sequenced, everyone would return to the lab to conduct their experiments in a business-as usual fashion, empowered with a richer set of fundamental data. The developments in automation, the resulting explosion of data, and the introduction of tools of information science to master this data have changed the playing field forever. There may be no 'lab' to return to. In its place is a workstation hooked to a massively parallel computer producing simulations by drawing on the data streams of the major databanks and carrying out 'experiments' in silico rather than in vitro. The results of biology's metamorphosis into an information science just may be the relocation of the lab to the industrial park and the dustbin of history.

(Lenoir 1998:41)

The transformation of biology was clearly on the minds of the scientists who met at Asilomar to discuss how to protect their discipline from the government as well as society from new and possibly dangerous bacterium. Like the damp surroundings of the conference though, their visions were probably those of the wet lab. Not far from

Pacific Grove another revolution was underway in the Silicon Valley that would make possible the dramatic developments in molecular biology that we are beginning to take for granted today. An electronic revolution that clustered around a number of different technologies, such as the microprocessor, microcomputer, resulted in a new technological paradigm that has become an inextricable aspect of the information age. They have become “two of the most important modern technologies, gene technology and information technology” (Burnett and Marshall 2003:57). Biology has not only developed alongside the electronic revolution, but it has fused with innovations in computing, software, and data management, becoming as much an information science as a biological one (Capra 2002; Marturano 2003, 2004; Interview 1011). In short, the wet labs have increasingly shared (and given up) space with the dry labs of bioinformatics, computational biology, and genomics. An example of this new configuration is the newly built Molecular and Computational Biology Building at the University of Southern California. The focus of the building is genomics and brings together molecular and computational biology research, which had already merged formally. The first two floors house the wet labs of molecular biology. On the third floor are dry labs designed for an emerging type of biologist schooled in both experimental biology and computational biology. Finally, the fourth floor comprises of a number of computational suites for scientists to mine the loads of data produced by the first three floors. When it opened, USC university President Sample commented that the new building is not simply about new office and lab space, it “will be a complex and interdependent ecosystem of scientific creativity and invention” (Emerson 2005:Online). In these new spaces of scientific

innovation, biologists, computer scientists, and engineers work side by side, borrowing methodologically, theoretically, and culturally. In the process, biology becomes bound up in data.

As modern science has increasingly relied on computer simulations, computational models and computational analyses of large data sets, scholars argue that this process has led to a theoretical convergence between information and genetics technological fields (Gezelter 1999; Haraway 1997). Since the 1970s, there have been massive transformations in the fields of biology and micro-electronics that have grown from convergence to interdependence. Key innovations in biological research into genetics and the burgeoning field of genomics have only proceeded because of innovations in supercomputing. Interviewees from the HapMap project unanimously agree that there could be no new genetics without computing science. Marturano (2003) suggests that human genome projects are not only biomedical projects, but bio-informatic ones as well. Genetics, considered to be the realm of human blood and protein function, is not entirely independent from microelectronics, the world of processors and bytes. Genetics technologies are obviously information technologies, since they are focused on the decoding and eventually reprogramming of DNA, the information code of living matter (Burk 2002). Genetics would not have advanced at the pace or with the intensity it has in the past twenty years without advances in computing. Further, specific projects, such as the HGP would simply not have been possible without the aid of computers, especially database technologies and data mining techniques that were not even in existence in the early conceptual stages in the 1980s.

A philosophical problem arises from the view that DNA and the Human Genome are pure informational concepts. The convergence between the biological and computing might be argued as an instrumental association with the massive use of computer technologies in biology. That is, computer technologies are simply used as tools and are purely external entities to biology. However, Holdsworth (1999) suggests, “It is not just that computer tools are rather convenient for doing genomics and protein sequencing. Rather these... disciplines have re-organised themselves around the bioinformatics paradigm” (85). This convergence has incorporated Shannon and Weaver’s (1949) notion of information that views all information as capable of being broken down into discrete quantifiable bits that can be measured and analyzed (Lyon 2005). Genome science begins from the position that the human body and, specifically, the human genome, can be perceived as information. The genome is a long string of information that can be managed and understood through identification and analysis of the different parts of the genome, whether those parts are whole genes, haplotype blocks, single nucleotide proteins, or base pairs.

Genome science has emerged as the next wave of human scientific research. Derived from molecular biology, genomics became widely known for the Human Genome Project. As Francis Collins, the Director of the National Human Genome Research Institute (NHGRI; one of the National Institutes of Health) states about the future of the genome,

Genomics has been at the forefront of giving serious attention...to the impact of science and technology on society. Although the major benefits to be realized from genomics are in the area of health...genomics can also contribute to other aspects of society. Just as the [Human Genome Project] and related developments have spawned new areas of research in basic

biology and in health, they have also created opportunities for research on social issues, even to the extent of understanding more fully how we define ourselves and each other. (2003:483)

Evelyn Fox Keller (2000) has illustrated how gene talk became firmly embedded in scientific as well as popular discourse over the last century; the twentieth century was the century of the gene (See also Gelbart 1998). As genomics moves from mapping to function, from being just a tool to a working process and as scientific research and discourse turn to the genome to find solutions to widespread health problems and the code the human network, then the twenty-first century could quite possibly become the century of the genome.

One of the world's foremost geneticists stressed to me the under appreciated role that communication technologies play in the development of genomic research (Interview 1001). He often points this out in his lectures to students. The amounts of data that are required to map the human genome and haplotype blocks have previously made research of this scope and magnitude prohibitive (Interview 1005).

Well I don't think we would be able to do it if it wasn't for technology. Because the genotyping technology is so advanced and so high through-put and there is such a large amount of data that if we didn't have the computers and bio-informaticians and databases to process all that data, it wouldn't be feasible by hand. (Interview 1003)

This opinion was widely shared, if not unanimous, among HapMap participants.

When asked about the impact of communication technologies on genome research the first words used to describe them were "central" (Interviews 1001, 1002), "essential" (1005, 1009, 1013, 1014, 1017), "paramount" (1010), "fundamental" (1016), and "foundational" (1005).

Oh they're absolutely essential. I mean we couldn't be doing nearly what we're doing in genomics without computers. In fact, I think they're foundational. (Interview 1005)

You just cannot do genome science without the use of the technologies that have been developed to handle the very workload. (Interview 1006)

[T]he Human Genome Project would essentially be inconceivable and not-doable without...computer technology. (Interview 1014)

A vast network of scientific centers are scattered across the globe. Genome scientists piece together the “blueprint of human life” by way of the assembly of the haplotype blocks of “major geographical groups,” as they are named in the project, a database of the evolutionary traces of DNA histories. Each team of the HapMap project sequences a portion of the genome, such as Chromosome 2 and Chromosome 4p by the McGill University/Genome Quebec group in Canada, Chromosome 7p by the group at Washington University in St. Louis and the University of California at San Francisco, or others, both academic labs and biotechnology companies, in China, Japan, and the United Kingdom. The data from each group is collected, curated, and stored for distribution in a database in Bethesda, Maryland, at the National Institutes of Health and released online over the Internet for public access within twenty-four hours. The most important tools for these scientists are the digital technologies that enable them to produce and reproduce, store, retrieve, and manipulate genome sequence.

Developments in computer power, databases, and the Internet have made the archiving, management, and distribution of the vast amount of data possible not only in local labs and internal networks, but on a global scale. Genome research produces enormous amounts of data that bench scientists could never analyze by hand and

“would be simply impossible to process without computers” (Interview 1009). This includes statistical calculations, which have required the development of new algorithms and software. Biologists are not traditionally quantitative and are unaccustomed to working with such large data sets.

And there has been over the last decade increasing, a trickle first and then increasing in flux of computationally sophisticated people into the field who have brought with them sophisticated computational methods for data mining and data analysis. But there’s still a big divide that exists between most working biologists and any of those methods. And so it requires not just an intellectual shift, but also a real cultural shift because biologists are used to... the limiting step being their ability to collect data with their hands. (Interview 1001)

This shift from observation to a “data-bound science” (Lenoir 1999:35) is at the core of the transformation of biology.

The cultural shift in biology originates in the team-based approach to genomic research. Genomics generates enormous amounts of raw data that a single person cannot make sense of on her own. A scientist at the NIH working on HapMap recalled how painfully slow the labor of aligning sequences was when he first began genetic research (Interview 1016). Computational techniques such as computer algorithms and data mining have made significant impacts on this process.

Sequence reads tend to be fairly short stretches of 500 to 1000 base pairs of DNA, and yet you want to make a single, continuous sequence read for an entire chromosome, consisting of hundreds of millions of base pairs of DNA. And so that software was, without doubt, absolutely essential. (Interview 1014)

The days of the individual scientists working in isolation in her lab, scribing notes and models in a notebook, have given way to multi-disciplinary teams of researchers. For example, the HapMap Project is made up of biologists, geneticists,

statistical geneticists, doctors, legal scholars, bioethicists, bioinformaticians, anthropologists, and sociologists. As this consortium of experts shows, a broad range of knowledge is needed to conduct large-scale genome research. As the inclusion of social scientists in the list of personnel shows, a significant part of the research team belongs to the Ethical, Legal, and Social Implications (ELSI) committees. Team-based projects are often focused on a particular problem and located in a particular lab or located across a number of different centers, often in different countries, sharing information in a common, digital database. The database itself may be curated in a university lab, accessible only to the project group, or in a centralized location, such as the National Institutes of Health, open to the public, and accessible to various research teams around the world. As the interviewee commented above, genomics requires computers and programs that biologists are not familiar with. Biologists and computationalists, or bioinformaticians, work together, but with skill sets that, usually, do not overlap.

...the computationalists, who often have techniques, don't have any idea what the interesting questions are because they're not biologists. So it inevitably leads to maybe some day, all this will become codified enough that single people, single investigators will have all the capabilities they need to do all the genetics and no biology and no computation. Probably there will be a new generation trained that can go back to being more individualistic. But for now there's no one out there who's really good, who knows all these things. And it may be that no one ever does know all these things, because there's too many things to know. (Interview 1001)

Teams can be as small as three or in the hundreds as in the case of big science projects such as the Human Genome Project. While the cultural shift in biology is embodied in the team-based approach, institutionally the domain has become 'big science.' Big science projects differ from team-based projects simply in the sheer

numbers of researchers needed to tackle a project and the cultural shifts in the latter described above. Big science can be team-based, such as the HapMap Project, or it can be mono disciplinary (Interview 1001). Evidence of biology becoming big science includes the standardization and routinization of particular practices (Jordan 1998). The farming out of “cookbook techniques,” that is, techniques that have become routine practices and procedures, is viewed as a sign of a successful science (Gilbert 1992:93). Biotechnology companies now specialize in practices such as sequencing and provide outsourcing for techniques that used to be performed by skilled researchers. There are a number of biotech companies, such as Illumina, Sequenom, and ParAllele, which were genotyping centers in the HapMap Project. The industrialization of biology has not completely left academic labs. A senior scientist at one of the world’s largest biotech companies expressed concern that graduate students were not only in the lab to learn the craft of science but as a “pair of hands” (Interview 2001). They are being used “like cheap labor” to further some professors’ own, private sector oriented goals.

The interaction of computer science and molecular biology that characterizes genomics has moved biomedical research to computational biology (Interview 1006). While scientists’ definitions of genomics focus on the way that they approach studying the genome, they seldom include a nod to technology even though genome study has moved from theory to application only through digital technology. Leroy Hood, one of the scientists who attended the early Human Genome Project meetings in the 1980s and the leader of the CalTech team who invented one of the most important technological developments in genomics, the protein sequencer, noted that

many biologists are “indifferent to technology - they use it, but they don't really see it as a fundamental part of biology. Indeed, it is new or more sensitive technology that can open up new horizons in biology” (Hood 2001:Online). While an argument for technological determinism would be misguided as the science and motivations derive from human actions, it is clear that genome research in particular and molecular biology more generally are not only expressions of advancements in scientific discovery, but of computing technology.

I think that in fact in many circles genomic research has been discussed as developing out of DNA technology. I think it is fair to say that the entire concept of genomics, which is really one of data rich studies in biology where you have archival quality data that is comprehensive and is shared freely, is as much about, if not more about, computers and the Internet as it is about DNA technology. (Interview 1001)

Accordingly, a number of respondents agreed that the impact of genomics would be trivial compared to what it is. Two technological developments in particular were commonly discussed among HapMap participants, databases/data mining and the Internet. New databases have been designed to store, analyze, and distribute the data and findings. Data mining techniques and “large, easily-accessible databases that would allow the extraction and comparison of data was absolutely essential for being able to put together any kind of sequence database” (Interview 1014). The Internet enables genome projects to move data between global locations and labs in the same building as well as provide open access from anyone interested in the information. The HapMap Project follows an open access approach to data by making the findings available publicly on the Internet within twenty-four hours of the data being collected from the multiple sites. The Internet has increased the ability of scientists

to undertake international collaborations. Also, new technologies have played an integral part in restructuring paternal models of consent.

Data Mining the Code of Human Life

One consequence of the human genome project is that we will see more and more clearly how connected all life really is... The data base of the human genome... promises to reveal patterns of genes and to show us how we ourselves are embedded in the sweep of evolution that created our world.
(Gilbert 1992:97)

Through the 1970s, a small group of individuals began to realize that computers and sequence information were a natural marriage. Bride and groom struggled to overcome vast cultural differences. Computer scientists and molecular biologists traced their lineage through difference tribes, with vastly different norms, and only a few hardy souls could converse in both languages and command respect in both communities. The database that stored sequence data became their meeting ground.
(Cook-Deegan 1994:285)

The information processing techniques of data mining and knowledge discovery in databases have become widely used in biology, and especially in human genetics and the emerging field of genomics. Data mining is the digital technique of reading databases, creating stories, and drawing pictures from their content. Hine refers to them as “new communication regimes, new forms of collaboration and new spatial organizations for science” (2006:270). Biologists began using computers to study DNA in the 1970s. With the development of computer processors, software, and complex algorithms, scientists have been employing the same techniques for analyzing data in databases as commercial companies and governments. This new scientific process is called “discovery science” and is largely credited with the success of the Human Genome Project and no the HapMap Project. Much like the basic assumptions of data mining described above, discovery science is “the idea that

you take an object and you define all its elements and you create a database of information quite independent of the more conventional hypothesis-driven view” (Hood 2001:Online). In contrast to the meticulous method of making theoretically sound hypothesis before collecting and analyzing data, discovery science is more of a collect first and asks questions later approach. According to Leroy Hood, the genome posed such technological problems not only with sequencing and mapping, but also in computation and analysis that a new paradigm, discovery science, was needed to tackle the enormous obstacles posed by creating and analyzing a comprehensive database. The process of discovery science looks quite similar to “enterprise’ systems in other domains such as eBusiness and eCommerce where linking diverse databases and processes (customer data warehouses, billing and auditing software, just-in-time scheduling and inventory systems, reporting systems, delivery tracking processes, online web sales, etc.) has been the object of intense activity over the last decade” (MacKenzie 2003:328). Innovations in database and computer technology utilize shared application across disparate sectors such as insurance, book sales, and genomics.

KDD is a central technology in genomics where theory meets practice. Lenoir (1999) describes computational biology and bioinformatics as the theoretical and instrumental/experimental components of genomics. The database is where they come together to construct scientific knowledge through the core technique of data mining. The development of this relationship was key to the success of the Human Genome Project. The data mining technique developed by Craig Venter’s team at Celera, the private firm that co-sequenced the human genome, is the Shotgun

method. The Shotgun method takes random cloned sections of a genome and sequences them. A computer takes a number of these partial sections, rearranges and stitches them together to form a complete sequence. Since the geneticist works at an abstract level, much like software developers, the time-consuming work of mapping is eliminated. Venter's contribution to the mapping of the human genome sped up the actual process of completing a working map of the human genome, and compelled Celera's public counterpart the HGP, led by Francis Collins, to accelerate their approach. The result was an announcement by President Bill Clinton of the completed draft of the human genome in 2001, four years ahead of schedule. Despite the joint announcement that was largely a media event featuring Collins, Venter, President Clinton, and Prime Minister Tony Blair beamed in via satellite, the Human Genome Project was the most spectacular manifestation of the methodological, theoretical, and technical convergence between the fields of genetics and information.

Databases, dbSNP, and the DNA banking system

The databases built from the Human Genome Projects are only two among a boom of DNA databases, databanks, and population databases that has occurred in the last decade. The Department of Defense (DoD) collects DNA from all troops to identify remains, police departments collect DNA from suspects and convicted criminals, the federal government collects DNA, Iceland maintains a DNA databank of its entire population, and Latvia has its own genome project. Databases of human DNA, sort of personalized bar codes, have become ubiquitous in the modern age for managing

populations for crime, health, and science. Foucault argues a surveillance system “compares, differentiates, hierarchizes, homogenizes, excludes. In short, it *normalizes*” (1978:183). Foucault was specifically concerned about the relationship between knowledge and power, how a state came to know its citizens. Nelkin and Andrews (2003) claim there is much more involved the collection DNA samples than just identification. Employers and insurance companies can find out information about health and predispositions to disease, which can lead to discrimination, the reproduction of racial and ethnic stereotypes, and the invasion of personal privacy.

In law enforcement, DNA is a special form of surveillance. Its counterparts, fingerprinting and closed circuit television, are technologies of the past and present respectively. Fingerprinting records a history of criminals and suspects and CCTVs record events as they happen. DNA, however, is a technology of the future. While DNA can act as a genetic fingerprint, law enforcement collects DNA to protect against the mitigation of risk in the future. The function of individual nucleotides that make up a strand of DNA is not well known and the range of information that may be contained in a sample is still being discovered. At this point mapping and sequencing of DNA is used in forensics for the purposes of identification. The 1994 DNA Identification Act and the Omnibus Crime Control Act authorized the FBI to create the national Combined DNA Index System (CODIS), a networked database system that links DNA databanks from all 50 states, the US Army Crime Lab, and Puerto Rico (Cho and Sankar 2004). Each state has its own regulations for who is included in the system. Some only include convicted felons while others include misdemeanors. Louisiana, Texas, and Virginia collect samples from everyone who is

arrested, whether they are convicted or not (Ossorio 2005). By April 2004, the CODIS databank contained 1,762,005 samples, including 80,302 from crime-scenes and 1,681,703 from convicted offenders (Cho and Sankar 2004:S10). One of the issues in regards to the samples that populate these databanks is overrepresentation of minorities as the collections are biased against those who are already touched by the criminal system. With known practices of racial profiling and a focus on certain types of crimes, such as street crimes, racial bias in law enforcement means that racial minorities, especially African Americans and Latinos will be subject to a disproportionate intensity of surveillance (Duster 2004; Ossorio 2005). Further, the predictive capabilities of DNA are only beginning to emerge, linking identity and behavior.

Evans and Relling, leaders in the field of pharmacogenomics (how an individual's genetics affects the body's response to drugs) published in *Science* the statement, "All pharmacogenetic polymorphisms studied to date differ in frequency among ethnic and racial groups," followed by, "marked racial and ethnic diversity... dictates that race be considered in studies aimed at discovering whether specific genotypes or phenotypes are associated with disease risk or drug toxicity" (1999:488). Here, DNA information moves from ethnic and racial identification to ethnic differentiation of disease, sliding into gene behavior. Duster remarks that subsequent correlation data generated by behavioral genetics would assuredly follow "in an attempt to link such behaviors to violence, impulsivity and crime – and lurking in the background – race" (2003:148). Just over two years after Even and Relling's claim in one of the most reputable science journals in the world, the same

journal published initial evidence from Caspi et al (2002) stating a polymorphism in the MAOA gene “moderates the impact of early childhood maltreatment on the development of antisocial behaviors in males” (2002:853). This research suggests, with low correlations, first, a connection between genes and behavior and, second, drug intervention at the molecular level can ‘treat’ people who have been “maltreated” as children and prevent them from becoming “antisocial” which is leading towards criminality. Correlation does not mean causation, however. There is no suggestion of the environmental factors and social dynamics at play in someone getting into trouble with the law. As mentioned above, individuals from minority groups are under high levels of surveillance, which attribute to the disproportionate incarceration rates of African Americans and Latinos.

A number of scholars are concerned about how the functions of DNA databases will “creep” beyond their mandates. Nelkin and Andrews (2003) describe how DNA fingerprint tests have been used to assist governments in screening immigrants. In 1989, the Thatcher government began using the test on prospective immigrants to prove they had family in Britain. Canada began using this practice in 1991. Due to the origin countries of the immigrants and the costs of the tests, this practice has been called discriminatory and used to discourage migration from countries of the global south. At the same time in the US, pilot programs developed worker ID cards that would carry, among other information, DNA sequences to ensure that only legal aliens could hold jobs. With reduced cost of genetic testing, concerns about a surveillance creep were realized when a senior member of the British Police called for the entire population to be entered into a national DNA

database. The DoD DNA database contains a full range of genetic information, not just a DNA sequence. Garfinkel (2000) warns that a “mission creep” is likely as the DoD could release the information for health and scientific research.

Cho and Sankar (2003) raise concerns about the “function creep” (S10) of racially profiling of DNA in forensics. In the 1990s, a series of scientific papers from forensics argued that race is coded in a number of sections of DNA (Devlin and Risch 1992; Evett et al 1993; Evett et al 1996; Lowe et al 2001). When scientists make claims about the relationship between race and DNA, they usually examine variation between groups at a number of sections or loci. The series of papers identify five racial/ethnic groups, Caucasian, Afro-Caribbean, Indian sub-continental, Southeast Asian and Middle Eastern, used in the British law enforcement databases. There they look for the frequency of an allele at that locus for a specific population. The adequate number of locations varied through the 1990s from three to fifteen. The markers for variation, called short-tandem-repeats (STRs), were initially developed for analysis to identify or non-identify a suspect’s DNA sample with one from a crime scene. However, Cho and Sankar explain how the same information is being used to “create suspects where there are none” (2003:S10). Some forensic scientists claim that certain STRs are associated with racialized phenotypes, like skin color. So, instead of matching samples, this type of analysis creates suspects, such as in a Louisiana serial killer case where the police were searching for a ‘white’ suspect, but a company that markets such techniques called DNAPrint, suggested that the suspect was actually African American. This type of analysis elides the fluid and contested nature of race. Also, it reduces race to

static notions of identity, which exclude the lived experience of racial difference. In spite of the problematic assumptions of racial profiling of DNA and questions about the connections between DNA and race (often assessed by what a police officer observes rather than self report) genotyping of race continues, as does the expansion of CODIS databases. While the FBI maintains DNA databases for security, the NIH has been building them for health research.

