

PLAYING THE GENE CARD?

*A Report on
Race and Human
Biotechnology*

Osagie K. Obasogie

**Center for
Genetics and Society**

Preface by Dorothy Roberts

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Executive Summary

Race has become a prominent focus for human biotechnology. Despite often good intentions, genetic technologies are being applied in a manner that may provide new justification for thinking about racial difference and racial disparities in biological terms—as if social categories of race reflect *natural* or *inherent* group differences.

The Human Genome Project (HGP) and subsequent research showed that there is less than 1% genetic variation among all humans. Patterns of mating and geographic isolation over thousands of years have conferred genetic signatures to certain populations. Yet scientists have found little evidence to support lay understandings that social categories of race reflect discrete groups of human difference. While HGP findings initially led many to conclude that race (as it is commonly conceived and used) is not genetically significant, the hope that science would promote racial healing has largely not materialized.

In fact, trends in life science research have shifted the other way. There are increasing efforts to demonstrate the genetic relevance of race by mapping this less than 1% of variation onto social categories of race to find genetic explanations for racial disparities and differences.

Many celebrate these developments as an opportunity to learn more about who we are and why certain groups are sicker than others. Yet some are struck by the extent to which these new conversations aimed at benefiting minority com-

munities echo past discussions in which the science of biological difference was used to justify racial hierarchies.

Although this new research is rapidly evolving and is fraught with controversy, it is being used to develop several commercial and forensic applications that may give new credence to biological understandings of racial difference—often with more certainty than is supported by the available evidence. This unrestrained rush to market race-specific applications and to use DNA technologies in law enforcement can have significant implications for racial minorities:

- **Race-based medicines** have been promoted as a way to reduce inequities in healthcare and health outcomes. Yet the methodological assumptions behind them raise as many issues as the questionable market incentives leading to their development.
- **Genetic ancestry tests** rely on incomplete scientific methods that may lead to overstated claims. The companies that sell them often suggest that biotechnology can authoritatively tell us who we are and where we come from.
- **DNA forensics** have been used to exonerate those who have been wrongly convicted and can provide important tools for law enforcement. However, some forensic applications of genetic technologies might undermine civil rights—especially in minority communities.

While each of these applications has been examined individually, this report looks at them together to highlight a fundamental concern: that commercial incentives and other pressures may distort or oversimplify the complex and discordant relationship between race, population, and genes. Applications based on such distortions or oversimplifications may give undue legitimacy to the idea that social categories of race reflect discrete biological differences.

The concerns raised in this report should not be read as impugning all genetic research that implicates social categories of race. There is evidence that socially constructed notions of race may

loosely reflect patterns of genetic variation created by evolutionary forces, and that knowledge about them may ultimately serve important social or medical goals. Yet, given our unfortunate history of linking biological understandings of racial difference to notions of racial superiority and inferiority, it would be unwise to ignore the possibility that 21st century technologies may be used to revive long discredited 19th century theories of race.

Advances in human biotechnology hold great promise. But if they are to benefit all of us, closer attention should be paid to the social risks they entail and their particular impacts on minority communities.

About the Author

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of Liberty (1997) and *Shattered Bonds: The Color of Child Welfare* (2002) and a frequent speaker at university campuses, social justice organizations, and other public forums. She serves on the boards of directors of the Black Women's Health Imperative, the National Coalition for Child Protection Reform, and Generations Ahead, and on the Standards Working Group of the California Institute for Regenerative Medicine. She is writing a book on the politics of race-based technologies.

Acknowledgments

I am deeply appreciative of the thoughtful and supportive environment provided by the Center for Genetics and Society while drafting this report. Staff members Richard Hayes, Marcy Darnovsky, Jesse Reynolds, Charles Garzon, and Jenna Burton have been extraordinary in reviewing drafts, offering suggestions, and simply being the best group of people anyone could ever work with. I am also thankful to CGS interns Claudette Mestayer and Nancy Zhang for their excellent research assistance. A special thanks to Pete Shanks for his editorial assistance and help with coordinating the production of

this document, to Jonathan Peck of Dovetail Publishing Services for designing the report's layout, and to John Sullivan of Visual Strategies for designing the cover.

I am also grateful to those who took precious time out of their schedules to review this report at various stages: Deborah Bolnick, David Chae, David Faigman, Julie Harris, Lisa Ikemoto, Elizabeth Joh, David Jones, Jonathan Kahn, Jaime King, Ethan Leib, Susan Reverby, Dorothy Roberts, Aliya Saperstein, Tania Simoncelli, Kim Tallbear, Jessica Vasquez, and David Winickoff.

O.K.O.

Preface

Dorothy Roberts

In his 2000 manifesto against racial thinking, *Against Race*, sociologist Paul Gilroy predicted that advances in genomic research would eventually discredit the idea of “specifically racial differences” by rendering race a useless way of classifying people.¹ Many researchers similarly anticipated that the science of human genetic diversity would replace race as the preeminent means of grouping people for scientific purposes. After all, social scientists’ conclusion that race is socially, politically, and legally constructed was confirmed by genomic studies of human variation, including the Human Genome Project. These studies showed high levels of genetic similarity within the human species. Most genetic variation occurs within populations, not between them.

But reports of the demise of race as a biological category were premature. Instead of hammering the last nail in the coffin of an obsolete system, the new genomics is producing a resurgence of scientific interest in race-based genetic variation and an explosion of race-based technologies. Fueled by research funding and commercial interests, scientists are incorporating race as an organizing principle in cutting-edge genetic research.²

Race-specific pharmaceuticals, commercial genetic technologies for determining racial genealogy, and law enforcement’s use of large DNA data banks for suspect identification are prominent examples of this scientific development. *Playing the Gene Card? A Report on Race and*

Human Biotechnology analyzes the social implications of this technology’s potential to reaffirm the biological meaning of race. Although each of these technologies merits intense investigation, it is important to consider the impact of their simultaneous development. This Report not only documents the expansion of race-based technologies, but analyzes how they are linked and why we should be concerned about them. By considering common themes marking all of these technologies, *Playing the Gene Card?* uncovers the full scope of their power to affect the racial order in America.

There are three key problems that should worry us. First, many of the scientific claims promoting race-based biotechnologies are suspect; we should question the validity of using race as a proxy for both genetic difference and group commonality. Scientists, entrepreneurs, and government agents have oversold the ability of race as a biological category to improve medicine, reveal our true identities, and solve crime. Second, race-based biotechnologies threaten to reinforce the myth that racial categories are natural rather than a classification system invented for political ends.

Finally, these technologies reinforce the related pretense that health and other disparities between groups are caused by biological differences rather than social inequities. Race-specific pharmaceuticals are promoted as the solution to

health disparities that result from the experience of discrimination, inferior living conditions, and inadequate health care. Commercial ancestry testing companies attempt to restore the genealogical histories irreparably broken by the slave trade. And, although DNA forensics has famously helped to exonerate innocent people, the collection of genetic material to identify suspects poses threats to civil liberties that will fall disproportionately on minority communities.

How can we explain the rise of race consciousness at the heart of the 21st century genomic revolution? Science historian Evelyn Hammonds observes, “. . . the appeal of a story that links race to medical and scientific progress is in the way in which it naturalizes the social order in a racially stratified society such as ours.”³ Explaining racial inequality in biological terms rather than in terms of white political privilege has profoundly shaped science in America for three centuries, beginning with the scientific defense of slavery.⁴ Race-based technologies have tremendous potential to influence state efforts to address racial inequality by diverting attention from the structural causes of racial inequities towards genetic explanations and technological solutions.⁵ Their expansion may help to encourage a shift in responsibility for addressing disparities from the government to the very individuals who suffer most from inequality.

It is critical to place these biotechnological advances in their contemporary political context.⁶ The controversy over race-based technologies is occurring against the sociopolitical backdrop of an equally heated debate about approaches to racial equality. Colorblindness and race consciousness compete as major frameworks for defining the proper treatment of race in social policy. In the political arena, advocates for colorblind policies assert that racism has ceased to be the cause of social inequities while race conscious policies are promoted as a necessary means for remedying persistent institutional racism. In June 2007, the United States Supreme Court spotlighted this contest in its 5–4 decision striking down

race-conscious plans to desegregate elementary schools in Seattle and Jefferson County, Kentucky.⁷ The Court adopted the position that the Constitution requires the government to be colorblind by paying no explicit attention to race in policy making. As Chief Justice John Roberts concluded, “[t]he way to stop discrimination on the basis of race is to stop discriminating on the basis of race.” Thus, race consciousness is decreasing in government social policy at the very moment it is increasing in biotechnology.

The political context of race-based technologies is complicated by the tension experienced by racial justice advocates seeking to directly confront the very real impact of systemic racism without reifying race as a natural division of human beings. Some African Americans have demanded inclusion in technological innovations that incorporate biological definitions of race for the express purpose of promoting racial equality. There is strong support for race-based medicine, for example, among some black advocates, researchers, and physicians precisely to redress past discrimination and fulfill longstanding demands for science to attend to the health needs of African Americans.⁸

Race-based biotechnologies are likely to affect an even more powerful political agenda. The diversion of attention from social to molecular causes and solutions reinforces privatization, the hallmark of the neoliberal state that pervades every aspect of public policy. In the wake of globalization, the United States has led industrialized and developing nations in drastically cutting social welfare programs while promoting the free market conditions conducive to capital accumulation.⁹ Critical to this process of state restructuring is the transfer of social services from the welfare state to the private realm of the market, family, and individual while advancing private sector interests in the market economy. Just as imperative to the neoliberal regime is the state’s brutal intervention in communities of color in the form of mass incarceration, foster care, welfare behavior modification programs, and harsh immigration enforcement and deportation. The

public is more likely to support these trends if it is convinced that race-based technological innovations can replace the need for social change.

Sociologist Nikolas Rose argues that the effort “to control the biological makeup of the population as a whole” distinguishes eugenics from contemporary biological politics’ concern with the genetic health of individuals.¹⁰ Today’s biopolitics reflects a radical change from state management of the population’s health to individual management of genetic risk, aided by new genetic technologies. But we should not dismiss the relevance of eugenics so categorically. Critical aspects of past eugenics programs characterize both contemporary population control policies and some genetic advances. The eugenic approach to social problems locates them in biology rather than social struc-

ture; eugenic programs therefore sought to improve society by eliminating disfavored people instead of social inequities. Its chief device was to make the social order seem natural by casting its inequitable features as biological facts.

There is an intense debate among genetic and social scientists about the appropriate use of race as a category in scientific research. The question of biology’s proper role in defining race and addressing racial inequality is far from resolved. But to reach ethical answers, we must put social justice at the center of the public debate. This report concludes with helpful proposals that take social justice into account to avoid the potential for race-based technologies to reinforce rather than reduce inequality. Those concerned with racial justice in America should take heed.

Race Cards and Gene Cards: A Note About the Report's Title

The title of this report draws upon a rhetorical phrase common in the United States: playing the race card. This expression alludes to a less-than-honorable move in a proverbial card game—where race, or an accusation of racism, is used as a winning “trump card” that beats all other players’ hands.

Stanford Law Professor Richard Ford notes that “playing the race card typically involves jumping to a conclusion not compelled by the facts.”¹¹ It is most often used to suggest that someone has illegitimately inserted the emotionally charged issues of race or racism into an otherwise rational conversation as a way to divert attention away from more substantive issues.

One of the more famous “race card” accusations was used in the 1995 O.J. Simpson trial. University of California, Berkeley film studies Professor Linda Williams writes

The “race card” was invoked as a term during the first O.J. Simpson double-murder trial when the prosecution accused [defense attorney] Johnny Cochran’s team of cheating by introducing evidence of detective Mark Fuhrman’s racism. This evidence—of Fuhrman’s prior use of the word “nigger”—was called an “ace of spades” by prosecutor Christopher Darden: “Mr. Cochran wants to play the ace of spades and play the race

card. . . . If you allow Mr. Cochran to use this word and play this race card, not only does the direction and focus of the case change, but the entire complexion of the case changes. It’s a race case then. It’s white versus black.”¹²

The admittedly provocative analogy implied by the report’s title should not be understood as dismissing all genetic research that alludes to race (or any of its many surrogates) as illegitimate. *Playing the Gene Card?* readily acknowledges the many potential benefits that may come from race-conscious biomedical and biotechnical innovations. Rather, this title is offered to raise a series of important questions that should be taken seriously, including whether the less-than-precise—and at times sensationalistic—statements about the genetic underpinnings of race and racial disparities might obscure the former’s social construction and the latter’s social determinants.

Playing the Gene Card? asks whether the commercial and forensic applications of recent developments in genetics are being used—perhaps unwittingly—as trump cards that hide the social and molecular complexities underlying racial disparities in health, our genealogical heritages, and forensic analyses. To the extent that this may be occurring, the report explores the ways that it may reassert race as a discrete biological entity.

Introduction

Are 21st Century Technologies Reviving 19th Century Theories of Race?

“The problem of the 20th century is the problem of the color line,”¹³ wrote W.E.B. DuBois in 1903. Rarely have so few words been so prescient yet so understated. DuBois prophetically captures the significant role that race played in many of the nation’s struggles during the last century, from the ravages of Jim Crow to *Brown v. Board of Education* to the Civil Rights Movement to the War on Drugs.

Despite significant advances in race relations and the status of people of color, racial minorities face new challenges in the 21st century that are unmistakably connected to past injustices. The persistent gap in wealth between racial minorities and their White counterparts,¹⁴ the substantial disparity in infant mortality between Black and White babies,¹⁵ and the continued racial segregation of public schools fifty years after *Brown* that leaves minority children with substandard educations¹⁶ are but a few examples of the enduring legacy of racial discrimination in America.

Yet a series of applications relying upon genetic technologies are lending support to explanations of racial disparities that rely more on biology than on social conditions. We are seeing a revival of previously discredited beliefs that the social problems and inequities that characterize the color line come from *inherent biological differences* between racial groups. In a nutshell, the color line that still divides racial groups is in-

creasingly taking on, in the view of some, a genetic character.

But these new articulations of biological race have a different overtone from their predecessors. In the name of resolving racial disparities in health, addressing disrupted genealogies, and improving law enforcement, they *explicitly reject* the racial subordination that fueled past efforts to link social categories of race to inherent biological differences. Yet they may inadvertently lead to similar conclusions: that various racial disparities—from why certain groups are sicker than others to why arrest and incarceration rates are higher among some populations—can be more meaningfully understood through genetic than social or environmental mechanisms.

How Have New Genetic Theories of Racial Difference Developed?

For most of the 19th century, science played a key role in shaping lay understandings of race. A variety of scientific theories suggested that Blacks, Native Americans, and other racial minorities were either an entirely separate (and inferior) breed of humankind, or that they were less evolved than White Americans and Europeans.¹⁷ These beliefs were instrumental in maintaining systems of racial subordination.¹⁸

By the latter half of the 20th century, a largely shared (but by no means universal)¹⁹ understand-

ing emerged: humanity is one species, environmental and social pressures play a significant part in the variations observed across human groups and their outcomes, and the racial distinctions drawn by society reflect shifting cultural, political, and economic forces.

In 1950 a group of leading biologists and social scientists issued *The Race Question*, a statement under the auspices of UNESCO, the United Nations Educational, Social, and Cultural Organization. It read in part,

“The biological fact of race and the myth of ‘race’ should be distinguished. For all practical social purposes, ‘race’ is not so much a biological phenomenon as a social myth [which has] created an enormous amount of human and social damage.”²⁰

Fujimura et. al. point out that “the 1950 and 1951 UNESCO statements on race are often cited as demonstrating that Euro-American scientists in the post Second World War era were vigilant against biological notions of racial difference [without acknowledging] that subsequent UNESCO statements critiqued racial prejudice and racism but did not disown the biological concept of race itself.”²¹ Shortly afterwards, genetic researchers began demonstrating the limited correlation between outward physical appearance (typically the driving force behind racial categorizations) and underlying genetic variation.²²

Although conceptions of race ebbed and flowed throughout the 20th century, the social construction thesis and the scientific data supporting it have encouraged egalitarian sentiments and advances in civil and human rights for racial minorities. Today the constructionist approach to race is itself receiving significant challenges from some developments in the life sciences. A considerable amount of research is now being devoted to finding genetic differences that map onto social understandings of race. Much of this research is premised on the idea that group differences in social, behavioral, and health outcomes may, in

large part, be explained by genetic variations or frequencies associated with each group. While the scientific evidence for these hypotheses is in flux, it is not too soon to consider their social, ethical, and legal implications.

At the same time that academic researchers ferret out the significance of these studies, new industries are emerging based on biotech products that may have important consequences for communities of color. Drug companies are beginning to offer medicines for specific racial groups, suggesting that *genetic* differences between races are significant determinants of health disparities. Genetic tests are being marketed to provide answers about our ancestry that were thought to be lost forever due to past geopolitical conflicts. And biotech companies are offering law enforcement agencies high-tech tools with which to profile and catch criminals.

Context: After the Human Genome Project

In October 1990, the United States Department of Energy and the National Institutes of Health (NIH) launched an ambitious project: mapping the entire human genome. The Human Genome Project (HGP) announced a first draft in 2000 to great fanfare. The project was formally completed in 2003, though work continues on some details. Its findings have been the basis of much improved understandings about the way genes influence health outcomes.

One of the HGP’s most heralded findings was that all humans are over 99.9% similar at the molecular level, a discovery that supports the social rather than genetic character of racial categories. (Subsequent research has slightly raised the initial estimate of difference, to around 0.5%.³³) At the time that the HGP’s results became public, numerous scientists and other observers predicted that its finding of human genetic similarity would finally move society beyond biological theories of racial difference that have fueled centuries of racial strife.³⁴ This became the basis of broader social and political

What Does It Mean to Say that Race Is Not Biologically Significant or that It Is a Social Construction?

Researchers in the social and life sciences have argued that race is not a meaningful biological category, that it is a “social construction” rather than a scientific fact.

But what does this mean? These phrases are typically used to convey the ideas that

- the importance placed on the outward physical distinctions that societies traditionally use to draw racial boundaries vary substantially over time and place,
- these physical distinctions do not reflect any inherent meanings, abilities, or disabilities, and
- racial differences in social and health outcomes do not correlate meaningfully with underlying biological or genetic mechanisms.

In short, as University of California, Berkeley Law Professor Ian Haney Lopez argues, the constructionist view “rejects the most widely accepted understanding of race . . . [which holds that] there exist natural, physical, divisions among humans that are hereditary, reflected in morphology, and roughly captured by terms like Black, White, and Asian.”²³

There are certainly biological components to race and health outcomes, though often only because of the way certain groups are treated in relation to how they are perceived.²⁴ A key example of this phenomenon was demonstrated by John Hopkins epidemiologist Michael Klag, who found that rates of hypertension among Black Americans correspond to skin complexion; those with darker skin have higher rates.²⁵ Klag showed that this is not simply a genetic or biological phenomenon, but rather a health outcome linked to skin tone discrimination and the higher degree of stress experienced by dark-skinned Blacks.²⁶ While the effect was biological, the cause was largely social.

Of course, genes (along with other biological and environmental factors) shape human variation and

outward physical appearance, and many of these characteristics are heritable. Evolutionary dynamics have conferred some different phenotypic traits and genetic signatures to geographically separated groups that may loosely resemble social categories of race. Thus, as Francis Collins notes, the ability to identify genetic variations that provide “reasonably accurate” yet “blurry” estimates of portions of an individual’s ancestry suggest that “it is not strictly true that race or ethnicity has no biological connection.”²⁷

But it is important to put even loose correlations between race and genes or genetic predispositions in an appropriate context. An early and enduring finding in human genetic studies is that there is typically more genetic variation within socially defined racial groups than between them.²⁸ Another consistent finding is that for any observable “racial” trait, there are no corresponding genetic boundaries between population groups. They are discordant—that is, the collection of observable physical cues that society often uses to create the idea of discrete racial groups are not mirrored by corresponding genetic boundaries.²⁹ Instead, biologists find graded variations in the percentages of groups with each characteristic.

In other words, the sharp delineations that society makes with regards to racial categories are not meaningfully reflected in our genes.³⁰ That is why scientists such as Yale geneticist Kenneth Kidd conclude that “there’s no such thing as race in *Homo sapiens*. . . . There’s no place [in our genes] where you can draw a line and say there’s a major difference on one side of the line from what’s on the other side.”³¹ To say that race is a social construction is to emphasize that in most cases, racial categories based upon phenotype (physical appearance) ultimately provide a poor way to proxy³² individual genotype, or genetic variations that may be exclusive to certain populations.

pronouncements such as those made by then President Bill Clinton:

“I believe one of the great truths to emerge from this triumphant expedition inside the human genome is that in genetic terms, all

human beings, regardless of race, are more than 99.9 percent the same. What this means is that modern science has confirmed what we first learned from ancient fates. The most important fact of life on this Earth is our common humanity.”³⁵

The truths of science, it was hoped, could promote racial healing. Yet almost as soon as this result was announced, mapping the less than 1% of human genetic variation onto social categories of race became the focus of several research projects.³⁶ Harvard anthropologist Duana Fullwiley provides an example of the conflicting directions of this research: “The same year that the heads [of the Human Genome Project] repudiated race as genetically significant [the NIH’s Pharmacogenomics Research Network] hypothesized its necessity for ‘rational medicine.’”³⁷

Since then, biomedical researchers and companies have become increasingly interested in developing treatments that use race and ancestry (both perceived and self-identified) as proxies for groups’ genetic predispositions. Put differently, these efforts presume that social categories of race reflect medically relevant genetic differences, even when such differences have not been identified. This is better known as *race-based medicine*: drugs that are developed, approved, and marketed for specified racial groups. Only one of these drugs, BiDil, has received FDA approval. But others are in development and are likely to be next in line.