The NIH launched Genbank, the first DNA database to collect and annotate all publicly available DNA sequences, in 1982. This particular database has become important in biomedical research not only as a resource but as a way of encouraging scientists to make their data public. Many journals require submission to a database before authors can submit articles. Sequencing of DNA was slow in the early days. After four years, Genbank had only 680,000 base pairs and by 1986 that number had grown to almost 10,000,000 (Moody 2004:26). Other difficulties included a backlog of available sequences so that only a fraction could be entered and even those could be years old. Now, Genbank holds approximately sixty billion bases (Genbank 2006). There are a number of other public databases at various institutes of the NIH such as dbSNP, at the National Center for Biotechnology Information, which holds Single Nucleotide Polymorphisms (SNPs). SNPs are locations of genetic variation where people's genomes differ by one nucleotide. For example, at the same position on the genome one person may have a T base and another may have a C. SNPs have been found to act as markers on chromosomes that assist in locating important genes that could be involved in disease. With the turn to difference in genome research, rates of SNPs have been used to measure variation between racial and ethnic groups.

There is also the DNA Polymorphism Discovery Resource (National Human Genome Research Institute) and Pharmgkb, the pharmacogenetics and pharmacogenomics knowledge base, developed at Stanford University and funded by the NIH. Globally, genome databases exist in Iceland, the UK, Switzerland, Japan, and both Latvia and Estonia have their own genome projects (Kaiser 2002).

HapMap Databases and the Turn to Difference

One of the most important claims of the Human Genome Project (HGP) is that humans are 99.9 percent the same at the genetic level. We all share the same genetic makeup and are much more alike than different. This claim dates back to the work of biologist Richard Lewontin in the 1960s.⁶ However, the mapping of the human genome by the public/private ventures of the National Institutes of Health and Celera Genomics, headed by Francis Collins and Craig Venter respectively, has given the claim authenticity. Also, with the media events that surrounded the announcement of the completion of the first draft of the human genome in 2001, it is not only often repeated in biomedical and scientific journals and by scientists, but has taken a place in the public sphere. While the HGP found that human groups are all the same, the HapMap Project is researching differences between groups.

The HapMap consortium collected samples from “populations with ancestry from parts of Africa, Asia, and Europe” (International HapMap Consortium

⁶ While Lewontin has been credited with the 99.9 percent figure (Gannett 2001), the discursive move to sameness was a prominent feature of the UNESCO Statements on race (See Reardon 2005). I discuss terminology and slippage in concepts further in chapter 5.

2003:789). While project organizers deliberately decided to refer to the sample groups in terms of “populations” and not racial groups, the initial groups do match a traditional western taxonomy of race as well as the racial groups in the American census. Lee (2005) points out that choosing such geographically disparate groups accentuates any genetic distances/differences, rather than using more gradual differences between more historically proximate groups. The gradual differences, she argues, “might uproot conventional notions of racial boundaries and inspire new trajectories of research that dispense with age-old notions of racial difference” (2135). This reinforces the racial triangulation of black, white, and Asian. When the National Human Genome Research Institute (NHGRI) of the National Institutes of Health (NIH) decided to build databases and a haplotype map the scientists involved had to make a decision on which markers to distinguish the data sets would be included. The impetus for avoiding racial names can from the attendees who would largely make up the ELSI committee.

it’s been an educational process for some, especially the genetic scientists, but also for the people involved in all aspects. Some scientists were using... East Asian or even Asian as a name for the Japanese and Han-Chinese sample. We insisted that this is inappropriate as Asia includes too many different groups, I mean thousands of different groups. China itself includes fifty groups and you can’t call people like this. Therefore we adopted the name JPT, and it was a long discussion and I think everyone had a kind of contention on this in the end. I think the question of concern about racial discrimination and racial discrimination and classifying these HapMap samples in that way was a serious concern for everyone involved. That was the reason for the care in taking the naming of the samples. Inside Japan, I don’t think the concern is of any discrimination of Japanese people in Japan, the concern for the Japanese people discrimination when the population exists as a minority, for example in the Americas or Europe or Asia, other Asian countries anywhere. (Interview 1011)

HapMap organizers decided that the groups would be labeled according to geographical rather than racial signifiers. I have been told that the discussions at the preliminary HapMap meetings held in the summer of 2001 were very open about the issue of racial identification. When asked about the place of race in the schedule of items being discussed and whether or not it was an important issue or a marginal one, a leading bioethicist in attendance commented that it was “in the fabric of the meeting.” Another attendee described the discussions of race and community as at an elementary level.

When interviewed, most HapMap members are quick to point out that they do not use race but geographical ancestry to define the population groups. Not all the members referred to the groups by geographic ancestry, however. A statistical geneticist suggested equivalence between “the three sort of major continental groups or racial groups or whatever your preferred term is” (Interview1002). The HapMap sample populations are from different continents that closely resemble the main racial categories in the US census and that are commonly used in biomedical research. Risch (2002) and Petsko (2004) are examples of scientists who advocate for using the racial categories set out by the Office of Management and Budget in 1977 (See chapter 4). When the NIH decided to build databases and a haplotype map the scientists and bioethicists involved had to choose which markers would be included. Should they include geographical location or not? They only decided that racial names should not be included. Attendees to the planning meeting who ended up on the ELSI committee pushed for the labels for the groups to be geo-markers. However, it would be remiss to overlook the significance of choosing the three major

racial groups, African, Asian, and European that have largely defined the social and scientific construction of race for centuries. Lee raises a more important question, “if there is no genetic basis for race, then why do large scale mapping projects continue to use racial categories in identifying research populations?” (2005:2135).

The answer lies partly in the tradition of population genetics and physical anthropology that provides the scientific basis for choosing the four groups. Clearly, there was an opportunity lost in debunking the relationship between genes and race by choosing populations that are geographically distant from one another, rather than ones closer together genetically and geographically. In addition, and this is an equally important issue for identity, there are socio-political opportunities for states who participate in large-scale genome projects. China and Japan have been eager to assert themselves not only regionally, as leading countries geopolitically in Asia, but on the world stage. Nigeria occupies a similar position in Africa. HapMap organizers chose

...groups that were either already being engaged in some genetic research or they were groups that researchers had already a relationship or a collaboration with these groups or with persons in those communities... They had contacts. They re-consented most of the people who were alive or whose families were part of... CEPH. With the other populations, the Chinese population and the Japanese, those populations, the specific populations, the groups that were targeted, well I shouldn't say targeted, were identified and participated, were really groups where there was some contact or some existing collaboration with those groups, for some researchers who was doing some research for that group or that community or a collaborator in that community. (Interview 1022)

Choosing the research sites and initial sample populations in the case of HapMap was a matter of convenience and accessibility (Duster 2005). This is a common occurrence across the natural and social sciences. As the dominant organizing

principle in the information age is the network, power operates through the space of flows. In the case of HapMap, flows of scientific knowledge and social/professional networks are accessible to scholars and states who can tap into them. In the early 1990s, Gilbert (1999) warned that the proliferation of databases would create a digital divide: “The next tenfold increase in the amount of information in the databases will divide the world into haves and have-nots, unless each of us connects to that information and learns how to sift through it for the parts we need” (Gilbert in Lenoir 1999:18). Cambodia or Vietnam were not ‘chosen’ or ‘targeted’ to represent Asia nor was Sierra Leone for Africa, for example, because HapMap organizers did not have relationships with anyone there and state governments lack the funds or the international political capital to participate in the new global venture. However, some members see the data coming out of HapMap being able to overcome this kind of digital divide.

I think it’s an opportunity for the West and the industrialized economies to efficiently transfer the intellectual benefits of wealth and investment and this technology to the developing world. There’s no reason that South Africa has to re-sequence the human genome to study the parts that are relevant to urban disease there, they can leverage off of what we’ve done internationally. So, I think that’s a fantastic opportunity for international science and humanities as a whole. I think science can bridge boundaries in a way that other cultural enterprises can’t do. (Interview 1016)

The HapMap database will expand with samples from more populations in latter phases of the project. Phase II of the project has genotyped more SNPs from the original four groups. There are future plans to sample more groups, but they are yet unnamed.

The Role of the Internet in Networking Knowledge Production, Open Access to Data, and Informed Consent

I don't think [HapMap] could have happened without the Internet, honestly.
(Interview 1016)

The impact of the Internet on biomedical research in general and the HapMap project in particular has a number of facets. Broad changes can be observed in network and distribution, form and knowledge creation, and ownership of data. The Internet is a crucial form of communication for a global project with the geographical, technical, and data intensive scope of HapMap. Many of the HapMap members expressed the fundamental role of the Internet in facilitating a number of capacities. The four data collection locations and the multiple sites in six countries were networked through the Internet, making possible data distribution and retrieval as well as collaborative communication between scientists. The project followed an open access model to data ownership and distribution. Finally, this section will discuss how access to the Internet has also empowered everyday people in negotiating the terms of consent in biomedical research and practice.

Networking and Distribution

The Internet has transformed scientific research in terms of the networking of scientists and information. Many of the interviewees cited information sharing, online communication, and online collaboration as the main areas where the Internet has impacted their work and made possible massive genome projects such as HapMap. The Internet enables genome projects to move data between global locations and labs in the same building as well as provide open access from anyone

interested in using the information. The genetic information collected from Nigeria, China, Japan, and Utah are sent to the participating labs located in six different countries. When the sequencing has been performed, that data is uploaded to the central HapMap database in Bethesda, Maryland, where it is curated, checked for quality control, and stored. Since the project follows an open access model, the data can be downloaded by anyone who has broadband Internet. Scientists can, in turn, submit their own annotations for publication with the data on the HapMap website.

Distributing the enormous amounts of data that are produced from genomic research used to be a serious problem, even in the earlier days of the Internet. Different commentators have suggested what a paper based system of collecting and moving around data would look like. In the early days of the Human Genome Project and the nascent days of DNA sequencing, renowned Harvard biologist Walter Gilbert speculated that a copy of the genome would be the size of “1000 1000-page phone books” (1992:84). Gina Smith (2005), writing after the completion of the Human Genome Project, thought that it may be “about 200 New York City phone books worth of As, Cs, T,s and Gs” (2005:3). A top international geneticist explained, without digital media and the Internet, distributing the data would be like sending around “seven copies of the New York phone book” on a regular basis. “The impact would be trivial compared to what it is.”

The Internet and digital media is not only necessary for moving the information around, but also structuring the data itself. Digital technologies allow for constant updating, cleaning, and translation:

I had to imagine a model where all of this was done on paper. I don't think a system could comport itself because number one you'd always be transcribing something, you'd be bound by the limitations of whatever media you're stuck putting the content on. So it's just inefficiency upon inefficiency and every time you'd have to move data from one media to another there's an opportunity for error. So just data correction and tracking errors and finding out what's in sync and what isn't in sync, which could be a nightmare. (Interview 1016)

Unlike the phone book, which can only be read in a very linear manner, the Internet and digital media allows for the embedding of numerous supporting sorts of information.

...a DNA sequence of 3 billion base pairs is cool, but an annotated DNA sequence of 3 billion base pairs with take your pick of 22 thousand or 30 thousand genes is together with lots of regulatory elements and lots of information in terms of where the polymorphisms and in particular the coating polymorphisms non-synonymous ones and spliced variants and all those different things. The ability not just to identify these different bits of interesting information, annotation about the sequence but also to integrate them in a useful way and in a very easily queryable set of databases is an incredible advantage. Perhaps a more prosaic level perhaps just our ability now to generate, to query databases about literature of all different sorts, you know rather than going to the library and sitting around and looking for things in the stacks, you know finding everything we want at a touch of a keyboard in very short time is another huge advantage and then being able to do searches and queries through those sorts of data is just a fantastic thing. (Interview 1002)

The computer, database, and Internet facilitate the sharing of information in many different ways. One of the more powerful features of an electronic database is the cross referencing of information, which resides in different databases, simultaneously, enabling very complex searches to be done on huge amounts of information and complex analysis algorithms to be run easily (Interview 1009). Like the anti-narrative logic of Manovich's database-like films, genome databases can tell different stories depending on the needs of the individual scientists. In turn, the

outcome of a scientists work on a particular chapter of the ‘book of life’ can be uploaded back into the database, thus changing the detail and scope of the original.

If you had not had a means of sharing that electronically it would have been impossible to communicate any other way because the data is changing on a daily basis. It is being added to, it is being refined, it's being developed, the interpretations, the mistakes are being corrected and so on. You could not do that if you didn't have a way of sharing that electronically. I mean you'd have to fell the whole of the Canadian pine forest to make the paper on a daily basis. (Interview 1007)

The HapMap database is a living, growing entity built from the original genomic data from the project and subsequent additions from scientists around the globe. The overall narratives are evolving in the sense that the mechanism of user feedback constantly pushes the discursive possibilities and actual boundaries of the HapMap genomic database in real time.

Further, HapMap does not operate in isolation from other sources of genome data. The DNA information can be combined with other public genomic databases. Originally, the database was governed by a click-wrap, licensing agreement as an “interim protective strategy” before being completely released into the public domain at the end of the project (International HapMap Consortium 2004:474). Users of the genetic information could not combine the data with other DNA data sets or, more importantly, patent it and prevent others from free access to the information. As mentioned above, HapMap organizers did not want to completely nullify the patenting process. The goal of the project is to make available detailed DNA information that would enable researchers to link a specific disease to a haplotype region and develop a pharmaceutical treatment. In December 2004, the click-wrap agreement was dropped (NIH News Release 2004). This occurred earlier

than originally planned because the initial agreement's restricted use clause prevented researchers from utilizing the information in combination with other NIH databases.

Through the digital storing of genetic information, the Internet and related technologies change the form of the data and the process of knowledge creation. Again, the telephone book as a repository of information is a useful way to conceptualize the impact of the Internet. DNA data in phonebook-like form is in an order that is a series of letters. This is not really interpretable in any real way. With the development of computers and the Internet, the same underlying data can have many different representations.

So you can have representations that say I want to see what the genes are across this region. You get some picture of here are the genes. But someone else might come along and say, well I want to see how the genes vary in their sequence. You get a different view of them. You say I want to see which one's are expressed somewhere. There are all these different views of the data and so without changing the underlying data you can customize to each user the particular feature they're interested in. So it's profoundly different than having the same data in a phonebook. (Interview 1001)

The shared master version is constantly updated, instead of the changes from individual teams or individual labs storing their changes locally, waiting for the next round of data transfer. One of the main challenges for scientists has always been access to the conduits of the Internet. In the nascent stages of the networking technology, scientists transferring data on the few nodes of the system had to take turns with limited university computing resources. This problem persisted with in terms of storage disk space so that when there were more computers online, users

could ‘borrow’ disk space from others in the network. A recent technological innovation built to overcome the problem of disk space, bandwidth, and computing power is the Grid.

The Grid has been called the future of scientific computing (Butler 2003). The technology builds on the model of computing where computers on a network would share their storage capacity. The Grid takes this architecture to open up computing power, speed, and functionality in the same way that the World Wide Web did for content. Once the Grid is given a particular job, its bundle of programs goes off in the network and finds data and information and the computer space that is needed to perform the task. Computer power is maximized through a network of computers that may include a supercomputer or hundreds of smaller PCs logged into the network. The “resource bookkeeper” keeps real time information on what is available and what is happening on the Grid. With the massive amounts of data being produced in the terabytes neighborhood (1024 gigabytes), the bounds of local computing are again being pushed. While innovations like the Internet and the Grid transform the technological possibilities of scientific research, they also change the way scientists think about the culture of research.

Increasingly, argue Grid enthusiasts, scientists will see themselves less as belonging to individual bricks-and-mortar institutions, and more as members of ‘virtual organizations’, communities of researchers in defined research areas or associated with particular experiments, who together decide what computing and data resources they will share over the Grid. Gone will be the logjams caused by limitations in computing power and data storage at one institution, and the need to rack up endless frequent-flyer miles to participate effectively in a project. (Butler 2003:800)

Interestingly, one interviewee commented that his phone calls with collaborators had decreased and his overall communication has increased with the diffusion of the Internet. Other interviewees made similar comments about how the Internet facilitated communication and collaborations. These processes are fundamental to scientific research today as evidenced by global genome studies such as HapMap, which can operate on a 24-hour basis with research sites scattered across the world. HapMap members suggested that writing papers has become easier with electronic mail (Interview 1005), the Internet makes it possible for international ventures to work together in real time (Interview 1007) and with greater quantities of data (Interview 1011). Like many other segments of society, cyberspace has clearly impacted the manner in which biologists work with one another and, as the next section will show, how the storage of genome data has become a public issue.

Genome Data as a Public Good: Democratizing the Data Through the Public Domain

Gilbert's warnings about the digital divide of information have and have nots amongst scientists and nations globally have become partially true. As projects like HapMap show, those who come to the genome table are mostly from developed countries, mostly from the west, but at least regional powers. However, one of the mandates of the project is that the information contained in the database will be "freely available in the public domain, at no cost to users" (<http://www.hapmap.org/cgi-perl/registration>). The HapMap Project follows an immediate data access approach by making the findings available publicly on the

Internet within twenty-four hours of the data being collected from the multiple sites. The open access model represents a movement in the academic and public sector scientific community. This type of approach goes against the traditional practice of scientists in keeping their data private until publication and the proprietary nature of the biotechnology industry (Collins 2006). The open access model originated at a 1996 meeting between British and American scientists in Bermuda, chosen for its neutral location. The attendees decided that DNA data should be made available freely, in a timely manner, and protected from copyright (Shreeve 2004:46). The resulting guidelines have come to be known as the “Bermuda Principles.” Within HapMap, however, there were heated discussions about the open access mandate and the ability to patent the genetic information (Interview 1017).

The Internet provides the means for this mandate to be carried out. Like other battles over intellectual property and copyright, such as the downloading of music and the Napster case, human DNA has virtually unlimited opportunities for developments of cures for disease. Since the 1980s, the philosophy and practice of the Internet has been between copyright and the open source idea of copyleft, where programs are released free over the Internet with the intention that any improvements made by users would, in turn, be released back onto the web. The most famous of the open source model is Linus Torvalds’s Linux operating system. HapMap members are particularly enthusiastic and principled about this practice (Interview 1016):

If you look at some of the databases now that are open to all researchers that constitute international resources, the collaboration used to be one on one in terms of disease or in terms of friendship even between different scientists. Now we have international databases that are curated, annotated, put up to date where people can share. So in terms of making science really

international and making science open in the humanistic, old sense of science, open as in belonging to the public, I think its been absolutely tremendous. (Interview 1008)

A number of the participants of the project referred to this process as “democratizing the data.” There are a number of features to open access. The information needs to be accessible through files that can be downloaded from a public website. Of course, the user needs to have access to the Internet and, ideally, a broadband connection as well as the facilities to store the data. In the case of HapMap, the project’s homepage serves as the portal to the project databases. Simple queries that return responses and graphical interfaces for browsing data are critical to the sharing of data. One respondent felt that, in the long run, this approach will have a “great and profound impact on the way biomedical science is being done because it’s a very infectious idea and it’s not an idea that existed in biomedicine before” (Interview 1001).

Biomedical research has been a process of doing one’s own experiment, writing the result in a notebook, which sits there until the publication of the results that may only share parts of the primary data. Prior to the Internet, the data would be held locally as there was no pressure, technologically or in the scientific research culture, to freely distribute it as “ researchers enjoyed a luxury of primary access and unique access to their data” (Interview 1016). A scientist would share the information with colleagues by presenting the work at a conference or writing a paper that goes through peer review. Either way, the end result is a highly extracted and interpreted diversion of an experiment. That paradigm is evolving due to research like genomics and the use of ICTs.

When you collect the data using a more objective device that sort of collects the raw data and then you share it over the Internet the next person can come along and do a different interpretation of that data. And that is totally, that is dependent on technologies for collecting data. But it's, it's most fundamentally about archiving and distributing data, which is based on the Internet. (Interview 1001)

Democratizing the data depends on the network capacity of databases and the Internet as well as a social movement from within the biomedical sciences. It appears to directly confront private models of the biotechnology industry where the keeping of trade secrets in closed labs is considered crucial to competing in the marketplace.

Organizers of HapMap are not against the practice of patenting. The HapMap “Data Release Policy” states:

All data generated by the Project will be released into the public domain. The participants in the Project believe that patents should not be issued for a SNP or haplotype for which a "specific utility" -- as defined in patent law -- has not been generated. However, if a specific utility can be demonstrated for a SNP or haplotype, any group, whether associated with the Project or not, should be able to apply for a patent, as long as this action does not prevent others from obtaining access to data from the Project.
(<http://www.hapmap.org/datareleasepolicy.html>)

Democratizing the data works in terms of access, however, one HapMap member pointed out the limitations of this approach in terms of the quality of data. Differing from the copyleft movement and open source, where the codes can be redesigned and released into cyberspace, HapMap data has curators to monitor data quality. The job of curator takes place at the National Center for Biotechnology Information at the NIH's National Library of Medicine and works as a kind of gatekeeper of the information, not in terms of access, but of the actual content.

The problem with data is that not all, in a democracy all voices of reason should have an equal opportunity to be voted and heard. There is a tension in science between having all possible voices heard and in running the risk of

some of those are not accurate, meaning that you know we do need a way of establishing standards of quality and content and then being you know, either saying you know the stuff we distribute is known to be of high quality and we don't need to individually measure the quality of every datum as it moves through a plate. Or we need a transport mechanism that accepts everything but allows a user to filter easily for high or low quality at every step. You see that redundancy is good when everything's being measured well, but a project that just introduces a lot of noise and low quality data into a system could probably be, everyone's worse off, it's a tragedy of the commons kind of effect. (Interview 1016)

Marturano (2003) explores the notion that molecular biologists can be understood as hackers of human data. He suggests that scientists should adopt the open source philosophy followed by many computer hackers where the source codes are shared, modified, and redistributed. This would strengthen the scientific community and refocus the emerging patent-and-perish culture to a gift economy where status among peers comes from the sharing of knowledge, which is already part of the practice of scientists. Ultimately, an open source philosophy seeks to protect genomic data as a public good, rather than something that can be owned by a corporation. The immediate release into the public domain approach could have far reaching affects in terms of the divide between information haves and have nots.

Techno-Consent and Community Engagement

The social movements of the 1960s and 1970s challenged existing norms about the order of society and, primarily, the subordinate positions of racial minorities, women, and gay men and lesbians. One set of the institutions that were especially targeted by the feminist and gay liberation movements was the biomedical sciences. Science and medicine had long kept a distance from the public with legitimacy,

credibility, and expertise exercised from within. Scientists and doctors talked and everyday people listened with a sense of awe. Trust in doctors was automatically assumed. This arrangement became disrupted from the 1960s to the 1980s. Radical critiques of the medical-industrial complex in the 1960s were joined by women working to regain control over their own bodies in the 1970s, which was built on by AIDS activists working with and inside biomedical institutions in the 1980s (Epstein 1996). Issues such as patient or subject participation and trust moved from being assumed though the authority of the doctor or scientists to informed consent being earned through ethical regulations and conversation between the two parties. Ordinary people have become much more involved in the health process in understanding their personal health issues.

An internationally renowned bioethicist and biologist explained that the older, paternalistic models do not work in the information age (Interview 1011). This is largely due to the social movements described by Epstein, but also due to the diffusion of ICTs. In top-down approaches to scientific research, samples were simply taken from individuals without being informed of the risks or outcomes. This is no longer ethically acceptable as subjects must give their consent through an informed process. Informed consent is negotiated at both the community and individual levels. For example, the HapMap Project engaged the four participating populations in community consent, which differs from traditional consent models in two key ways. First, consent must be gained at the local level through representative community groups. Second, the terms of consent are not simply presented by researchers and signed by individuals. Consent is negotiated between the researchers

and community representatives. Organizers of the Human Genome Diversity Project (HGDP) encountered massive resistance from numerous indigenous groups when approached using the traditional top-down approach. The HGDP was nicknamed the “Vampire Project” as community groups recalled a history of mistreatment by western scientists and protested the seeking of the blood of indigenous people with no clear outcome of improved health (Reardon 2005). Native American representatives from Indigenous People’s Against Biocolonialism attended the initial HapMap meetings in the summer of 2001 and declined to participate until the research showed that their inclusion was necessary for scientific reasons (Interview 1022).

At the individual level, people are able to make better-informed decisions about participating in research and their own health situations. The international bioethicist referred to this emerging phenomenon as a “choice model” and linked its development to the rise of information technologies.

...this transition is clearly happening in every society around the world at different speeds, different rates, and different ways... information technology is behind that. The development of personal computers, access to the Internet, new forms of communication... I think even new parts of personal identity is represented in information technology, is clear for people, they spend increasing amounts of their daily life involved in communication, on mobile telephones, email, and other forms of communication. (Interview 1011)

Information technologies, such as the Internet, have been important in creating a “leveling effect” between different groups in society. Information about health and scientific studies has become much more accessible to everyday people. A consistent trend in rankings of top Internet usages since the mid 1990s has been for finding

health information (Cline and Haynes 2001; Cole 2004; Leaffer 2006; PEW 2005).

People commonly use the information to ask new questions or a second opinion (Williams-Jones 2003). While ICTs have been key in making people more informed, some argue that there are ways in which ICTs may be threatening informed consent.

Tavani (2004) argues that the same technologies that have made it possible to find genes that cause certain diseases which speeds up the process of discovering cures are undermining the principle of informed consent by threatening research subject's privacy. The route to personalized medicine is currently through the studying of group differences in proclivity to disease and reaction to treatments. Hunting for disease genes produces huge amounts of data that is stored in databases. This data is sorted through and analyzed using data mining techniques which 'discover' hidden patterns, properties, and statistical correlations. New aggregates of groups or categories can be produced in the process. These types of community formation "make up new citizens" through biomedical and biological languages and practices combined with everyday people organizing along lines of disease knowledge and prevention (Rose and Novas 2004:445). While subjects contribute their DNA to health research, they are unwittingly contributing to this process. The creation of a controversial group could produce stigmatization. This was an ethical issue clearly identified by HapMap interviewees (Interview 1011). While the Internet has made the information about diseases, treatment, and other areas of health more transparent to the public, Tavani suggests that databases are making informed consent more opaque.

Conclusion

Innovations in information and communication technologies have been intimately tied to the biological revolution since the discovery of rDNA made possible the genetic engineering of life. Since that key discovery in the early 1970s and the discussions at the Asilomar Conference, a new type of biology based on computational techniques has emerged and joined the wet labs of experimental biology. In the process, biology has incorporated theoretical and practical aspects of computing, becoming an informational science. The convergence of the biological and electronic revolutions has been fundamental to the new science of genomics. Genome projects such as the Human Genome Project and the International HapMap Project have not only incorporated the technological and scientific transformations, but also motivated them.

Two of the key technologies that are having major impacts on genomic and the production of scientific knowledge are databases and the Internet. The massive amounts of information that are created from genome mapping and sequencing are stored, sorted, analyzed, and networked in DNA databases. Other sectors of society such as commerce and law enforcement are building databases for the surveillance of populations, such the FBI's CODIS database. The Internet is the conduit for the transfer of genome information. It also networks labs, scientists, and international projects, such as HapMap. Scientists and bioethicists have also been utilizing open access models to "democratize the data" and keep DNA information in the public domain. While open access attempts to keep DNA data public rather than proprietary, everyday people use communication technologies to challenge the

traditional paternal models in biomedical research and clinical practice. Access to information has been key in this “leveling effect.” Through the Internet patients and research subjects can gain information on research projects and their health care needs. However, ICTs such as databases are also increasing surveillance and threatening the privacy of subjects, patients, and anyone else caught in the informational net of data gathering.

The next chapter will turn to the institutional and legal changes that have transformed the sciences, biomedical research, and genomics from 1977 to 2004. A series of government policies and legal cases since the 1970s focused on deregulating the relationships between commerce and universities. Contrary to the fears of the scientists at Asilomar in 1975 about outside control over the methods and conditions of biology, the federal government has facilitated the industrialization of biological research in an effort to make the US a world leader in biotechnology. This produced a climate where some scientists became weary of research submitted to journals that was increasingly being funded by corporate interests. Journal editorials, comments, and letters to the editor become forums for discussing conflict of interest policies. Finally, another set of institutional changes also occurred in the same journals as well as government organizations such as the National Institutes of Health that were aimed at the inclusion and treatment of ethnic and racial minorities in biomedical and scientific research.

Chapter 4

The Legal and Institutional Formation of Biotechnology and Genomics, 1977-2004

The informationalization of race has emerged as new communication technologies evolved since the 1970s and become integrated across social institutions and as society has undergone transformations in the organization of race. As this dissertation argues, the informationalization of race is not only due to the social shaping of new technologies, but also the transformation of regulatory and cultural infrastructures. While the previous chapter showed the technological and organizational changes that occurred in biology and genomics, this chapter focuses on what has become one of the most controversial topics in the development of modern societies, regulation. The HapMap Project in particular and biomedical research more generally has been formed not only by scientific, politico-cultural, and technological developments, but a series of regulatory changes from the courts to the senate to the editorial boards of scientific and medical journals. This chapter shows how genome research has been formed, in part, by changes in legal and institutional structures and mapping the genealogy of changes is central to understanding the ethical and legal infrastructure that under girds HapMap. There are two different trajectories of regulation that I address in this chapter. The first is a common one in the constellation of neo-liberal policies enacted by government administrations in US and elsewhere as capitalism underwent restructuring in the 1980s. In order for the United States to become a world leader in the nascent field of biotechnology, the

Reagan government needed to create the conditions that would allow and encourage interaction between private industry and academic labs. The early 1980s was a period of deregulation in the biotechnology industry. The second trajectory concerns the regulation of racial identity. As diversity and multiculturalism became goals across institutions in the post-civil rights era, biomedical models of research underwent significant transformations in terms of inclusion of women and visible minorities. In this chapter, I show how biomedical research has been formed by color conscious policies from the Office of Management and Budget to the National Institutes of Health to the editorial policies of scientific and biomedical journals. I begin this chapter by discussing the role of regulation in the field of communication.

Regulation is an important object of study in the field of communication. Communication scholars have made important contributions to broad areas of media research such as policy analysis of the telecommunication industries around the world (Galperin 2004), the deregulation of media industries in the United States (Kellner 1990; McChesney 1993, 1999), and the emerging area of wifi networks (Bar and Galperin 2004, 2005; Galperin 2005; Park 2007; Park and Bar 2006). The deregulation of media and telecommunications in the United States has been a crucial trajectory followed by media scholars. From the enactment of the 1984 Cable Act to the 1996 Telecommunications Act under President Clinton, various media industries were opened up for convergence and conglomeration as decades old anti-monopoly laws were struck down in favor of neo-liberal economic policies. While the Reagan administration began to deregulate decades old FCC rules governing media and telecommunications industries, they were also writing laws to facilitate

the burgeoning biotechnology industry. At stake in biotech are not only interventions into human identity at the genetic level, thus altering the molecular material that constitutes our physical, emotional, and cognitive selves, but the symbolics of the body: “biotechnologies are disrupting some of what are our most fundamental social categories and boundaries” (Gerlach and Hamilton 2005:80). The deregulation of biotechnology has not been a traditional sphere of analysis for media and communication. Recently, however, there have been calls for communication scholars to examine biotechnology’s impact on society. The February 2005 issue of *Communication Theory* was a special edition devoted to biotech. Cultural scholars in the issue focus on representation in terms of media coverage of biotechnology, identity and the body. Other papers examine the current legal debates about ownership, patenting, and ethics of scientific research, such as cloning and stem cell research.

While battles over media representations have been prominent in scholarly literature and public discourse, representation through information and communication technologies and biotechnology has focused mainly on futuristic scenarios for stem cell research and cloning. Biotechnology is a representational form and, unlike the media industry, it is a sector and system of knowledge production that is in the early stages. The emerging “biomedia” (Thacker 2004) warrants closer attention as a political economic process.

Some of the changes below have been discussed in the context of the deregulation in the 1980s that fostered the biotechnology industry. Scholars of university-industrial relations have paid particular attention to the industrialization of

academic research and the influence that commercial funding exerts on academic labs, science departments, and university administrations (Kenny 1986; Krinsky 1991, 1999, 2004; Kleinman 2003). Scholars of race have widely discussed the OMB's Directive 15, which set the current racial and ethnic categories for the U.S. census (Wright 1997; Skerry 2000). Biomedical researchers have examined the impact regulations aimed at diversity in bio-scientific studies have had on publicly funded research (Brawley 1995; Epstein 2004). The above scholars have all examined different parts of regulation and biotechnology. Even more include some of these changes in mapping out the institutional context of emerging phenomena such as the new drug targeted for African Americans with heart disease, BiDil (Kahn, 2003, 2004). Almost all of the roads to regulation begin with the Baye-Dole Act of 1980 (See below). Big science genome projects, such as the HapMap project, have become characterized by the participation of public and private entities, which is the result of the deregulation of university-industrial relations that began in the early 1980s. Typical histories of sector policy changes would end there. However, big science, at least the kind that is funded by the U.S. government through agencies such as the National Institutes of Health and the National Science Foundation, has been transformed not only by deregulation, but changes in how subjects are recruited to be more inclusive and diverse in study populations and how major journals in the field have developed editorial policies for disclosing financial conflicts of interest and for using race and ethnicity in research protocols. This chapter seeks to connect this web of legal and institutional changes and bring together significant legal and institutional developments in the (re)regulation of biotechnology research.

The Legal Signal for the Commercialization of Biotechnology: *Diamond vs. Chakrabarty*

The discovery of recombinant DNA in 1973 marked the coming of age of biology. Chemistry and physics had already been creating innovative technologies that could be useful for society and made into commercial products for well over 100 years. It was not until the ability to remove, splice, and transplant genes was possible that molecular biology became an industrial tool. As Krimsky (1991a) states in his historical account of the emergence of the biotechnology industry, even though the ancestral roots of industrial microbiology date back a number of centuries, its rapid and industrial growth occurred in the 1970s.

Each new scientific advancement became a media event designed to capture investment confidence and public support. Market expectations and social benefits of new products were frequently overstated. It was part of the “geneticization” of the social mind. People were being prepared to see genetics as the next great advance in technological progress. (Krimsky 1991a:21)

While the social was being primed, the institutional environment that constrained the industry required overhauling. In 1980, a number of significant changes occurred in law and government policy such as the patenting of a microorganism and the beginning of the deregulation of university and industry relations that would provide the institutional foundation for the biotechnology industry.

Ananda Chakrabarty was a scientist working for General Electric Company when he made a discovery that would challenge centuries old patent laws and begin the rapid pace of growth in the biotechnology industry. He developed a bacterium that could break down the components of crude oil and filed a patent for the microbe,

the process for making it, and the method of its distribution. The U.S. Patent and Trademark Office (PTO) initially accepted the application, except for the patent for the microbe itself. The PTO examiner objected stating that modifying life-forms through genetic rearrangement does not create a product of manufacture. Only man-made products are capable of private ownership by U.S. patent law that dated back to 1790. Chakrabarty's microbe was deemed a product of nature and, hence, not a matter that could be patented. Two higher patent courts, the Patent and Trademark Office board of appeals and then the Court of Customs and Patent Appeals (CCPA), reversed the initial decision on the grounds that the modified bacteria are in fact not naturally occurring and qualify for a patent like other products of manufacture. The CCPA added that being of living matter did not exclude such a product from patenting. The case had its final hearing on June 16 when the Supreme Court upheld the ruling of the CCPA by a 5-4 decision. Speaking on behalf of the majority, Chief Justice Warren stated that new types of living matter are no different than lifeless products and that the main distinction in patenting cases is whether or not the products are man-made. The Supreme Court broadened the scope of patentable material to "include anything under the sun that is made by man" (Krimsky 1991a:47-8).

There is disagreement on the significance of the Supreme Court's decision on the patenting of organisms for the biotechnology industry. Many consider this case a watershed mark and see the issue of patent as crucial for propelling the industry forward. Business representatives testifying at a Senate hearing on the industrial application of rDNA in 1980 argued that patenting would be crucial to the growth of

the industry. The threat here, of course, was that without patents biotechnical knowledge would be forced into trade secrecy. Legal critics argued, however, that the Chakrabarty case is less significant and can be considered “trivial law” as the Supreme Court did not break legal ground. Either way, the importance of the case lies in it indicating to entrepreneurs and scientists that this new technology was open to commercialization (Kenny 1986). With the Chakrabarty case, the courts signaled the rise of the biotechnology industry. The U.S. government was another body that anticipated the potential of the industry and was quick to further facilitate its early formation.

Deregulating University-Industrial Relations

From 1980 to 1986, the U.S. government introduced a number of acts, amendments, executive orders, and memorandums to facilitate the growth of the biotechnology industry, signaling the aim of the United States to become a global leader in biotechnology. These policy changes were aimed at transforming relations and building crucial relationships between university labs, industry, and government agencies for the transfer of scientific knowledge and collaboration. President Carter signed the first pair of bills in 1980, the Stevenson-Wydler Technology Transfer Act and the Bay-Dole Patent and Trademark Laws Agreement. Stevenson-Wydler encouraged collaborations between universities, government labs, and industry. The goal was to convert scientific knowledge from the labs in to commercial products. Baye-Dole, along with the Government Patent Policy Act (GPPA) of the same year, gave university research institutions funded by the federal government property

rights over their discoveries (Kahn 2004; Krinsky 1991a). Obligating universities to apply for patents was aimed at protecting commercially valuable discoveries from foreign competition before the information was released into the public domain (Shreeve 2004). A 1983 presidential memorandum extended the GGPA from small firms and universities to federally funded large businesses and contractors. The GGPA was amended again, this time by Congress, in 1984. Companies were awarded tax credits for investing in basic research in universities through the Economic Recovery Tax Act of 1981 (Buctuanon 2001). President Reagan extended the Baye-Dole Act to all industry by executive order in 1983 (Krinsky 1991a).

To close the circle of research partnerships among industry, universities and government, Congress passed the Federal Technology Transfer Act of 1986, which expanded science-industry collaboration to laboratories run by the federal government. Governmental standards for keeping an arm's length from industry were being turned on their head. Through this act, a government scientist could form a "Cooperative Research and Development Agreement" ("CRADA") with a company as a route to commercializing discoveries made in a federal laboratory. Government scientists could accept royalty income up to a given amount, fifteen percent of the National Institutes of Health (the "NIH") share, to supplement their salaries. At the time this policy was enacted, there was virtually no public discussion about the blatant conflicts of interest that this would introduce. The CRADA required government scientists to keep company data confidential and impeded the sharing of information in government laboratories. (Krinsky 1999:21-2)

The completion of the 1986 Federal Technology Transfer Act marked a significant deregulation of constraints between industry, the academy, and government agencies by encouraging federal laboratories to commercialize results (Buctuanon 2001). The institutional environment for the biotechnology industry at the end of the 1970s looked completely different by the end of the 1980s. Not only had the amount of biotech startups increased dramatically by the hundreds (Krinsky

et al 1991b:275), the number of patent applications from hospitals and universities increased over 300 percent in the years 1980 to 1985 compared to 1975 to 1980 (OTA 1987). As the biotech industry grew, companies recruited university scientists. Some scientists became entrepreneurs and began their own companies. This created a crisis for scientific fields in terms of conflict of interest where private companies funded basic research.

Conflict of Interest Policies in Biomedical and Science Journals

In the formative stage of the biotechnology where the regulatory changes outlined above encouraged university-industry-government partnerships and collaborations, there was a general concern about the how the changing norms, motivations, and values of the new entrepreneurial scientist would affect scientific research and its social benefits. Krinsky et al (1991b:276) suggest a number of possible negative consequences such as conflicts of interest, shifting of research agendas from basic to applied, and an erosion of the open model of communication between scientists in favor of a corporate model based on secrecy. Kleinman (2003) has delineated consequences into direct and indirect effects. A direct effect would be the disruption of an open model of communication between scientists as a stipulation of external, private funding. Direct effects have been the focus of much of the research and media interest in the commercialization of university research. Indirect effects suggest a more systemic change in the values, norms, and culture that structure academic research. For example, the erosion of the free flow of information would be much more subtle and pervasive than a contractual obligation to knowledge

secrecy. Instead of an imposition from without to guard information, university scientists begin to regulate their own conduct which signals a shift in academic culture from a scholarly one to a corporate one. Scientists and scholars have been concerned about the movement from the protected ivory tower to, what Krimsky refers to as “academic enterprise zones” (2004:5).

The concerns over the development of university-industrial interactions in the early 1980s coalesced around the issue of conflict of interest. Questions were raised about the way that entrepreneurship would infect the pursuit of pure science and the role of scientific research in the betterment of society. Simply put, instead of science being in the interest of the social good, research aims would serve the interests of private companies. The *New England Journal of Medicine (NEJM)* was the first major medical journal to include commentary about conflict of interest and has been a leader in setting ethical standards in publication. In a 1984 editorial, Relman argued that “it is not possible for medical investigators to have their research subsidized by business whose products they are studying, or act as paid consultants for them, but they are sometimes also principles in those businesses or hold equity interests in them (1182). Shortly thereafter, *NEJM* introduced a policy of conflict of interest, becoming the first major medical journal to require authors indicate if any part of their original research was privately funded or had any financial interest (Krimsky 2004:166). Others journals in the biotechnology and biomedical fields followed suit, but with varying speeds of inclusion and not without serious dispute over the merit of such a policy.

The leading scientific journal *Nature* was a notable holdout to a conflict of interest policy. A 1997 editorial, entitled “Avoid financial ‘correctness,’” played on the wave of conservative discourse in the 1990s against progressive social policies and discursive changes in references to minorities and women, referred to as ‘political correctness’. The editorial argued that declaring business interests is “beside the point” and that virtually every paper in biotechnology from the east and west coasts of the U.S. and European laboratories “has at least one author with financial interest” (Editorial 1997:469). In spite of the editorial acknowledging the ubiquitousness of the industrialization of science, it states that the “measurements and conclusions are in principle unaffected” and concludes “this journal will persist in its stubborn that research as we publish it is indeed research, not business” (Ibid). At the time, 16 percent of the top one thousand science and medical journals had conflict of interest policies (Krimsky 2004:169). *Nature* refused to include such a statement until 2001 when it adopted a “declaration of financial interest” policy (751). Conflict of interest policies have become much more commonplace. The leading genetics journal, *Nature Genetics*, requires a “competing interests statement,” and *Pharmacogenomics Journal* calls theirs a “duality of interest.” *Science* has similar requirements of authors. While concerns and criticisms about conflicts of interest have been around for over two decades, it is only in the last few years that conflict of interest policies have become the norm in biomedical and biotechnology journals. In spite of widespread adoption, journals have been found to be uneven in their compliance to their own conflict of interest policies (See Krimsky 2004; Krimsky and Rothenberg 2001).

Color Consciousness in a Time of Colorblindness: OMB Directive 15, NIH Revitalization Act of 1993, and Editorial Policies on Race and Ethnicity

While biomedical journals argued the merits of acknowledging the industrialization of scientific research in conflict of interest statements, the scientific community was also confronting ethical issues about diversity. Since the 1960s, women, sexual minorities, and people of color have challenged the closed, hierarchical nature of the biomedical sciences. For example, the doctor-patient relationship has changed from a paternal model to a choice model where ordinary people have more access the health information and, as a consequence, are becoming much more knowledgeable and active about their personal health. Epstein (1996) refers to this transformation as a “crisis of credibility.” Patients have access to varying types of health information due to communication technologies such as the Internet. The feminist movement in the 1970s and AIDS activism in the 1980s challenged existing norms and forced outside participation in the conduct of biomedical research. The underrepresentation of these groups as well as racial minorities became a recognized social problem in the United States in the 1990s (Epstein 2004). In terms of race and ethnicity, the mounting shift to diversity as a social problem was address institutionally though the revision of OMB Directive 15, the NIH Revitalization Act of 1993, and, journal policies on race. Each is reflective of changing social and political norms about race and representation as well as resulting in internal struggles over identity in the biomedical sciences. The combination of these changes ushered in what Epstein refers to as a “new common sense” in research policies and practices “that had

seemed uncontroversial and even ethically advisable suddenly began to appear ludicrous, offensive, and unscientific” (2004:187). The taken for grantedness of the white, male centered approach to the object of scientific and medical research was disrupted by voices from the margins, women, gay men and lesbians, and minorities. The new common sense refers to the inclusion of these groups and the institutionalization of their voices and bodies. Instead of the tradition of marginalization of women and people of color from the power structure of the biomedical sciences and the omission of them as research subjects, the focus of the new common sense became diversity.

As diversity and color consciousness became a focus of biomedical institutions in the 1990s, the dominant racial ideology emerging in the wider society was colorblindness. The color conscious programs that originated from the civil rights movement came under serious attack not only from the right, but the political center. At the same time, the US Office of Management and Budget, the NIH, and various journals in the biomedical sciences created color conscious policies that were in reaction to earlier social movements as well as setting the stage for a new wave of scientific research. The institutional structures that enable and constrain the HapMap Project, the way in which it recruits subjects, and the manner in which it frames its questions around race is the result of changes in NIH policies aimed at diversity in research subjects, revisions to the US census, and the creation of biomedical journals editorial policies regarding the use of race in research. The next section of the chapter will discuss the institutional changes that have shaped the ways that scientists use race as a category in scientific research. In particular, this section will

discuss the OMB's Directive 15 of 1977, the NIH Revitalization Act of 1993, and journal policies on using and reporting on race in scientific research. All of these changes in the regulatory landscape of institutionalized identity shape the ways in which the genomics and the HapMap project define and use racial groups and recruit research subjects.