Meanwhile, dozens of biotechnology companies are marketing genetic testing services directly to consumers, bypassing physicians and other health care professionals. Combined with the power and reach of the Internet, direct-to-consumer (DTC) genetic testing offers people the ability to swab their cheeks at home, mail the sample (along with a fee ranging from \$100 to \$1000), and receive information a few weeks later. Various testing companies claim to reveal insight into their customers’ predisposition for certain diseases, the optimal diet for their genotypes,³⁸ and even the sport in which their children are most likely to excel.³⁹

The growth of DTC genetic testing has been accompanied by much skepticism. Many medical professionals feel that without proper counseling, people can easily misinterpret test results and draw inaccurate conclusions about their health. The usefulness of the information conveyed by such tests has also come under fire. The United States Gov-

ernment Accountability Office—Congress’ investigative arm—reports that many DTC tests purporting to give genetically tailored nutritional and health advice “mislead the consumer by making health-related predictions that are medically unproven and so ambiguous that they do not provide meaningful information to consumers.”⁴⁰

To date, there has been less public discussion about the significant concerns stemming from genetic tests claiming to reveal information about consumers’ ancestral origins, which are often interpreted as tests of racial purity and mixture. But genetic ancestry tests are gaining popularity, especially among African Americans.

Biotechnology is also making an impact in forensics, a field that uses techniques such as ballistics, fingerprinting, and toxicology to investigate crime. Two decades ago, the UK’s Sir Alec Jeffreys revolutionized forensics by developing genetic profiling. This capacity to extract genetic profiles from hair or body fluids left at crime scenes has given police a powerful tool to identify suspects.

A good part of DNA forensics’ power now comes from massive databases storing large numbers of genetic profiles. Once a DNA sample is gathered from a crime scene, it can be checked against stored profiles for matches.

Whose DNA winds up in police databases? Typically, it is people who have had previous run-ins with law enforcement. And herein lies the risk for minority communities: given that Blacks and Latinos are disproportionately policed, arrested, and prosecuted, their profiles are likely to be over-represented. This means that the significant civil liberties concerns raised by DNA forensics will disproportionately burden these communities.

Key Concern: Will Commercial and Forensic Applications Revive Biological Theories of Race?

By considering these biotech applications together, this report intends to deepen the way we understand and evaluate scientific approaches to race in the 21st century. It appreciates and acknowledges the medical, scientific and social ad-

vances biotechnology may yield. But it focuses on the risk that, if we are not extremely careful, commercial and forensic applications utilizing human biotechnology may resuscitate harmful ideas about race. Some biotechnological applications, however well-intentioned, may in practice encourage the questionable idea that social categories of race accurately reflect genetic difference, and that groups' social and health outcomes are determined largely by genetic predispositions rather than social forces and institutional practices. In doing so, this report reconsiders DuBois' color line thesis to suggest that the problem of the 21st century may not simply be the color line, but its geneticization: increasingly sophisticated arguments that social categories of race reflect inherent genetic differences, and that these biological variations can explain racial differences and disparities without broader consideration of their social determinants.

There is some evidence that social categories of race may be genetically relevant to the extent that they may correlate with geographical origin, broadly defined. This, in turn, may reflect the histories of isolation and evolution experienced by some groups. Yet there is also evidence that today's applications in biomedicine, genealogy, and forensics might treat race in a circular fashion. Unexamined ideas and assumptions about the genetic relevance of race, often reflecting lay perspectives, may inform research questions and methodologies. Though the results in fact reflect the starting assumptions, they might reinforce the notion that social categories of race map onto meaningful genetic differences. These findings may then get diffused throughout scientific fields, align with folk notions of race, and become reference points as hard evidence of a genetic basis of race.⁴¹

This is what Troy Duster and others have called the *reification of race*: transforming race as a social concept into a specific, definite, concrete,

and now presumably genetic category which can feed back into preexisting lay understandings of racial difference.⁴²

The potential of race-specific medicine, genetic ancestry tests, and DNA forensics to revive biological thinking about race is not necessarily due to any ill intent on the part of researchers working in the area of race and genetics. To the contrary, many scientists have devoted their careers to egalitarian and praiseworthy pursuits such as resolving health disparities and assisting law enforcement. For example, the use of racial categories in biomedical research has been proposed as a way to make biomedicine more inclusive.⁴³ But even with the best of intentions, commercial and forensic applications of this research can unwittingly create the very difference they seek to find. As in other areas, racial injustice is best understood as a matter of systematic outcomes rather than a question of intentions.

Social categories of race are at times folded uncritically into these applications, and health disparities are often treated as if they stem from slight genetic variations rather than from well-documented social inequalities. These dynamics might allow less-than-robust scientific studies or weak correlations between genetic variations and social categories of race to be marketed as commercially viable genetic tests or biomedicines. Society's continued stake in the idea that social categories of race reflect significant genetic differences—even when faced with substantial evidence to the contrary—contributes to the acceptance of these products. And this process might work to reconstitute an inaccurate and unsubstantiated view of racial difference and disparities.

In This Report

These technologies raise particular questions for minority populations as patients, consumers, and as the disproportionate subject of law enforcement.

Playing the Gene Card? is designed to provide an accessible assessment of three emerging biotechnology applications—race-based medicine, genetic ancestry tests, and DNA forensics—to examine their effects on minority communities and on our understanding of race.

Chapter 1, Race-Based Medicine: One Step Forward, Two Steps Back? describes the controversies around BiDil, the first drug developed for a specific racial group.

Attempts to understand the relationship between genetic variations and drug response represent a first step towards what has been described as personalized medicine: therapies that are custom-tailored to patients with a particular genetic makeup. This is a promising field when considered in terms of individual patients. But marketing relies on appeals tailored to large numbers of people—that is, to particular *groups*. Racial groups have become an initial focus for such marketing campaigns despite significant questions regarding claims that the drugs in question are in fact race-specific.

Chapter 2, Ancestry Tests: Back to the Future? explains both the attraction and the significant limitations of genetic ancestry tests, as well as their broader implications for renewing biological theories of race.

Biotech companies target African Americans for direct-to-consumer genetic tests that purport to give information about their family origins. They often present these ancestry tests as an end run around the genealogical dead end produced by the slave trade, which detached millions of African Americans from their roots. But many of these companies make unsupported claims about the reliability and significance of the test results. And their social implications may be broader and

more significant than commonly acknowledged. Are ancestry tests helping to revive outmoded theories of race, while offering misleading hope that technology can somehow compensate for the genealogical ruptures produced by the slave trade?

Chapter 3, Race and DNA Forensics in the Criminal Justice System, discusses how rapidly expanding DNA databases and related technologies are a civil liberties concern for all, and raise particular concerns for communities of color.

DNA analysis has become an important tool for law enforcement; it has also led to the exoneration of many people wrongly convicted of crimes. But critical questions need to be asked: Whose DNA should be included in police databases? How should we interpret the data? How long should the government keep genetic profiles in these databases? Should police be allowed to store the DNA of people merely suspected of crimes but never charged or convicted? Should relatives of suspects and criminals be subjected to familial searches that implicate their privacy? Since the representation of Blacks and Hispanics in the criminal justice system is grossly disproportionate, there is an acute possibility that this data may exacerbate discrimination in law enforcement.

Though numerous differences abound, today's commercial and forensic applications of human biotechnology may potentially verge on echoing 19th and early 20th century biological essentialism in prioritizing racial typology over social determinants. Given our history of using presumed biological differences between races to justify unequal treatment, *Playing the Gene Card?* suggests that we pay much closer attention to the ways in which market forces and misunderstood or misapplied science may give new legitimacy to old theories of racial difference.

Chapter 1

Race-Based Medicine: One Step Forward, Two Steps Back?

It is well known that people often have different reactions to medications. In most cases, the causes of these differences are unknown, but they may be connected to subtle variations in individuals' DNA. Efforts to prescribe the right medication for each patient's genome, to custom-tailor therapies for patients with a particular genetic makeup, are known as "personalized medicine" and considered by many one of the great promises of modern biology.

This promise of personalized medicine, however, has barely begun to be realized. While there are limited examples where drugs can be tailored to individual genotypes, genetic knowledge is not yet robust enough to do this on a large scale. Nevertheless, pharmaceutical companies are beginning to develop drugs that claim to be tailored for a specific racial group, otherwise known as race-based medicines. Such medicines are based upon the idea that specific genetic variations that are most common within particular racial populations explain certain health outcomes and disparities.

The first race-specific drug was BiDil, approved in 2005 by the FDA to treat African Americans suffering from heart failure. Marketed by the biotechnology company NitroMed as a way to address what were perceived as racial disparities in heart failure, BiDil quickly became the poster child for revamped efforts to approach

race not merely as a social category, but as a genetically relevant mechanism for understanding human difference and medical outcomes.

This interest in race-based medicines is part of a broader trend, most notably articulated by doctors such as Sally Satel who believe racial profiling in medicine is good, or even necessary.⁴⁴ For Satel and others, social categories of race are useful proxies for understanding underlying genetic variations that may be unique to certain racial populations—even when such variation is known to be relatively small.⁴⁵ From this perspective, race-specific therapies "illuminate the future of medicine."⁴⁶

Despite this enthusiasm and the supposed benefits for minority health care, the story of BiDil is a cautionary tale that raises a number of important questions:

- Is it reasonable to assume without specific evidence that genetic variations, which can play a substantial role in individuals' drug response, can be meaningfully grouped by social categories of race?
- How might lingering biological theories of race influence well-intentioned research agendas?
- Is race-specific medicine the best way to use limited resources to address racial disparities in health?

Major Projects on Human Genetic Variation

- **The NIH Pharmacogenetics Research Network** examines the less than 1% of human genetic difference to explore how tiny variations might underpin group differences in disease susceptibility and drug response.⁴⁷
- **The Human Genome Diversity Project** (now defunct) tried to use genetic data from indigenous groups around the world in order to examine human genetic diversity.⁴⁸
- **The International HapMap Project** compares the genetic sequences of individuals with African, Asian, and European ancestry to catalogue genetic differences and similarities that may help find genes linked to certain diseases or that affect drug response.⁴⁹
- **The NIH Center on Genomics and Health Disparities**, launched in March 2008, promises to devote substantial resources to using genomics to understand health disparities across different populations. The Center’s director, Dr. Charles N. Rotimi, notes that “the priority of our center will be to understand how we can use the tools of genomics to address some of the issues we see with health disparities.”⁵⁰

These efforts do have scientific merit. Many researchers hypothesize that the less than 1% of variation in DNA might be relevant to racial disparities in health outcomes. The tiny difference among individuals’ shared three billion base pairs corresponds to up to 15 million genetic dissimilarities; these may correspond to genetic variations that are linked to ancestral evolutionary dynamics in a manner that can be proxied by individuals’ outward appearance, or phenotype.

Before delving into these questions, it is necessary to have a brief understanding of the underlying scientific concepts used to support not only claims about the propriety of race-based medicines, but also other claims linking race and racial outcomes to genetic difference.

Pharmacogenomics: The Concept Behind Race-Based Medicines

The Human Genome Project (HGP) revealed that humans have between 20,000 and 25,000 genes, many fewer than was once thought. The completed sequence can now identify their locations; further research is likely to shed greater light on how these genes work.

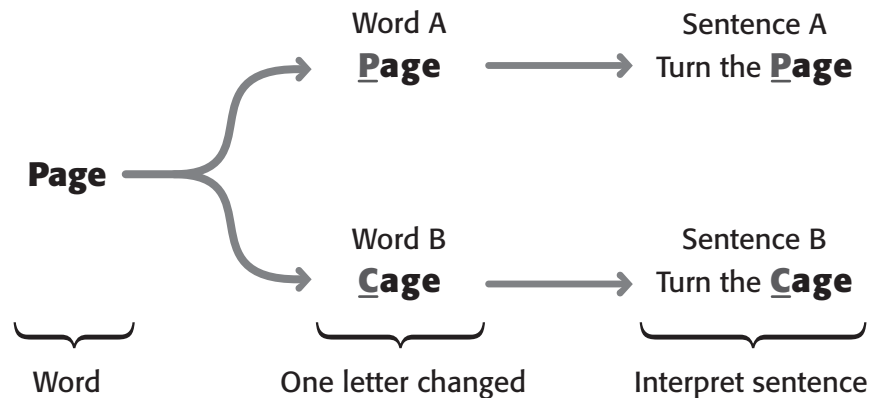
Individuals’ genetic sequences are remarkably similar. When two people’s chromosomes are compared, their DNA sequences can be identical for several hundred bases.⁵¹ But the sequences will differ at about one in every 1,200 “letters”; one person might have an “C” (cytosine) at a given location while another person has a “T” (thymine), or a person might miss part of a DNA segment at any given point or have extra bases.

Each unique “spelling” in a chromosomal region is called an *allele*, while the collection of

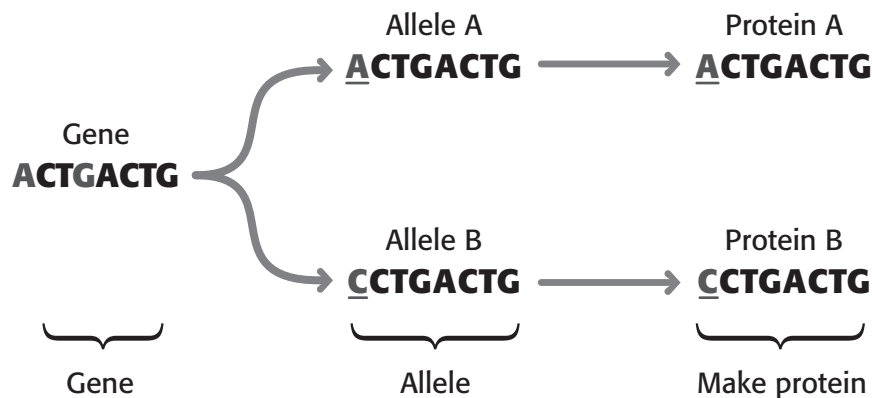
alleles in a person’s chromosomes is called a *genotype*. This is often contrasted with *phenotype*, which is a person’s outward characteristics resulting from their genes’ interaction with the environment during development. For example, identical twins have the same genotype but their phenotypes differ, though sometimes only slightly.

Pharmacogenomics is a biomedical field that studies how these different spellings, or genetic variations, might affect which drugs are most effective for particular genotypes. (See Figure 1, on page 9, and “Why Genetic Variations Matter,” on page 10.) Knowing that, researchers hope to be able to predict which patients will respond best to certain medications.

Pharmacogenomic research into which genetic variants correlate with drug response or disease susceptibility coupled with population geneticists’ research into which haplotypes correlate with particular ancestries—what many scientists and laypersons closely associate with “race”—are slowly but surely moving biomedicine in the direction of developing treatments that use race and ancestry as *proxies* for groups’ genetic predispositions.⁵² In other words, race-based medicine works from the premise that social categories of race defined largely by pheno-



A Changing one letter in a word.



B Changing one base in a gene sequence.

Figure 1 Grammatical analogy. (A) A one-letter variation can change the meaning of a word or affect its meaning in a sentence. (B) Similarly, a one-letter variation in a gene sequence can affect its meaning and the proteins that are produced. The different protein may also have further consequences, such as affecting a person's susceptibility to certain diseases or their response to certain drugs. (Image based upon work by Esteban González Burchard.)

type or self-identification can “stand in” for specific genetic differences between races that have yet to be found—and may never be.

First on the Scene: BiDil

The FDA's approval of NitroMed's BiDil in June 2005 as a treatment for African Americans with heart failure was the first time that regulatory approval had ever been given to a drug specified only for one racial group.

Five million Americans currently suffer from heart failure.⁵³ Medical literature and popular media frequently repeat the claim that Blacks die from heart failure twice as often as their White counterparts. This two-to-one disparity has been shown to be misleading,⁵⁴ but it has nevertheless provided the moral, scientific, and commercial justifications for a race-specific approach to treating Black heart failure. The National Association for the Advancement of Colored People, the

Why Genetic Variations Matter

The “letters” or base pairs in a genetic sequence make up “words” (in this analogy, genes) that instruct cells to make proteins that allow them to perform their assigned functions. These genetic sequences contain information that might influence physical traits, predisposition to disease, and responses to environmental influences.

The misspelling of one letter can change a word’s connotation and thus how it functions in a sentence to convey meaning, as shown in Figure 1A. This is no less true for genes, as shown in Figure 1B.

The most common types of genetic variation are these alternate spellings in individual base pairs, which affect whether and how certain proteins are made. These genetic differences are called *single nucleotide polymorphisms*, or SNPs (pronounced “snips”). Several million have been identified, but the total number is not known. Some of these differences seem to be immaterial or compensated for elsewhere; others can be critically important.

In addition, SNPs can be used as markers to identify and find particular genes in sequences of DNA. For example, a “spelling change” in a gene might increase the likelihood that a person suffers from asthma, but researchers might not know its location on a chromosome. They might be able to compare the SNPs in people who suffer from asthma with those of people who do not. If they find a particular SNP that is more frequent among asthma sufferers, that SNP could be used as a marker to locate and identify genes that may influence this outcome. As the International HapMap Consortium notes, “systematic studies of common genetic variants are facilitated by the fact that individuals who carry a particular SNP allele at one site often predictably carry specific alleles at other nearby variant sites. This correlation is known as linkage disequilibrium; a particular combination of alleles along a chromosome is termed a haplotype.”⁵⁵

Association of Black Cardiologists, and other organizations have supported BiDil as an effective way to curb the perceived disparity in heart failure between Blacks and Whites.⁵⁶

The story of BiDil’s clinical development goes back many years. The original patent, which did not mention race, was submitted in 1987.⁵⁷ Even then, BiDil was not entirely new; rather, it combined two generic drugs (hydralazine and isosorbide dinitrate) into one pill.

This is not to underestimate BiDil’s potential contribution to treating heart failure; simplifying administration can increase the likelihood that patients will use prescription drugs correctly and thus optimize benefits. But it does draw attention to the curious fact that these particular drugs have been used to treat heart failure in all races for decades.

BiDil was put through the required clinical trials, but initially failed to receive FDA approval in 1997.⁵⁸ Only then, through a retrospective analysis of data from older clinical trials, did researchers begin to argue that the outcomes of Blacks taking BiDil were better than those of other racial groups. In 2002, after researchers published a paper highlighting these race-specific findings, the United States Patent and Trademark Office issued a patent for BiDil to treat heart failure in African Americans. This patent was subsequently assigned to the biotech firm NitroMed.

With this new patent in hand—and an extended thirteen years of market exclusivity—NitroMed amended BiDil’s failed application for FDA approval with a new clinical trial, called the African-American Heart Failure Trial, or A-HeFT. This study included only “self-identified” Blacks, and yielded astonishing results: adding BiDil to conventional heart failure therapy reduced one-year mortality by 43%. This finding, along with the oft-cited 2:1 racial disparity in heart failure mortality, fast-tracked BiDil for the FDA’s 2005 approval as the first race-specific medicine.

BiDil’s approval represented at least three different claims about the relevance of race to health care and health disparities. It was:

- the first drug to be patented as race specific (a *legal* claim about race and biology)
- the first to receive FDA approval as race specific (a *regulatory* claim about race and biology)
- the first to be marketed as race specific (an *economic* claim about race and biology)

BiDil represents an important step in framing racial difference as an indicator of significant genetic differences in human populations. Steven

Nissen (chair of the FDA Cardiovascular and Renal Drugs Advisory Committee that endorsed BiDil's approval) could not have been clearer in affirming this, noting that his committee took self-identified race in the A-HeFT studies "as a surrogate for genomic-based medicine."⁵⁹ In the absence of knowing the specific genetic markers that presumably correspond with BiDil's efficacy in some patients, the advisory committee concluded that self-identified race is a suitable stand-in for this genetic difference.

Concerns about BiDil

Many ask, why not support BiDil, if it really helps African Americans who suffer from heart failure? The issue is that much of the evidence supporting this claim is not as convincing as it initially seems.

African Americans are not twice as likely to die from heart failure as anyone else. The statistic behind the moral impetus for a race-specific approach to treating Black heart failure—the 2:1 ratio—is not accurate. Legal scholar Jonathan Kahn, who followed the BiDil story very closely, traces this claim to a series of misquotes concerning what is now quarter-century-old data.⁶⁰ More recent data from the Centers for Disease Control puts the ratio at 1.1:1. Essentially, there is no difference in population-wide mortality between Blacks and Whites.

After this inaccuracy was brought to NitroMed's attention, the company amended its claim to say that "African Americans *between the ages of 45 and 64* are 2.5 times more likely to die from heart failure than Caucasians in the same age range." This is technically correct. Yet it fails to highlight a key point: the population aged 45 to 64 accounts for only 6% of heart failure mortality; after age 65—when most heart failure mortality occurs—the statistical difference evaporates.⁶⁹

Top-Down Marketing to the Black Community

*"NitroMed did what other pharmaceutical companies have always done. It gave money to people who later gave its medication the thumbs up."*⁶¹

NitroMed invested heavily in mainstream Black organizations to promote BiDil. It gave the National Association for the Advancement of Colored People \$1.5 million "to develop health advocacy initiatives towards equal access to quality healthcare."⁶² The Association of Black Cardiologists was a co-sponsor of its clinical trials, and was paid \$200,000.⁶³ The company also gained the support of the Congressional Black Caucus.⁶⁴

Analysts predicted sales of \$200 million in 2007 and potentially as much as \$825 million a year.⁶⁵ In practice, however, physicians and insurance companies were reluctant to spend the extra \$3000 a year that BiDil cost compared with the existing generic counterparts.⁶⁶ Sales for the first nine months of 2007 were only \$11 million, and in January 2008 the company announced that it was laying off most of its staff and suspending marketing of BiDil while still making it available.⁶⁷ In October 2008, NitroMed announced that it planned to sell all of its BiDil-related assets to JHP Pharmaceutical.⁶⁸

These data undermine the claims about racial disparity upon which BiDil's supporters have based their moral argument. And given the robust research demonstrating that environmental and socio-economic factors such as poverty and lack of preventive health care worsen cardiovascular health outcomes, it is difficult to assert *a priori* that genes play a significant role in any population-wide disparities in heart failure that might exist.

The clinical trial showing that BiDil is a race-specific drug had significant flaws. The A-HeFT trial that propelled BiDil's FDA approval does not clearly support the claims of race specificity made by the drug's proponents. Those affiliated with the

Historical Theories of Race

Concepts of difference have been part of the human experience for millennia, as have prejudicial attitudes towards groups perceived to be physically different. During the taxonomic phase of biology, capped by Linnaeus in 1758, there were several attempts to categorize humanity into races; Linnaeus identified four.⁷⁰

The 19th century ushered in more systematic attempts to give subjective prejudices an air of objective truth by using biological theories of race. Among those who tried were such notables as Georges Cuvier, who effectively established the discipline of paleontology, and Louis Agassiz, perhaps the leading biologist of his day, who identified twelve human races. Agassiz and others advocated for “polygenism,” the theory that human races had separate origins.