OMB Directive 15

In 1977, the federal government's Office of Management and Budget issued Statistical Policy Directive 15 that set the standard for racial and ethnic identity for the census. The OMB instituted four racial and two ethnic categories: American Indian or Alaskan Native, Asian or Pacific Islander, black, and white; Hispanic origin and not of Hispanic origin. The racial groupings draw on Linnaeus's 300 year-old taxonomies of race, lending weight to the existence of biologically distinct human groups so entrenched in the popular imagination. His classification drew on the image of geographically separate groups, *Afer* (African), *Americanus* (Native American), *Asiaticus*, and *Europaeus*. Gould (1994) argues that Linnaeus' groups are not linear or hierarchical but cartographic. Donna Haraway suggests that cartographic models are fetishized forms of troping that, on the surface, appear value free but actually are steeped in colonial desire (Haraway 1997). The obvious mixing of behavioral traits (humor and disposition) and physical features (color and posture) in Linnaeus's model are more reflective of European sentiments of the Other than any objective standards. However, it is not Linnaeus but his student, Blumenbach, who is credited with the origins of racial classification. Blumenbach made two

additions to the Linnaean system. He added a fifth group, the Malay, making a geometric shift in the configuration of human groups, and ranked them according to European ideals of beauty. Instead of the groups occupying the four corners of the earth, the five-race system “radically changed the geometry of human order... fanning out in two directions from a Caucasian ideal” (Gould 1994:66). Blumenbach took the name Caucasian from, what he considered to be, the superior beauty of the people from the Mount Caucasus region in Eastern Europe. Both Linnaeus and Blumenbach created their taxonomies during a time of European expansion and colonialism, and American slavery. These systems of oppression were rationalized in scientific race thinking, the biologizing of race, and scientific racism in the nineteenth century. During the twentieth century in the United States, the racial categories have been changed twenty-six times in the US census to categorize:

...those from the Indian subcontinent as ‘white,’ then ‘black’ and more recently as ‘Asian Indian.’ The most recent addition of the categories of ‘Native Hawaiian,’ ‘Gumanian or Chamorro,’ ‘Samoan,’ ‘Other Pacific Islander,’ and the miscellaneous class of ‘Some Other Race’ reveals these categories a socio-political struggles for representation. (Lee 2003:388)

At different points, various European ethnic groups, such as Italians and Irish, were considered distinct racial groups. Both groups have gained entrance into whiteness and would now be subsumed under the category ‘white’.⁷ Different racial

⁷ For historical analyses of the social construction of whiteness see Ignatiev (1995) *How the Irish Became White* and Jacobson (1998) *Whiteness of a Different Color: European Immigrants and the Alchemy of Race*. Many European ethnicities outside of the dominant groups such as the English, French, and German were considered to be lower ‘races.’ Ignatiev explores the case of the Irish and how they used labor unions, the Catholic Church, and occupied an oppositional position to African Americans in order to gain entrance into white America. Jacobson masterfully explains how different European groups became white through three great racial

designations have come and gone such as octoroon and quadroon in the 1790 census to indicate shades of blackness (Epstein 2003; Goldberg 1993). Historically, 'black' has included anyone with one drop of 'black' blood. The census currently relies on self-report, people naming themselves from a limited list of options. With new genomic technologies and the informationalization of race, could the future hold the possibility of racial identity being determined by a single location on the genome, or a common haplotype? Even through self-report, what people imagine themselves to be is intimately bound up with who they are told they are by social norms. One's racial identity is given at birth. Once genotype creeps into the popular imagination alongside phenotype, like blood, the genomic structure of race re-locates that imagination under the skin. These various changes show how the original racial categories, proposed by Linneaus and then Blumenbach, have been particularly malleable and subject to political negotiation. The addition of the 'Ethnicity' categories in 1977 was the latest efforts of lobbyists and advocacy groups.

A number of criticisms of the OMB categories state that the US population has become increasingly diverse (American Anthropological Association 1997; Ver Ploeg 2004). This position indicates that the population was moderately diverse before the institution of the four racial and two ethnic categories in 1977. It is indicative of a historical amnesia of the history of the United States. The inaccuracy

projects of U.S. immigration history. Entrance into whiteness was intimately bound to changing notions of citizenship, naturalization laws, and white ethnic consolidation. See also Michael Rogin (1996) *Blackface, White Noise: Jewish Immigrants in the Hollywood Melting Pot* and Karen Brodtkin (1998) *How Jews Became White Folks and What That Says About Race in America* on how Jews navigated between racial other and white through constructing their own identities in different eras.

of this statement may not be in the quantifiable position of being diverse or not diverse, but in the changing nature and political boundaries of the concept of diversity. Obviously, the US has historically been diverse. Whether this is measured in terms of the different European ethnic groups, Native peoples, or African populations that have existed since the dawn of America, or the subsequent groups that have characterized the formation of US citizenry, this country has never been homogenous. However, diversity as part of the imagination of American identity has transformed in the late twentieth century and diversity has become part of the imagination of American identity, a cultural ‘goal,’ and political issue. The 1977 OMB categories are reflective of the major state recognized racial groups. As mentioned above, they also reflect the changing politics of identity with the inclusion of two ethnic categories aimed at people of Hispanic decent. The categories are not reflective, however, of the lived experiences of people’s racial and ethnic identity or the extent of different identities. Identity is treated in a limited and homogenous fashion. They are limited in the extent of distinct cultural and national origin groups as well as the collapsing of these groups into static categories. In genome research that is concerned with the variation between diverse groups, in terms of both socio-cultural and genetic markers, some scientists and bioethicists view the OMB categories as a barrier to understanding diversity as the categories force individuals into proxy groups (Interview 1022).

Mounting criticisms of the categories and their inadequacy in accounting for diversity lead to a governmental review that began in 1993, the same year as the enactment of the NIH Revitalization Act (Nobles 2004). After four years of

consultation and debate that included Congressional hearings, public hearings in Boston, Denver, San Francisco, and Honolulu, a conference organized by the National Academy of Sciences, a review by an OMB instituted Interagency Committee, and research (both secondary and primary) by a subcommittee, the OMD declined to overhaul the categories. Instead, the OMB did allow respondents to report multiple categories by checking more than one box. The designations remained, however, like Linneaus to Blumenbach, a racial category was added, from four to five, and an addition of “Latino” to the ethnic categories: for race, American Indian or Alaska Native, Asian, black or African American, Native Hawaiian⁸ or Other Pacific Islander, and white, and for ethnicity, Hispanic or Latino and not Hispanic or Latino. The OMB maintained the position that these were “basic” categories. While they were not “biological or genetic,” they were to be thought of in terms of culture and ancestry (US Office of Management and Budget 1995). However, the OMB provided no distinction between race and ethnicity.

In a “Special Communication” in the *Journal of the American Medical Association*, Kaplan (2003) outlines a number of common criticisms of the OMB categories and the October 1997 revisions. The OMB Directive 15 of 1977 added ethnicity to the US census. According to the state organization, there are only two ethnicities, Hispanic or not Hispanic, and now, Hispanic or Latino and not Hispanic or Latino. As mentioned above, respondents were allowed to check more than one category to indicate a multiple racial identity but the OMD would not include a

⁸ The inclusion of the Native Hawaiian category was largely the result of the OMB receiving 7000 postcards from Hawaiians (Marshall 1998).

multiracial category (Skerry 2000). The issue of multiracial identity was contentious as civil rights groups opposed its inclusion while other groups marched on Washington in support of the change (Bowker and Star 1999). The changing status of the categories indicates their political nature and the compromises made in the creation of standards. Racial classification has been discussed as a mode of state surveillance (Bowker and Star 1999). Racial categories and their maintenance have also been used to organize political voice for minority populations. The latest wave of civil rights has turned to the sphere of health in the 1990s. Minority groups often marshal state statistics to illustrate health and health care disparities between racial groups. Critical theorists have referred to this type strategy as strategic essentialism. Kaplan also suggests, however, that the classification system homogenizes disparate groups and erases within group diversity. Becerra et al's (1991) seminal study shows how birth weights and infant mortality rates differ between Puerto Rican and Cuban ethnic groups that would be included under "Hispanic or Latino" (See also Marshall 1998). Ver Ploeg (2004) adds that public health agencies need more refined information on local communities to target programs and interventions, such as Filipinos and Japanese. The American Anthropological Association (1997) published a response to Directive 15 shortly after the release of the revisions. Among a number of recommendations, the authors suggested that the category of race be eliminated altogether by the 2010 census due to its racist nature and as an unscientific category (See also Lawrence 1997). Presently, there exists the problem of seemingly contradictory deployments of race: how do we pay attention to the systemic exclusion of minority populations from access to health and the subsequent

disparities in health without reproducing the conditions that perpetuated inequality? How do we combat racism, without re-producing the racial order? The NIH attempted to answer this question in a 1993 initiative administered by the Clinton administration.

The NIH Revitalization Act of 1993

While the OMB was beginning the process of revising Directive 15, Congress was putting the finishing touches on new legislation that would institutionalize diversity in biomedical and scientific research. After decades of women, sexual minorities, and people of color protesting against the traditional biomedical model and becoming part of medical and scientific institutions, President Clinton signed the NIH Revitalization Act of 1993. The 1993 act of Congress ensured that women and minorities must be included as subjects in clinical research in order to receive public funding from 1995 onwards. In 1994, the NIH released “NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research,” which states,

...the guidelines published here are intended to ensure that all future NIH-supported biomedical and behavioral research involving human subjects will be carried out in a manner sufficient to elicit information about individuals of both genders and the diverse racial and ethnic groups and, in the case of clinical trials, to examine differential effects on such groups. Increased attention, therefore, must be given to gender, race, and ethnicity in earlier stages of research to allow for informed decisions at the Phase III clinical trial stage. (NIH 1994)

The act also mandated an office of Research on Women’s Health and an Office of Research on Minority Health. In addition to the inclusion of women and minorities and the focus on variation and difference, the cost of a study was not acceptable as

grounds for exemption. The Revitalization Act did not, however, state how to operationalize racial minorities. The NIH followed the direction of other government agencies by adopting the categories from the census set by the OMB in 1977. The NIH uses the five race and two ethnicity categories for evaluating grant applications and assessing compliance with the act. When researchers apply for grants, they must indicate how their protocol includes women and minorities and offer rationales if the research design is not inclusive. The OMB coding scheme also allows comparison with other databases, especially ones concerned with health (Epstein 2003). In the same year, the FDA released a similar set of guidelines for conducting drug trials. While the increased attention to difference in a progressive fashion was new in the 1990s, accounting for difference was not. Epstein suggests that the “real questions, at each historical moment, have less to do with *whether* differences are recognized than with *precisely how* they are imagined and taken into account and *where* differences are understood to be located” (191). By 2000, the NIH issued guidelines with alterations in the language to include “sex/gender” instead of “women” and “and/or” race/ethnicity (NIH 2000). In terms of gender, the NIH changed from a position of advocacy for the inclusion of women to a position of gender neutrality.

The changes in NIH policy were not received without controversy. Some supported the inclusion of race as a variable in research while others called for the end of its use. Many groups applauded the policy changes as a break from a history of discrimination and exclusion of minorities in science and medicine. For example, African American men who had syphilis were treated with placebos without their knowledge in the Tuskegee experiments (Jones 1981). Others who supported these

measures argued that “they heralded the end of privileging the health research needs of white men” (Reardon 2005: 153). However, color conscious medical research also ushered in a new phase that re-articulated disease and racial difference. During the 1990s, increasing evidence emerged that suggested there exists an ethnic differentiation of diseases, such as high rates of sickle cell among African Americans and Tay Sachs among Ashkenazi Jews (Duster 2003), and ethnic differences in drug response (Tate and Goldstein 2004). Historically, different racial groups have been stigmatized as ill and diseased as a strategy of colonial control and surveillance (Gilman 1985, 1988; Levine 2003). Critics of the NIH guidelines charges that focusing on race in clinical research would have detrimental effects for racialized groups, if not racist outcomes. Brawley (1995), a noted African American oncologist, argues that the guidelines continue to link race and biology spuriously.

The implementation of the Guidelines may eventually do more harm than good for the minority populations that it hopes to benefit. The legislation’s emphasis on potential racial differences fosters the racism that its creators want to abrogate by establishing government-sponsored research on the basis of the belief that there are significant biological differences among the races. (293)

Focusing on the links between race and disease not only reinforces the biologizing of race, but it attributes health outcomes to genetics rather than environmental factors such as economics and diet. Some went even further to insist that race be abandoned, as it has no biological basis (Freeman 1998). While there may be no right answer to the dilemmas that arose out of the Revitalization Act, the discussions are more illustrative of the changing racial politics. The line between racist and non-racist scientific research and medical practice became increasingly blurred in the 1990s.

While these debates gained momentum and attention, disrupting long held traditions in scientific research and medical practice along the way, race thinking and race became further embedded in the discourse and research of the biomedical fields. Science and medical journals responded to institutional and social changes by self-regulation through editorial policies in the use of race and ethnicity as variables in journal submissions.

Editorial Policies on Race and Ethnicity (EPRE), 1991-2004

Discussions about the use and effects of race and ethnicity in biomedical and scientific research first appeared in the area of public health in the United Kingdom. Two papers published in the *Journal of Public Health* in 1991 and 1992 prompted the early journal debates. Bhopal (1991) argued that describing people as ‘Asian’ in the context of the UK was inappropriate. ‘Asian’ simultaneously homogenizes everyone from the Indian subcontinent and excludes those in Britain from south and east Asia. The concept is also lacks scientific clarity and signifies an Other racial identity, i.e. not white and, therefore, an outsider in British culture. This seminal paper was a call for a debate that crosses all sectors of biomedical and scientific research with the aim of establishing international principles for the classification and description of ethnic groups. In the following year, Sheldon and Parker (1992) pointed out that race and ethnicity were increasingly being used in health research, however, the data was being collected in an ad hoc manner. He argued that the concepts of race and ethnicity were being employed uncritically and without discussion of the nature of the constructs, which was leading to inconsistency in their

use. The danger in race being treated as a statistical variable, according to Sheldon and Parker, was that stereotypes could be reinforced. Also, the emerging research tended to focus on disease rather than environmental factors that could attribute to health outcomes. Shortly after these two papers, the debate migrated into the larger sphere of medicine in the *British Medical Journal (BMJ)*.

In a 1994 issue of *BMJ*, Senior and Bhopal and McKenzie and Crowcroft each tried to de-couple race and ethnicity. Senior and Bhopal differentiate race and ethnicity by locating the history of race in taxonomy of the eighteenth century and epidemiology as “physical characteristics,” “classification,” “evolution,” “variation,” and geography (327-8). They claim that there is increasing agreement that race is a “social and political phenomenon” and “more useful for social rather than biological explanations of variations in the prevalence of disease” (Ibid). Ethnicity is also a “socially constructed phenomenon” whose “boundaries are imprecise and fluid” (Ibid). The two terms tend to be used interchangeable with the underlying assumption that differences in disease frequencies between groups can be genetic. Often ethnicity acts as a euphemism for race and is used to avoid associations with racism. Skin color (observed rather than self reported), country of birth, names, and self-classification, what would come to be known as “self-identify,” are all identified as means of indexing ethnicity. Especially in the use of skin color, ethnicity tends to become a proxy for race. In spite of the shortcomings of the use of ethnicity, the authors make a number of recommendations to improve its value in research such as researchers stating explicitly how they classified ethnic groups, reflexivity in regard to ethnocentrism in personal values, recognizing the

contingency of producing data on dynamic categories, and including the relevance of environmental factors in variations of disease.

McKenzie and Crowcroft (1994) elaborate on Senior and Bhopal by finding that the problems with race and ethnicity are in the lack of clear definitions, inconsistency in use, and arbitrary group assignment. Another problematic concept, culture, is also used with varying definitions and applications. The authors explain that the biological basis of race is undermined by findings in genetics that show there is more variation within 'racial' groups than between them. Ethnicity is equally problematic. For example, they cite a longitudinal study where people self-reported different ethnicities in two different years. Even widely used categories such as Asian, white, and black are heterogeneous and defy easy categorization. They also tend to obfuscate local variations in the conditions of health services and disparities in health. "To discover why different groups have different experiences of health and what can be done to redress the balance we need to disentangle the influences of racism, education, unemployment, and social deprivation" (287). Calling for an "investigation of the validity of the current classifications" that employs the same rigorous approach as used in the field of biomedical research, they nod to Senior and Bhopal's recommendations. Interestingly, these early papers discussed culture alongside race and ethnicity, treating it as another variable that stands for group identity. This shows how culture would often times stand in as a more acceptable yet coded way of expressing racial categories. The work by Bhopal, Senior, McKenzie, and Crowcroft were precursors to the first editorial policy on race and ethnicity.

The *British Medical Journal* published guidelines for the reporting and use of race, ethnicity, and culture in the April issue of 1996 for describing individuals and groups. The guidelines focus on the differences between the concepts and their contingent, imprecise, but important role in biomedical research. The *BMJ* editor urges authors to describe the logic behind their choice of categories and be as descriptive as possible about the identity of the participant, instead of using “catch all terms in common use” (1094). The process of classification should closely match the hypothesis as well. The guidelines also make a distinction between biological research and health services research, stating that ethnicity and culture are useful for the latter, but limited for the former. The *BMJ* guidelines and the preceding discussions tend to construct a continuum of fluidity between race, ethnicity, and culture. On one side of the continuum, race is treated as the most static and biologically determined concept, even though many of the authors state that it is socially constructed. Occupying the opposite limit is culture, whose lines of demarcation, states the guidelines, are always arbitrary. Ethnicity sits between race and culture. In spite of its explanatory limits, there is an attempt to recoup ethnicity.

While the debates about bio-race and genetics in public health, biomedicine, and science resurfaced in the late 1980s and early 1990s, social scientists and cultural critics had been deconstructing race as a biological concept and reconfiguring ethnicity. Stuart Hall (1988), Robert Miles (1989), and others are also arguing for the abandonment of race as a marker of social identity. Race reduces difference to hierarchical and static notions of culture and group belonging. It has no validity as a biological concept and there is no scientific justification for race

identifying a set number of human groups arranged in a hierarchy. Miles states that race is an idea that should be “explicitly and consistently confined to the dustbin of analytically useless terms” (1989:72). Racial identity is indeed a dynamic and fluid process intimately bound to the social order and power relations. While race is a social and political concept, it may be too bound up in histories of colonialization, institutional racism, and genetic determinism. Instead, group identity needs to account for changing forces of migration, language, culture, and nationality. Ethnicity, Hall argues, “acknowledges the place of history, language and culture in the construction of subjectivity and identity, as well as the fact that all discourse is placed, positioned, situated, and all knowledge is contextual” (1996:446). Like Hall, the *BMJ* seeks to engage rather than suppress difference and decouple ethnicity from its equivalence with race and racism. This is symptomatic of a turn in the 1990s where cultural politics at once recognized difference while attempting to subsume difference in a discourse of sameness.

In an editorial in the same issue of the *BMJ* guidelines, McKenzie and Crowcroft, two of the leading advocates in biomedicine who assisted in devising the guidelines, continue to recommend that ethnicity be considered in an in depth manner in the context of a range of environmental factors. The categories set out by the Office of Population Censuses and Surveys (OPCS) in the 1991 census should be starting points, they argue, not homogenizing, catch-all categories for a number of other types of information, including diet and socio-economic status. In 1991, the official categories were White and Ethnic Minorities comprising of Black, South Asian, Chinese, and Others (NEMDA 1991). The minority categories were further

defined as Black-Caribbean, Black-African, Black-Other, Indian, Pakistani, Bangladeshi, Other-Asian, and Other-Other.⁹ The final category, “Other-Other” would not seem to have any relevance to race, ethnicity, or culture and, obviously, would require the additional information the authors call for. Discursively, Other-Other erases any sorts of history, health or material, political organization, or basic recognition within the nation state. The “Other-Other” individuals are counted but rendered categorically invisible. Because of the shortcomings of the OPCS categories, McKenzie and Crowcroft maintain the need for detailed demographic and environmental local data measured against categories that can be compared across geography, time, and census data. Calling for the abandonment of racial and ethnic data in favor of colorblind practices would make invisible the social disparities in health outcomes and health services. At the same time, however, reproducing racial and ethnic categories has the tendency to reify group differences and locate them in biology.

Journals across the Atlantic in the US did not pick up on this trend of editorial policies on race and ethnicity (EPREs) until the turn of the century. This, despite Osbourne and Feit’s challenge, in 1992, to the editors of the *Journal of American Medical Association* to “do no harm” in the journal’s articles that study on racial difference. They argue that using race as a variable in research reduces medical causes to genetics, rather than environmental factors. Also, the authors state

⁹ The OPCS was subsumed under the Office for National Statistics in 1996, which revised the categories for the 2001 census. In the major group, Mixed, Asian British, and Black British were added. Also, South Asian was changed to “Asian or Asian Other” and Chinese and Other became separate major categories (Office for National Statistics 2001). Can be accessed at www.statistics.gov.uk

that comparisons of medical conditions between racial groups leads readers to “assume that certain racial groups have a special predisposition to, risk, or susceptibility to the illness studied” (275). Calling this a “subtle form of racism” and implicating the practice of biomedical research, they appeal to the Hippocratic oath in urging researchers to write about race in an ethical manner. It was more than ten years before JAMA would address this issue and not until the late 1990s that American journals began to follow the lead of their British colleagues.

Like the UK, the first area to publish an article addressing the issue of race and ethnicity in biomedical research was in public health. In 1998, Raj Bhopal, the British doctor and professor of public health, sought a wider audience in the *American Journal of Public Health*. Along with Donaldson, Bhopal sought to widen the race and ethnicity debate by questioning the use of the term ‘white.’ Bhopal points out that ‘white’ is often used but rarely defined even though it is often compared to many non-white groups. Similar to Osborne and Feit (1992) and Sheldon and Parker (1992), he argues that such lack of clarity and inconsistency leaves the reader to think about such groups in stereotypical terms. Often in this type of research, race is presented as an independent variable rather than a social and political process that interacts with its material and ideological surroundings. Further, race is also assumed to be a mutually exclusive category, which homogenizes heterogeneous populations, whether they are black or white, for example. As discussed above, biomedical and scientific research often relies on the racial and ethnic categories set out by the state, which themselves are not absolute, mutually exclusive, or static formations. In the case of the US, the Office of

Management and Budget sets the standards and, in the UK, it is the categories used by Office of Population Censuses and Surveys. In the same edition, Fullilove suggested that the term ‘race’ be abandoned in public health research (1998). Oppenheimer (2001) called this solution a case of “paradigm lost” (2001). He wonders if the term race can be easily expunged and if there is something to be lost analytically in the process. Also, Oppenheimer questions the neutrality of ethnicity, which has its own set of negative associations.