It is noteworthy that Charles Darwin was a “monogenist” who rejected race as a biological construct, having lived with South American natives and been struck by “how similar their minds were to ours.”⁷¹ Nevertheless, he did suggest that stronger tribes would always eliminate the weaker, and what became known as “Social Darwinism” provided a foundation for racist investigation.

The development of eugenics by Francis Galton (1822–1911), who helped pioneer skull measurements and the statistical technique of correlation, was closely related to theories of race.⁷² Among his many and varied efforts, Galton once advocated introducing “the Chinaman” to Africa, in order to “out-breed and finally displace the negro,” since “the Chinaman [has] a remarkable aptitude for a high material civilization.”⁷³

FDA have justified this trial design by noting that “the decision to conduct the trial in [only] black patients reflected careful analyses of 2 previous trials in racially mixed populations [V-HeFT I and V-HeFT II]. . . . Both trials showed little or no overall effect . . . in the mostly white patient population but hinted at substantial effect in subsets of black patients.”⁷⁴ They also note that conducting a full study within a mixed race population would have been an “unreasonable delay” in approving a drug for a group for which there is evidence of its benefits.

Any clinical trial that yields a 43% reduction in mortality is a stunning feat. Yet by only enroll-

ing self-identified Blacks, the trial strongly implies (and is indeed used to show) that it is *only* effective in African American populations. But this is not the case. Dr. Jay Cohn, the person who developed BiDil, has repeatedly noted that non-Blacks can receive a substantial benefit from the medication.⁷⁵

Since patients other than African Americans were not included in the clinical trial, the results cannot speak to whether the drug works differently in Blacks. As Kahn notes, “The only responsible scientific claim that can be made on the basis of these trials is that BiDil works in some people who have heart failure, period.”⁷⁶

There is little robust evidence that race is a suitable proxy for genetic differences in drug response. No genetic component to BiDil’s efficacy has been demonstrated, despite assumptions by Dr. Nissen and other BiDil supporters who believe that self-identified race can be used as a proxy for genetic differences until specific genetic variations are located. Racial pharmacogenomics, as discussed above, is based upon the idea that specific genetic variations that are most common within particular populations explain certain health disparities, and that these disparities can be remedied with therapies that take such knowledge into consideration. BiDil’s clinical trials arguably put the cart before the horse, replacing a scientific approach with the theory that racial difference equals genetic difference connected to heart failure.

BiDil’s presumed race specificity is based upon the idea that self-identified race can be a reliable placeholder for inherited genetic variations that ostensibly explain disparate health outcomes. However, Francis Collins, former director of the National Human Genome Research Institute, writes: “A true understanding of disease risk requires a thorough examination of root causes. ‘Race’ and ‘ethnicity’ are poorly defined terms that serve as flawed surrogates for multiple environmental and genetic factors in disease causation, including ancestral geographic origins, socioeconomic status, education and access to health

Are More Race-Based Medicines Around the Corner?

University College London biologists Sarah Tate and David Goldstein note in a 2004 *Nature Genetics* article that while controversial, “at least 29 medicines (or combination of medicines) have been claimed, in peer reviewed scientific or medical journals, to have differences in either safety or, more commonly, efficacy among racial or ethnic groups.”⁷⁸ Examples include:

- AstraZeneca is currently trying to salvage Iressa—a drug that blocks carcinogenic cell growth—after a clinical trial showed its efficacy to be statistically insignificant.⁷⁹ The company claims to have found data suggesting that Asians responded particularly well to it and has begun developing marketing strategies for Asian countries.⁸⁰
- While the cholesterol-lowering drug Crestor is currently available to all qualifying patients, AstraZeneca has conducted a racially exclusive clinical trial (similar to A-HeFT) called STARSHIP to demonstrate its particular effectiveness in Hispanics.⁸¹ The FDA has also issued a Public Health Advisory because some Asian Americans had an unusually strong reaction to Crestor at some dosages.⁸²
- In 2003, the pharmaceutical company VaxGen took another look at data showing that its HIV vaccine,

AIDSVAX, was not effective in the general population. It hoped to find that the vaccine significantly reduced HIV infections in Blacks and Asians, but abandoned the effort after a subsequent clinical trial in Thailand also failed to demonstrate efficacy.⁸³

The Pharmaceutical Research and Manufacturers of America (PhRMA), the pharmaceutical industry’s trade group, released a report in December 2007 noting that its member companies “are developing 691 medicines for diseases that disproportionately affect African Americans or diseases that are among the top 10 causes of death for African Americans . . . [to] help close the health disparity.”⁸⁴ While this report does *not* specifically pertain to medicines claiming to be genetically tailored for Blacks, the report’s framing highlights a perspective that drug companies are promoting and that is becoming increasingly popular within the biomedical sciences: health disparities are linked to group predispositions that are best addressed through targeted medications. The idea that some racial groups are inherently different from others is at the heart of the moral impetus for race-based medications.

care. Research must move beyond these weak and imperfect proxy relationships to define the more proximate factors that influence health.”⁷⁷

Arguments based on loose correlations and unreliable proxies can play dangerously into lay notions that racial difference equals fixed genetic difference and may thus erroneously give the impression that racial disparities are caused by genes.

Addressing Disparities in Health Through Race-Specific Pharmaceuticals

The assumptions and missteps embedded in efforts to develop and market race-specific medicines raise some concerns. They contribute to three possible outcomes that may work against sensible approaches to addressing health disparities.

Social determinants of health may take a back seat. Studies have repeatedly demonstrated the relevance of poverty, environmental contaminants, lack of education, and other social determinants to overall health and health disparities.⁸⁵ Even the most enthusiastic supporter of BiDil’s race-specific indication acknowledges that many factors—such as diet and stress—contribute to hypertension, diabetes, and other conditions that lead to heart failure.

Scientific studies that root health disparities in genetic differences might obscure the social and environmental factors that affect groups’ disparate health outcomes. Thinking about race in genetic terms attracts public attention and deemphasizes the ways in which poor social treatment leads to poor health outcomes.⁸⁶

Claims about a genetic basis for racial disparities in health outcomes can quickly influence how we understand other social disparities. A key concern is the temptation to use the notion that “racial disparities in health are genetically linked” to explain racial disparities in other areas such as employment, education, and criminal justice. These disparate outcomes might then be attributed to people’s genes rather than to the treatment groups are afforded and their access to resources. Discussion of Blacks’ unemployment rate, educational underachievement, and grossly disproportionate representation in the criminal justice system becomes detached from society’s long history of discriminatory practices, and can become intertwined with assumptions about groups’ inherent (and inheritable) tendencies. This may allow old theories of racial minorities’ biological inferiority to be legitimated in new and different terms, shaping how we understand inequalities in other fields.

Race-specific medicines can shift the responsibility for resolving racial disparities in health from public health initiatives to private biomedical ventures. This is not to say that profit interests can never converge with genuine opportunities to reduce health disparities. Indeed, profit-driven research and development might lead to treatments that can greatly benefit minority communities. But there is significant evidence that commercial motives might also lead companies to make claims about race, genes, and medicine that the available scientific evidence simply does not support. And ceding the problem of racial disparities in health to biomedical companies might devalue public health mechanisms that tackle these disparities’ core social and environmental causes.

Examples abound of how commercial dynamics can distort the public interest in drug development. With regards to race-based medicine, BiDil’s original patent as a race-neutral drug expired in 2007; the new patent based on the claim of racial specificity extended exclusive rights over what is essentially two generic drugs packaged as one. It is

The Slavery Hypothesis

Exaggerated ideas about what genes can explain have shaped popular culture to the point of creating urban legends.⁸⁷ And genetic reductionism affects medical professionals as well as pop culture. One example is the so-called “slavery hypothesis,” which has received high-profile coverage on *The Oprah Winfrey Show* and the CNN mini-series *Black in America*.

According to this theory, African Americans tend to have high blood pressure because the slaves who survived the grueling journey across the Atlantic to North America had a genetic predisposition to retain salt—in short supply on the slave ships—which gave them a survival advantage. Given the supposed genetic roots of this advantage, the heritable characteristic was supposedly passed on to subsequent generations, who then developed hypertension in epidemic proportions once their daily salt intake increased.

No evidence supports this theory despite its prevalence and persistence. Even if there were a “salt sensitivity” gene, slave ships’ overall mortality rate, while high, was insufficient to create a lasting genetic bottleneck effect that would shape the entire African American gene pool in perpetuity.⁸⁸ And there is no evidence for this hypothesized gene among native Africans. Indeed, Nigerians have lower hypertension rates than White Americans, while Finns have higher rates than Black Americans.⁸⁹

Such genetic reductionism can distract from the documented social determinants that affect hypertension such as poverty, diet and stress. Saying something is “in the genes” is tantamount to saying we can do nothing about it—except perhaps sell expensive custom-made medications. And that is a prescription not for health equity, but for continuing disparities.

not unlikely that this influenced Nitromed’s re-packaging of BiDil as a race-specific drug.

Such intellectual property rights have the potential to increase some African Americans’ cost for heart failure treatment. Some have been encouraged to pay BiDil’s premium rather than continue a medical practice that has been going on for years prior to BiDil’s FDA approval: taking its generic counterpart. Though there is some contention as to whether BiDil and its generic components are bioequivalent,⁹⁰ the broader point is that leaving the resolution of health disparities to the market can increase costs in ways that, in the

end, make health care less accessible to minority populations.

In a similar vein, using less-than-robust scientific evidence to racialize drug indications might prevent broader populations from potentially benefiting from a therapy. Some doctors may avoid prescribing what the federal government deems to be a Black drug to non-Black patients. And some non-Black heart failure sufferers might not want to take a so-called “Black” drug.

Conclusion: Evaluating Race-Based Medicine

Taken together, BiDil presents at least four inter-related concerns that should give pause when considering continued efforts to produce and market race-based medicines:

1. The claim that BiDil’s effects are race-specific is based on less than convincing science.
2. Its marketing suggests that health disparities are best addressed through technology rather than by addressing social determinants.
3. It might give unwarranted credence to biological notions of racial difference.
4. It may obscure the real potential of personalized medicines based upon individuals’ genotypes rather than self-identified race or group phenotype.

What unites these initial forays into personalized medicine with our broader concerns about race and biotechnology is their tendency to work from the outside in: to assume that race (self-identified or otherwise) reflects genetic variation that explains groups’ disparate health outcomes. This is fundamentally different than pharmacogenomics’ scientific promise: that specific genotypes, regardless of an individual’s racial categorization, can be identified and correlated with particular therapies to improve drug response. Loose correlations between the phenotypes and genotypes of racial groups belie the promising science behind pharmacogenomics.

Recommendations

- The Food and Drug Administration should require that clinical trials used to support race-specific indications *not* be racially exclusive. Rather, these clinical trials should occur across racial populations and empirically demonstrate not only that the proposed drug is more effective than standard therapy in the targeted population, but also no better than standard therapy in the non-targeted group.⁹¹
- When race-specific drug labels are sought, the FDA should seek authority to convene separate advisory committees that look at implications beyond safety and efficacy. In particular, these committees should examine the broader social impact that might occur. A key concern should be the avoidance of any government action that might give undue legitimacy to biological understandings of racial difference or unnecessarily restrict medications that might benefit more than one racial population.⁹²

Chapter 2

Ancestry Tests: Back to the Future?

Genetic testing is often presented as a major breakthrough in healthcare, as DNA technologies may give us special insights into individuals' predisposition for disease and drugs' optimal use. A more questionable approach to these technologies is what some have termed recreational genetics⁹³—DNA tests focused not on health but on giving customers some type of ancillary information, such as insights into their genealogy.

The marketing and sale of direct-to-consumer genetic ancestry tests is projected to become a multi-billion dollar industry over the next several years. One sector is particularly booming: African Americans seeking to find their ancestral origins.

Ancestry tests are based on scientific research in the field of population genetics. It is one thing, as this field attempts, to investigate the frequency of various genetic markers within certain *populations*. However, using these markers to provide ostensibly accurate information to *individuals* about their ancestry is something quite different. Nevertheless, a number of companies have already commercialized this questionable link between population-based research and individual ancestry. Many observers believe that they are selling products to the public with far more confidence than the science warrants. Results can and do vary, and many tests do not accurately reflect significant parts of an individual's ancestry.

From both scientific and consumer perspectives, genetic ancestry tests raise a series of im-

portant issues. Key among these is their likely social outcome: that industry euphemisms such as “biogeographical ancestry” will more often than not be understood as “race,” and that the perceived immutability of this social and political construct can somehow, even minimally, be genetically verified by a simple cheek swab.

Ancestry tests unavoidably veer into the questionable realm of using social categories of race and ethnicity to shape the interpretation of human genetic variation. In so doing, they can give race an “organic” and “natural” feel, and fuel the idea that social categories of race are genetically significant—that phenotypes are an outward designation of hard-and-fast genetic differences.

African American Ancestry

While genetic ancestry tests appeal to people of diverse racial and ethnic backgrounds, they have been particularly alluring for African Americans whose genealogical histories were disrupted by the slave trade. In his award-winning PBS documentary *African American Lives*, Henry Louis Gates, Jr., Professor of African American Studies at Harvard University and Director of the W.E.B. DuBois Institute, gives voice to the power and allure DNA technologies hold for Black Americans:

“I envy my friends who can come [to Ellis Island] and celebrate their ancestors' journey and trace them through the records so

diligently compiled here. Unfortunately there is no Ellis Island for those of us who are descendants of survivors of the African slave trade. Our ancestors were brought to this country against their will. When they arrived, they were stripped of their history and their identities. For generations we have been unable to learn about African heritage or our family trees. But what if we could trace our roots? What stories would we discover? What ancestors would we meet? What if we could even travel through time across the Atlantic Ocean and find where our ancestors came from in Africa? Now, thanks to miraculous breakthroughs in genealogy and genetics, we can begin to do just that.”⁹⁴

Gates’ sentiments reflect many African Americans’ enduring frustration with the slave trade’s lasting ravages. This legacy affects not only the community’s current social, political, and economic situation, but also how Blacks understand their past. In this context, many African Americans hope genetic ancestry tests will provide answers about themselves, their families, and their communities that were presumed to be lost forever.

One of the celebrities profiled in Gates’ documentary, actress and comedian Whoopi Goldberg, reacted in a manner that reflects this sentiment after hearing about the potential of genetic ancestry tests:

“It’s possible to find out what I am and who I am and what part? Oh my goodness!”⁹⁵

Such hopes and emotion make basic questions raised by genetic ancestry tests especially poignant: Are these tests able to show what they say they do? Can genetic testing give Blacks or any other group the precise understanding of their genealogy that it claims?

Before considering these questions in detail, it is useful to have a basic understanding of the science underlying this endeavor.

Context: Population Genetics

Genetic ancestry tests examine individuals’ DNA to see if they have certain genetic markers. People who are closely related inherit the same markers from shared ancestors, allowing the identification of relationships between them. Moreover, some

Native Americans and Ancestry Tests

While many genetic ancestry tests are aimed at African Americans, the ability to trace Native American ancestry has also been significant part for this emerging industry. Genelex, for example, ran the following advertisement in a prominent newspaper for the Native American community:

*Do you need to confirm that you are of Native American descent? Recent advances in genetic ancestry testing have put the answer to this question at your fingertips. Whether your goal is to assist in validating your eligibility for government entitlements such as Native American Rights or just to satisfy your curiosity, our Ancestry DNA test is the only scientifically rigorous method available for this purpose in existence today.*⁹⁶

University of California, Berkeley Professor Kim Tallbear notes that “categories such as ‘Native American’ are not genetically definitive but politically, historically, and socially negotiated. . . . Genetic markers offer only weak evidence for making meaningful personal claims about heritage and identity.”⁹⁷

But genetic ancestry testing is nonetheless being used to reconfigure the traditional genealogical basis on which resources and entitlements for Native Americans are distributed. Treating Native American ancestry as solely a question of genetics rather than culture and history raises a number of concerns not only for Native American identity, but also sovereignty.

For example, after failing to gain recognition from the federal government as a Native American tribe, the Western Mohegan Tribe and Nation used DNA testing to demonstrate their heritage in order to assert a claim on the lucrative gaming business.⁹⁸ Others have tried to use such testing to gain affirmative action or diversity-based admission to universities.⁹⁹

As Tallbear and University of Texas anthropologist Deborah Bolnick note, “For 150 years, Native American rights have been determined by legal criteria that support the idea of tribal sovereignty. Are tribes willing to give up authority to the scientists, entrepreneurs, and investors who run DNA testing companies and who seem less familiar with Native American politics and history?”¹⁰⁰

Race, Intelligence, and James Watson

The notion that evolutionary forces confer specific abilities and disabilities to different population groups has been at the crux of a long debate over race and intelligence. This conversation predated the existence of population genetics' modern tools, which have been able to track certain genetic markers as they pass through specific populations.

The early contours of this conversation were strongly shaped by prejudice. For example, IQ tests¹⁰² of immigrants in 1913 "revealed" that 83% of Jews and 79% of Italians (among others) were "feeble-minded."¹⁰³ Racism against Blacks existed in tests conducted by the Army during World War I, whose results were bolstered by personal observations such as:

"All officers without exception agree that the negro lacks initiative, displays little or no leadership, and cannot accept responsibility."¹⁰⁴

It would be easier to dismiss such reprehensible sentiments as relics of a bygone day were it not for recent statements that recast such bigotry through the language of population genetics. For example, a 2007 article about Nobel Laureate James Watson quotes him as saying that he is

"inherently gloomy about the prospect of Africa" because "all our social policies are based on the fact that their intelligence is the same as ours—

whereas all the testing says not really" . . . [and] "there is no firm reason to anticipate that the intellectual capacities of peoples geographically separated in their evolution should prove to have evolved identically."¹⁰⁵

Watson has long been notorious for offensive remarks about "stupid kids," "ugly women," "fat people," and "oversexed Latins," among others.¹⁰⁶ While many have condemned these statements or explained them as the aberrational musings by an eccentric provocateur, his 2007 comments were not so easily excused. Indeed, he himself apologized and was forced to step down from his position as Chancellor of Cold Spring Harbor Laboratory.¹⁰⁷

Nevertheless, some pundits sprang to Watson's defense,¹⁰⁸ demonstrating that his original comments reflect a point of view that remains all too common: that genes are linked to social categories of race in a manner that reflects a natural racial hierarchy.

Less than two months after Watson's comments, a test of his own DNA (which is publicly available through deCode Genetics) was said to demonstrate that Watson himself is 16% African.¹⁰⁹ As this chapter explains, the findings of genetic ancestry testing can often be misleading. But the irony of this high-profile result was nonetheless striking.

genetic markers are found more frequently in certain parts of the world than others, which may give clues to the geographical origin of a particular genetic sequence.

The technological developments underlying the commercial viability of genetic ancestry tests stem in large part from population genetics, a field that looks at how evolutionary forces shape groups' genetic makeup. Advocates of genetic genealogy tests rarely use the term race, preferring terms such as "biogeographical ancestry" or "continental ancestry."¹⁰¹

Academic researchers have expended substantial resources over the past several decades

to studying the relationship between genetic variation and ancestry, largely to reconstruct the history of human populations. For example:

- **The Human Genome Diversity Project**, mentioned in Chapter 1, attempted to sample, bank, and analyze genetic data from "isolated indigenous populations"¹¹⁰ across the globe to study human genetic diversity, migration, and evolution. The key effort here was to collect and identify genetic markers that are thought to be unique to certain groups, in order to investigate the genetic underpinnings of human difference.¹¹¹

■ **The International HapMap Project**, also previously described, takes DNA samples from several groups to identify their shared patterns of genetic variation—but this time with an eye towards understanding the genetic component of certain diseases. This project is based upon 270 DNA samples taken from four groups: the Yoruba in Ibadan, Nigeria; Japanese in Tokyo; Han Chinese in Beijing; and Utah residents with ancestry from northern and western Europe. The idea is that single nucleotide polymorphisms (SNPs)—the single-base differences in DNA segments that represent a common type of genetic variation—can be isolated and tagged to analyze differences between groups. Researchers have shown that “many sets of adjacent SNPs have been passed down

through the generations largely intact.”¹¹² Known as haplotypes, these related SNP variants enable researchers to compare populations by looking at roughly 500,000 tagged SNPs rather than all ten million (or more) individually known SNPs.

■ **The Genographic Project** is a collaboration between the National Geographic Society, IBM and the Waitt Family Foundation. Considered by some to be the successor to the Human Genome Diversity Project,¹¹³ it collects samples from around the world in order to “map humanity’s genetic journey through the ages.”¹¹⁴ The Genographic Project has established ten research laboratories across the globe to acquire “genetic samples from the world’s remaining indigenous and tradi-

Bioprospecting and Biopiracy

The collection of genetic data from around the world has provoked strong reactions. For example, the United Nations Permanent Forum on Indigenous Issues (UNPFII) recommended in 2006

“that the Genographic Project be immediately suspended and report to the Indigenous peoples on the free, prior and informed consent of all the communities where activities are conducted or planned.”¹¹⁶

In the 1990s, efforts by public interest groups including the Rural Advancement Foundation International (RAFI, now the ETC Group) and the Indigenous Peoples Council on Biocolonialism (IPCB) led to widespread condemnation and the virtual stalling of the Human Genome Diversity Project, which was widely derided as the “Vampire Project.”¹¹⁷ Particular offense was taken to the terminology “isolates of historical interest” which led to comments such as this, by Victoria Tauli-Corpuz of the Cordillera People’s Alliance, Philippines:

“After being subjected to ethnocide and genocide for 500 years, which is why we are endangered, the alternative is for our DNA to be stored and collected. . . . Why don’t they address the causes of our being endangered, instead of spending \$20 million for five years to collect and store us in cold laboratories?”¹¹⁸

In part, this was a reaction to efforts dating back at least to the 1950s to collect biological samples—plants, generally—containing possibly therapeutic chemicals and to isolate, patent and commercialize these compounds without compensating the inhabitants of the areas where they were found.¹¹⁹ This was extended to attempts to patent the ingredients of long-standing traditional medicines and even foods.¹²⁰

The same pattern was seen with human populations. For instance, in the mid-1990s, DNA was collected from 272 of the 295 inhabitants of Tristan da Cunha, a tiny island in the South Atlantic, with the explicit goal of trying to isolate genes that lead to asthma, which is endemic in this tiny population.¹²¹ The islanders, who would not have benefited from any patent income, have grown tired of intrusive visitors, as shown in this response to a journalist doing a follow-up story in 2004:

“And how civilized are those in that world who look down their noses at those from isolated communities like ours, or less developed nations?”¹²²

The general problem for researchers was well summarized in a 2006 *New York Times* headline: “DNA Gatherers Hit Snag: Tribes Don’t Trust Them.”¹²³

tional peoples whose ethnic and genetic identities are isolated.”¹¹⁵

These projects’ attempts to learn more about genetic variations among human populations may be valuable, whether they are aimed at developing new biomedicines or learning more about human history. Nevertheless, critics have argued that “the view that isolated populations can be treated as genetically discrete is simplistic. This kind of ‘typological’ thinking—which underpins all notions of racial differences—has been in retreat for years . . . and for good reason: it assumes not only that human groups are de-

finied solely by genetic characteristics but that these vary from group to group in a distinctive manner.”¹²⁴

It is this question of typological thinking that connects past and present, raising serious concerns about projects looking at the relationship between genes, human variation, and what is popularly understood as race. Even when ventures such as the International HapMap Project try to be sensitive to questionable conflation between lay understandings of race and scientific approaches to genetic variation,¹²⁵ social categories of race can still influence the way scientists and the public think about human populations.

From Race to Population and Back

Notions of race employed by today’s geneticists and biomedical researchers are not the same as 19th century essentialist conceptions that drew hard and fast distinctions between groups. The earlier efforts were defined by a typological approach “that cast human differences as static and unchanging.”¹²⁶ They assumed that phenotypes—outward physical distinctions such as skin color, facial features, and body type—were meaningful and measurable proxies for groups’ inherent worth.

With the end of World War II and the exposure of Nazi atrocities, most scientists stopped talking about races in favor of talking about *populations*. Population genetics is widely interpreted as representing a crucial scientific turn away from examining *qualitative* or typological categories of difference and towards measuring *quantitative* differences in the distribution and frequency of genetic variations among and between certain groups.¹²⁷ Rather than focusing on categorizing people by *phenotype*, population genetics is thought to have put scientific racism in the past by focusing its attention on the *genotypes* of various populations.

But a number of scholars question this interpretation. Rather than marking a clear move in an anti-racist direction,¹²⁸ they argue that the shift¹²⁹ in the life sciences from “race” to “population” is ambiguous and that typological approaches to human difference

continue to influence population approaches to race and genetics.¹³⁰ As University of California, Santa Cruz, sociologist Jenny Reardon concludes in her historical account of this period and its reverberating effects on modern research agendas such as the Human Genome Diversity Project:

“No consensus about the role of race in studying human origins and diversity emerged following World War II. Physical anthropologists and geneticists did not all agree—contrary to prevalent historical opinion—that race had no biological meaning, and should be replaced by a study of populations. Not even did all agree that typologies had no use in science. Rather, most sought to redefine scientific ideas and practices for studying race (including typologies) in the wake of what many perceived as the abuse of these ideas and practices by eugenicists, segregationists, and the Nazis. . . . These questions would not be resolved by the time the [Human Genome] Diversity Project was proposed forty years later.”¹³¹

The difficulties with the population and essentialist conceptions of race, as compared with the actual pattern of observed genetic variability, are graphically illustrated in Figure 2.

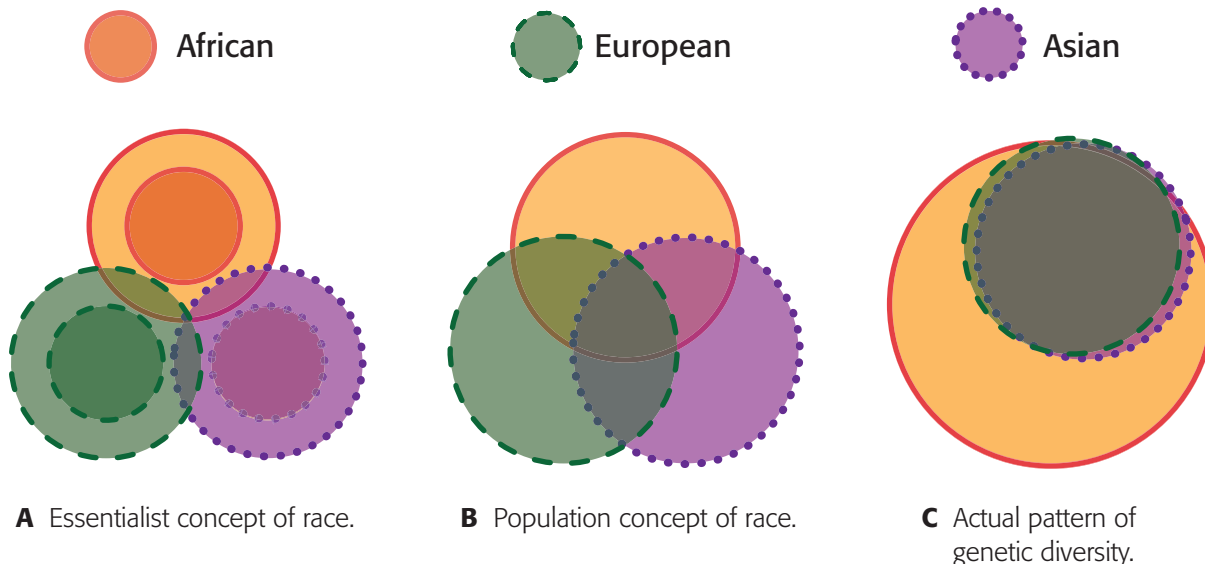


Figure 2 The essentialist and population concepts of race contrasted with the actual patterns of genetic variation (simplified to three geographic categories). Based on the work of Dr. Jeffrey Long at the University of Michigan and depictions created by the *Race—Are We So Different?* project of the American Anthropological Association.

A Essentialist concepts of race that were popular throughout the 19th and early 20th century held that the human species was divided into several mutually exclusive yet tangentially overlapping groups based largely upon physical features such as skin color and facial features.

B Population approaches treat race as clusters of local populations that differ genetically from one another, whereby each group is considered a race. As depicted, this concept suggests an outer periphery of unshared distinctiveness as well as substantial genetic similarity that is highlighted by the overlapping regions.

C Contemporary data on human diversity supports a “nested subset” approach to race. This reflects the fact that “people have lived in Africa far longer than anywhere else, which has allowed the population in Africa to accumulate more of the small mutations that make up [human] genetic variation. Because only a part of the African population migrated out of Africa, only part of Africa’s genetic variation moved with them. For this reason, most genetic variation found in people living outside Africa is a subset of that found among Africans.”¹³²

Some argue that social categories of race and genetic understandings of human difference are strongly correlated, and that five main human groups, each with notable genetic variation from the rest, can be defined by continental ancestry. This perspective is defended through the use of at least three sets of studies in population genetics.¹³³

1. Genetic sampling across several continents has allowed researchers to design tree diagrams that reflect human ancestry in a manner that corresponds with the five main continents.
2. Cluster analyses of other genetic data have revealed genetic differences between groups of different continental origins that roughly map onto self-identified race.
3. Researchers have been able to show that genetic variants (alleles) at specific chromosomal locations that occur in 20% or more of one continental population are likely to appear in others, but those appearing less frequently are more likely to be unique to the one group. Since people of African descent are thought to have greater genetic variability but more low-frequency alleles,

some conclude that they have more race-specific genetic variations that provide greater opportunities to link individuals with specific sampled groups from sub-Saharan Africa.

However, University of California, San Diego sociologist Steven Epstein notes that it is imperative to keep two crucial points in mind:

“First, the best way to understand genetic diversity is in terms of geography. According to Rick Kittles and Kenneth Weiss: ‘Human genetic variation is actually characterized by clines (spatial gradients) of allele frequency rather than categorical variation between populations, and the pattern varies among genes for the historic reasons of drift, selection, and demographic history. . . . The pattern of variation can generally be described as isolation by distance: genetic differences between populations are roughly proportional to the geographic distance between them.’

Second, and as a consequence of the preceding, population differences at the level of SNPs are invariably gradational rather than absolute: there is no known example of a polymorphism that is found exclusively in a single social group (as defined by race, ethnicity, nation, continent, etc.) or found universally within it. Hence, all of the claims about group-relevant polymorphisms . . . are actually statements about percentages.”¹³⁴

From Groups and Populations to Individuals

This academic research on genetic differences between continental groups underlies commercial services offering genetic ancestry testing.

But there is an often unnoticed leap of logic between discussions of *group* genetic differences and genetic ancestry tests’ ability to reliably say anything meaningful about *individual* ancestry. Studies of groups investigate frequency distributions of different populations’ genetic variations whose boundaries are recognized as being inherently blurry. Their applicability to the genealogy of any individual is limited.

Moreover, there has been insufficient discussion of how translating academic research on groups and populations into commercial ventures on individual ancestry can breathe new life into biological notions of race. Physical anthropologist Deborah Bolnick notes that

“although [ancestry tests] emphasize the individual as the crucial unit of analysis, individual ancestry inference is closely tied to our understanding of human groups and the distribution of genetic variation among them. Inferring an individual’s genetic ancestry entails deciding that his or her DNA was inherited from a certain group or groups, and that cannot be accomplished unless one first distinguishes groups that differ genetically in some way. Thus, even such individually-oriented genetic research has implications for our understanding of race and the pattern of human biological diversity.”¹³⁵

We can start to see how these various wings of population genetics have converged around the idea that individuals’ genetic markers can map onto group-based social understandings of race. To get a better sense of this relationship between group-based genetic research and individual ancestry inference, it is worth looking closely at the products being offered and their underlying technologies.

Techniques Used by Ancestry Tests

Currently, genetic ancestry tests take three main approaches.

1. **Mitochondrial DNA (mtDNA)** tests rely on the fact that this tiny, specialized part of our DNA is passed only from mother to child (unlike most DNA, which is a mixture from both parents). It can therefore be used in order to test a direct maternal line.
2. **Y-chromosome** tests analyze genetic markers passed from father to son to trace paternal ancestry.
3. **Admixture mapping** examines genetic markers on non-sex chromosomes that contain DNA from both parents to estimate a person's percentages of African, Native American, European, and East Asian ancestry.¹⁴⁵ Significant methodological questions remain concerning whether these tests accurately do what they say.

In the first two cases, ancestry is deduced by determining the tested individual's set of associated variations (haplotype) and comparing it with haplotypes from individuals sampled from different geographic locations. This process can identify whether any two *individuals* are related with a high degree of certainty. However, it is also used to determine which *populations* share the individual's haplotypes to give customers a sense of where they come from geographically as a proxy for what race they might be. This second use of mtDNA and Y-chromosome tests has severe limitations.

That is because both of these tests examine only a very small fraction of the genetic material contributing to an individual's genome. Each of our parents, grandparents, great grandparents, etc., contribute to our genetic makeup. Going back seven generations, that is 128 great-great-great-great-great-grandparents who have an equal "say" in an individual's genome. Yet, mtDNA and Y-chromosome testing—combined—only provide information about two of those ancestors whose genetic in-

The Business of DNA Ancestry Testing

Genealogy has been a solid business for years, using technologies from microfilm to databases.¹³⁶ The advent of DNA testing has triggered a major shift in the industry, accompanied by an influx of capital that is likely to fuel further changes.

In late 2007, Spectrum Equity Investors paid \$300 million for a controlling interest in The Generations Network Inc. (TGN).¹³⁷ TGN is the parent organization of Ancestry.com (which advertises a specialty in African connections) and several other websites.¹³⁸

DNA testing has led directly to the founding of several companies, the most high-profile being 23andMe of Mountain View, California (funded in part by Google).¹³⁹ The longer-established deCode Genetics obtained a much-criticized agreement with Iceland in 2000 to create a database of the entire population's personal medical records.¹⁴⁰ In 2007, DeCode established a gene-analysis service. Both companies initially offered SNP analysis for around \$1000, with ancestry testing as just one component, but 23and Me has since cut its price to \$399, while deCode's future is in some doubt for financial reasons.¹⁴¹

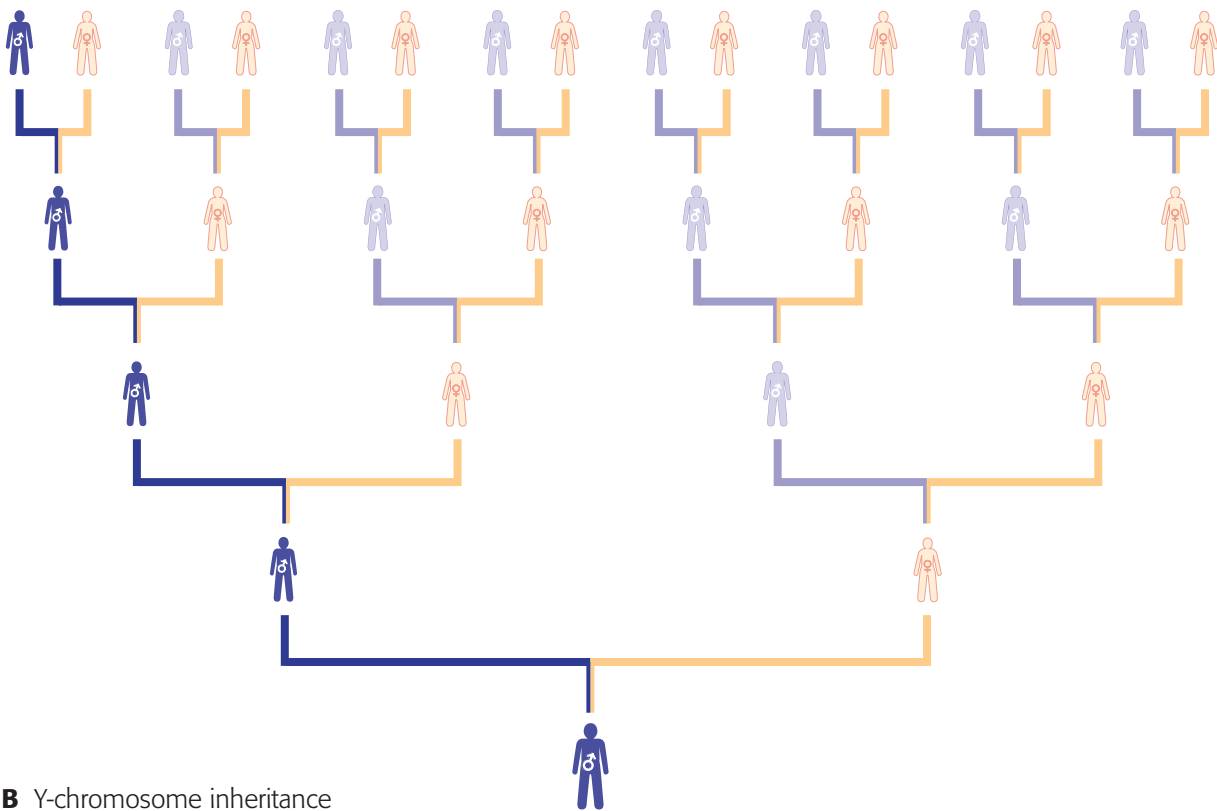
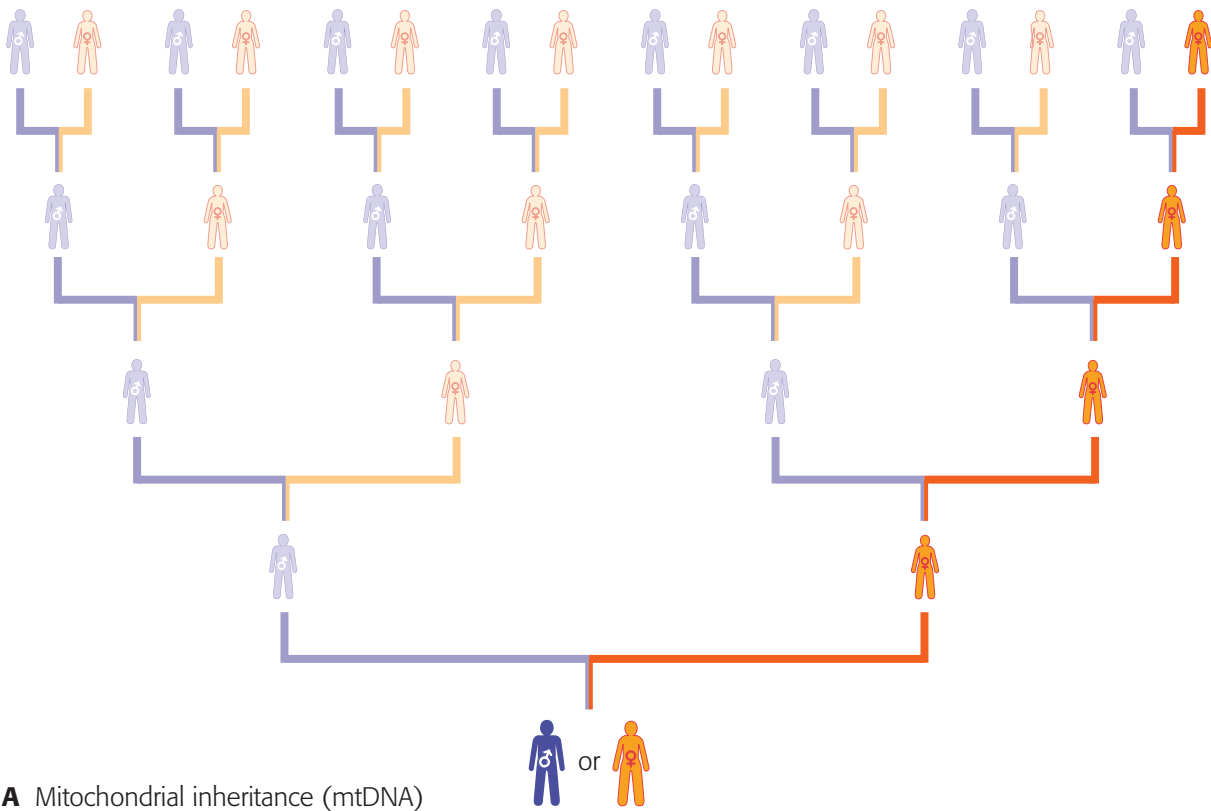
The companies specializing in ancestry offer somewhat cheaper tests, with prices ranging from around \$140 to \$350.¹⁴² The African American market is often specifically targeted. For example, African Ancestry claims a database of 25,000 indigenous African samples from which to compare consumers' genetic profiles.¹⁴³ Others, such as DNA Tribes, clearly view African Americans as a major market, but also emphasize Native American and other lineages.¹⁴⁴

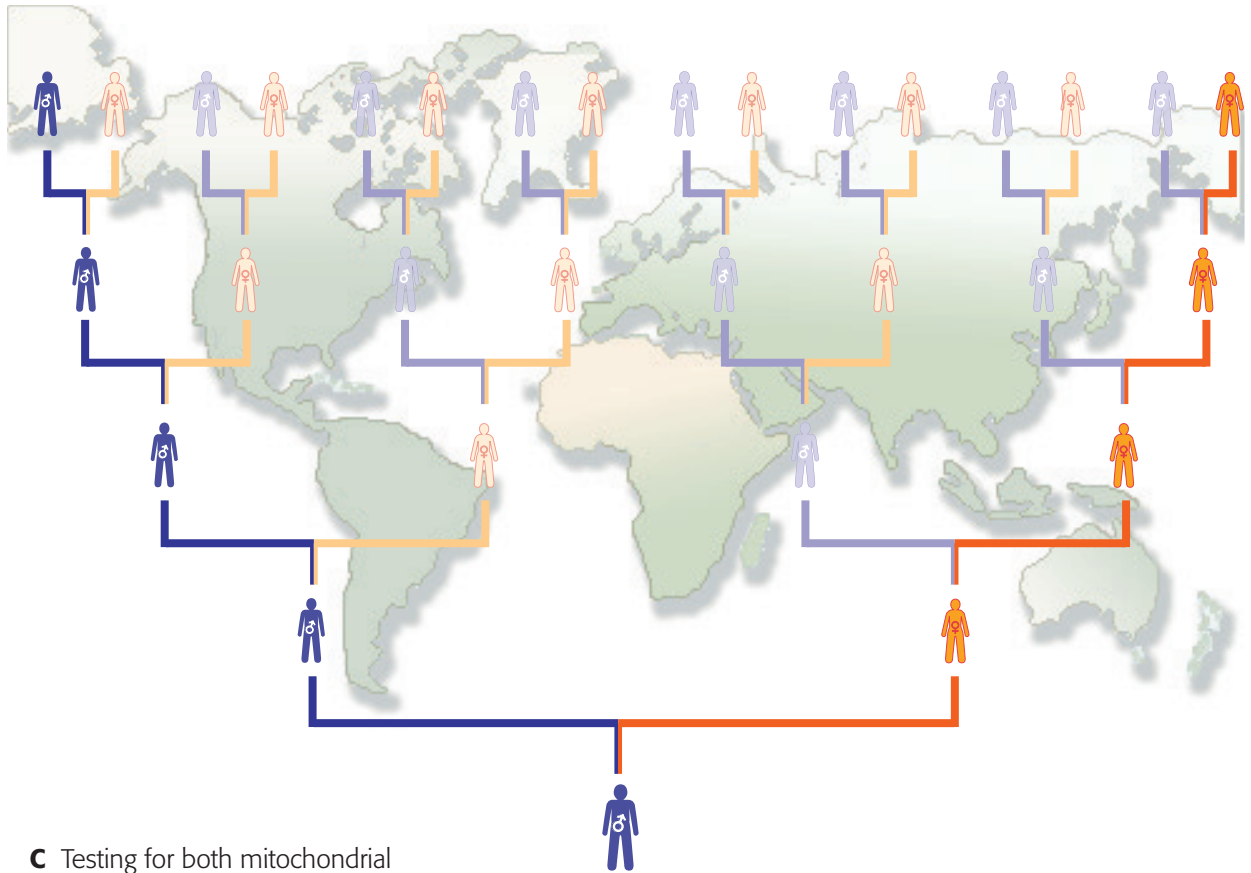
The companies in the sample list on the next page all specialize in genetic ancestry tests. Virtually all offer both mtDNA and Y-chromosome tests, at prices ranging from \$119 to \$495 each, rounded to the nearest dollar. Most also offer autosomal tests, and many offer premium services. Many use "Ancestry by DNA 2.5" software, developed by DNAPrint Genomics, which owns Ancestral Origins and also markets forensic DNA products.

formation has been passed down throughout time, presumably unchanged, as shown in Figure 3.