By 2000, the conflict of interest policies in biomedical and public health journals discussed above had become the norm, but EPREs were only beginning to become institutionalized and, unsurprisingly, gathered much animated attention. In fact, what can be called the great race debate had begun to ramp up in the biomedical and scientific journals since the mid 1990s. In epidemiology, public health, oncology, genetics, medicine, pediatrics, dentistry, pharmacogenomics, to name a few domains, race and ethnicity and their pitfalls, inconsistencies, misuses, and opportunities had become part of the general journal discourse. The adoption of EPREs is a case where the content of biomedical and science research met the social and political changes of the time and where activism moved from discussion to practice to institutionalization, however unevenly. The widespread adoption of biomedical journals was largely due to the International Committee of Journal Editors.

Three years after the Asilomar conference a group of editors of medical journals met in an unremarkable meeting in Canada to discuss the future of their field. While the agenda for the 1975 meeting was heavy on ethical ramifications of

recombinant DNA research and government intervention, the heady debates that characterized Asilomar were probably not replicated in the shadows of the north shore mountains of Vancouver. The Vancouver Group, as they would come to be known, gathered to discuss common formatting procedures for manuscripts, such as aligning with National Library of Medicine standards for a bibliography. They published its first set of requirements in 1979. In subsequent years, however, the collection of editors expanded in size and evolved in scope to become the International Committee of Medical Journal Editors (ICMJE). As social movements prompted transformations in the biomedical sciences over the past three decades, the ICMJE continued to address ethical issues. By 1997, their mandate had expanded in scope beyond table formatting and pagination to patient privacy and ethics (ICMJE 1997). In 2000, language was added that directed authors to explicitly justify the inclusion and relevance of race and ethnicity as variables (ICMJE 2006).

Hundreds of biomedical journals follow the ICMJE requirements including the *New England Journal of Medicine (NEJM)* and the *Journal of the American Medical Association*. Even though *NEJM* and *JAMA* subscribed to the ICMJE guidelines, neither has instituted EPREs in 2000. However, in 2001 Richard Schwartz, an editor of *NEJM*, condemned the practice of “racial profiling” in medicine and echoed the argument that race is not a scientific concept.

As for medical research, any investigation that entails so-called racial distinctions, whether a clinical trial or a laboratory study, should begin with a plausible, clearly defined, and testable hypothesis. Before studying a possible relation between skin color and sodium excretion, for instance, investigators should have a credible reason for believing that such a link could exist and a plan for finding the relevant genetic network. Research to root out social

injustice in medical practice needs continued support, but tax supported trolling of data bases to find racial distinctions in human biology must end. (2001:1393)

Schwartz goes further than Osborne and Feit, who wrote almost ten years earlier, and called for the end of doctors using race as a proxy for genetic variation and disease. He also indicates the emerging proliferation of database and practices of knowledge production in genetics and refers to race-based medical research as “pseudoscience” (2001:1392). As Phimister, another *NEJM* editor, points out though science is in an age of discovery. She argues that it would be unwise to abandon race “when we have barely begun to understand the architecture of the human genome” (2003:1081). These two commentaries by *NEJM* editors show the disagreements in the biomedical sciences about the place and role of race in research and clinical practice. For example, Cooper et al (2003) argue that the history of racism and potential for future racial discrimination is cause for excluding race from biomedical and genetic studies. In the same issue of *NEJM*, Burchard et al (2003) contend that the only way to uncover inequality in health practices and policies is by recording race. While the *New England Journal of Medicine* was a leader in the issue of conflict of interest and journal publication, it has lagged behind in establishing EPREs. As of the writing of this dissertation in 2006, the journal does not have a stated EPRE, although it is listed on the ICMJE website. In 2003, Kaplan set out a number of recommendations in *JAMA*. The journal expanded on the ICMJE guidelines and instituted their own policy the next year (Winker 2004). Reflecting the *BMJ*’s policies, authors were required to fully explain the rationale and significance of using race or ethnicity as a variable and attempt to measure as many other environmental variables as possible.

The guidelines and policies on race and ethnicity by the ICMJE, *JAMA*, and *NEJM* show how ubiquitous the issue had become. They also signal a turn from appeals for abandoning race to instructions on how to rationalize its use. If one could identify the impetus for this change in direction at the turn of the millennium, it would have to be the intersection of disease research and genetics, the Human Genome Project.

Nature was the first scientific journal to institute an EPRE. *Nature Genetics* (*NG*), a node in the network of *Nature* journals, requires authors to “explain why they make use of a particular ethnic population and how classification was achieved, and are asking reviewers to consider those parameters when judging the merits of a manuscript” (Nature Genetics 2000). The editorial discusses the limits of the OMB categories and the constraints put on researchers by the NIH adoption of such categories in the Revitalization Act of 1993 as well as the ethnic differentiation of disease and genetic variation. Medical and public health guidelines focused on environmental factors and a breadth of epidemiological data. *NG* mentions this issue in passing, but focuses mainly on the problem of definition, terminology, and precision. One of the main barriers the editorial identifies is the combination of the OMB categories and “sloppy language” that comes from “poorly defined” lay conceptions of race and ethnicity. A bioethicist from the HapMap project succinctly called this shift, from race to a combination of factors, from proxy to precision.

...we don't really want to change the paradigm from race to human genome variation. It may be human genome variation. But it also may be diet. It may be socio-economic status. It may be something else in terms of what specific variable we are looking at. So, now I am talking about changing from proxy to precision. And the precision is based on what it is we are trying to find. (Interview 1022)

Instead of using race to stand in for a range of possible environmental or genetic factors, studies must be more specific in what their research questions are trying to identify. This bioethicist agreed that one of the main barriers to precision and reproducing imprecise groups, at best, and the biologizing of race is the OMB categories. She explains, “It forces you to put people in these categories” (Ibid). The paradox in scientists using race or ethnicity as a variable lies in the attempt at precision using an inherently imprecise concept and blunt instrument.

The adoption of an EPRE by *Nature Genetics* is significant as it is a leading journal in the scientific community. Journal adoption of EPREs in the fields of science, medicine, pharmacogenomics, and biotechnology has been uneven and slow, and not without controversy. In the *Pharmacogenomics Journal*, Nebert (2001), writes that the *Nature Genetics* policy for requiring authors to explain their process of classification is an important step in doing better science and better decision making in care and prevention. However, the author also adds, “This should be accomplished by mechanisms based on scientific reason, rather than mandates for ‘racial inclusion’ in all human studies.” A notable absence is the leading scientific journal of record, *Science*. Many HapMap interview respondents expressed reservations about the enforcement of such policies. While they welcomed this mechanism to address the problems with using race and ethnicity as categories of scientific research, there was common concern that either the policies were not being adopted widely enough, or, when they were institutionalized, the editors and reviewers were not making enough effort to ensure that articles accepted for publication had stated rationales for using race or ethnicity. One respondent

suggested that there is less need to justify hypotheses with superficial assumptions currently, where authors had to much more in the 1990s. At best, the impact of editorial policies of transparency has been neither strong nor effective (Interview 1022).

Conclusion

There are a number of regulatory components that institutionally enable and constrain the HapMap Project. This chapter has described three major regulatory areas that structure the HapMap Project institutionally: the deregulation of university-industrial relations, journal conflict of interest policies, and government and journal policies on race and ethnicity. Academic biologists took their first steps out of the labs towards private industry in the 1970s. Chemistry and physics had long been engaged in collaborations with commercial entities, however private interest in biology was quite new. The discovery of rDNA and the Chakrabarty case signaled the emergence of genetic engineering and biotechnology and the recognition by government of the economic and scientific potential of this new sector. In an age of neoliberal economic policies there exists an ideology that the market will operate in a natural and productive fashion without the interference of the state. As the first part of this chapter showed, collaborations between the academy and industry were facilitated and encouraged by government deregulation. Primarily, through state participation genome science has progressed, notably through funding for projects, such as the Human Genome Project and HapMap, from the National Instituted of Health.

Through the process of deregulation and collaboration with the private sector, the culture and practices in university labs underwent industrialization. As private funded research in science, both in industry and academia, increased and many university labs partnered with firms, professors began donning two hats by holding academic posts and working for biotech. This prompted many scientists to question the motivations of pure research. For some, the ‘soul’ of academic research and the integrity of research goals and findings was at stake. Journals responded by requiring authors to state whether or not their study was privately funded through conflict of interest declarations. The concern was that findings from scientific studies would validate the interests of the entrepreneur, rather than ‘pure’ knowledge or the public good. Scholars such as Dorothy Nelkin argued, “Science is a big business, a costly enterprise commonly funded by corporations and driven by the logic of the market. Entrepreneurial values, economic interests, and the promise of profits are shaping the scientific ethos” (1998:893).

Finally, due to pressures from the great social movements at the end of the twentieth century, a new common sense of diversity in research practices became institutionalized in color consciousness government and journal policies. Racial and ethnic minority populations who were marginalized and mistreated in biomedical research and clinical practice became visible participants through the NIH Revitalization Act of 1993. While the racial and ethnic categories set out by the OMB in 1977 largely dictated the terms of identity in research and clinical practice, public health, medicine, and genetic science struggled with histories of discrimination and imprecise racial and ethnic categories. Discussions about how to

properly identify minority communities began in public health journals and migrated across medicine and genetics, prompting a number of journals to institute editorial policies. These regulatory changes play an important role in researching different social groups.

As a population geneticist from the HapMap Project comments, “We could have gone forward with the sequencing without bringing other populations using the CEPH samples (DNA samples collected and stored at the Centre d’Etude du Polymorphisme Humain in France). But we didn’t want to use only white Northern Europeans and potentially miss out on the variation that exists among Asian, Africans and other populations. We are trying to be as inclusive as possible” (Lee and Koenig 2003:235). While the speaker locates the decision making process among the members of the project, the institutional and cultural structures are evident. As discussed above, diversity among research subjects has become more prevalent in biomedical research. Further, NIH funding guidelines from the Revitalization Act of 1993 stipulates the inclusion of minorities. HapMap comes out of the NHGRI, one of the institutes of the NIH. In spite of the Act and the ubiquitousness of diversity, the statement also reveals how the white European is normative in scientific research. The readily available samples are European, rather than from a minority group. Chapter Five will examine cultural discourses about race and populations that circulate in genomics.

Chapter 5

Discursive Formations of the Informationalization of Race:

Race Talk in Genomics and the HapMap Project

The informationalization of race encapsulates new mechanisms of racialization in a post-civil rights, information age where technology and identity become increasingly intertwined. The third component of this analysis shifts to the realm of culture. Scientific discourse about the genome and race is embedded in cultural assumptions and power relations about the nature of human identity and behavior and the ‘proper’ social order. When I first began conceptualizing the relationship between science and race, my hypothesis placed race as the dependent variable and science the independent variable. I began to problematize this popular notion of the relationship between science and culture scientific research affects the larger society, operating from a position of neutrality and objective truth. This chapter takes the position that the relationship between science and race is a recursive relationship. At times, however, there is strong evidence that science is the *dependent* variable and common sense racial knowledge informs the way in which scientists design their own research, ask questions, and report results. Through a textual analysis of leading journals in the biomedical sciences, statements on science and race, and interviews with members of the HapMap Project, this chapter explores the central discursive frames of the informationalization of race and how they are manifested in race talk in genomics. Fifty years after the UNESCO Statements on race and decades of the

social sciences, the humanities, and the natural sciences battling to wrench race away from its biological moorings, genomics has re-ignited the debate on race.

Race talk in genomics and the biomedical sciences has emerged within a discursive and social context that is much different from the context of the UNESCO statements half a century ago. Bonilla-Silva (2001, 2003), Brown et al (2003), and Kim (1999) and others argue the current dominant racial ideology is colorblind racism. Bell (1995) and Wolfe (1998), however, suggest that we are in a time of racial realism. Both may be right. One of the main interventions of the UNESCO authors was to argue that race is a social construct rather than a biological one. This position has been repeated often by scholars of race since then and has, largely, become common sense. The distinction between the existence of races and race as a social and political identity has largely defined the differences between racist/conservative and anti-racist/progressive discourse (See Figure 1, Appendix A). In the post-Civil Rights era, however, what counted as good liberalism 30 years ago is now seen as centrist and in contrast to progressive politics of anti-racist groups, who often organize around race or some other essential identity category, such as gender or sexuality. Further, discourse has gone “underground” where race talk is coded and positions that once were the domain of liberalism have now been co-opted by conservative agendas. The social and political context of racial politics has shifted dramatically since the 1950s and, especially, in the last three decades. In spite of these challenges and shifting terrain, I argue there are four central discursive frames

that characterize the informationalization of race. The first section of this chapter delineates the four frames and then I will discuss each of them in the context of race talk in biomedical research and genomics.

Figure 2 (Appendix A) describes the four positions in the field of race talk in cultural discourse. Along the vertical axis lies “race/no race.” These two positions account for discursive positions that argue for or against the existence of race either scientifically or socio-politically. Along the horizontal axis lies the positions “progressive/conservative.” Progressive, anti-racist politics traditionally have argued against race through the deconstruction of race as a biological and hierarchical category and political mobilization against structural discrimination. Conservatives upheld a system of racial domination under Jim Crow, based on an ideology of ‘inherent’ inferiority of ‘races.’ In the 1990s, conservatism has adopted the discourse of multiculturalism and diversity, but not structural equality. More recently, neo-conservatism has returned to overt racial rhetoric, albeit in a ‘softer’ form. Also, the axes do not act as impermeable boundaries between the different frames. Signifiers can slide towards different positions or be shared by two or more of them. For example, both planetary humanism and colorblindness advocate for the abolition of racial categories. However, the former seeks social equality and the latter seeks to uphold the status quo.

Race talk in the informationalization of race takes shape in a field of four positions or discursive formations: strategic essentialism, planetary humanism, racial realism, and colorblindness. Gayatri Spivak (1987) has been credited with coining the term *strategic essentialism* and it has developed into an important concept in

postcolonial studies, feminism, queer theory, and critical race. While the strategic essentialism position may be anti-essentialist, there are instances when action calls for a strategic use of a fundamental racial category in order to further a group's political aims. Hall (1996) and Gilroy (1993) have both argued that a contingent racial essentialism can be tactically advantageous when minority communities are bounded by a history of systemic racism. Omi and Winant (1994) refer to this approach as purposeful racialization and have documented a number of its instantiations. *Planetary humanism*, on the other hand, advocates for the complete abandonment or end of race. Gilroy (2000) argues that new genomic technologies are able to bypass the epidermal layer that has anchored racial categories and reveal the truth of who we are at the molecular level. This knowledge can finally lead to the disruption of race as a regime of truth and move towards a politics of difference beyond the yoke of bio-race while retaining cultural difference and diversity as political ideals.

Colorblindness also seeks the end of racial identity, but not the end of racism. Unlike the futurism of planetary humanism, colorblindness argues that we are at the end of racism and the persistence of racial inequality is only because minorities have failed to take advantage of opportunities created by the civil rights revolution. There is little need for color conscious policies, such as affirmative action, as this position believes that the US is now a colorblind society. In the 2002 gubernatorial elections in California, UC Regent Ward Connelly, best known as the architect of Prop 209 that

struck down affirmative action in college admissions, advocated Prop 54 which banned government agencies or government funded organizations from collecting statistics on race.

Finally, the *racial realist* position also believes that human groups are fundamentally divided along racial lines. The concept of *racial realism* comes from the work of Derrick Bell (1990, 1992) who argued at the end of the 1980s that gains from the civil rights movement were being lost in the fervor of the rising reformist movement. Neo-conservative racial realists, on the other hand, argue that race is biological and that race reveals basic group differences. For example, Herrnstein and Murray (1994) suggest that there are differences between races in IQ while Rushton (2005) argues that different races have varying levels of criminality and sexual aggressiveness. In the remainder of this chapter, I explore how the cultural frames that characterize the informationalization of race structure the discourse new genetic research into the human genome.

In *The Century of the Gene*, feminist scientist Evelyn Fox Keller argues that gene talk has become outdated in terms of knowledge about the function of genes. The entrenchment of the gene in science and the popular imagination, however, is not only a function of scientific discovery but scientific discourse. Keller argues that science is, in part, discursively constructed and that words enable and constrain what scientists can say, think, and hypothesize. Scientific facts and the creation of knowledge are not independent of discourse. Nor is discourse merely reflective of the social and scientific world, but constitutive of it.

Like the rest of us, scientists are language-speaking actors. The words they use play a crucial (and, more often than not, indispensable) role in motivating them to act, in directing their attention, in framing their questions, and in guiding their experimental efforts. By their words, their very landscapes of possibility are shaped...What is missing – and would be absolutely required for understanding the role of language in biological research – is a far deeper investigation of the material, economic, and social context in which that language functions.” (Keller 2000:138-9)

Keller draws on the work of social theorists Saussure, Barthes, and Derrida to show how language is intimately connected to social action. Donna Haraway has shown how gene mapping and technoscience involves the inhabiting of stories (Haraway 1997). In this regard, genes have a social life, that is, stories about them are circulated through scientific circles as well as media representations and everyday discourse. Moving from the micro level of the individual scientist to macro level of social structure, Foucault has shown how modern power operates through a web of discourses. The formation of modern biology is the result of a 200 year-old “complex web of semiotic-material practices” focused on the body (Haraway 1997:217). Identity formation is not based on a unitary identity but emanates through a number of strategic points of negotiation over the meaning of identification and difference. Discursive formations are established hierarchical orders of ‘truth’ that organize language and determine communicative practices in a particular historical moment (Foucault 1972; Hall 1997). Put another way, the manner in which we talk and think about subjects or issues is limited to the choices of frames available to an actor in a given historical and social context. Discursive formations structure ways of thinking and storytelling that reinforce already taken for granted notions of identity and difference while limiting alternative constitutions (Lidchi 1997:191). Discourse

does not merely reflect social practices, relations, and structures. It plays a constitutive role in the construction and reproduction of them (Emirbayer and Goodwin 1994; Wetherell and Potter 1992). The way that scientists conceptualize and report findings about the race, human difference, and the genome is not simply a reflection of reality. The language and codes scientists deploy frames not only their perspectives, but their research design.

Research, editorials, and commentaries network ideas and frameworks of understanding or semantic networks. Semantic networks are shared cultural meanings about a particular phenomena; they are meanings by association (Du Gay 1997:15). They connect the descriptive or literal meanings of a word or concept with broader connotations and cultural discourses or discursive formations. The articles in the journals, websites, and research projects have their own networks of meaning about human variation, populations, genomics, and biology. However, they are connected to broader cultural discourses about genetics, race, and science. From a micro point of view, they are part of a particular discussion and, at the macro level, each contribute to a changing discursive formation about race and genomics. The overall narratives that structure genomic stories are evolving in the sense that each research paper, editorial, special issues, and commentaries constantly push discursive possibilities and actual boundaries. The readers are also writers. No entry in the discussion is a self-contained unit. This dynamic is similar to how Foucault viewed the borders of books as ambiguously demarcated.

...beyond the title, the first lines, and the last full stop, beyond its eternal configuration and its autonomous form, it is caught up in a system of references to other books, other texts, other sentences: it is a node within a network. (1972:23)

Journal articles literally reference other texts in the tradition of academic citation.

However, concepts and language do the cultural work of connecting to previous frameworks while acting on them in a constantly evolving formation.

Likewise, genomic stories contribute to larger discussions while, at the same time, being constrained by the topic and the type of storytelling about that topic which is already underway. They are nodes within a broader semantic network. That is, within the broader collection of stories across journals, websites, and domains and within broader cultural formations.

Cultural formations are interrelated symbols that have a “nonmaterial structure” and are organized in a manner similar to material structures while, analytically, being separate from them (Alexander and Smith 1993). While human agency has traditionally been dependent on material (meaning economic and network) structures, Emirbayer and Goodwin argue “cultural formations are significant because they both constrain and enable historical actors, in much the same way as do network structures themselves” (1994:1440). Actors are both enabled and constrained by cultural formations. They are enabled by “ordering their understandings of the social world and of themselves, by constructing their identities, goals, and aspirations, and by rendering certain issues significant or salient and others not” (1994:1441). In a recursive and relational manner, actors are constrained by a foreclosing of certain options or possibilities for action as well as having to rely

on established frames. Throughout his work, Foucault theorizes a model of social and political power that contrasts traditional top-down configurations. Instead, he postulates that social power is arranged in a diffuse fashion and works through strategic points in a web of discourses (1977:26, 1978:95-96, 1980:98). While the points of power are diffused, this does not necessarily make for a more democratic formation. Domination can and does exist and persist. Foucault's conceptualization of power can be understood as a network theory.

Treating the various journal articles, editorials, commentaries, and websites as a whole, the themes across the different strings and sub-categories of organization can be conceptualized as nodes in a network, a semantic network of genomics and race. The discursive formations or nodes in the semantic network enables and constrains stories about race, the genome, and science. They are constitutive of the social and scientific world. As the analysis below will show, the central frames of the informationalization of race can be found across discursive formations of genomics and race. Each of the below themes tends to sit in one quadrant of the grid in figure 2. However, true to the complexity of race talk today, this tendency is just that. Strict classification into mutually exclusive categories can be elusive. First, a brief discussion about how scientists define race as a variable is necessary.

Definitions of Race in Genomics

Discussions of race and ethnicity tend to start with the dictionary or history.

“Ethnicity is derived from a Greek word meaning a people or tribe” (Senior and Bhopal 1994), “ethnicity and culture are ideas derived from social theory” and

“characterised by a sense of belonging or group identity” and “social pressures and psychological needs; and they are dynamic” (McKenzie and Crowcroft 1994); “Race is a social construct, not a scientific classification.” (Schwartz 2001:1392); The *Nature Genetics* editorial that set the guidelines for the use of race and ethnicity in submission even began with Jesus:

Jesus Christ was born in Bethlehem because his parents had to register there with the Roman authorities, who sought information on the population of their Empire. Roughly two millennia later, the United States government will ask its citizens to take part in a similar endeavour, the Census 2000... the concept of race is a social and cultural construction. (Nature Genetics 2000)

Often, definitions of race either are biological, social, or both. While the mainstream of discussions has given at least some incorporation of the social and political nature of race, by far the social-political is only mentioned before entering into a discussion of race as biology or research findings using race as a category of analysis. Often, biology and culture are conflated which leads to a lack of precision. While discussions about the proper uses and conceptualizing of race have been increasing with genomics, race “is frequently employed in a routine an uncritical manner” (Williams 1994:261). Cooper et al (2003) begin their discussion of race and genomics by stating the race is a “contentious” topic (1166). It is an “idea that intrudes on the everyday life of so many people” (Ibid). Race as a concept is modern and “grew out of the experience of Europeans in naming and organizing populations encountered in the rapid expansion of their empires” (Ibid). The “plasticity of race” comes from its “wide range of meanings” that mix “social and biologic ingredients in varied proportions” (Ibid). Cooper et al’s definition is typical of a blend of social and biological references in race-talk in the sciences. While the authors state that race

affects many people, it is relegated to the domain of ideas, rather than political and cultural practices originating in rational human action or the normal outcome of social structures. By locating race in a frame of origins, European colonialism, its formation is in the distant past indicating that it may be remnants we are grappling with today. There is no mention of its relationship to contemporary structures.