What about the other 126 equal contributors? Genetic tests based on mitochondrial DNA and Y-chromosomes cannot "get to" their information at all. They are therefore unlikely to provide a full picture of the diverse contributions making up an individual's ancestry. Nevertheless, some

| Ancestry-Test Companies | What They Say | Additional Products |
|---|---|--|
| African Ancestry African DNA | “Once you unlock the mystery of your genetic ancestry, your life will never be the same!” (<i>African Ancestry</i>) | EuroDNA \$429–\$995 (<i>various companies; may be discounted if purchased as upgrades</i>) |
| All My Roots | “African-American DNA tests confirm. . . we have powerful roots!” (<i>All My Roots</i>) | Eurasian DNA, \$430–567 (<i>various</i>) |
| Ancestral Origins Ancestry.com | “Discover your GeoGenetic links with populations around the world.” (<i>Ancestral Origins</i>) | Hindu ancestry, \$499 (<i>DNA Testing</i>) |
| Ancestry by DNA Cambridge DNA | “Your Y-chromosome made you the man you are today. . . Picture yours about 300 million years ago. . . Earth was dominated by plants and insects, but this time had also given rise to mammal-like reptiles. This is where your Y-chromosome started. Say hello to your ancestors.” (<i>DNA Heritage</i>) | Native American testing for tribal rights (<i>various, price perhaps included</i>) |
| DNA Diagnostics Center DNA Heritage DNA Testing | “Your Consumer Genetics Source™ since 2003.” (<i>DNA Testing</i>) | “The world’s only ‘Cohanim’ test, which will identify those people who share this set of markers with the family of the Biblical character Aaron.” (<i>Family Tree DNA, price unclear</i>) |
| DNA Tribes | “Your Y-chromosome made you the man you are today. . . Picture yours about 300 million years ago. . . Earth was dominated by plants and insects, but this time had also given rise to mammal-like reptiles. This is where your Y-chromosome started. Say hello to your ancestors.” (<i>DNA Heritage</i>) | Genealogy packages, up to \$895 (<i>Genelex</i>) |
| DNA Worldwide EthnoAncestry | “Our goal is to go beyond the basic DNA tests offered by other companies with bold new innovations in ancestry testing and interpretation.” (<i>EthnoAncestry</i>) | Paternity tests and relationship tests for immigration, \$149–649 (<i>various</i>) |
| Family Tree DNA Genebase | “History Unearthed Daily” (<i>Family Tree DNA</i>) | Optional wall map, \$15 (<i>Chromosomal Laboratories</i>) |
| Genelex GeneTree | “Using revolutionary DNA analysis, find out how you are related to Marie Antoinette—one of the most illustrious women in European history.” (<i>Genebase</i>) | T-shirts with “country of origin,” \$20 (<i>African Ancestry</i>) |
| GeoGene Identigene | “From a simple mouth swab our scientists can trace your genetic lineage back thousands of years, to the dawn of humanity itself. From just this tiny DNA sample we can draw up a personalized wallchart that follows your epic family journey from its ancient outset and brings the distant past a whole lot closer.” (<i>GeoGene</i>) | Money-back guarantee on wallcharts (<i>GeoGene</i>) |
| My Genetic Heritage (Chromosomal Laboratories) | “From a simple mouth swab our scientists can trace your genetic lineage back thousands of years, to the dawn of humanity itself. From just this tiny DNA sample we can draw up a personalized wallchart that follows your epic family journey from its ancient outset and brings the distant past a whole lot closer.” (<i>GeoGene</i>) | |
| Oxford Ancestors Roots for Real | “Heritage. History. Humanity.” (<i>Identigene</i>) | |





C Testing for both mitochondrial and Y-chromosome inheritance.

Figure 3 Inheritance patterns of mitochondrial DNA (mtDNA) and the Y chromosome.

Ancestors whose contribution to an individual's DNA cannot be ascertained from the given test are shaded lightly. Note that these simplified diagrams do not include siblings. The person tested is at the bottom of each sequence; above, in order, are the parents, grandparents and so on.

A Mitochondrial inheritance (mtDNA) runs from mother to child, but only daughters pass it on. Therefore both males and females can be tested, but only the female line of ancestry (mother, maternal grandmother, etc.) is described by an mtDNA test.

B Only males have a Y-chromosome, so this test is not applicable to females and only the male line (father, paternal grandfather, etc.) is described.

C Testing for both mtDNA and the Y-chromosome still fails to account for the DNA of all but two members of each generation, or 14 of 16 great-great-grandparents, 30 of 32 of the previous generation, and so on. All the ancestors, however, do contribute to an individual's DNA, even if they do not show up on these particular tests.

companies continue to market their mitochondrial and Y-chromosome tests as definitively revealing individuals' ancestries, giving an impression of precision that is undermined by the tests' limitations.¹⁴⁸

The third type of test, **admixture mapping**, is thought to resolve some of these problems. It checks 175 autosomal markers—SNPs or other markers that are thought to be related to certain ancestral backgrounds. The alleles, or genetic variants, used as markers are “those that have the most uniqueness, or the largest differences in allele frequency among populations.”¹⁴⁹ They are referred to as Ancestry Informative Markers (AIMs).

For example, a database might show that one genetic marker is prevalent among samples from West Africans but not Native Americans, leading the admixture test to conclude that any person with this marker has some West African heritage. While most genetic markers do not reflect this type of variation, admixture mapping relies upon the few markers that do and are also connected to a geographically distinct population.¹⁵⁰

This blend of genetic information is thought to be able to convey a better sense of overall ancestry, but admixture mapping has its own limitations. To talk about genes and ancestry in terms of percentages and mixtures seems to presume that racial purity exists, or existed at one time. This can give a misleading impression that genetically distinct populations are real (or were so at some point) and that social categories of race are genetically verifiable.¹⁵¹

Moreover, as Harvard's Duana Fullwiley points out, “the very continents and peoples chosen for DNAPrint's AIMs product were selected due to their perceived proximity to what we in North America imagine race to be. Although the language of scientists who invented this panel of AIMs is now that of ‘biogeographical ancestry’ the conceptual configuration of human racial typology remains intact.”¹⁵²

Put differently, the very concept that AIMs purport to objectively or genetically represent can be understood as the driving assumption behind

Special Types of DNA

Mitochondria are specialized, and essential, parts of a cell, with their own 37-gene DNA, known as mitochondrial DNA (mtDNA).¹⁴⁶ This is separate from the rest of our DNA, which is collected in chromosomes in the nucleus of each cell. Mitochondrial DNA is inherited from the mother, as part of the outer egg.

Human cells, aside from egg and sperm, contain 46 chromosomes, in 23 pairs, one of which is sex-specific: women have two X-chromosomes, men one X- and one Y-chromosome.¹⁴⁷ Eggs have 23 unpaired chromosomes, including an X, while sperm have 23 including either an X- or a Y-chromosome but not both. The Y-chromosome, which only males have, is therefore always inherited from the father.

The 44 non-sex chromosomes (22 pairs) are known as *autosomes*. They are inherited equally from both parents; sperm and egg each contribute 22. Ancestry testing based on autosomes may therefore give information about either parent.

their configuration. And, while concepts such as ‘biogeographical ancestry’ are designed to support the notion that race is a social construction and resist the idea that race is a genetic category, an application to patent AIMs belies this sensibility through statements such as “BioGeographical Ancestry (BGA) is the heritable component of ‘race.’”¹⁵³ As this example highlights, even dialogues on genes, ancestry, and human populations that attempt to be sensitive to the fraught nature of this conversation often wind up bolstering the view that race reflects inherent biological differences.

Concerns about the Genetic Ancestry Industry

No genetic variations are exclusive to any racial group. A group of researchers recently noted in *Science* magazine,

“Questionable scientific assumptions are sometimes made [with] . . . genetic ancestry tests. When an allele of haplotypes is most common in one population, companies often assume it to be diagnostic of that population. This can be problematic because high genetic diversity exists within populations and gene

flow occurs between populations. Very few alleles are therefore diagnostic of membership in a specific population, but companies sometimes fail to mention that an allele could have been inherited from a population in which it is less common. Consequently, many consumers do not realize that the tests are probabilistic and can reach incorrect conclusions.¹⁵⁴

As previously demonstrated in Figure 2, the rules and delineations society makes in defining who belongs to which group are not reflected at the genetic level.

While researchers may be able to determine that certain genetic variations occur more or less frequently in certain geographically defined populations, they cannot conclusively connect an individual with that variation to the group in question. Nor have they shown that these variations align with social categories of race that are largely defined by phenotype or other cultural norms. Once again, it is important to note that these tests look at less than one percent of any individuals' genome. While not insubstantial, this is nonetheless quite distant from an exhaustive understanding.¹⁵⁵

Database limitations. Another issue is that inferences linking an individual's genetic background to a particular group of people are only as good as the underlying group samples used by the genetic ancestry industry. The entire enterprise depends upon data from very small samples of people; what might appear to be clear markers of a certain group's ancestry may, after broader sampling, turn out not to define the group after all.¹⁵⁶

Moreover, many of these databases and methods for deducing ancestral connections are proprietary and have not been subjected to the rigor of peer review. Even the largest available databases do not come close to capturing all of human genetic diversity; individual matches made to one region or group do not preclude the possibility that there

Human Genetic Variation—A Work in Progress

At the end of 2007, *Science* magazine named work on human genetic variation its "Breakthrough of the Year":¹⁶²

"The unveiling of the human genome almost 7 years ago cast the first faint light on our complete genetic makeup. . . . In 2007, researchers came to appreciate the extent to which our genomes differ from person to person and the implications of this variation for deciphering the genetics of complex diseases and personal traits."

This is not, however, an announcement of answers. Rather, it celebrates the formulation of new questions—which is good science, but less encouraging for already commercialized applications that claim to use genetic science. The rush to market the fruits of genetic research might leapfrog the validation necessary for science to make its strongest contributions. The *Science* article concludes by saying,

"We have yet to fully comprehend the degree to which our DNA differs from one person to the next."

may be similar matches with people from other locations that have not yet been sampled.

These methodological issues are the likely reason that individuals who take genetic tests from multiple companies often receive conflicting results about their ancestral backgrounds.¹⁵⁷ Each private database captures a different set of haplotypes from across the globe. They are necessarily incomplete, and the genetic variations they examine may be present in a given population but not recorded in the sample used for testing.

Hype goes beyond the science. Genetic ancestry companies often make claims beyond what can be supported by science with regard to their ability to accurately pinpoint individuals' ancestral origins. For example, Genetic Testing Laboratories (GTL) offers a service called EarthOrigins

DNA Ancestry Testing, which purports to

“discover your anthropological roots. This simple DNA test can tell you where on earth your ancestors originated and traveled . . . your unique geographical and racial heritage.”¹⁵⁸

Yet, such claims fail to tell consumers that, as anthropologist Deborah Bolnick explains,

“present-day patterns of residence are rarely identical to what existed in the past, and social groups have changed over time, in name and composition. Databases of present-day samples may therefore provide false leads.”¹⁵⁹

Using today’s social categories of race and geographical distribution of populations as transcendent reference points from which to understand groups’ past identities and locations is not only scientifically unverifiable, but directly contradicts what we do know about the fluidity of social categorizations and migration patterns.¹⁶⁰

More generally, language widely used in the marketing of ancestry tests often suggests that racial or ethnic group affiliation reflects a series of discrete, measurable human categories in which there are clear connections between an individual’s DNA and group membership. For example, *determogene.com* notes that

“our DNA Ancestry Test will provide you with a simple and objective description of your ancestral origins. The test gives you an

estimated percentage of ancestry from four population groups: Native Americans, Indo-Europeans, East Asian, and Africans.”¹⁶¹

This and other DTC genetic ancestry companies often fail to clearly tell their customers that there are no genetic variations that are exclusive to any one racial group.

Conclusion: Resisting Racial Typologies

The questionable claims made by some companies that market genetic ancestry tests are certainly cause for concern from a consumer protection standpoint. In addition, these tests raise more subtle issues with broader social significance.

At best, using group-based population studies to speak to individuals’ ancestral pasts provides a sliver of information about a person’s ancestry. At worst, however, these commercial endeavors can give new legitimacy to racial typologies and revive discredited beliefs that race reflects fixed inherent differences.

Many scientists are highly skeptical of claims made by commercial genetic testing in general, not just those involving race and ancestry.¹⁶³ Given our historical tendencies to use presumed biological differences between races to justify unequal treatment, we should pay close attention to how market forces may allow the less-than-forthright claims stemming from genetic ancestry testing to breathe new life into archaic theories of race.

Recommendations

■ Consumers should be protected from misleading and inaccurate marketing statements about the accuracy of genetic ancestry tests. This regulatory function should be taken on by the federal government and by individual states. In spring 2008, New York and California¹⁶⁴ sent “cease and desist” letters to companies offering genetic testing services to their residents without the proper licensing due to the public health concerns raised by such practices. (Many of these companies subsequently reached agreements with regu-

lators and continue to market their products.) Similar types of regulatory scrutiny of genetic ancestry companies and the questionable claims they make to consumers may be warranted.

■ The United States Patent and Trademark Office should give greater scrutiny to patent applications claiming to find biological components to race. While such claims should not necessarily be disallowed, a high evidentiary threshold should be required.

Chapter 3

Race and DNA Forensics in the Criminal Justice System

For centuries, forensic analysis of physical evidence has been used to help identify and convict criminals. Tools such as traditional fingerprinting and ballistics are often key parts of criminal investigations. Many police departments have entire forensics departments to assist officers and the court.

Today, DNA technologies have radically reshaped the role of forensics in police work; even small amounts of blood, saliva, or other biological materials left at a crime scene can crack open a case. This dramatic change has been amplified in popular culture to the extent that some express concern about a “CSI effect”: without DNA evidence, prosecutors may find it difficult to convince juries of a person’s guilt.¹⁶⁵ On the other hand, some defense attorneys worry that once jurors hear that there is DNA evidence, they take it as infallible.

It is important to note that DNA forensics can be an appropriate and important tool. DNA evidence has been used to identify perpetrators and to exonerate people previously found guilty on less reliable evidence, overturning many wrongful convictions, including scores of people on death row.¹⁶⁶

But a number of significant questions about DNA forensics are beginning to emerge. The limitations of traditional or first-generation forensic analyses (ballistics, fingerprinting, lie detectors, etc.) have been discussed,¹⁶⁷ and now scrutiny of

seemingly foolproof applications of DNA forensics is mounting. This section focuses on three different aspects of DNA forensics—DNA databases, the use of DNA samples to build racial profiles of suspects, and familial searching—and the impact they may have on minority communities.

How Does It Work?

DNA typing is the method used to identify individuals from DNA samples. Although humans are over 99% genetically similar, the remaining fraction is enough to ensure that each individual’s DNA code is unique, with the exception of identical twins.

But forensic analyses do not check every part of a person’s DNA to find out whether it matches a given sample. Scientists have identified chromosomal regions called loci where there are short tandem repeats (STRs)—“stretches of DNA where the DNA replicating mechanism appears to ‘stutter,’ resulting in different numbers of copies of repeated sequences.”¹⁷¹ For example, the four-base sequence ATCG might repeat at a particular locus any number of times. Each sequence with a different number of repetitions is a variant. Since these variants’ chromosomal locations are known, they provide a marker for the location of nearby genes.

The number of repeats across a predetermined set of loci in a chromosome makes up an individual’s unique genetic profile. The more loci

DNA Entrapment?

Sometimes police think that DNA analysis will help link a suspect to a crime, but do not have enough evidence to get a court order to force the suspect to give a sample. In at least one case, police nonetheless obtained the DNA they wanted by mailing a letter inviting the suspect to join a fake class-action lawsuit on letterhead from a non-existent law firm. The recipient licked the return envelope—providing enough DNA to connect him with a rape.¹⁶⁸

Does that violate the Fourth Amendment? Clearly the police did not have probable cause in the legal sense, or they would have obtained a court order. So should the DNA evidence be admissible? The American Civil Liberties Union (ACLU) argued that it should not be, but the Washington Supreme Court ruled 6–3 to allow it.¹⁶⁹ Similar issues are being discussed in many jurisdictions, such as the legality of DNA dragnets where all individuals who fit a suspect’s profile in a particular locale have their DNA taken and compared to materials left by an unknown suspect. Such dragnets have not been widely successful in identifying perpetrators.¹⁷⁰

that are checked, the more accurate the results. The United States federal government uses 13 STRs as a standard. Its use of DNA forensics is based upon calculations purporting to demonstrate that the chance that any two unrelated persons share the same set of 13 STRs making up a genetic profile is one in several billion.¹⁷²

Very little biological material is needed to run these tests.¹⁷³ Forensic scientists are able to amplify trace amounts of DNA into samples suitable for analysis using a method known as polymerase chain reaction (PCR), which mimics the normal cellular process that replicates organisms’ DNA. Once a sample with a known identity is secured—for example, from a DNA profile stored in a database—tiny samples of unidentified materials (blood, hair, saliva, etc.) can be compared across the 13-loci profile by using PCR to yield “sufficient . . . product to allow detection of variation in DNA sequence or length from the original biological sample.”¹⁷⁴ This enables investigators to determine whether the samples match or not.

How Reliable Are DNA Forensic Technologies?

DNA evidence itself is quite reliable. However, a separate question involves the *handling and interpretation of this evidence*. The significant number of mistakes that have been documented suggests that a closer look is warranted.

Misinterpreted results have led to false convictions. Timothy Durham of Tulsa, Oklahoma, spent four years in jail despite the testimony of eleven witnesses that he was in another state at the time of the rape for which he was convicted. Poor interpretation of his DNA sample produced false evidence, but it was taken to be more convincing than the witnesses. A re-test in 1997 exonerated him.¹⁷⁵

Durham’s case highlights a characteristic that distinguishes the current approach to DNA forensics from the way its first-generation predecessors are used and from other activities engaged by law enforcement to produce leads: it has sometimes been *the only evidence implicating a subject*.¹⁷⁶ This practice arguably puts a tremendous and perhaps undue amount of faith in a technical procedure with known interpretive and methodological limitations.

Forensic scientist Dr. Elizabeth A. Johnson puts the matter succinctly. DNA evidence, she says, “is very, very reliable if you do two things right: if you test it right, and if you interpret the results right. The problem is that jurors think it’s absolute and infallible.”¹⁷⁷

Among the problems with DNA forensics:

- **Contamination** If a sample is mixed with other DNA, which can happen at any stage in collection, handling, and testing, both false positives and false negatives can result.
- **Clerical errors** Opportunities for introducing error arise during the procedures involved with logging samples and computer data entry.
- **Misinterpretation** When samples are small or old, they are particularly susceptible to being misinterpreted by laboratory personnel. Misinterpreting can also occur in

The Scandal in Houston

In 2002, the Houston Police Department Crime Lab was called “the worst in the country.”¹⁷⁸ A leaky roof contaminated evidence; technicians were poorly trained and kept poor records. In addition, some believe that analysts in the lab falsified—or simply made up—results that could be used to obtain convictions.¹⁷⁹

A two-year, \$5.3 million investigation raised questions about 599 cases:¹⁸⁰

- 274 in which evidence was screened positively for blood or semen, but no ABO typing was performed
- 139 in which the Crime Lab performed ABO typing on evidence samples, but no comparison to known reference samples was made
- 6 in which DNA analyses also performed by an outside laboratory failed to include the suspect implicated by the Crime Lab

- 180 identified as containing a major issue with the reliability of the Crime Lab’s work or the accuracy of its reported results

In some of the few cases that have been examined closely, it seems that defendants were persuaded to avoid the death penalty by pleading guilty to lesser charges of which they were innocent.¹⁸¹ This was because they were presented with faked—or incompetently analyzed—DNA evidence. When one defense attorney who had accepted a deal for his client found out what happened, he remarked:

“If they had told me that, I would have come unglued. I would have said, ‘Kiss my ass. Dismiss the whole case.’”¹⁸²

cases of “mixtures,” e.g. when the DNA from the crime scene consists of a mixture from two or more individuals.

- **False matches** Random false matches do occur. They are most likely with close relatives.¹⁸³

DNA Databases

At the heart of the emerging controversy over forensic DNA technologies is the expanding use of DNA databases. These databases store the genetic profiles of felons and, in some jurisdictions, also of people arrested or detained for felonies without ever being charged. Police argue that larger collections of genetic profiles will allow rapid identification of offenders who leave behind samples containing DNA and help solve cold or future cases.

This approach to criminal justice has so far been most prevalent in the United Kingdom, where the technique was first developed. The UK

database now includes over 4.5 million profiles—more than 5% of its population.¹⁸⁴ Given the UK’s policy of including almost anyone detained by the police, some of the profiles routinely scanned to identify criminal perpetrators are from children as young as seven months old.¹⁸⁵

While the United States’ approach to DNA databases to date has not been as aggressive as

The Innocence Project

The Innocence Project was started in 1992 at the Benjamin N. Cardozo School of Law in New York by civil rights attorneys Barry Scheck and Peter Neufeld. Its goal is to exonerate the innocent through post-conviction DNA testing.

As of November 2008, DNA testing has helped exonerate 223 people. In most cases, mistaken eyewitnesses and/or bad laboratory work contributed to the convictions; false confessions played a role in a quarter of the cases. Well over half of the exonerated people were African American.¹⁸⁶

“The Informer in Your Blood”¹⁸⁷

Professor (now Sir) Alec Jeffreys at the University of Leicester (UK) developed DNA typing over two decades ago.¹⁸⁸ On September 10, 1984, he recognized similarities and differences in samples of DNA from related subjects, and immediately understood its forensic potential.¹⁸⁹

Since then, however, Jeffreys has become an outspoken critic of the abuse and “mission creep” that has accompanied the implementation of his discovery.¹⁹⁰ In particular, he believes “the retention of innocent people’s DNA raises significant ethical and social issues.”¹⁹¹

Jeffreys has suggested that one way to resolve the issue is to profile the entire UK population, and to store the data under the control of an independent body.¹⁹² (Many civil liberties experts oppose storing the DNA of innocent people.¹⁹³) Under the present circumstances, however, Jeffreys is against attempts to extrapolate or create profiles from DNA:

“If these scientists are successful they will provide police with the means of working out people’s racial and medical histories just from the DNA they leave behind. That is just not [ok].”¹⁹⁴

the UK’s, recent developments suggest a shifting dynamic. The FBI has been using DNA testing in its investigations for about 20 years, as have other state and federal agencies. A system known as CODIS (Combined DNA Index System) was launched in 1998 to integrate the DNA profiles held by local, state, and national databases.

Although every state participates in CODIS, each has different laws authorizing the collection of DNA samples. Convicted violent offenders are almost universally included in state databases. At least 34 states have adopted “all felony” inclusion rules; twelve other states also include DNA samples from those convicted of misdemeanors.¹⁹⁵

But the new trend is to include persons *arrested* for suspicion of committing a crime—*regardless of whether they are ever charged or convicted*. In 2003, then–Attorney General John Ashcroft announced plans to spend \$1 billion to upgrade the quality of federal DNA testing.¹⁹⁶ Three years later, Congress authorized the Justice Department to collect DNA from most people arrested or held by federal agents through a 2006

amendment to the Violence Against Women Act.¹⁹⁷ States are following suit; eleven (including California) have passed laws allowing law enforcement to take DNA samples from any adult arrested for a felony.

The new rules include authority to collect DNA from those detained for immigration violations. Deborah Notkin, former president of the American Immigration Lawyers Association, responded to the change by noting, “This has taken us by storm. It’s so broad, it’s scary. It is a terrible thing to do because people are sometimes detained erroneously in the immigration system.”¹⁹⁸

Cold Hits and Partial Matches

The rapid expansion of state and federal DNA databases has given rise to a new type of case in law enforcement: the cold hit. University of California, Berkeley Law Professor Erin Murphy describes cold-hit cases as occurring when

“the major or only evidence is biological material linking the defendant to the offense. In these cases, the government has no investigatory leads, but develops a genetic profile based upon some material left at a crime scene. The government then runs that forensic profile in a database and uncovers a ‘match’—a stored sample associated with a known person or offender.”¹⁹⁹

As DNA databases have grown, so too has the cold-hit approach to solving crimes. As an example, Murphy notes that “whereas it took Virginia nearly eight years, from 1993 to 2001, to reach its first 1,000 cold hits, the state reached its second 1,000 in a matter of eighteen months. Since 2001, the laboratory has averaged at least one cold hit a day, and as of July 2002, that figure had doubled to two and one half hits a day.”²⁰⁰

While some take cold hits as unassailable proof of suspects’ guilt, much closer scrutiny is warranted. The possibilities of contamination, clerical error, misinterpretation, and random matches apply to cold-hit cases as well as others.

Moreover, it is important is to distinguish between what forensic scientists call full and partial

Juking Stats

Those familiar with HBO's critically acclaimed series *The Wire* might recognize the term "juking stats" and its relation to criminal investigations. In the show, this occurs when the police define terms and categories—particularly those involving numerical values—in ways that are most favorable to their underlying self-interest and, in the process, distort what is really happening on the ground. Or as the character Roman Pryzbylewski succinctly put it, "Making robberies into larcenies. Making rapes disappear. You juke the stats and majors become colonels."²⁰¹

Is something similar happening with the presentation of cold-hit evidence to juries? Take the case of John Puckett as an example. Puckett was charged in 2004 with the 1972 murder of a San Francisco woman after three-decades-old sperm from the assailant turned up a hit in California's offender database that implicated him. No other evidence linked Puckett to the crime, outside of the fact that he lived in the area at the time the crime was committed. Based on the DNA evidence alone, a jury convicted Puckett of first degree murder.

During the trial, prosecutors told the jury that the chance that the cold-hit match across five and a half

loci was coincidental was 1 in 1.1 million. After the trial, jurors said this played a significant part in their decision to convict.²⁰²

What prosecutors did not tell the jury is that these odds were calculated by using general population figures as a referent, which estimates the chances of matching DNA found at a crime to a person that is randomly selected from the population. However, as discussed in the sidebar "The Birthday Problem" (see page 36), the odds that the cold hit reflects any one suspect are significantly reduced once the size of the DNA database is taken into consideration. The *Los Angeles Times* reported²⁰³ that for Puckett, taking the database size into consideration dramatically increased the odds of the match being coincidental: from 1 in 1.1 million to 1 in 3.²⁰⁴

Two expert committees—one assembled by the FBI,²⁰⁵ the other by the National Research Council²⁰⁶—have recommended adjusting the portrayal of these odds to reflect the limitations in play with cold hits in a DNA database. Remarkably, neither local nor federal prosecutors have followed these recommendations.

matches. A full match occurs when crime scene evidence matches a known sample in a database across the aforementioned 13 loci standard introduced by CODIS. Matches across fewer than 13 loci are known as partial matches.²⁰⁷ Increasingly, partial matches are used even in cold-hit cases as incriminating evidence. Some experts have testified that nine-locus matches constitute a unique identification.²⁰⁸

But new questions about partial matches are emerging. Bicka Barlow, a California attorney representing a defendant implicated in a rape/murder by a cold hit matching across 13 loci, heard that Arizona's DNA database had two profiles that matched across nine loci. After filing a subpoena to find out more about this, she received a puzzling report: out of 65,493 offenders in Arizona's

database in 2005, 122 pairs of people had genetic profiles matching at 9 loci, 20 pairs matched at 10 loci, one pair of siblings matched at 11 loci, and another pair of siblings matched at 12.²⁰⁹

Such findings seem implausible, given the accepted statistical norm that the odds of a random match happening between any two people across nine loci are about one in a billion. But therein lies the problem: cold-hit matches that occur *within databases* do not reflect the same odds as finding a match *within entire populations*. University of California, Irvine criminologist William C. Thompson explains this paradox:

"The risk of obtaining a match by coincidence is far higher when authorities search through thousands or millions of profiles

“The Birthday Problem” and the Limits of Forensic Database Matches

One way to think about the issues raised by finding genetic profiles in DNA databases that match across nine or more loci is through what is known among statisticians as the birthday problem.²¹⁰ This problem asks a broad question: “What is the probability that any two people in a room with at least 23 persons share the same birthday?”

Most people think that the probability is fairly small, e.g. 1 in 365. This is a population-wide figure that reflects the chances that any two randomly chosen people share the same birthday. However, when the pool of compared profiles is limited in a way that comparisons are only being made among 23 or more other people in a room—not unlike making comparisons in a DNA database with a defined number of profiles—the probability of a match substantially increases.

This surprising result becomes more understandable when you consider that, in a room with 23 people, there are 253 distinct pairs of people ($23 \times 22/2$). Therefore, there are 253 chances for a match—a far cry from the population-wide 1-in-365 probability.

While not a perfect parallel to DNA databases, the birthday problem illustrates the often radically different chances in finding a match when probabilities are expressed in relation to the general population as opposed to a defined number of profiles in a database.

for a match than when they compare the evidentiary profile to the profile of a single individual who has been identified as a suspect for other reasons. As an illustration, suppose that a partial DNA profile from a crime scene occurs with a frequency of 1 in 10 million in the general population. If this profile is compared to a single innocent suspect, the probability of a coincidental match is only 1 in 10 million. Consequently, if one finds such a match in a single-suspect case it seems safe to assume the match was no coincidence.

“By contrast, when searching through a database as large as the FBI’s National DNA Index System (NDIS), which reportedly contains nearly 6 million profiles, there are literally

millions of opportunities to find a match by coincidence. Even if everyone in the database is innocent, there is a substantial probability that one (or more) will have the 1-in-10 million profile. Hence, a match obtained in a database search might very well be coincidental.

“Consider that among the 6 billion or so people on planet earth we would expect about 600 to have the one-in-10-million DNA profile; among the 30 million or so in the United States we would expect to find about 30 people with the profile. How certain can we be that the one matching profile identified in a database search is really that of the person who committed the crime?”²¹¹

Therefore it is not accurate to say, as many prosecutors in criminal cases do, that a 1 in 10 million probability match to a cold hit means that the chances that the profile is not the suspect’s is 1 in 10 million.²¹² Cold hits cannot distinguish between any one of the approximately 600 people in the world with this profile. Innocence or guilt cannot be established without other evidence.

But what is remarkable is how state and federal governments are resisting calls to fully investigate the existence of numerous database matches across nine or more loci. An Arizona judge has barred Barlow from circulating the report on Arizona’s multiple database matches. A California judge has denied her access to similar data concerning California’s rapidly expanding DNA database.²¹³ These judicial rulings, in addition to the FBI’s continued resistance,²¹⁴ led University of California, Berkeley population geneticist Montgomery Slatkin to comment that “when the government works very hard to hide something, it suggests that they have something to hide.”²¹⁵

Whose DNA Is in These Databases?

DNA forensics’ implications must be considered in light of the sheer number of Americans involved with the criminal justice system and the cyclical, revolving-door experience some communities have with prisons, jails, and parole offices.

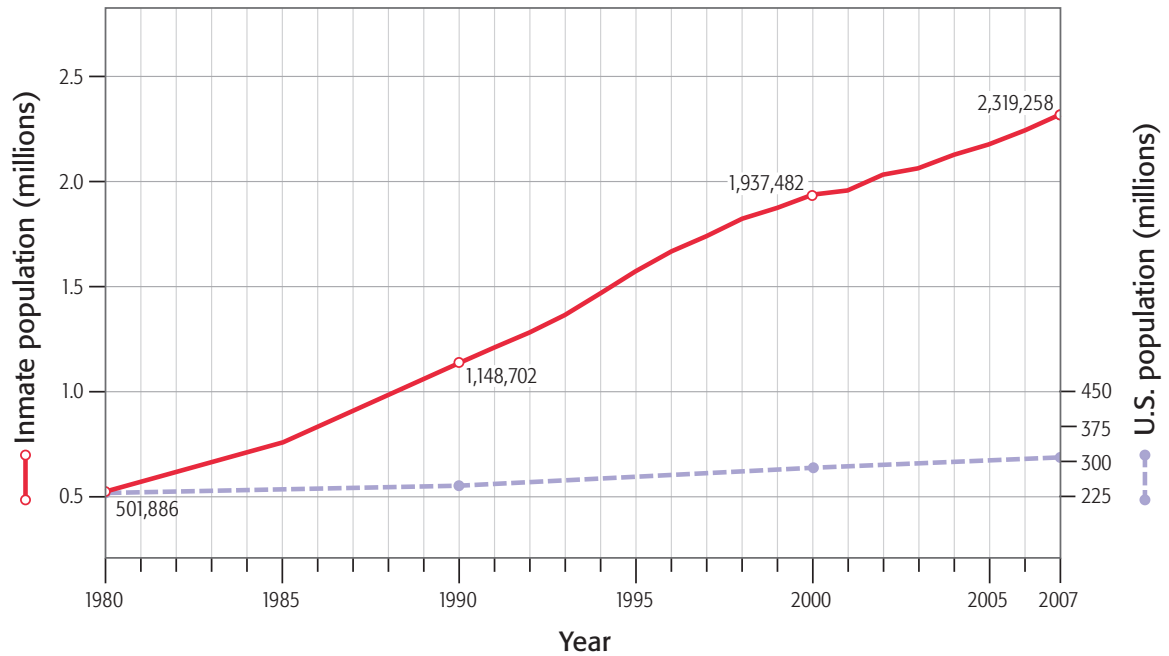


Figure 4 Prisoners in U.S. federal and state prisons and local jails, 1980–2007. The main graph (left y-axis) shows the number of inmates; the dashed one (using the y-axis on the right) shows the total U.S. population. Over less than three decades, the number of inmates grew by 362%, from 0.5 million to 2.3 million, while the total population grew by only 33%, from 227 million to 302 million. Prisoners data, 1980–2006, from Bureau of Justice annual reports; 2007 estimate from *One in 100: Behind Bars in America 2008*, The Pew Center on the States, 2008. Population data from the U.S. Census Bureau.

A February 2008 report from the Pew Center on the States found that “for the first time, more than one in every 100 adults is now confined in an American jail or prison.”²¹⁶ At over 2.3 million adults, the number of incarcerated individuals in the United States far outpaces the number incarcerated in China (1.5 million), despite its much greater population.²¹⁷ Russia is a distant third with 890,000 in jail. The United States’ prison population has increased dramatically over the last quarter-century, as shown in Figure 4. It doubled in the 1980s alone, and the increase has barely slowed since.

Discussions of law enforcement in the United States that fail to consider race are fundamentally incomplete. When considering how laws authorizing more aggressive DNA collection intersect

with a rapidly expanding prison population, it is important to question not only *how many* people are being included in these databases, but also *which* people are being sampled. A comparison of incarceration rates by race shows that Whites are dramatically less likely to be imprisoned than Hispanics or Blacks, as shown in Table 1.

The trend shown in the table is true for every age group. To go a bit further, one in every nine Black men between the ages of 20 and 34 is incarcerated, and one in ten of those aged 35–39.²²¹ For women between the ages of 35 and 39, one in 355 White women is incarcerated; the figure is one in 100 for Black women of the same age.²²²

Different groups have very different experiences with the criminal justice system. The divergences in incarceration rates reflect, in part,

Table 1 Incarceration Rates by Age and Ethnicity

| | White | Black | Hispanic |
|---------------------------|--------------|--------------|-----------------|
| All | 1 in 245 | 1 in 41 | 1 in 96 |
| Men, 18 or older | 1 in 106 | 1 in 15 | 1 in 36 |
| Men, 20–24 | 1 in 60 | 1 in 9 | 1 in 24 |
| Women, 18 or older | 1 in 859 | 1 in 203 | 1 in 436 |
| Women, 20–24 | 1 in 453 | 1 in 157 | 1 in 289 |

Source: Pew Center on the States, *1 in 100: Behind Bars in America*, p. 34.

policing practices that disproportionately target minority communities.²²³ These practices—not to mention the thousands arrested or detained without being charged—suggest that Blacks and Latinos are significantly overrepresented in state and federal DNA databases. While actual numbers are not available, Greely et. al. estimate that profiles from Blacks make up at least 40% of the federal government’s offender database.²²⁴

With minorities disproportionately represented in these DNA databases, their communities will increasingly find themselves under genetic surveillance, and all too often subject to the injustices that may stem from inaccurate interpretations of DNA tests. According to D. H. Kaye and Michael E. Smith of Arizona State University,

“Without seismic changes in Americans’ behavior or in the criminal justice system,

nearly 30% of Black Males, but less than 5% of white males, will be imprisoned on a felony conviction at some point in their lives. Arrest, prosecution, and conviction are so pervasive in Black communities that, on any given day, a Black American is five times more likely to be in jail than is a White. An adult Black male is four times more likely to be under some form of correctional supervision, six-and-a-half times more likely to be incarcerated somewhere, and eight times more likely to be in prison than his white counterpart.”²²⁵

They conclude, “There can be no doubt that any database of DNA profiles will be dramatically skewed by race if the sampling and typing of DNA becomes a routine consequence of criminal convictions.”²²⁶

Minority Communities and the War on Drugs

Between 1995 and 2003, the number of people incarcerated for drug offenses in federal or state prison has risen 21%, and the number in jail rose an astonishing 47%.²¹⁸ According to the Justice Policy Institute,

*“The growing rate of incarceration for drug offenses is not borne equally by all members of society. African Americans are disproportionately incarcerated for drug offenses in the U.S., though they use and sell drugs at similar rates to whites. . . . African Americans made up 13 percent of the total U.S. population, but accounted for 53 percent of sentenced drug offenders in state prisons in 2003.”*²¹⁹

These disparities are often attributed to the fact that crack cocaine (presumed to be used largely by Blacks) draws higher sentences than powdered cocaine (used largely by Whites). But the statistics suggest that something deeper is at work. Only 24% of crack users are African American, yet they make up over 80% of those sentenced for crack offenses.²²⁰

Given that both federal and state governments are expanding DNA databases by including arrestees in addition to those charged or convicted with crimes, the disproportionate character of the war on drugs is likely to lead to distinctively racialized DNA databases.

Moreover, the civil liberties concerns linked to warehousing DNA profiles—including privacy concerns related to disease predisposition, familial relations, etc.—will disproportionately fall on minority communities.

Sifting DNA Databases to Catch Family Members

On an evening in May 2003, an inebriated Craig Harmon stumbled to a bridge overlooking a highway in Southern England. For no apparent reason or motive, he decided to drop a brick from the overpass into oncoming traffic. That brick crashed through the window of a cab driven by Michael Little and hit him in the chest, causing a fatal heart attack.²²⁸

The police were initially without any suspects, but had one clue: the brick had blood on it from someone other than the victim—presumably from the brick-thrower. The profile gathered from this evidence did not turn up a full hit when checked against the UK's DNA database. But a search for partial matches—which indicate that the sample might belong to a relative of a person in the database—found a list of people who shared a high number of genetic markers with the then-unknown suspect. After restricting this list by neighborhood, the police were led to a man who mentioned he had a brother living near the town where the brick was thrown. That brother was Craig Harmon, who later confessed.

This case highlights the growing use of DNA databases by law enforcement to go beyond their original purpose of cataloging certain criminals' DNA on the chance that they might commit another crime. While the outcome in this case was apparently just, this approach to law enforcement raises serious questions and opens up possibilities for abuse. Police are now using partial matches in DNA databases to bring extended families under surveillance—most of whom have never broken the law.

Civil Liberties and DNA Databases

DNA is the most personal of data. The privacy issues around it are just beginning to reach public attention. This includes growing concern about the expansion of DNA databases in criminal cases. In particular, civil liberties experts are worried about the increasing tendency to not only include convicted criminals in these databases, but also those arrested yet never charged as well as people cleared as innocent.

ACLU Science Advisor Tania Simoncelli and Tufts University Professor Sheldon Krinsky write:

“As a matter of policy, the notion that innocent individuals should not have DNA taken without their knowledge or consent or retained permanently in a database, or be coerced into providing samples, is reasonable for a society that values freedom and individual privacy. Yet, exactly the opposite is happening . . . the default position seems to be that DNA is open for the taking.”²²⁷

Bieber et. al. note in a 2006 *Science Policy Forum* article that the consequences of familial searching are that “a new category of people effectively would be placed under lifetime genetic surveillance. Its composition would reflect existing demographic disparities in the criminal justice system, in which arrests and convictions differ widely based on race, ethnicity, geographic location, and social class. Familial searching potentially amplifies these existing disparities.”²²⁹

Close relatives such as parents, siblings and children share about 50% of each other's genetic variants and STR lengths; more distant relatives such as uncles, aunts, nephews, and nieces share about 25% of each other's DNA variants.²³⁰ Thus, using partial matches to identify potential suspects radically expands the power and purpose of

DNA databases from the individual to the family, implicating a number of people who may have nothing to do with the original crime. And given these databases' composition, racial minorities are the most likely to be implicated in crimes they may very well not have committed.

Indeed, recent figures from the UK—where policing practices are similarly skewed against racial minorities—show that “nearly four in 10 black men in the UK are on the police’s national [DNA] database compared with fewer than one in 10 white men.”²³¹ As one UK commentator noted, the racial architecture of DNA databases fosters a presumption that “if you are black you are going to be guilty—if not now but in the future . . . [which amounts to] genetic surveillance. . . . Anyone on the database—and family members—can more easily be linked to a crime scene if their DNA is found there. This may be because they are a criminal, or because they [merely] visited the scene prior to the crime.”²³²

All available evidence suggests that a comparable racial architecture is developing in the United States, with similar consequences for extended families in communities of color. Given Blacks' disproportionate representation in the American criminal justice system, Greely et. al. estimate that “more than four times as much of the African-American population as the U.S. Caucasian population would be ‘under surveillance’ as a result of family forensic DNA and the vast majority of those people would be relatives of offenders, not offenders themselves.”²³³

The consequence of this could soon be a situation where effectively people who live in Black neighborhoods are on file, while those who live in White neighborhoods are probably not. Simon Cole of the University of California, Irvine, explains:

“Familial searching exacerbates the discriminatory effects of database composition. . . . Inclusion of an individual in a database effectively adds that individual’s close relatives to the database as well. In the context of an

arrestee database, in a society in which young African-American males have a one in three chance of experiencing some form of state custody, this could quickly result in effectively incorporating entire neighborhoods and ethnic communities into the database.”²³⁴

Predicting Criminality

The mass collection and storage of genetic profiles raises further concerns when considered together with continued efforts by behavioral geneticists to find genetic predispositions for criminality. Despite the string of discredited theories concerning a genetic basis to crime, some scientists continue to search for genetic variations that might underlie a propensity to engage in anti-social behaviors that are often criminal.²³⁵ These efforts are converging with DNA forensics in ways that, as Troy Duster puts it, raise the “specter of a 21st century phrenology”:

“It is almost inevitable that a research agenda will surface to try to find patterns of allele frequencies, DNA markers, and genetic profiles of different types of criminals. One could do a SNP profile of rapists and sex offenders, and find some markers that they putatively share[;] ‘ethnic-affiliation estimations of allele-frequencies’ is high on the research agenda in forensic science. . . . But like the phrenology of the 19th century, these markers will be precisely that, ‘markers’ and not explanatory of the causes of violent crime.”²³⁶

While the scenario laid out by Duster may sound unlikely to some, a project like this would not be unprecedented. In the early 1990s, a number of federal administrators including Dr. Frederick Goodwin (then head of the Alcohol, Drug Abuse, and Mental Health Administration) and Louis Sullivan (then Health and Human Services Secretary) put forth a failed proposal known as the Violence Initiative, which was seen as a mechanism for the federal government to combat inner city violence through policymaking. It



Phrenology, a Classic Pseudo-Science

The theory of phrenology held that bumps on the skull marked the development of traits in the brain. German physician Franz Joseph Gall identified 27 such traits around 1800, including several kinds of memory (of people, words, and facts), several senses (including a sense of the connectedness of numbers), wit, pride, affection and the tendency to commit murder.²³⁷

Gall claimed to be able to run his fingers over individuals' heads and identify them as a pacifist, a priest or a violent criminal. This was very popular in the 19th century, and to a lesser extent into the 20th. In practice, however, like its relatives craniology and anthropometry (which measured skulls and bodies, respectively), these measurements largely reflected then-prevalent social prejudices.

worked from two essential premises: (1) that inner city violence has a genetic or biological basis and (2) that such genetic predispositions to violence can be detected and mitigated through early intervention.²³⁸ As Goodwin noted in a 1992 address to the American Psychiatric Association, the purpose of the Violence Initiative was to “design and evaluate psychosocial, psychological, and medical interventions for at risk children before they become labeled as delinquent or criminal. This is the point of it all . . . identifying at risk kids at a very early age before they have become criminalized.”²³⁹

As Nicole Hahn Rafter notes, “Today, biological explanations are once again leading in efforts to account for human behavior, and biological theories of crime have once again begun to attract serious attention.”²⁴⁰ And race is likely to play a central role in how genetic predispositions to criminality are researched and communicated, as it did in the proposal for the Violence Initiative.²⁴¹ As new biotechnologies—perhaps aided by racially skewed forensic databases—are used to propose

what may be seen as more sophisticated connections between individual criminality, genetic markers, and group membership, it is not difficult to guess which groups are likely to receive a disproportionate amount of attention.