The supporting reference for the Cooper article is Ashley Montagu's 1964 book *The Concept of Race*. While Montagu was a central figure in historical debates within anthropology about race and society and one of the authors of the first UNESCO statement on race, his book came out in 1964, nearly forty years before the publication of Cooper et al, which appeared in the *New England Journal of Medicine*. This situates social science discussions of race as historical and the concept of race as a static phenomenon. The status of race in 1964 is profoundly different than its contemporary origins. Namely, Montagu's text pre-dates the 'end' of the civil rights movement with the 1965 Voting Rights Act. Not only have the social structures and everyday realities of race changed since the 1960s, social science scholarship in the very way it approaches race has undergone a revolution as well. Finally, the authors admit that race is social in nature with the reference to ideas and the European process of "naming and organizing populations," however the "plasticity" of the concept comes from various biological-social concoctions. Scientific race-talk aims at precision in the biological nature of race, but is limited and inexact when it comes to the socio-political. The normative mantra in science, "race is a social construct, not a biological one" (See Gannett 2001, especially S482), appears to be superficial or, at least, underdeveloped.

Decades of research in the social sciences and humanities define race in multifarious ways within the social construction framework. Race as performance (Spivak 1987), race as politics (Omi and Winant 1994; Seito 1998), race as power (Bonilla-Silva 2001), race as media representations (Gray 1995), race as segmented labor force (Hall 1980, Miles 1982), race as nation (Barker 1999; Bhabha 1994, Hall 1997), race as immigration (Jacobson 1998), race as gender (Mohanty 2003), race as sexuality (Stoler 1995; Young 1995), and race as law (Crenshaw 1995), are just a few. Biomedical researchers tend to define race quite superficially, as a social category, at first. Some use a dictionary definition (Nebert et al 2001), suggest its derivations from the romantic languages (Bamshad et al 2004), or its classification in anthropology (Cooper et al 2003). However, once the social nature of race has been acknowledged, the bulk of the discussion usually focuses on the biological nature of the differences or similarities between groups, such as, which alleles have tendencies in what group and linkage disequilibrium between populations. According to Duster, this conflict is widespread in biomedical and scientific research and, sometimes, “in the brain of a single author” (Rotman 2004:69). Whatever markers are chosen the method is statistical and normative. Common sense categories are employed rather than discovering the clusters of people in the data. Even more oddly, some argue that self-report of racial identity is the best way to determine the categories. When imprecision is a major issue in determining the utility of research variables (internal validity), it seems odd that a scientist would leave the definitions and boundaries of those variables purely up to the subjects.

Planetary Humanism

One of the main positions in the struggle over racial identity in the twentieth century has been the validity of the concept. The racial taxonomies of the seventeenth to the nineteenth centuries and their status as biological entities came under fire in the early twentieth century from scholars and political activists alike, such as Franz Boas and W.E.B. du Bois. Social movements in the mid-twentieth century appealed to a discourse of sameness in the battle for social equality. Scholars largely agree that the UNESCO statements on race in 1950 and 1952 represent an intellectual and political paradigm shift in the social and the natural sciences as they renounced race as a biological phenomenon. On the front lines, African Americans in the United States, South Asians and Afro-Caribbeans in the UK, and First Nations peoples in Canada protested from a moral-ethical position that, in essence, ‘we’ are all the same. That is, people of color have the political and human right to equal treatment and status under the law and in everyday life. Since color had been such a divisive mechanism of social organization, then people should be seen not in terms of their skin color or race but, according to Dr. King, the content of their character. For many groups, the goal was not only the disruption of racial hierarchies but the destruction of race itself.

This position has evolved in the twentieth century into what Gilroy (2000) calls, planetary humanism. The goal of planetary humanism is the abandonment of bio-race while retaining difference and diversity as political ideals. It differs from colorblindness in its direct confrontation and call to abandon “race” through an acknowledgement of

The sufferings that raciology has wrought. The most valuable resources for its elaboration derive from a principled, cross-cultural approach to the history and literature of extreme situations in which the boundaries of what it means to be human were being negotiated and tested minute by minute, day by day. (Gilroy 2000:18)

Gilroy sees genomics as a potentially powerful technology capable of subverting bio-race gene by gene, allele by allele.

The contemporary focus on the largely hidden potency of genes promotes a fundamental change in scale in the perception and comprehension of the human body. This change is not automatic product of only the most recent scientific developments and needs to be connected to an understanding of techno-science, particularly biotechnology, over a longer period of time. Its impact upon the status of old, that is, essentially eighteenth-century, racial typologies has been inexcusably neglected by most writers on "race. (Gilroy 2000:19)

There are five main frames that planetary humanism operates from in discursive formations of race in genomics: single origin, 99.9 percent the same, within/between, the existence of race, and from proxy to precision. Unlike earlier social and scientific movements, they appeal to both sameness and difference.

Out of Africa: The Single Origin Story

While globalization, migration, and global communication have been producing hybrid identities or what Hall (1992) refers to as new ethnicities, research into the human genome reconstructs origin narratives of human history. In the single origin story, all of humanity began in the eastern part of Africa (Interview 1006). Both the 1950 and 1952 UNESCO statements being by stating that all humans “are derived from a common stock” (UNESCO 1950, 1952). Closely following this is displacement theory or the ‘Out of Africa’ story that posits a single group migrated

to the old world more than 80,000 years ago (Nebert and Menon 2001; See also Tishkoff and Kidd 2003). The visual representation of this exodus usually includes an arrow that vaguely points from somewhere in Africa to the areas now known as Europe and Asia. The whole of human diversity has been explained by this type of simple diagram and legitimizes the search in the genome for the ancient origins of human variation. As mentioned in the previous chapter, Gould writes that visualization plays an important part in how scientific knowledge is articulated. A geometric reformulation is key to conceptualization rather than factual information. Many scientific revolutions have embodied geometric shifts (Gould 1994). Genomics is such a scientific revolution and there is a significant focus in-group comparison studies on the ‘founding’ human groups from Asia, Europe, and Africa.

Racial identity is a complex formation that exists at the confluence of politics, science, culture, and power. While scientists draw on the history of population genetics, biology, and physical anthropology to rationalize the nature of the categories they employ as research variables, there is no decoupling the social meaning of race. Further, the overarching categories are not even derived from anthropology or population genetics, but the US Office of Management and Budget. The OMB categories do not represent neutral and natural classifications, but, more accurately, the history of political and ideological struggle from the top down and the bottom up over racialization and identity in the United States. The categories themselves obscure the political wrangling and the history of racial segregation in the US as they are presented as neutral codes. The OMB categories have always changed and will continue to do so. Just recently, in the 2000 census allowed people

to check off more than one racial category. This single revision upends a tradition in the US of distinct racial groups and a deep seeded fear of mixing, what use to be referred to as miscegenation and is referred to in genomics as admixture. Interracial relationships have always been part of the fabric of American society, but the dividing lines between groups have been carefully policed in the maintenance of a racial order. The discourse itself in mixing, past and present, suggests some distant ‘founding’ races. Young (1995) has argued that the term “interracial” reproduces racism as it harks back to nineteenth century ideologies of separate and distinct races. Admixture, understood in genetics as the “formation of a hybrid population through the mixing of two ancestral populations” (Jobling and Gill 2004:749), does the same work of constructing an ideology of ‘pure’ populations.

We Are All 99.9% the Same

The Out of Africa hypothesis was confirmed with the completion of the Human Genome Project. The historical process of racial classification explicitly stated a hierarchy of humans ‘races’ in an extension of the Great Chain of Being. In practice, this often meant that people of color were considered, in varying degrees, to be less than the white norm. Appeals to the sameness of humanity have been used to combat an emphasis on difference and dehumanization of the Other. This position received crucial support with the announcement of the completion of the Human Genome Project. One of the highly publicized conclusions of the HGP was that that human genetic makeup is 99.9% the same. President Bill Clinton cited this number in his speech at the joint announcement of the completion of the draft genome on June 26,

2000, and both Francis Collins and Craig Venter have repeated this statement often. Venter has been a particular advocate of the 99.9% finding and the shared genetic heritage of humans. In his White House speech, Venter claimed that there is no way to tell the difference between the five different ethnicities in the Celera samples (Venter 2000). This statement follows American Anthropological Association's 1997 "Response to OMB Directive 15," UNESCO's Replacement Statement on biological Aspects of Race issued (1995) revised at a meeting in Italy, and a number of other scientific associations official positions¹⁰. Differences in the remaining .1% of the genome (which is about 3 million nucleotides) have been described as superficial and meaningless.

The Within/Between Debate

The "99.9%" statement tends to be located near a statement about the differences between groups: the variation within a population is far greater than the difference between them. Both original UNESCO statements included similar statements: "With respect to most, if not all, measurable characters, the difference among individuals belonging to the same race are greater than the differences that occur between the observed averages for two or more races within the same major group"

¹⁰ There has been a host of special issues and websites set up to address the renewed interest in the relationship of genomics and race. The journal of the American Psychological Association *American Psychologist* released a special issue in January of 2005, which included sociologists and bioethicists. The Social Sciences Research Council's web forum, *Is Race "Real"?*, came online in the same year, partly in response to demand by media outlets for information on the subject. *Nature Genetics* also published a special supplement in 2004, which was sponsored by the Department of Energy.

(UNESCO 1952:12-13). Among population geneticists, there is agreement that the “bulk” of within genetic variation is about 90-95% (Cooper 2003). Another common statistic finds eighty-five percent of all human variation can be found in all populations, while approximately fifteen percent can found between populations (Fausto-Sterling 2003). Measures of sameness and difference have contributed to scientists announcing the end of race as a biological concept.

From the contemporary standpoint of genotypes, there is no biological basis for racial categorization. It would seem that the existence of bio-races could be adequately debunked by the logic of sameness and within/between. However, as Cooper writes, "Into this storm of controversy rides genomics" (2003:1166). While the HGP registered a strong empirical salvo against the validity of bio-race and scientists largely agree on the within/between position, genomic technologies have allowed for a closer look at the .1% and the 5-15% of variation between groups. Genomics has only fueled the debates about population/racial differences and genome projects, such as HapMap are contributing millions of dollars to research on them. Debates about the existence of race are not going away anytime soon. They are only transforming.

Does Race Exist?

I don't think we should be so politically correct or so afraid and become so ambiguous and tiptoe around what we're actually doing. We should just be transparent, open, about what the nature of the research is that we're doing, what the purpose is, what the outcome is. And I think that kind of honesty and professional integrity is more important than endless, endless, endless discussions on definitions of whether race exists or not.

(Interview 1008)

In biomedical debates about the reality of race as a discrete biological category and sub-group of humanity there is a strong sentiment that this very discussion is problematic and “getting in the way” of progress. Weiss and Fullerton (2005) suggest that this discussion is “getting nowhere” and that the issue continues to go “round and round” (165). The data on human variation being produced by current research in population genetics and genomics is not showing anything new. This position holds that physical anthropology has long been making the case for one human race. Further, that there is some utility in using racial groups to understand health, for instance. Epidemiological data has shown that focusing on race, such as in research on sickle cell disease, is productive making a sickle cell study in a Japanese population nonsensical and misguided.

There is a sense among HapMap respondents that fear and anxiety should not stop such projects from moving forward. While there is general knowledge of the risks in terms of linking genetics and race, those risks, which may not be tangible in their eyes, do not outweigh the benefits of the production of scientific knowledge in the discovery of genetic causes for common diseases. Using groups that correspond to common sense and historically grounded notions of racial groups is not going away soon. As a HapMap geneticist and expert in bioethics explained, “I think there is a general recognition that certain things need to change and we need to do things in a more careful way. But I don’t think there is really the consciousness about actually doing it” (Interview 1022). Critics who urge caution in the use of racial groups in genetic research, and many of them are not scientists and doctors, but

social scientists, are deemed naysayers (Rotman 2004). Their concerns often are relegated to the irrational (fear), emotional (anxiety), and political (impure) rather than the products of social and historical knowledge. Scientists argue that there are observable racial differences between populations that require investigation.

“Unfortunately, race is a politically charged topic, and there will be evildoers. But the fear should not outweigh the benefit of looking” (Burchard in Rotman 2005). The question remains, when does ‘fear’ become justified? When does one decide not to do something even though it seems possible and, in fact, may be accomplishable and could better humanity, even if the costs include reproducing social inequities

I think that the issue is going to be figuring out which differences make a difference, and for what purpose. And to recognize that it’s a basic human characteristic, sadly, that many people really focus on trying to found out ways that they’re better than other people. This is another tool. On the other hand, treating everybody the same when they’re not runs other sorts of risks. So I think that any time you focus on the way individuals vary from each other, you open up a series of questions that can be pretty hard. (Interview 1005)

Both scientist and bioethicist interviewees from HapMap tended to see the issue of race and subsequent discussions as a distraction when the goal is to develop therapeutic interventions from genomic research (Interview 1008). Further, some even suggested that there is a general resentment of the NHGRI directing a set amount of its operating budget to social science research. A joke amongst scientists is that ELSI is simply a philosophy class for scientists. The implication in the joke is that ELSI is, to an extent, public relations and a soft pursuit that is taking resources away from the real research needs in the hard sciences.

While there is much discussion in the scientific literature about what race is exactly, there is little effort made to define it. As mentioned above, many acknowledge that it is a social-political category whose origins have dubious intentions and then go on to use it as a variable for some population group. Race has no biological basis, but it is constantly used, without an explicit rationale as a biological category. “The concept of race is as slippery as an eel, and so elusive that it even eludes itself” (Weiss and Fullerton 2005:168). While scientific research diminishes the historical record as unjustified fear, the HapMap is an example of the creep of racial classification back into the mainstream of scientific research. This classification is justified in the potential benefits that genome projects, such as HapMap, promise for health. Advocates of color consciousness research argue that there will be important discoveries to be found by looking at ethnic or racial differences in medicine. Disparities in health between different racial groups are key sites to disentangle environmental and genetic factors. Some, such as Esteben Gonzalez Burchard, a physician and assistant professor of medicine and biopharmaceutical sciences at the University of California, San Francisco, argue that it is essential to follow the clues in racial science research (Rotman 2005). There are others, however, who would rather see race eliminated altogether from clinical and scientific research.

Advocates of color-blindness argue that race does not matter any longer and any references to race, whether in diversity hiring policies, college admissions, or the collection of government statistics, should be eliminated. Society needs to just get over race. The construction of distinct human sub-groups was a project of

enlightenment thinkers and the science of modernity from the seventeenth to nineteenth centuries. The twentieth century has witnessed a profound intervention in the construction of race through a deconstruction of not only the category of race itself, as biological reality, but the process of racial (re)construction. Du Bois' seminal text, *The Souls Black Folk*, began this process in 1903.

Currently, there are social and natural scientists that continue to argue for the utility of race as a meaningful category of human groups or that there are distinguishable and measurable differences between them. The lineage of racial classification that is largely credited to Blumenbach (1795) but really began with his teacher Linneaus (1758) has been carried through the nineteenth and twentieth centuries via Galton (1869), Darwin's cousin, Jensen (1969), Herrnstein and Murray (1994), and Rushton (1995). The fervor from the left and the right of the political spectrum with the publication of *The Bell Curve* has died down in the popular press. However, Philippe Rushton has, almost single handedly, been trying to keep the discussion of the evolutionary origins of modern racial differences afloat. This, in spite of threats of dismissal from his academic post, charges of human rights violations, and having to give his lectures via recorded video tapes due to the controversy that ensued with the publication of *Race, Evolution, and Behavior: A Life History Perspective*. Primarily he argues that, in his terminology, Mongloids/Orientals, Caucasoids, and Negroids differ in terms of brain and genital size and a number of other 'racial' differences.¹¹ The three exist on a continuum of

¹¹ The differences Rushton examines include brain size, genital size, rate of sexual maturation, length of menstrual cycle, frequency of sexual intercourse, gamete

human evolution with Africans at the underdeveloped end, East Asians occupying the overdeveloped end and Europeans playing a mediating role. Rushton may be avoiding a hierarchy of races where Europeans occupy the dominant position. This is, however, in alignment with a colorblind racial ideology where whiteness holds the normative position from which all other races are measured.

Recently, Rushton and Jensen published a review article of race and intelligence research over the past thirty years (2005). In it, they continue to argue that culture-only hypotheses of group differences fail to account for differences in IQ between blacks and whites. Drawing on Herrnstein and Murray, they suggest that responsible social policies and good science needs to incorporate the extent to which heredity affects group differences. They suggest that “discrimination policies” or race-based social policies, such as affirmative action, and “the value of diversity” (281), that recognize structural inequalities are harming the rights of the individual and merit reconsideration. Rather than suggesting that racial discrimination has disappeared, they make the observation that racial harmony is disrupted by the persistence of discrimination policies. For them, the view that racism is responsible for social inequality causes mutual resentment between blacks and whites. Overt racism is a thing of the past and blacks equate their lack of success compared to whites with a white racism that is invisible. In turn, whites “resent that nonfalsifiable accusation and the demands to compensate Blacks for harm they do not believe they

production, sexual hormone levels, the tendency to produce dizygotic twins, marital stability, infant mortality, altruism, law abidingness, and mental health. See Herrnstein and Murray 1994:642. For a discussion of the link between Herrnstein and Murray’s and Rushton’s work see Graves 2002:58-61.

caused” (282). Racism itself is not the outcome of discriminatory institutions and everyday racism. Rather, it is now the result of a misunderstanding resulting from “the view that one segment of the population is largely to blame for the problems of another segment” (Ibid.). They argue that the burden of proof of group differences should shift to the culture-only perspective, as “there is too little evidence of any environmental effects” (279).

De-Racializing the Genome: From Proxy to Precision

When researchers use race as a variable in biomedical research, it is as a proxy for environmental (culture, diet, class, geographic location) or genetic influences. Used in this way, race tends to ‘explain’ complex processes that may be unrelated to racialized identity, thus, re-producing biological notions of race. In scientific discussions and among HapMap project members some argue that race is still useful in scientific studies. The ‘correct’ way to employ race is by having a clear, scientific rationale and definitions.

I don’t think that we should you know invent new words simply because we’re scared of the old one, and especially when those new words will be misunderstood and make it scientifically impossible to validate studies cause we’re not really sure where people came from, what they were meant when they were using the word race. (Interview 1008)

Many scientists find the use of race as a proxy for populations highly problematic (Interview 1006). Grouping people by race produces a “disconnect at the molecular level” (Interview 1006) from the cultural level. How we are grouped politically and culturally is at odds with how our genes group us together in terms of haplotypes that code for a particular disease, for example. Genomics can produce the specific of

genes at the individual level. This may produce what Rose and Novas (2004) refers to as “biological citizenship” where new communities are being created based on a shared relationship to a particular disease and form of treatment. Scientists argue that genome markers are a “much more refined tool to try to track biology than the crude gross level of race” (Interview 1006). One of the promises of genomics is to decouple the link between the biological and the social that was forged in the rise of eighteenth and nineteenth century scientific racism. Keita et al (2004) find that biological variation does not structure individuals into distinct racial groups. However, by using three “continental groups,” from Africa, Asia, and Europe as orienting points for genomic studies, it should be no surprise that not only the “lay” translations through the media but scientists themselves have trouble making the disconnect between “human genome variation” or “geographical ancestry” and race. A number of scientists and health researchers suggest that race is a poor proxy for genomic differences (Havranek and Masoudi 2006).

...alot of our characterizations have been based on the group, and everybody in the group may not have a given characteristic that's common in the group. And when we use these terms interchangeably as we often do in medicine, that's where you begin to introduce problems. For example, a gene may have a high frequency like Sickle Cell. It's found common in African Americans but the frequency of the heterozygote is 10 or 12 percent. That means 90 to 88 percent of folk who are equally, quote, “black” don't have the Sickle gene. So when we tend to equate the whole with what is common, or what might be a differential frequency in a group, we got problems when we now have to deal with the individual level, because when a person comes into the physician with all the characteristics of an anemic kind of problem, and for the physician to say, well this person is black so they obviously have Sickle Cell... But, now the genomics in particular has pushed us to a point in biology where we need to dissociate equating or using race as a surrogate for biology. That's the point we're making exactly, that we need to at best be looking at the markers that track with whatever biology you want to study,

wherever they fall. Because a black person, and we have examples of this too, a black person may have Tay Sachs disease and never get diagnosed because you equate that with Jews! (Interview 1006)

Tay Sachs disease has been shown to have high rates with Ashkenazi Jews and sickle cell has been associated with African-Americans since the 1970s. Both of these discoveries have been important in identifying at risk populations for early screening. However, scientists and medical practitioners are now arguing that race needs to be disconnected from disease as genomics provides better tools for identifying disease risk in individuals. Using race or ethnicity as a tool to identify groups that have proclivities to certain diseases frames out members of other groups who may be affected. Linking race and ethnicity to disease frames out environmental factors as well. Winker (2006) argues that new immigrants' experiences and cultural practices may be different than long time residents of the US. Despite these possible differences, both groups are lumped together across racial groups. In the *Journal of Epidemiology and Community Health*, Agyemang et al (2005) concur with Winker and add that difference in socioeconomic status within African Americans is ignored by using race as a proxy.

In a special issue in *Nature Genetics* dedicated to "'Race' and the human genome," Royal and Dunston (2004) suggest that the paradigm for genome research needs to change from race to "human genome variation." Instead of stratifying groups by race, individuals can be clustered according to shared patterns of variation in their DNA. While this strategy shifts the discourse from anthropologic and biological notions of race, it continues to locate the causes of complex disease in the genome and neglects to integrate environmental factors. A population geneticist

suggests that shifting the paradigm from race to “human genome variation” does not solve the problem. Substituting one biological term for another is not the paradigmatic shift that will drag science out of the racial drift it has been entangled in for over 200 years. The change that needs to be made is from biological determinism to a more ecological approach that is flexible and recognizes the outcomes of the specific research questions.