Using DNA to Build Racial Profiles

Biological materials left behind at a crime scene are no longer simply matched to suspects or used to generate cold hits. Technology similar to the admixture mapping employed by genetic ancestry tests is now being used to generate phenotypical descriptions of suspects.

Private companies are offering these new services to law enforcement. One, DNAPrint Genomics, is heavily marketing its product, DNAWitness, as a way to save time, money, and lives. From the DNAWitness website:

“Law enforcement officers use this testing service to determine genetic heritage from DNA samples obtained from crime scenes,

narrowing the potential suspect pool to a more focused group of likely candidates. The test enables law enforcement agencies to reduce both the cost and time needed to apprehend suspects. Current forensic DNA products in the market act like a fingerprint and can only be used to match DNA specimens. DNAPrint® is the first forensic product that provides predictive capability.”²⁴²

An example of this technology in action is the high-profile case of Louisiana serial killer Derrick Todd Lee (see Figure 5). Studies suggesting that most serial killers are White, along with an eyewitness account, led police to look for a White male as the perpetrator of several heinous murders. But scientists at DNAPrint Genomics analyzed DNA samples provided by police and identified the suspect as having 85% African and 15% American Indian ancestry. This led local police to change their profile, contributing to Lee’s arrest.

Certainly, the arrest and conviction of Lee is a positive outcome, and the contribution of DNA forensics should not be disregarded. Moreover, many law enforcement officers would argue that in this example, DNA technologies are being used to generate leads, not to convict people. While this is a point well taken, we should not overlook the possible abuses and misconceptions that may come from presuming that definitive links can be made between race and genes.

The problems underlying biotechnologies that estimate a person’s “bio-geographical ancestry” as a proxy for physical appearance or racial background are discussed in Chapter 2. Of course, the stakes become drastically higher once we shift the conversation from recreational genetics to law enforcement.

It is one thing when implicitly or explicitly conflating social categories of race with genetic categories leads to less-than-accurate understandings of an individual’s ancestry. It is quite another when these less-than-precise mechanisms become part of a criminal justice system. And it is this type of market transition from rec-

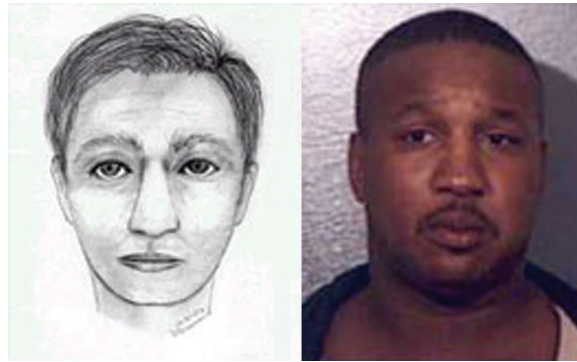


Figure 5. *Left:* Police sketch of suspect from eyewitness account and profiling. *Right:* Convicted serial killer Derrick Todd Lee.²⁴³

reational genetics to law enforcement that DNAPrint Genomics is proposing with what it calls *molecular photofitting*: “methods to produce forensically (or biomedically) useful predictions of physical features or phenotypes from an analysis of DNA variations . . . [to provide] a summary list of physical traits like height, weight, hair color, eye color, and race, and a fuzzy or low resolution picture.”²⁴⁴

DNAPrint Genomics has expanded its DNAWitness product line, to offer EUROWitness 1.0. An initial test showing greater than 50% Indo-European admixture can be further refined to provide details of percentage Northwestern European, Southeastern European, Middle Eastern and South Asian ancestry.²⁴⁵ The company also offers a test called RETINOME claiming to predict a suspect’s eye color.

While law enforcement uses all types of methods to produce leads, the presumed infallibility of DNA technologies can lead prosecutors, judges, juries, and others involved in the criminal justice system to think differently about the evidence in relation to the suspect. As seen with the cold-hit approach, DNA forensics, unlike other methods of law enforcement, has been used as the *sole* piece of evidence in a number of prosecutions. That means that any methodological or interpretive imprecision can have a much greater impact on outcomes.

Moreover, the DNA techniques employed by private companies to assist law enforcement are proprietary, so the methods and assumptions underlying their claims have not been scrutinized by the broader scientific community. This raises a number of serious questions, most importantly that the scientific community has not yet been able to evaluate a technique that is being used to imprison people.

Conclusion: Effects on Minority Communities

DNA forensics began as a limited tool to track particularly egregious offenders—essentially murderers and rapists only. In 20 years, its uses have expanded enormously. DNA technologies are now used

- To build large databases of genetic profiles that often permanently include the DNA of people who have not been convicted, but only arrested or detained
- To charge and convict people even when there is no other evidence of their guilt, through the use of “cold hits” that are sometimes “partial matches”
- To construct predictive racial profiles through “molecular photofitting”
- To place families and communities under surveillance through “familial searches.”

This is what Troy Duster has called molecular genetics’ function creep: the ever-expanding use of DNA technologies into new spheres that may not have been contemplated during the technology’s original development.²⁴⁶

These applications of DNA technologies are likely to be deployed without fully examining their assumptions, methodologies, and implications—all too often leading them to unfairly burden minority suspects and communities.

One close observer of DNA forensics, University of California, Irvine’s William C. Thompson, summarizes the situation:

“DNA tests are not now and have never been infallible. Errors in DNA testing do occur. DNA evidence has caused false incriminations and false convictions, and will continue to do so. Although DNA tests incriminate the correct person in the great majority of cases, the risk of false incrimination is high enough to deserve serious consideration in debates about expansion of DNA databases. The risk of false incrimination is borne primarily by individuals whose profiles are included in government databases (and perhaps by their relatives). Because there are racial, ethnic, and class disparities in the composition of databases, the risk of false incrimination will fall disproportionately on members of the included groups.”²⁴⁷

The misuse of DNA forensics threatens all people’s civil liberties. But the threat to minority communities is significantly greater; groups with disproportionate contact with law enforcement (who are disproportionately represented in criminal databases) will disproportionately bear its burdens. Unless we address the underlying inequities in the criminal justice system, DNA technologies are all too likely to aggravate racial injustice.

Recommendations

- To uphold the presumption of innocence, DNA databases should include only people convicted of serious felonies such as murder or sexual assault. Profiles of arrestees and detainees should be relinquished if and when they are no longer considered suspects.
- To protect civil liberties, DNA collection should be permitted only when there is a court warrant supported by probable cause or truly informed voluntary consent. Surreptitious collection of DNA samples should be prohibited and DNA dragnets should not be based upon race (e.g. taking samples from all Black males in a given area) except under extraordinary circumstances.
- To minimize the potential for racial profiling, DNA technologies that are used to describe a suspect's race should be permitted only when the underlying methodologies are openly known and subject to scrutiny by the scientific community. Proprietary applications leave too many unanswered questions about the underlying techniques and assumptions, which exacerbates the potential for abuse.
- When cold-hit evidence is presented to a jury, calculated probabilities should reflect the size of the database, which provides a more statistically accurate depiction of the likelihood of finding a match.

Conclusion

Racially tailored medicines, new ways of investigating individual ancestry, and expanding forensic tools for law enforcement are laudable attempts at harnessing the power of biotechnology to improve everyday life. But these and other developments in human biotechnology also have the potential to negatively affect communities of color and, moreover, to distort public understandings of race.

Playing the Gene Card? highlights the significant concerns that come to the forefront when *social* categories of race are treated as *genetic* boundaries of human difference. This tendency leads to a key question: are these applications and their high public visibility reinventing the biological notions of racial difference that figured so prominently in the 19th and early 20th centuries? Put another way, is biological race back?

These are difficult questions to answer. What is clear, however, is that we are at a critical moment. Over the past half century, progress in race relations has been fundamentally linked to the shift from thinking about race as a category marking inherent differences to understanding it as reflecting culture and social choices. What will happen if or when biological notions of racial difference once again become routine parts of scientific and public conversations on racial difference and disparities?

Whether new human biotechnologies turn out to disproportionately burden racial minorities and distort lay understandings of race de-

pends heavily upon the care with which researchers, biotech companies, and policymakers treat race in their work. It is crucial that we require sound evidence for any claims attempting to link social categories of race to genetic differences.

Towards that end, we propose the following:

- Encourage researchers to adopt guidelines (discussed below) for using racial categories in human biotechnology research
- Require government agencies and publicly funded researchers to include Race Impact Assessments when developing human biotechnology research, products and services
- Establish additional regulatory requirements to prevent producing or legitimating racial inequities in the development and use of human biotechnology

Racial Categories in Human Biotechnology Research

A group of faculty members from Stanford University recently published a set of guidelines for using race in human genetics research.²⁴⁸ These guidelines, which the *New Scientist* termed the “Ten Commandments of Race and Genetics,”²⁴⁹ provide both a *descriptive* account of the relevance of race to biomedical research and *normative* suggestions for using racial categories in a responsible manner.

The authors recognize that there is no scientific basis for the idea that human genetic variation reflects any sort of racial hierarchy and acknowledge that racial categories exist within social and political contexts that shift over time. They discourage researchers from using race as a proxy for biological similarity, and caution against what they term the “naïve leap” to genetic explanations of complex social phenomena such as IQ or propensity for violence. Yet they believe that research on race and human genetics can proceed responsibly.

These guidelines are an important contribution, and should be adopted widely. But as *Playing the Gene Card?* clearly demonstrates, concerns about race and human biotechnologies cannot be limited to individual research agendas or best practices in clinical settings. Instead, it is crucial to consider how these technologies, particularly when taken together, are likely to have a public impact. However laudatory, no set of voluntary guidelines or recommendations can obviate the need for greater public oversight of how racial categories are deployed in biotech research and marketing. This point is particularly relevant since the approval of regulatory bodies such as the Food and Drug Administration and the United States Patent and Trademark Office can allow the State to give official legitimacy to claims about race and genes.

Race Impact Assessments

Given the remarkably high stakes involved and the rapid development of biotechnology products and services that implicate racial categories, it is time for policymakers to take these matters under serious consideration. Responsible regulation and oversight can go a long way towards ensuring that these products and services are based on sound scientific research, and that they do not promote unfounded biological theories of racial difference. Regulators can help prevent or minimize inappropriate commercial pressures, less-than-forthright marketing, and the often unintentional re-articulation of folk notions of biological race. The goal is to create an environment in which research and scientific innovation

can move forward while guarding against potentially harmful social outcomes.

How can this be accomplished? In order to encourage more forethought in regulatory decision-making and implementation, other fields have adopted the use of impact assessments. One relevant example is the *health impact assessment*,²⁵⁰ which is a set of procedures, methods, and tools that, according to the World Health Organization,

“provide a structured framework to map the full range of health consequences of any proposal, whether these are negative or positive. It helps clarify the expected health implications of a given action, and of any alternatives being considered, for the population groups affected by the proposal. It allows health to be considered early in the process of policy development and so helps ensure that health impacts are not overlooked.”²⁵¹

Public health researcher John Kemm notes that despite different definitions, two essential characteristics of health impact assessments are that they “seek to predict the future consequences for health of possible decisions; and that [they] seek to inform decision-making.”²⁵² For example, a health impact assessment of a proposal for a new factory would look at a number of ways it may affect the local population’s health, such as whether emissions from the building are linked to adverse health outcomes and how best to contain them.

Similar regulatory assessments of the possible public impact of an innovation or initiative may be instructive for identifying and mitigating their possible adverse effects for racial minorities. *Race impact assessments*²⁵³ could encourage shared responsibility among multiple actors—including regulators, researchers, internal review boards, and affected communities and their representatives—in making sure that human biotechnologies are not used to promote unfounded biological understandings of race and that claims made about the relationship between race and genetics are legitimate. Just as health impact assessments aim “to en-

hance recognition of societal determinants of health and of intersectoral responsibility for health,”²⁵⁴ race impact assessments could promote recognition of the social construction of race and the social determinants of racial disparities.

What might such race impact assessments look like in the context of human biotechnology? As an example, the Food and Drug Administration could convene an advisory committee as part of its review process to evaluate whether medicines like BiDil might reinforce biological understandings of race when no biological or genetic mechanism has been identified.

The composition of such a committee would have to accurately reflect the impacted stakeholders and constituents. Its assessment would not be limited to reviewing biostatistical evidence from clinical trials. It would also consider the effects race-specific medicines might have on broader commitments to racial justice, specifically in the context of past discrimination based on biological notions of race. While the FDA’s authority is currently restricted to issues concerning safety and efficacy, this approach might encourage narrowly tailored mechanisms to ensure that a drug’s beneficiaries have access without prematurely giving legitimacy to biological understandings of racial difference.

A race impact assessment of ancestry tests might lead federal and/or state governments to closely scrutinize marketing claims to ensure that they do not overstate the current state of the science. Such assessments might lead regulators to require genetic testing companies to limit their advertising to scientifically verifiable statements, and to give consumers adequate information about the tests’ limitations.

In the context of DNA forensics, a race impact assessment could shed light on policy shifts that might disproportionately affect certain com-

munities, such as familial searching or including arrestees that have not been convicted in DNA databases. This assessment might encourage refinements and recalibrations that could lessen the burden on those communities while ensuring that law enforcement has the tools it needs.

The overall goal of a race impact assessment would be the same as its counterparts in public health and other realms: to increase dialogue between stakeholders and policymakers so as to balance competing interests through strategic planning that promotes the public good.

Responsible Regulation

Race impact assessments would be just one part of the answer to the emerging challenge of promoting racial and social justice in the development of human biotechnologies. Specific regulatory protections, including those recommended in *Playing the Gene Card?* are also needed. In sum, these recommendations are:

Race-specific drugs

- The Food and Drug Administration should approve race-specific drugs only when well-designed clinical trials show them to be efficacious in the specified population, and inefficacious in other populations.
- The FDA should seek the authority to consider the broader social implications of race-specific drugs, in order to avoid any government action that might give legitimacy to biological understandings of racial difference.

Genetic ancestry tests

- The Federal Trade Commission should ensure the accuracy of marketing claims by companies that offer genetic ancestry tests.

- The United States Patent and Trademark Office should require a high evidentiary threshold for patent applications claiming to find biological components of socio-political constructs such as race.

DNA forensics

- To uphold the presumption of innocence, federal and state governments should permit DNA databases to store only profiles of people convicted of serious felonies such as murder or sexual assault.
- To protect civil liberties, surreptitious DNA collection should not be permitted, and DNA dragnets should not be based upon race except under extraordinary circumstances.
- To minimize the potential for racial profiling, using DNA technologies to describe a suspect's race should be permitted only when the underlying methodologies are openly known and subject to scrutiny by the scientific community.

- When cold-hit evidence is presented to a jury, calculated probabilities regarding the strength of the match should take into consideration the size of the database.

Used responsibly, human biotechnologies hold great promise for improving human health and other aspects of our lives. But it is also important to acknowledge the concerns that arise when promising research is prematurely translated into commercial and forensic applications that may exacerbate health disparities and encourage new forms of inequality.

Scientific research should certainly be permitted the latitude to answer some of the deep mysteries about humanity and human difference. Yet, it is similarly important to realize that we may be at the precipice of a new era of biologizing racial difference. If we are to avoid the despair produced by previous eras of racial essentialism while also seeing that these technologies realize their benefits, sensible regulation and oversight—at local, state, and federal levels—are essential. Time is short; the very character of race and equality in the 21st century are at stake.

The complete text of *Playing the Gene Card? A Report on Race and Human Biotechnology*, including endnotes, and links to related material, are available at <http://www.thegenecard.org>.

Endnotes

1. Paul Gilroy, *Against Race: Imagining Political Culture Beyond the Color Line* (Cambridge: Harvard University Press, 2000), 37.
2. Duana Fullwiley, "The Molecularization of Race: Institutionalizing Human Difference in Pharmacogenetics Practice," *Science as Culture* 16, no. 1 (2007): 1–30.
3. Evelyn M. Hammonds, "Straw Men and Their Followers: The Return of Biological Race," *Social Science Research Council Is "Race" Real?* <http://raceandgenomics.ssrc.org/Hammonds> (accessed May 27, 2008).
4. Troy Duster, "The Lessons of History: How Race and Ethnicity Have Figured in Biomedical Research," *Journal of Law, Medicine & Ethics* 34, no. 3 (2006): 487–498.
5. Troy Duster, *Backdoor to Eugenics* (New York: Routledge, 1990); Jonathan Kahn, "From Disparity to Difference: How Race-Specific Medicines May Undermine Policies to Address Inequalities in Health Care," *Southern California Interdisciplinary Law Journal* 15 (2005): 105 et seq.; Dorothy E. Roberts, "Privatization and Punishment in the New Age of Reprogenetics," *Emory Law Journal* 54 (2005): 1343–1360.
6. I elaborate this point in "Is Race-Based Medicine Good for Us?: African American Approaches to Race, Biomedicine and Equality," *Journal of Law, Medicine, and Ethics* 36, no. 3: 537–545 (2008).
7. *Parents Involved in Community Schools v. Seattle School District No. 1*, 551 U.S. ____ (2007).
8. See, for example, Gary Puckrein, "BiDil: From Another Vantage Point," *Health Affairs* 25, no. 5 (2006): w368–w374.
9. David Harvey, *A Brief History of Neoliberalism* (New York: Oxford University Press, 2005).
10. Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (Princeton, NJ: Princeton University Press, 2007), pp. 54–68.
11. Richard Thompson Ford, *The Race Card: How Bluffing About Bias Makes Race Relations Worse* (New York: Farrar, Straus and Giroux 2008) 7.
12. Linda Williams, *Playing the Race Card: Melodramas of Black and White From Uncle Tom to O.J. Simpson* (Princeton: Princeton University Press, 2001), 3.
13. W.E.B. DuBois, *The Souls of Black Folk: Essays and Sketches*, vii (1907).
14. Melvin Oliver and Thomas Shapiro, *Black Wealth/White Wealth: A New Perspective on Racial Equality* (2nd edition) 2006.
15. Centers for Disease Control, "Racial and Ethnic Disparities in Infant Mortality Rates—60 Largest U.S. Cities, 1995–1998," *Morbidity and Mortality Weekly Report*, April 19, 2002, 51(15):329–332, 343, <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5115a4.htm>.
16. Gary Orfield and Susan Eaton, *Dismantling Desegregation: The Quiet Reversal of Brown v. Board of Education* (1997).
17. Gould writes, "Preevolutionary justifications for racial ranking proceeded in two modes. The 'softer' argument—again using some inappropriate definitions from modern perspectives—upheld the scriptural unity of all people in the single creation of Adam and Eve. This view was called monogenism—or origin from a single source. Human races are a product of degeneration from Eden's perfection. Races have declined to different degrees, whites least and blacks most. Climate proved most popular as a primary cause for racial distinction. Degenerationists differed on the remediability of modern deficits. Some held that the differences, though developed gradually under the influence of climate, were now fixed and could

never be reversed. Others argued that the fact of gradual development implied reversibility in appropriate environments. Samuel Stanhope Smith, president of the College of New Jersey, hoped that American blacks, in a climate more suited to Caucasian temperaments, would soon turn white. But other degenerationists felt that improvement in benevolent climes could not proceed rapidly enough to have any impact on human history. The “harder” argument abandoned scripture as allegorical and held that human races were separate biological species, the descendents of different Adams. As another form of life, blacks need not participate in the “equality of man.” Proponents of this argument were called “polygenists.” Stephen Jay Gould, *The Mismeasure of Man* (New York: W.W. Norton & Company, Inc., 1981), 39.