...we don't really want to change the paradigm from race to human genome variation. It may be human genome variation. But it also may be diet. It may be socio-economic status. It may be something else in terms of what specific variable we are looking at. So, now I am talking about changing from proxy to precision. And the precision is based on what it is we are trying to find. (Interview 1022)

There are a number of barriers to moving from proxy to precision, from using a blunt instrument like race or ethnicity, which some view as an “interim solution” (Duster 2005), to actually measuring and targeting the underlying cause(s) to a person's specific health issue. Cultural assumptions about the racial order in scientific research are clearly one of the barriers. The OMB categories and the regulation of public research forces researchers group people into narrow racial and ethnic categories (Interview 1022). An international bioethicist suggested there needs to be changes in “all entities of the research process” (Ibid.) from the granting agencies, such as the NIH, and how they require grantees to categorize study groups, to the way institutional review boards review protocols, to the journals and how editors and reviews look at and review manuscripts. As discussed in the previous chapter, some journal editors

...have actually in years past issued, quote un-quote, guidelines about what researchers need to do and needing researchers to be more specific about why they use a particular group and how they're defining this group. I think the problem is that some of those guidelines have not really been implemented. And I think unless they are, then people are not going to feel the need to make that change. I think there has to be a concerted effort to implement the things that we know we need to do to move this discussion forward. And I think unless there are consequences. Unless manuscripts are not published, unless you define your group properly. Then there is not going to be a change. (Ibid.)

Moving from proxy to precision is a step towards personalized medicine.

Pharmacogenomics and genomics has been aiming at individualizing medical care with the goal of “the prediction of risk and the treatment of disease on the basis of a person’s genetic profile – which would render biological considerations of race obsolete” (Phimster 2003:1082; See also Bamshad 2005). One of the steepest hurdles to personal medical profiles is the cost of sequencing a genome. The first draft of the human genome from the Human Genome Project and Celera cost \$300 million. This year, nonhuman genomes have been completed at costs of \$22 million and close to \$100,000 (Service 2006). Others cite the current cost to be in the neighborhood of \$30 million for a human genome (Willis et al 2005). In 2003, Francis Collins suggested the future of genome research should be aiming for a \$1000 genome (Collins et al 2003). Continuing the competition from the Human Genome Project, Craig Venter’s Science Foundation offered a reward of \$500,000 for meeting that goal and others have made similar offers. Recently, Venter contributed his reward to the X Prize Foundation who is offering a prize of \$10 million dollars to someone who can map 100 different human genomes in ten days. In spite of these much hyped genome races, the \$1000 genome is considered the “ultimate goal” and represents a shift in

the technology of sequencing as well as impacting the way in which medicine can be done. For example, Kreiner (2005) considers the financial impact population wide screening could have on the health care system. Screening all four million babies born every year could reduce medical costs by improving disease targeting and treatment. HapMap participants clearly viewed genome research as a direct route to individualized medicine (Interviews 1005, 1006, 1008, 1020).

Strategic Essentialism

There appears to be two processes at work in health and biomedical research that, on first glance, appear to be contradictory. On the one hand, the promise of new genetics is to uncouple the biological and the social, to de-racialize the human body. Once and for all, biology has the technological tools to show that racialized differences are truly skin deep and bare no causal relationship to behavior or intelligence and are, in fact, socio-political constructs. As the Human Genome Project found, all of humanity is 99.9% the same. On the other hand, race is being used as a category for marshalling resources and inclusion in health research and to address disparities in health. In the 1990s, health became the next wave of civil rights, following political equality in the 1960s, and economic equality in the 1980s. Social theorists refer to the process of political mobilization around an identity category as strategic essentialism.

One interviewee, an African-American geneticist, commented about being attacked on this issue, “I get a direct question how can you on one hand say, there’s no biological race, and then you specifically study disease in a particular group?”

(Interview 1006). This question implies there is a contradiction in claiming that race is not biological and then studying a particular racial group. I have to admit that I asked the interviewee a similar question. In a series in *Discover Magazine* about genes, race, and medicine, science reporter Jeff Wheelwright considers this same relationship. He writes that the “two positions don’t fit together neatly – at least they don’t to me, but that’s probably because the social dimensions of race complicate my view” (2005:Online). What Wheelwright is suggesting is that his perspective, and mine, is a white point of view. Shifting perspective entails disentangling the two processes by situating them socially and historically. The interviewee was gently telling me there is no contradiction as the relationship between the two positions is historically specific and conjunctural. In the struggle for racial equality, bio-race needed to be deconstructed. At the same time, race has been useful for minority groups for political organization and community formation.

As outlined in the previous chapter, public health practitioners and biomedical researchers began discussing disparities in health and health services in minority communities in journals in the late 1980s. Color conscious policies in government-funded research has addressed the issue of discrimination in health care and health related studies. The NIH Revitalization Act of 1993 sought to bring diversity to clinical research where most human subjects had been white men. The act ensured that NIH funded clinical studies must include members of racial minority groups and women as research subjects and the trials be designed to discern whether or not the variables being studied affect women or minorities in a different manner than other subjects (Epstein 2004).

In the context of a color blind society, race based social policies are at odds with color blind social policies. The former acknowledges that race and racial discrimination remain as structuring devices in society that enable some groups access to resources and restricts others. In terms of health, a race conscious perspective takes into consideration the history of discrimination of health services and the environmental factors that lead to disparities of health. The latter, however, views any racial discrimination as a remnant of the past and not part of the current social structure. Therefore, there is no need for color conscious programs, such as affirmative action. For health and biomedical researchers, there is value in using race to cast one's net when fishing for a gene. For example, epidemiological data shows that Type II diabetes occurs more frequently in inner city blacks than in suburban whites. In the search for the gene that causes Type II diabetes, researchers would draw from inner city blacks. This is not to say that a researcher could not look for the same gene in suburban whites, but the choice would not make sound scientific sense, based on the epidemiological data. According to one of the interview respondents, recruiting 50% blacks and 50% whites would not enrich such a study (Interview 1006). Further, because humanity began in Africa, African populations have a much more diverse and more developed genome, compared to groups that migrated out of Africa, such as Europeans. This means that the haplotype blocks of people of European decent are much larger than that of people of African decent, such as African-Americans. European haplotype blocks have not had as long for the DNA to recombine into smaller blocks. In terms of trying to find a gene,

I have a yardstick in one case and with another population I'm trying to find a gene, but my yardstick is divided up into rulers, 12 inch rulers. Now if the gene is somewhere within the distance of the yardstick, if I find a linkage or association with that gene in the European population, I just know its somewhere in this yard. But with blacks, for that same reason because there's greater variation, the block sizes are smaller. I can see which, where does that gene, does it associate with the first 12 inches, or the middle 12 inches, or the end 12, the other end 12 inches. And so I can come closer into the gene just by tracking markers in this group where the block size is more refined. (Interview 1006)

While biological determinism frames a causal relationship between the biological (the independent variable) and the social (the dependent variable), the no race/race contradiction dissolves if the two variables are arranged in a recursive relationship and embedded in social and historical context. While arguing the scientific validity of targeting a particular racial group, this researcher is also facing the history of marginalizing minority groups from scientific research and clinical trials. At the same time race is a strategy for marshalling resources and population sampling.

The contradiction between race as biologically invalid and used in scientific research is one of the great ironies of BiDil, the first race based drug. A pharmaceutical company such as Nitromed employs a racial strategy in combining two failed drugs and targeting African-Americans with heart disease. The American Association of Black Cardiologists not only supported this move, they were co-sponsors of the AeHeft trials. On the one hand, making a race-specific drug blurs the boundaries between cultural and biological difference. Cultural factors are easier to accept in cases of racial disparities in economics or education, for example. The solutions seem to easily lie in the sphere of the social. Disparities in health along racial lines have clear roots in the social, such as issues of access to services or early

detection of cancer and there are major federal initiatives supporting this point of view. Poverty is clearly a social problem, not a biological one. But using race in medicine is more complicated than other discussions. There is more slippage into biological determinism. Further, the commercialization of racialized health problems and parceling off drugs to this race or that one raises further complications. On the other hand, minority groups have used race as an organizing strategy to gain political access and representation. So why should health be any different? To address the issue of health disparities, race is being employed by the Black Caucus and the Association of Black Cardiologists as a tool of political organization. When the cause of disease is deemed biological and not social, the type of difference that is deployed is intimately related to historical conceptions of race being rooted in biology and not as the product of social struggles over economics, politics, and culture. For African American doctors, health care professionals, and scientists, the double consciousness afforded by the racialized position from which they speak is both a resource and a restriction (Helmreich 2003).

Colorblind Race Talk in Genomics

Colorblindness advocates the end of over references to race but not the end of racism. Race talk is often in veiled codes instead of overt statements about racial minorities. Bonilla-Silva delineates the semantic moves of whiteness that make-up the stylistic tools of colorblindness (2003:54). He makes a distinction between everyday conversation where talk is informal, such as among friends, and public forums where actors are much more careful about what they say. Race talk in new

genetics takes place largely in scientific and medical journals where the discourse is polished and the coded language that characterizes color blindness is much more difficult to pick up in highly educated elites than in everyday stories. One must be attentive to general frameworks, slippages, and contradictions in the formal narratives of the journal discourse and the less formal interviews. A recent trend in scientific literature is the discursive move to colorblind language in human genomics. There have been a plethora of editorials, letters, research studies, and commentaries on the subject of race and genomics in scientific, biomedical, pharmaceutical, and public health journals. Heated discussions have been raging in the journals about whether or not to use race in research, how to use race, and what other terms to substitute or employ in an attempt to shift the paradigm from bio-race. There are even cases where scientists say race is not biologically valid, and then go ahead and use it as a categorical variable. The usage is uneven at best.

A survey of the scientific literature shows a number of different semantic moves scientists utilize in trying to reconceptualize human populations in language that omits race. Terms such as “biogeography of human populations” (Tishkoff and Kidd 2004), “continentally defined groups” (Burchard 2003). “human genome variation” (Royal and Dunston 2004), and “ancient geographic ancestry” (Tang et al 2005) are but a sample employed to ‘get past’ race. Keita et al (2004) offer a whole host of alternatives: ethnoancestral, bioethnic, ethnobiohistorical, ancestral-ethnic, social-designation, biocultural, biopopulation, ethnosocial, ancestral, ancestor-historical, origin group, and ethnogeographical. No wonder there is confusion and disagreement.

Many studies use common sense labels for populations and some argue for using the categories on the U.S. census, originating in 1977 as Statistical Policy Directive No.15 from the Office of Management and Budget. There has been an equivalent move to use “ethnicity” instead of race as it is viewed as a “broader construct that takes into consideration cultural tradition, common history, religion, and often a shared genetic heritage” (Burchard 2003:1171). However, when ‘ethnic’ groups are compared, via the term “geographical ancestry,” they are often from one of the three major continental/racial groups, Africa, Asia, and Europe. In some cases, race does not even need to be mentioned. In a commentary in *Science*, Couzin (2002) describes controversies surrounding the concept of haplotype blocks and the early stages of the HapMap project. There are three pictures of faces that are placed prominently on the first page, in the middle of the text, a boy, a man, and a woman, of Asian, African, and European decent, respectively. The pictures feature normative images of these three ethnicities. Nowhere in the text does Couzin mention race or ethnicity. However, as Fausto-Sterling notes, “it stares out at us nonetheless” (2003:9). The underlying assumption in genomics is that the whole of humanity is being studied; the genome is the global human. However, in the pictures, the three racialized groups represent the human race.

In a response to colorblindness in genomics, a number of papers authored by Stanford geneticist Neil Risch argue for continuing the use of race, not racial, categories. Risch and his co-authors argue that “no biological basis for race” and “race-neutral” approaches do not “derive from objective scientific perspective” (Risch et al 2002:1). Instead, they advocate for an “objective and scientific (genetic

and epidemiologic) perspective” that contends there is “great validity in racial/ethnic self-categorizations” (Ibid). There is little difference between their categories and the census categories, except that even the census does not use “Caucasian.” The “evolutionary tree of human races” they provide includes Africans, Caucasians, Pacific Islanders, East Asians, and Native Americans, looks almost identical to Blumenbach’s eighteenth century classification scheme. The Out of Africa narrative has displaced the racial hierarchy theory. Risch et al’s assertion seems to be motivated by the backlash against the cultural politics of the 1990s. The authors contend their approach is free of politics and a sober assessment of the “facts” while any move to disassociate race from biology is politically motivated and ‘politically correct.’ Bio-race is a tool for understanding the biology of disease and addressing disease risk. Utilizing data mining techniques, Rosenberg et al (2002), examined DNA from fifty-two populations in an effort to show that clusters of similar DNA regions do not reflect an underlying racial structure to humanity. Cooper et al (2003) directly confront Risch et al’s use of census categories for racial categorization, arguing that there “is no evidence that the units of interest for medical genetics correspond to what we call races” (1167). Further, the ‘discovery’ of races in genomics is not a progressive step for health research, but “an extension of the atavistic belief that human populations are not just organized, but ordered” (1169). The massive amounts of data produced by genomics has not “provided evidence that race can act as a surrogate for genetic constitution in medicine... [and] has not been shown to provide a useful categorization of genetic information about the response to drugs, diagnosis or causes of disease” (1168). Risch et al’s response immediately

follows the Cooper et al article and reasserts the race as biology position (Burchard et al 2003). The scientists carefully admit that the desire to abandon race is understandable, especially if one believes that focusing on difference will exacerbate racial disparities in health. Then they oddly connect the authors in the Cooper article with the advocates of Prop 54, the conservative Racial Privacy Initiative in the 2004 gubernatorial ballot. This ballot has been referred to as a key strategy of colorblindness and laissez faire racism. Again, they equate the planetary humanism position that is against bio-race with the proposal erected by neo-conservative organizations, including its architect, Ward Connelly, the UC Regent who was key in the movement to strike down affirmative action in admissions to the University of California.

The Turn to Racial Realism

Risch et al's work is typical of the racial realism position that views dissenting voices against bio-race as politically motivated and scientifically naïve. The racial realism frame articulates race as biologically determined group differences (See Sarich and Miele 2004). Some argue for a non-hierarchical racial order while others maintain racist ideologies of superiority and inferiority. *The Bell Curve* and Rushton's work would align with the latter position. Risch's views (described above) are particularly interesting because of his proximity to the mainstream of biomedical research. Unlike Rushton, another racial realist who is widely shunned across the academic community, Risch is tenured faculty at Stanford and was an author in the 2004 *Nature Genetics Supplement* on race and the genome.

Stanford bioethicist Sandra Lee (personal communication) suggests that we are moving towards the idea of racial realism. Racial realism comes from the work of Derrick Bell (1990, 1992) who argued at the end of the 1980s gains from the civil rights movement were being lost in the fervor of the rising reformist movement. Brown et al (2003) elaborate on Bell. They argue that racial realists, such as Dinesh D'Souza (1995) and Shelby Steele (1990), claim that the progress has been made since the 1950s in addressing racial justice and that racism is a thing of the past. Contemporary inequalities are not due to white racism, but inactivity on the part of minorities, and that minority leaders keep racial fervor alive so they can benefit from government programs (Brown et al 2003:6-7). They do not suggest that racial discrimination has disappeared, but that discourse about race should reflect the 'reality' of biological differences between populations.

"I am a Racially Profiling Doctor"

Sally Satel is an example of a racial realist in the field of health. In a best selling book and numerous pieces in the press, Satel declares herself to be a racial profiling doctor (2002a). She borrows a term that social scientists and advocacy groups have used to highlight discrimination in stop and search procedures by police forces across the U.S. (See Duster 2004).

In practicing medicine, I am not colorblind. I always take note of my patient's race. So do many of my colleagues. We do it because certain diseases and treatment responses cluster by ethnicity. Recognizing these patterns can help us diagnose disease more efficiently and prescribe medications more effectively. When it comes to practicing medicine, stereotyping often works. (Satel 2002a: 56)

Like Risch, Satel is noticeably oppositional to “political correctness,” which she argues has its roots in what she, incorrectly, refers to as Foucault and postmodernism (2002b). For Satel, race is not a burden, but an individual characteristic where it is not an acknowledgment of racism per se, but someone of a particular race could have a certain drug response or disease. Race is a proxy for risk. Satel argues that the state and public health has become too involved in the doctor’s task to deliver medical solutions to patients. Because of the way that political correctness has “infected” the academy and even the natural sciences and medicine, health has become a means for addressing social problems. Satel’s position cascades into ideas about who is responsible for addressing the roots of disease.

For racial realism, race is no longer a burden but an individual characteristic. There is not an acknowledgement of racism per se, but that different races could have a genetic allele that could have a drug response or a particular disease. Race is an individual problem rather than a social phenomenon. When doctors such as Satel profile, they reduce race to an individual characteristic. At the same time when health is becoming a genetic phenomenon, rather than a biological phenomenon, it is no longer a distributive justice issue or social justice issue that the state becomes implicated in. This raises questions about who is responsible for social ills such as health disparities among minority groups and personal ills, such as cancer. Since there is no longer structural discrimination in society, goes this position, and any disparities are individual cases of lack of will, cultural differences, and bad choices. Color-conscious policies are not needed as the conditions they were meant to address have been alleviated. When health becomes a genetic phenomenon, rather than a

biological one combined with environmental causes, the state is no longer implicated in issues of distributive justice. Health becomes something that the individual has to deal with through pharmacogenomics or individualized medicine to address one's difference, not the state (Lee 2003).

In terms of the debates about group differences and the 'reality' of race, a disquieting situation looms on the horizon. One of the scientists who has been particularly outspoken about the focus on race in HapMap suggested that ongoing discussions about racialization in genomics is regressive and that such people who suggest HapMap and other projects can and will reproduce race are naysayers. However, the same scientists offered a future implication of genomics. He suggested to me, "the rubber has not really hit the road yet." For him, the ancestral information that may be contained in DNA is a superficial issue. Genome maps of human populations are not productive of or re-producing the scientific racism of the past or reifying race. For him, knowing where your mother came from through your mitochondria does not say much except what our geographical origins may be. This may be true if one removes social and historical context of that information. However, as this dissertation argues, such knowledge contributes to and is produced in discursive formations of the informationalization of race. The interviewee continued,

But what is going to be problematic and we're not prepared to deal with is what if, or not what if because it will happen, what about when someone does find a gene that does affect a trait of high interest that's not medical perhaps but behavioral, and that gene variant is not equally represented across different ethnic groups? All of sudden we won't be in this confused sort of

meaningless realm we've been in to some extent. We're going to be in a new realm where there are genes that effect traits and they're not evenly distributed across populations. Then we're going to have a real problem. (Interview 1001)

This particular problem is (re)surfacing at a time when science, technology, and race are interacting in new ways.

Misinterpretation of the Data

Scientists are aware of the problems with studying human groups and the history of racial categorization in population genetics. Mainstream discussions in all areas of the biomedical sciences and public health center around the utility of using race as a categorical variable and suggestions for alternative concepts. *Science*, *Nature*, the *Journal of the American Medical Association*, the *New England Journal of Medicine*, *Genome Biology*, and *Genomics* have all featured editorials, letters, research studies, and commentary on the subject of race and science. Scientists and medical researchers make concerted efforts to distinguish population groups from racial groups. Either by using geographically oriented concepts, such as “geographic ancestry,” specific names for groups, or indicating where race is used to indicate environmental rather than biological factors (Bamshad 2005). This is especially the case in research targeting disease. For the most part, the majority of scientists and doctors believe that these efforts avoid producing racial meaning into genetic research and elude historical biases. Interview respondents suggest that findings from population studies become racialized through misinterpretation of the data. For them, the key interpretation of population studies for the general population comes from

the media (Interview 1001). For example, a bioethicist gave the case of an article by Rosenberg et al (2002) that studied genetic variation in samples taken from a wide range of population throughout the world (Interview 1004). The researchers categorized the groups by genetic similarity and “were careful not to use the word race to describe the populations that they found were genetically similar to each other” (Ibid.). However, when the results entered the public sphere, she noted, “race very prominently used in the lay reporting of that particular research” (Ibid).

While the media do sensationalizes stories, such as calling BiDil the first race-based drug or black drug (Malik 2005), Risch (2006) cites the same study as evidence that genetic clusters do align with racial groups. Sometimes researchers mix up race and ethnicity in examining group differences in health issue. For example, Haiman et al (2006) investigate differences between African-American, Japanese-American, Latino, Native Hawaiian, and white men and women in their Multiethnic Cohort Study of the differences in rates of lung cancer from cigarette smoking. There are similar “black/white studies all over the place” (Interview 1006). Because of the technological advances in the last 10 years, there has become an astonishing capacity for gene mapping and typing. As discussed in Chapter Two, the cost for high throughput has declined dramatically making big science projects, such as HapMap, much more feasible economically. The existence of this technological infrastructure has enabled scientists to do certain types of comparative analyses simply because they can. Studies that compare geographically disparate groups and tend to follow an African/European/Asian model, may not be theoretically sound. Lee suggests that “researchers feel little pressure to be explicit about the meaning

and significance of racial and ethnic identity in framing their research hypotheses (2005: 2136). A bioethicist suggested that we are seeing more of these types of studies being published because of the existence of three difference data sets from three different people being fed into a computer (Interview 1017). When the surface of the hypothesis is scraped, however, the assumptions guiding the study are grounded in a particular view of the world. For example, Rosenberg et al (2002; not the Rosenberg above) compare MTHFR C677T polymorphism frequencies between three groups, whites, Japanese, and Africans. The authors use a mix of racial, national, and continental identity markers. Interestingly, the ‘white’ population is referred to as Israeli and Arab. Said (1978) has well documented the racialization of the Oriental Other in opposition to the white European. Also, there is no rationale for comparing the groups. However, the authors are from Israel, Japan, and Ghana. The increase in racial group comparisons, compared to the 1990s comes at a time when journals have been installing guidelines for submissions of research that employs racial categories (see Chapter 3). The scientist’s claim of inaccuracy may be unfounded. Bubela and Caulfield (2004) analyzed press reporting of scientific papers and found that the majority of the articles had high levels of accuracy (See also Condit 2004).

Conclusion

In this chapter, I attempted to disentangle the biological and social by situating the discourse of science in larger social discourses. I identified four frames that characterize current race talk in the information age and showed how they operate in

genomics in order to show how cultural discourse is embedded in the way that scientists and doctors discuss different populations, design research, and offer solutions to health problems. While scientific research is built on a position of neutrality from the object of study, it is impossible to study race without common sense understandings of racial difference ‘infecting’ the objectivity of science. Scientists’ work is formed both by their own research/theoretical traditions and cultural resources. The mix of political perspectives and scientific rationales for or against the use of race in biomedical research reveals a state of uncertainty and disagreement in the medical and biological sciences.

One of the key features of the current discursive terrain is the seeming equivalence between conservative and progressive positions on certain issues. The racial realism frame is juxtaposed with the use of race as a strategy to assemble resources for minority communities or include marginalized groups. Both deploy race as a primary category of human identity, but for very different purposes. Researchers such as Risch argue that when groups are statistically aggregated, they match up with the racial categories set out in the US census. This lends mainstream legitimacy to scholars such as Rushton who continue to not only argue that there are racial groups, but they differ in ways that perpetuate ideologies of scientific racism. At the same time, organizations such as the Association of Black Cardiologists use race to draw attention to racialized health disparities and the production of pharmaceutical interventions.

Thus far, the precision tools of genome science have not been successful in disarticulating race and biology. The original UNESCO statements on race articulated the position that race has no biological basis over half a century ago. Recently, there has been a renewed commitment to this position in the American Anthropological Association's response to the OMB census categories and the joint findings of the Human Genome Projects, among many others. However, the specter of race continues to shroud genomic research into human difference. Rather than race being solely a social concept or a biological one, they become entangled in one another.

Chapter 6

Conclusion

As a mode of representation, a structuring device, and as a biological category, race is undergoing a significant transformation. The informationalization of race conceptualizes this change, which lies at the articulation of new media, the digital network age, and colorblindness. Race as information differs from race as the body, culture, or nation due to the transformations and arrangement of organizational, institutional, and discursive infrastructures. While this process can be observed across social institutions, such as marketing and law enforcement, genetic engineering has emerged as a key technology in the informationalization of race. Rather than destroying race as a biological category and providing conclusive proof that we are indeed all the same, as the UNESCO statements in the 1950s tried to establish and leaders of the Human Genome Project proclaimed, the specter of genetic differences that distinguish human groups and their behavior has not only been raised once again, but given legitimacy. The context for this gene war is not slavery and colonialization in the eighteenth century, or scientific racism in the nineteenth century, or the eugenics movement across the west with its grossest expression in Hitler Germany in the first half of the twentieth century. The informationalization of race emerged within the rise of multiculturalism and the ideology of colorblindness, new communication technologies, and biotechnology and health.

The HapMap Project and human genomics has provided a case study of how the informationalization of race has developed in a specific institution through the use and shaping of technology, legal and institutional change, and cultural representation. Biology's transformation into an information science has been facilitated by innovations in computing science and communication technologies. While the new technological paradigm was taking shape from the 1970s onwards, biology was undergoing its own revolution. The discovery of rDNA in 1973 enabled genetic engineering. DNA science, however, increasingly demanded new types of data collection and analysis as well as the automation of sequencing techniques. Recently, genome projects have not only incorporated technological transformations, they have motivated them. The image of the lone scientist laboring over a microscope and a Petri dish has given way to global big science projects featuring a consortium of geneticists, doctors, biologists, statisticians, bioinformaticians, lawyers, and social scientists. Databases have been integral to the management of genetic information. Terabytes of data are collected, stored in local labs, uploaded to global databases such as dbSNP, the Single Nucleotide Polymorphism database at the National Institutes of Health in Bethesda, Maryland. While the Human Genome Project claimed that we are all 99.9 percent the same, the HapMap project has been creating a database that compares the differences in genomic variation between racialized groups.

The Internet provides the means of mobility not only for the DNA data, but also for HapMap to operate in real time in multiple sites on four continents. The Internet also increases the internal communication of the project as well its external

communication to the larger community of interested scientists and biotechnology companies. As a number of HapMap members expressed, genome projects would not be possible without the Internet. While the Internet has increased communication within science, it has also enabled patients and research subjects to play a more participatory role in the doctor-patient and researcher-subject relationships. HapMap participants pointed to these features of the Internet as a process of democratizing scientific and biomedical research. However, the democratizing effect is far from international. Developing nations also need to be able to build technological infrastructures that enable their scientists to adequately connect to the Internet. The haplotype maps that result from the HapMap Project are not global if they can only be accessed and used by scientists from technologically advanced nations. While technological advancement has been a central process in the growth and reorganization of biology, the disciplinary practices have also been shaped by changes in government regulation, law, and journal policies.

The material birth of genetic engineering and the maturation of biology as a scientific discipline also prompted a shift from academic based research to private enterprise. In chapter four, I highlighted a number of the key changes in the regulatory landscape of the emerging biotechnology industry and scientific research from 1977 to 2004 that enable and constrain HapMap and genomic research. The Chakrabarty case and the Baye-Dole and Stevenson-Wydler bills in 1980 encouraged the deregulation of university-industrial relations and industrialization of biology. The increased interaction between industry and academia produced an intellectual climate weary of privately funded research submitted to journals that

could compromise the integrity of pure science. Throughout the 1980s and 1990s, journals became the forums for the debates about conflict of interest policies. A number of leading journals began to require authors to disclose privately funded research. Finally, an obscure mandate from the US Office of Management and Budget in 1977 set forth the racial classification for the US census that continues to be the standard in publicly funded biomedical research. When President Clinton signed the NIH Revitalization Act in 1993, ensuring that women and minorities must be included in biomedical studies, it drew on the OMB categories, Black, White, Asian-Pacific Islander, and Native American as the measure for diversity. HapMap participants commented that the employment of this standard is a major reason why many genome studies, including HapMap, compare white, Asian, and African continental groups. The NIH Act followed calls from doctors, researchers, and advocacy groups to increase diversity in biomedical research. These discussions emerged in the 1980s in the US and the UK and also focused on the the reproduction of racism in the reporting of racial and ethnic groups. The *British Medical Journal* was the first major biomedical journal to publish guidelines for the reporting and use of race and ethnicity. The guidelines stated that doctors and scientists should be careful of the terms they use to describe different groups to avoid reproducing common sense stereotypes. By the 2000s, similar guidelines had been adopted unevenly across biomedical and scientific journals. Those editors who did often required researchers to state their rationales for the use of race as a variable. The discussions about ethnic and racial reporting and inclusion in biomedical research echoed larger debates about how race should be used in scientific research.

Finally, scientific discourse about race has its own history and specialization. Even though the scientific ethos is built on a position of neutrality from the object of study and a distance between science and society, cultural assumptions about the nature of race and the social order are deeply embedded in scientific discourses of race. Popular understandings of racial difference ‘infect’ the purity of science. While race becomes negotiated through the writing of computer codes such as complex algorithms in data mining, race talk operates through coded language that has become common sense since scholars began writing about the new racism in the 1980s. Overt references to racial hierarchies or outright racist statements have given way to a complex of references about the nature of difference, social inequality, and the allocation of societal resources. Biological claims of group superiority and inferiority have been replaced by discourses of cultural difference. This research began from the position that race talk operated through the dominant racial paradigm that has emerged since the 1970s, colorblindness. However, I found that racial claims making not only operates through the dominant ideology of colorblindness but through three additional discursive frames, strategic essentialism, racial realism, and planetary humanism. Instead of finding the legacy of scientific racism or the decoupling of race and biology in genomics, I found a confusion of complicated positions about the definition of race, its role in biomedical research, its relationship to biological or geographical ancestral groups, and its use to mobilize health resources. Technologically, institutionally, and discursively, the informationalization of race has been produced through a much more complex set of positions about racial difference than in previous eras.

Race and the Work of Information in the Age of the Digital Database

The informationalization of race foregrounds the relational nature of racialization between social groups (Kim 1999). A race relations framework, which characterizes much of the work on race and racism in the last century, and racial formation (Omi and Winant 1994) and racialization (Small 1999) perspectives often focus on the relationship between a particular minority group and the dominant white culture. Both approaches to the study of the racial order in the US tend to focus on the black/white binary. The informationalization of race follows a racialization approach to the extent that it traces emerging processes across social institutions and the relationship between structure and representation. The informationalization of race extends past work on race by placing technological change and innovation at the center of analysis (Gray 2005; Nakamura 2002). Race as information is a product of the digital age.

In the digital age, processes of creating, storing, and transmitting information become specific resources for production and power. The policies, politics, and procedures that make up information infrastructures are hidden in the seeming neutrality of codes and standards. We, the users, only see the interface. Information and the networks that comprise a communication infrastructure are much more than the denotative transmission of facts, computer algorithms, and data (Bowker and Star 1999). Information is not simply descriptive and reflective of the social world; the collection, storage, and analysis of information constitutes what is known and what can be imagined, both the basis for social action. Information in the global new

economy is deeply connotative. In this respect, race as information works in a similar manner to race as culture and race as (the epidermal) body. However, due to the hypertext of the Internet and the anti-narrative logic of databases, information is much more contingent and fluid (Manovich 1999). The end of Jim Crow signaled a retreat from a society structured in dominance. The subsequent rise of multiculturalism and post modernity loosened the moorings of racial identity. While structural inequalities persisted, the post civil rights era and the information age produced a contested field of racial meanings in representation, politics, and the biomedical sciences.

Genomics has emerged as the newest and possibly most powerful contributor to the debate about the existence of biologically distinct human races. On the one hand, the Human Genome Project concluded that we are all basically the same at the molecular level. However, whole genome projects, such as the HapMap Project, conceptualize human groups in such a manner as to highlight differences and similarities. Black, white, and Asian groups have been shown to differ in their configuration and arrangement of haplotype blocks. Further, HapMap data showed Chinese and Japanese groups to be so alike that they merged the two groups. While the scientific rationale for these groupings and the resulting amalgamation of the Han Chinese and Tokyo Japanese samples is accepted amongst scientists, the symbolic meaning needs to be placed in the context of both scientific and popular discourse about race. What is not confronted in the scientific literature is the entire phenomenon of migration, first, in the placements and displacements of people during the era of European expansion and, second, in the period of de-colonization

since World War II and globalization. Subsequent phases of human genomics will look at other groups and critics of the sample populations have argued that choosing groups that are so far apart geographically exaggerates difference. But what the initial three “continental groups” does is set up a base line, a normative position from which all others will be measured. Additionally, there appears to be little space to discuss the place of new ethnicities, whether they arise from migration or from practices of racial ‘mixing’. Admixture tends to reinforce a discourse of racial purity. Finally, there are a number of scholars who address the history of race and science (Gould 1994; Gilman 1985), the role of history, politics, and ethics in the Human Genome Diversity Project (Reardon 2005), how genetic data is racialized in labs (Fullwiley Forthcoming), race and pharmacogenomics (Lee 2003), and return of eugenics (Duster 2003). However, they all pass over the fundamental role of ICTs in the development of new genetics.

New genetic technologies have been particularly important in the racialization of information. They are the newest and most powerful tools for constructing differences between human groups. Filling human skulls with mustard seed or grape shot in the eighteenth century was highly unreliable in comparing differences between racial groups (not to mention the fact that some scientists fudged their data to put whites at the top of the human hierarchy. See: Gould 1996), but allele frequencies, SNP variation, and data mining techniques are perceived as much more precise. Contemporary biology has both motivated developments in automation, data mining, and communication technologies and re-organized itself around an information paradigm borrowed from computing science. The bulk of a

genome scientist's time is no longer looking through a microscope, but pouring through genetic data and re-imagining the order and function of human DNA. Scientists and genome project organizers argue that their discoveries will help in further understanding human health and the genetic origins of disease. At the same time, genetic technologies are being developed to build racialized databases, such as state databanks in the US and the UK. ICT's have been integral to the racialization of information and the rise of genetic technologies. At the heart of this transformation are the Internet and databases.

Information technologies based around the Internet and other networks have become commonplace. In an age of blogs, MySpace, and YouTube, database technologies that make up technological and informational infrastructures usually do not take center stage in public discourse and research agendas on new media. Yet, they are ubiquitous and their functionality is weaved throughout the circuits of the information economy. When linked in internal networks, such as the FBI's CODIS DNA database, or through the Internet, databases become powerful tools for surveillance and social sorting of populations. Database technologies have been innovating along with advances in the speed and capacity of computing. There is little work on the role, uses, development, and meaning making function of databases in society. With the increasing proliferation of databases, further research is crucial to compliment the growing body of knowledge about the Internet.

Many have argued that the Internet, with its hypertext architecture, is transforming the way we think. At the interface of web users and their mouse, this may very well be the case. However, I would suggest looking further into the net's

cyberinfrastructure where database technologies provide the source of data collection, storage, and analysis. The collection and archiving of information is characteristic of the modern practices of collective memory and social control in the management of societies. Digital technology, however, has transformed the processes of managing information and its form. Old media, from the printing press to film and television, largely worked in linear terms, from producer to audience, from beginning of the text to the end of the text. In McLuhanite terms, the narrative is the message. Media studies has shown that audiences do not accept media messages passively, but sometimes actively decode the text within a limited number of frames. With digitization and database technologies, the linearity of traditional media has been disrupted by the anti-narrative logic of the database. First, the sheer amount of content that can be stored in databases has reached terabyte levels and continues to grow. Second, with the aid of the Internet, digital information can be transmitted and accessed across the globe with the right equipment and, depending on the nature of the database, the right access key. Central repositories, networked through open access protocols over the Internet or over private intranets, enable real time access and also the ability of users to feed information back into the database. Finally, digital information in databases can be searched and arranged in different ways, depending on the goals of the user. In the case of genomics research, data mining enables tasks that would have previously been too cumbersome, time consuming, or expensive.

The Informationalization of Race: A Cultural Theory of Technology and Identity

The goals of this dissertation are two-fold. First, I wanted to draw attention to emerging trends in the relationship between technology and race. The second goal is to empirically observe and describe these trends in the context of the information age and colorblindness. The informationalization of race theorizes the racialization of technology and information in the digital age. While the innovations of new communication technologies induce this transformation in the construction of difference, this development has emerged under the conditions of political economic, organizational, and cultural changes. I have employed the HapMap Project and human genomics as a case study and an indicator of these changes.

Biotechnology is a form of new media. I argued that communication theory should pay more attention to the role of biomedica and that the tools of communication policy could be applied to the political economy of the biotechnology industry. Both the media and biotechnology provide sites that raise questions about political economy and power in organizations. Policy oriented communication theory largely focuses on the political economy of the telecommunications industry in the US, other national contexts, and, increasingly, as a force of globalization. I found that there was a concurrent deregulation of the biotechnology industry and telecommunications industry in the 1980s followed by the regulation of identity in the turn to diversity in the 1990s. Both industries raise important issues of identity, new technologies, and social inclusion.

Technology has never been a ‘cure’ for social ills. The inception of technology and its uses are entirely dependent on the work of social actors and institutions. This means that the virtual space of the Internet is not the end of raced identities, or gendered ones, in real life. As research has shown, practices of race and gender are at the same time transcribed and transcended into cyberspace as virtual space is deeply connected to real space. Further, the neutrality of data mining technologies is also dependent on the nature of the data and the algorithms that tell programs what to do. The standards and codes that make up the design infrastructure of databases and related technologies shape their function and meaning at the user interface. In the case of genome and DNA databases, race is inscribed into the front and back ends of the technology. Further, DNA databases have become part of the surveillance network of information societies.

Finally, scholars of communication and race need to address the role of new technologies and the information age in the process of racialization. The methods and theories of critical race scholarship have diversified and grown to well address the ways in which people of color are making opportunities out of digital media. New media forms are developing at a dizzying pace and are crucial tools for interventions into dominant forms of representation. While, genetic technologies are being used as forms of social control, scientists at the Human Genome Center at Howard University who are leaders in the field of genome research and members of the HapMap project are also shaping them.

The need for theoretical connections between technology and race from observations of the biomedical science is particularly important at this time. With the turn to difference in genomics, the 0.01 percent that differentiates one person from another amounts to about 30 million base pairs. Those points of difference are under intense scrutiny as governments and companies create public and private haplotype maps. While the public projects operate under the ethos of open access to democratize the data and community consent, private firms are under no obligation to adopt such policies as well as journal policies on the use and reporting of race and ethnicity. This should be cause for concern, especially as the mapping of DNA turns to the function of DNA. In order to avoid returning to the altar of biological determinism, debates about genomics and race need to be expanded to incorporate technology beyond simply its function. Like other sorts of information that are used to determine access to health care, employment, and insurance, genomic data will be used to sort people. Communication technologies create new possibilities not only in what can be done, but how we see the social and scientific world.

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Erin Stewart, Renee Strong, Ellen Suh, Reginald Thomas, Ni Ni Tint, Sukyee Tse, Claire Vech, Gary Wang, Jeremy Wetter, Sherita Williams, Monica Williams, Sandra Windsor, Emily Winn-Deen, Keriellen Wolfe, Jayshree Zaveri, Karena Zaveri, Josep F. Abril, Roderic Guigo, Michael J. Campbell, Kimmen V. Sjolander, Brian Karlak, Anish Kejariwal, Huaiyu Mi, Betty Lazareva, Thomas Hatton, and Apurva Narechania. 2001. The Sequence of the Human Genome. *Science* 291 (5507):1304-1351.

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Appendix A
Models of Racial Discourse

Figure 1. Traditional Race Talk

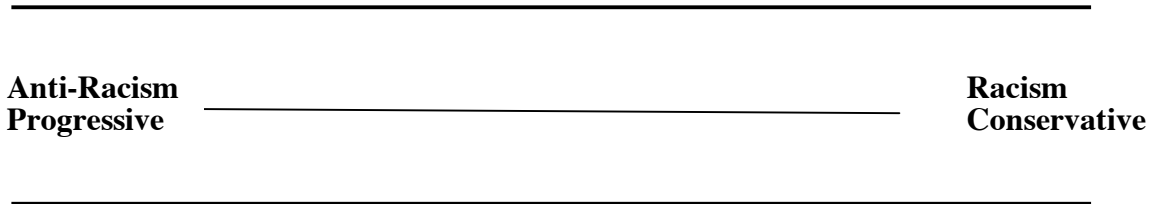
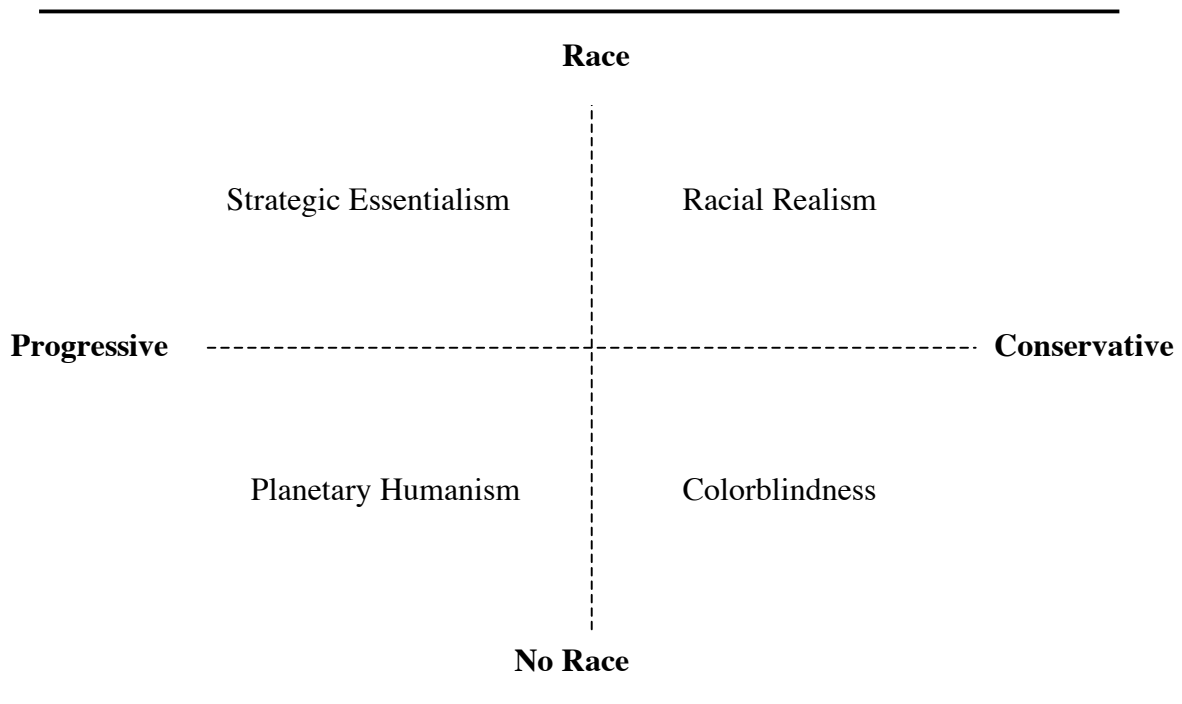


Figure 2. Central Frames of The Informationalization of Race



Appendix B

Code for Interviews

Interview 1001	Population geneticist, committee chair, site principle investigator	7 September 2005	Telephone
Interview 1002	Biostatistician	2 June 2005	Telephone
Interview 1003	Project manager	9 June 2005	Telephone
Interview 1004	Bioethicist	13 June 2005	Telephone
Interview 1005	Bioethicist, committee chair	27 July 2005	Telephone
Interview 1006	Microbiologist, site PI	6 October 2005	Telephone
Interview 1007	Director of NGO, site PI	7 May 2005	Telephone
Interview 1008	Lawyer, bioethicist, site PI	20 June 2005	Telephone
Interview 1009	Bioinformatician	10 June 2005	Email
Interview 1010	Population geneticist	10 June 2005	Telephone
Interview 1011	Bioethicist, site PI	22 September 2005	Telephone
Interview 1012	Medical geneticist, site PI	21 June 2005	Email
Interview 1013	Geneticist	11 July 2005	Telephone
Interview 1014	Human geneticist	11 July 2005	Telephone
Interview 1015	Biochemist	7 October 2005	Telephone
Interview 1016	Population geneticist, site PI	25 May 2005	Telephone
Interview 1017	Bioethicist	22 June 2005	Telephone
Interview 1018	Biologist	6 September 2005	Email
Interview 1019	Staff scientist	14 September 2005	Telephone
Interview 1020	Statistical geneticist	17 October 2005	Telephone
Interview 1021	Human Geneticist, site PI	17 October 2005	Telephone
Interview 1022	Human Geneticist, bioethicist	11 November 2005	Telephone
Interview 1023	Bioinformatician	22 September 2005	Telephone
Interview 1024	Microbiologist	10 May 2005	Telephone
Interview 2001	Biologist, senior scientist	12 May 2005	Biotechnology company
Interview 2002	Biologist, senior scientist	24 August 2005	Biotechnology company

Telephone and on-site interviews were digitally recorded, stored on a computer, and backed up on a CD. Even though the interviews were recorded, I also took notes to help guide questions in the interview and for reflection post-interview. When the interview was completed, I would go over the notes and make annotations for issues and items that could be addressed in subsequent interviews and/or analysis. After having them transcribed, I checked the transcripts against the recording for accuracy.

I developed a coding schedule (which was constantly being refined). Then, I used a qualitative software program, Nvivo to code the interviews. I coded the three sub-sections first, technology, university-industrial relations, and race. Further coding was necessary until the response had been categorized sufficiently, usually no more than three levels. After identifying a broad number of sub-codes, I refined them, merging similar codes and eliminating some if there were less than three responses to the code. In creating a report outline, I looked at what was said, how it corresponded to the literature in the area (or not), and then tried to develop report sections that would correspond to both the literature and data.