18. Gould writes that “biological determinism . . . holds that shared behavioral norms, and the social and economic differences between human groups—primarily races, classes, and sexes—arise from inherited, inborn distinctions and that society, in this sense, is an accurate reflection of biology. . . . [The idea of] racial inferiority may be as old as recorded human history, but its biological justification imposed the additional burden of intrinsic inferiority upon despised groups, and precluded redemption by conversion or assimilation. The “scientific” argument has formed a primary line of attack for more than a century.” Stephen Jay Gould, *The Mismeasure of Man* (New York: W.W. Norton & Company, Inc., 1996), 52, 31.
19. See Chapter Two for a more detailed discussion.
20. UNESCO, *The Race Question* (1950) 8. Jenny Reardon aptly notes that revised UNESCO statement the following year contained at least two critical changes. She notes “First, the physical anthropologists and geneticists of the [second UNESCO] Statement revised the sociologists’ assertion that all meaningful human traits are ‘raceless,’ reasserting the possibility that traits pertaining to ‘intellectual and emotional response’ could vary according to genetic differences between races. . . . The second significant change to the [first] statement was to remove the claim that biological studies support an ethic of universal human brotherhood.” Jenny Reardon, *Race to the Finish: Identity and Governance in an Age of Genomics* (2005) 30–31.
21. Joan H. Fujimora, Troy Duster, and Ramya Rajagopalan, “Race, Genetics, Disease: Questions of Evidence, Matters of Consequence,” *Social Studies of Science* 38:5 (October 2008) p. 645.
22. For a brief review of this literature, see Joseph L. Graves, Jr., “What We Know and What We Don’t Know: Human Genetic Variation and the Social Construction of Race, Is Race Real?” <http://race-andgenomics.ssrc.org/Graves/>.
23. Ian Haney Lopez, “The Social Construction of Race: Some Observations on Illusion, Fabrication, and Choice,” 29 *Harv. C.R. – C.L. L. Rev.* 1, 6 (1994).
24. Nancy Krieger writes that with regards to understanding the relationship between race and health, “Two diametrically opposed constructs are at issue, constructs that nevertheless are routinely conflated in the scientific literature. The first is *biological expressions of race relations*; the second is *racialized expressions of biology*. The former draws attention to how harmful physical and psychosocial exposures due to racism adversely affect our biology, in ways that ultimately are embodied and manifested in racial/ethnic disparities in health. The latter refers to how arbitrary biological traits are erroneously construed as markers of innate “racial” distinctions.” Nancy Krieger, “Does Racism Harm Health? Did Child Abuse Exist Before 1962? On Explicit Questions, Critical Science, and Current Controversies: An Ecosocial Perspective.” *American Journal of Public Health* Volume 93, Issue 2 (February 2003): 194–199.
25. M.J. Klag et. al., “The Association of Skin Color With Blood Pressure in US Blacks with Low Socioeconomic Status,” *JAMA* 265, 5 (1991): 599–602.
26. For a broader discussion of colorism or skin tone discrimination, see Taunya Lovell Banks, “Colorism: A Darker Shade of Pale,” 47 *UCLA L. Rev.* 1705, 1710 (1999) and Trina Jones, “Shades of Brown: The Law of Skin Color,” 49 *Duke L. J.* 1487, 1493 (1999).
27. Francis S. Collins, “What We Do and Don’t Know About ‘Race,’ ‘Ethnicity,’ Genetics and Health At the Dawn of the Genome Era,” 36 *Nature Genetics Supplement* S13 (2004).
28. Lewontin writes, “It is clear that our perception of relatively large differences between human races and subgroups, as compared to the variation within these groups, is indeed a biased perception and that, based on randomly chosen genetic differences, human races and populations are remarkably similar to each other, with the largest part by far of human variation being accounted for by the differences between individuals. Human racial classification is of no social value and is positively destructive of social and human relations. Since such racial classification is now seen to be of virtually no genetic or taxonomic significance either, no justification can be offered for its continuance.”

R. C. Lewontin, “The apportionment of human diversity,” *Evolutionary Biology* 6 (1972): 381–398. But see A.W.F. Edwards critique of Lewontin’s conclusion, where he states, in part, “In popular articles that play down the genetical differences among human populations, it is often stated that about 85% of the total genetical variation is due to individual differences within populations and only 15% to differences between populations or ethnic groups. It has therefore been proposed that the division of *Homo sapiens* into these groups is not justified by the genetic data. This conclusion, due to R. C. Lewontin in 1972, is unwarranted because the argument ignores the fact that most of the information that distinguishes populations is hidden in the correlation structure of the data and not simply in the variation of the individual factors. . . . There is nothing wrong with Lewontin’s statistical analysis of variation, only with the belief that it is relevant to classification.” A.W.F. Edwards, “Human Genetic Diversity: Lewontin’s fallacy,” *BioEssays* Volume 25, Issue 8 (2003): 798, 800.

29. In describing this concept, Graves writes, “Montagu pointed out that the physical features found in populations were not consistently correlated with each other (the principle of discordance.) For example, sub-Saharan Africans, East Indians, and Australian aborigines have dark skin, but differ in other anatomical traits, such as body proportions, skull proportions, hair type, or ear wax consistency. Indeed if one attempts to take multiple physical characters to define racial groups, you arrive at categorizations that are not indicative of their evolutionary history. Montagu wrote a series of articles for both scientific and popular journals between 1939 and 1942 outlining this concept. In fact, Edwards himself published a paper showing that using 63 physical traits you would classify Eskimos closer to Swedes and French populations than Eskimos are to North American Indians, with North American Indians closer to Swedes, French, and Eskimos than they are to South American Indians. Similar errors were observed with other populations, such as linking Australian aborigines with sub-Saharan Africans. In the same paper published in 1964, he and Cavalli-Sforza showed a tree based on 20 genes did not match the tree based on physical features! Neither is the discordance between physical features and genetic variation a phenomenon only found in humans.
30. Tim Ingold uses an interesting analogy to explain this: “Modern evolutionary biologists are concerned not with the enumeration of distinct types but with the mapping of genetic distributions. For any particular gene or characteristic, this map resembles the kind of chart we see every day on the television weather forecast, showing tomorrow’s expected temperatures. The lines on the chart are contours indicating temperature gradients; they are not absolute boundaries between hot and cold. Likewise, genetic distribution maps use contours to depict graded variations in the percentage of the population that carries a particular character. But for every character you might select, the map looks quite different. If you were to superimpose maps for a range of different characters, then you would find no neat correspondence but an apparently chaotic tangle of intersecting gradients. There is, then, no basis for a division of humankind into defined sub-groups on the basis of hereditary characteristics.” Tim Ingold, “When Biology Goes Underground: Genes and the Spectre of Race,” 4 *Genomics, Society, and Policy* 23, 26 (2008).
31. Eliot Marshall, “DNA Studies Challenge the Meaning of Race,” 282 *Science* 654 (1998).
32. Elaborating on the proxy relationship between race and genetics with regards to health outcomes, Collins writes, “The relationship between self-identified race or ethnicity and disease risk can be depicted as a series of surrogate relationships. On the nongenetic side of [things], race carries with it

certain social, cultural, educational, and economic variables, all of which influence disease risk. On the genetic side of the diagram, race is an imperfect surrogate for ancestral geographic origin, which in turn is a surrogate for genetic variation across individual's genome. Likewise, genome wide variation correlates albeit with far from perfect accuracy, with variation at specific loci associated with disease. Those variables interact with multiple environmental variables, with the ultimate outcome being health or disease. Considered in this context, it is apparent why self-identified race or ethnicity might be correlated with health status, through genetic or nongenetic surrogate relationships or a combination of the two. *It is also evident that a true understanding of disease risk requires us to go well beyond these weak and imperfect proxy relationships.*" [emphasis added]. Francis S. Collins, "What We Do and Don't Know About 'Race,' 'Ethnicity,' Genetics and Health At the Dawn of the Genome Era," 36 *Nature Genetics Supplement* S13 (2004).

33. Samuel Levy et. al. write "Comparison with previous reference human genome sequences, which were composites comprising multiple humans, revealed that the majority of genomic alterations are the well-studied class of variants based on single nucleotides (SNPs). However, the results also reveal that lesser studied genomic variants, insertions and deletions, while comprising a minority (22%) of genomic variation events, actually account for almost 74% of variant nucleotides. Inclusion of insertion and deletion genetic variation into our estimates of interchromosomal difference reveals that only 99.5% similarity exists between the two chromosomal copies of an individual and that genetic variation between two individuals is as much as five times higher than previously estimated. . . . [Therefore] we can, for the first time, make a conservative estimate that a minimum of 0.5% variation exists between two haploid genomes." Samuel Levy, "The Diploid Genome Sequence of an Individual Human," *PLoS Biology* 5:10 2113–44. (Cited passages at 2114 and 2132).
34. The *New York Times'* Amy Harmon writes that "When scientists first decoded the human genome in 2000, they were quick to portray it as proof of humankind's remarkable similarity. The DNA of any two people, they emphasized, is at least 99 percent identical. But new research is exploring the remaining fraction to explain differences between people of different continental origins." Amy Harmon, "In DNA Era, New Worries About Prejudice," *New York Times*, November 11, 2007, http://www.nytimes.com/2007/11/11/us/11dna.html?_r=1&hp&oref=slogin.
35. "Remarks Made by the President, Prime Minister Tony Blair of England (via satellite), Dr. Francis Collins, Director of the National Human Genome Research Institute, and Dr. Craig Venter, President and Chief Scientific Officer, Celera Genomics Corporation, on the Completion of the First Survey of the Entire Human Genome Project," Press Release, Office of the Press Secretary, White House, June 26, 2000, quoted in Steven Epstein, *Inclusion: The Politics of Difference in Medical Research* (2007) 211.
36. Duana Fullwiley, "The Molecularization of Race: Institutionalizing Human Difference in Pharmacogenomic Practice," 16 *Science As Culture* 1 (2007).
37. Duana Fullwiley, "The Molecularization of Race: Institutionalizing Human Difference in Pharmacogenomics Practice," 16 *Science as Culture* 1, 3 (2007).
38. Laura Hercher, "Diet Advice from DNA," *Scientific American*, November 2007, 84–89, <http://www.sciam.com/article.cfm?id=diet-advice-from-dna>.
39. For example, Genetic Technologies Limited offers genetic testing for medical diagnostics as well as a "sports gene test." Genetic Technologies Limited Webpage, <http://www.gtg.com.au/HumanDNA-Testing/index.asp?menuid=070.110> (accessed Mar. 25, 2008).
40. Gregory Kutz, "Nutrigenetic Testing: Tests Purchased From Four Websites Misled Consumers," Testimony Before the Special Committee on Aging, United States Senate, July 26, 2006.
41. For examples of how genetic research can be shaped and informed by lay understandings of race, see generally, Deborah Bolnick, "Individual Ancestry Inference and the Reification of Race as a Biological Phenomenon," in *Revisiting Race in a Genomic Age* (Barbara Koenig, Sandra Soo-Jin Lee, and Sarah Richardson, eds.) (2008).
42. Troy Duster, "Race and Reification in Science," *Science*, Volume 307, Issue 5712, (February 18 2005): 1050–1051.
43. Kahn writes "before proceeding with further debate about their own scientific practices, biomedical researchers and clinicians need to consider more fully and systematically the role of the federal government in shaping such practices. The recent proliferation of biomedical research that uses race and ethnicity as variables did not spontaneously emerge from a sudden discovery of their relevance. Rather, from funding requests to drug approval and market protection, specific federal initiatives mandating the use of such categories have played a critical role in promoting their inclusion as variables in biomedical research. Prominent among these federal mandates are the

National Institutes of Health (NIH) Revitalization Act of 1993, which directed the NIH to develop guidelines for including women and minorities in NIH-sponsored clinical research, and the Food and Drug Modernization Act of 1997, which directed the FDA to examine issues related to the inclusion of racial and ethnic groups in clinical trials of new drugs. Pursuant to these mandates, the NIH and FDA have issued detailed guidelines and guidance mandating certain procedures and practices concerning the inclusion of ethnic and racial minorities in clinical trials.” Kahn, Jonathan “Genes, Race, and Population: Avoiding a Collision of Categories” *American Journal of Public Health*, Volume 96, Issue 11 (November 2006): 6–7.

44. Sally Satel, “I Am a Racially Profiling Doctor,” *New York Times*, May 5, 2002, <http://query.nytimes.com/gst/fullpage.html?res=9B02E2DA1F3EF936A35756C0A9649C8B63&sec=&spn=&pagewanted=all>.
45. Satel writes “How is this possible when humans share 99.9% of their DNA, as the Human Genome Project has revealed? How can race-related variations be medically meaningful if we are so similar? Because that .1% difference means a great deal. After all, we share a large amount—98%—of our genetic makeup with chimpanzees. Or consider the DNA itself. The unshared amount residing in the .1% comprises over three million nucleotides—the building blocks of genes. A mutation of even a single nucleotide can cause the gene within which it is embedded to produce an altered protein or enzyme that determines disease or, theoretically, response to treatment. Many genetic variations are embedded in that .1% and those variations tend to cluster by racial groups—that is, by people whose ancestors came from a particular geographic region. This is called population genetics—the uncontested fact that people who share a common lineage are more likely to have more gene variants in common with each other than with people whose ancestors are from a different group.” Sally Satel, “Race and Medicine Can Mix Without Prejudice: How the Story of BiDil Illuminates the Future of Medicine,” *Medical Progress Today*, December 10, 2004, http://www.medical-progress-today.com/spotlight/spotlight_indarchive.php?id=449.
46. Sally Satel, “Race and Medicine Can Mix Without Prejudice: How the Story of BiDil Illuminates the Future of Medicine,” *Medical Progress Today*, December 10, 2004, http://www.medical-progress-today.com/spotlight/spotlight_indarchive.php?id=449.
47. Duana Fullwiley writes that “as the human genetic draft was prepped for publicity in the early summer of 2000, the NIH simultaneously launched the Pharmacogenetics Research Network (PGRN). With the PGRN, Homosapiens as ‘knowing beings’ set to rationalize the data (not yet knowledge) of human genomic variation for pharmacy. The PGRN would prove a less massive yet more concentrated effort than the HGP. Its purpose would be to exploit [what was then thought to be] the 0.01% minority fraction of human genetic difference that complemented the seemingly overwhelming (but for those interested in variation, somewhat less interesting) 99.9%. In short, as race was minimized by the public and private genome mapping teams (Shreeve, 2004, pp. 219–220, 356), the quantitatively peripheral points of difference in the sequence data (the 0.01%) provided lineaments for its successful restoration. The same year that the HGP heads repudiated race as genetically significant, certain PGRN teams hypothesized its necessity for ‘rational medicine.’”
 - Duana Fullwiley, “The Molecularization of Race: Institutionalizing Human Difference in Pharmacogenomic Practice,” *Science As Culture*, Volume 16, Issue 1 (March 2007): 3.
48. See generally, Jenny Reardon, *Race to the Finish: Identity and Governance in an Age of Genomics* (2005); Henry Greely, “Human Genome Diversity: What About the Other Human Genome Project?” *2 Nature Reviews Genetics*, 222 (2001); L. Luca Cavalli-Sforza, “The Human Genome Diversity Project: Past, Present, and Future,” *6 Nature Reviews Genetics*, 33 (2005).
49. See International HapMap Homepage (accessed Mar. 25, 2008), <http://www.hapmap.org>.
50. See “NIH Launches Center to Study Genomics and Health Disparities,” (accessed Mar. 25, 2008), <http://www.nih.gov/news/health/mar2008/nhgri-17.htm>.
51. Every multi-cellular organism’s hereditary material is encoded in its DNA (deoxyribonucleic acid), which is contained in the cell nucleus. DNA molecules contain the instructions for how each cell performs in the body. Their shape resembles a pair of twisting ladders that scientists call a double helix; the “rungs” are made of differing combina-

tions of four chemicals—A (Adenine), C (Cytosine), G (Guanine), and T (Thymine). More than 6 billion of these chemical base “letters” (strung together in 23 pairs of chromosomes) exist in a human cell.

52. For a general discussion of the relationship between population genetics and pharmacogenomics, see Craig L. Hanis, “The Implications of Population Genetics for Pharmacogenomics,” in Mark A. Rothstein, ed., *Pharmacogenomics: Social, Ethical, and Clinical Dimensions* (2003).
53. Heart failure is a debilitating condition that occurs when the heart becomes too weak to efficiently pump blood throughout the body. It is characterized by fatigue, shortness of breath, and fluid retention in the lungs and is most commonly caused by coronary artery disease, high blood pressure, and diabetes.
54. Jonathan Kahn writes “the claim that African Americans die from heart failure at a rate twice that of white Americans is widely cited in both medical literature and popular media. This 2:1 mortality ratio has been invoked by medical researchers to guide the search for race-based drug development and therapy for heart failure; by biotech corporations and financial journals exploring the economic potential of such drugs; by professional associations seeking to advise their constituents; and, of course, by scholars and commentators of all stripes arguing over the appropriate use of racial categories in science and medicine. Nonetheless, this statistic is wrong. The most current available data place the age-adjusted ratio of black: white mortality from heart failure at approximately 1.1:1 (CDC 1998, n.d.). Uncritical acceptance and promulgation of inaccurate data may be distorting current efforts to address the real health problems associated with heart failure and also lends credence to those who argue that race can and should be used as a biological category,” Jonathan Kahn, “Getting the Numbers Right: Statistical Mischief and Racial Profiling in Heart Failure Research,” *Perspectives in Biology and Medicine*, Volume 46, Number 4 (autumn 2003): 473–474.
55. The International HapMap Consortium, “A Haplotype Map of the Human Genome,” *Nature* 437 (27 October 2005) 1299–1320.
56. There have been some interesting tensions within the Black community regarding BiDil. Anne Pollack recounts the following exchange at a 2006 conference at MIT between Northwestern Law Professor Dorothy Roberts and NAACP spokesperson Juan Cofield: “Dorothy Roberts had just presented her paper on the diverse responses of African Americans to racial therapeutics such as BiDil. She explicated ways in which both conservative colorblindness and identity politics can lend support to racial therapeutics, while anti-race absolutism is less inclined to do so. After the talk, one questioner stood up. He identified himself as Juan Cofield, the president of the NAACP New England Area Conference, and then declared: ‘There is consensus in the black community that this drug is good for black people.’ Roberts, after a beat, said ‘There isn’t consensus among the black people *in this room*.’” Anne Pollack, *Medicating Race: Heart Disease and Durable Preoccupations With Race*, Unpublished Ph.D. dissertation on file with author (May 1, 2007) 242–243.
57. Jonathan Kahn and Pamela Sankar write: “In 1987, during the course of V-HeFT II, Jay Cohn, the lead cardiologist on the V-HeFT studies, submitted a “methods” patent on using the H/I combination to treat heart failure. Cohn could not get what is known as a “combination of matter” patent because the combined form of these two generic drugs did not act differently than using each separately. A methods patent would give the holder a monopoly on marketing the combination for a particular purpose—treating heart failure—but it would not give the holder the power to prevent generic manufacturers from producing and selling the individual drugs. The 1987 methods patent, which expires in 2007, was not race-specific. It claimed that H/I was appropriate as a therapy to treat heart failure—period. No mention was made of race. Cohn licensed the patent to Medco, a North Carolina pharmaceutical company, which spent the early 1990s conducting bioequivalence studies on BiDil and preparing documentation for submission of a new drug application (NDA) to the FDA to get approval for marketing BiDil as a method to treat heart failure. Again, like Cohn’s underlying methods patent, Medco’s NDA for BiDil was not race-specific.” Pamela Sankar and Jonathan Kahn, “BiDil: Race Medicine or Race Marketing?” *Health Affairs*, October 11, 2005, W5-456.
58. Sankar and Kahn write: “In early 1997 the FDA’s Cardiovascular and Renal Drug Advisory Committee rejected Medco’s NDA for BiDil. It is important to emphasize here that the advisory committee did not determine that BiDil failed to work. To the contrary, several members of the committee specifically stated their opinion that BiDil was clinically efficacious. The problem was that Medco’s statistics were in too much of a muddle to meet the FDA’s criteria for new drug approval. As Cohn himself has acknowledged, this was because the V-HeFT trials were not designed as new drug trials but as “test of theory” trials. Cohn recognized the problem with the data at the time when he urged the FDA Advisory Commit-

tee to “keep in mind that this is a study designed 20 years ago. This was a VA cooperative study. This was not designed really as a regulatory study so that careful selection of criteria for endpoint were not as precise as one would see in a protocol designed today with the goal to come to this committee to ask for approval.” Thus, while providing sufficient evidence to convince the American Heart Association (AHA), among others, to recommend H/I as a heart failure therapy, the V-HeFT trials did not produce the type of statistical information that the FDA needed to approve an NDA.” Pamela Sankar and Jonathan Kahn, “BiDil: Race Medicine or Race Marketing?” *Health Affairs*, October 11, 2005, W5-456–457.

59. “BiDil African-American Subset Is Surrogate For Genomics, Cmte. Chair Says,” 67 *The Pink Sheet* (Issue No. 25) 3 (June 20, 2005).
60. Kahn writes, “From where, then, did this statistic come? . . . The web site of the National Heart, Lung, and Blood Institute (NHLBI). One page on this web site, “Facts About Heart Failure,” stated: “Heart failure mortality is about twice as high for African Americans as whites for all age groups” (NHLBI 1995). And yet, while providing ample justification for the *Journal* reporter, the NHLBI itself provided no citation to any underlying study to support its own use of this statistic. The NHLBI fact sheet was apparently based on data from the National Health and Nutrition Examination Survey (NHANES; Striar 2002). The NHANES data were collected from 1988 to 1991; they were over 10 years old, and those intervening years had seen great strides in the treatment of heart failure. Moreover, NHANES data provide information about the *prevalence* of disease in a population, not about mortality. These are two very different things. The same government web site provided statistics of race-based differentials in mortality that ranged from 2:1, to nearly 1.5:1, to “slightly higher” (i.e., 1.12:1). And yet, the only statistic with a firm grounding in current mortality data from the CDC is the third. The confusing profusion of web-based data available at the NHLBI appears to provide some justification for those in the public media who disseminated the incorrect 2:1 statistic. But what of the doctors and medical researchers who develop therapies and publish papers in peer reviewed journals? The first mention of the statistic in the medical literature related to the development of BiDil came in 1999. . . . The

authors set their story against the backdrop of “population-based studies [that] have found that black patients with congestive heart failure have a higher mortality rate than white patients with the same condition” (p. 609). This initially posited statistical disparity led them to hypothesize “racial differences in the natural history of left ventricular dysfunction.” Thus, from the outset, the statistic was being used to rationalize a search for race-based biological differences. It was paving the way for reconceptualizing race in biological terms. . . . To document the racial difference in mortality from heart failure, Dries and colleagues cite two editorials by Richard Gillum (1987, 1996), from the National Center for Health Statistics. . . . Gillum’s 1987 editorial, which was based on examination of both published and unpublished data from the National Center for Health Statistics, does state: “the ratio of age adjusted [mortality] rates in blacks and whites was 1.8 for men and 2.4 for women.” But this is not a complete reference. The whole sentence reads: “*For persons aged 35 to 74 years, . . .*” Not only do Dries and colleagues misquote Gillum (1987) and conflate mortality in the 35-to-74 age group with population-wide mortality, but they also ignore more recent data showing that the overall black: white ratio of age-adjusted mortality rates from heart failure had declined to about 1.1:1 (CDC 1998). Indeed, this documented decline in the disparity between mortality rates over so short a time would seem to support the counter-hypothesis, that the disparity is due more to social, economic, or environmental factors than to any inherent biological difference between the races.” Jonathan Kahn, “Getting the Numbers Right: Statistical Mischief and Racial Profiling in Heart Failure Research,” *Perspectives in Biology and Medicine*, Volume 46, Number 4 (autumn, 2003): 475–478.

61. Margaret Kimberly, “A Bitter Pill for Black Hearts,” June 28, 2005, <http://www.alternet.org/story/23185/>.
62. “NitroMed, NAACP Partnership Will Help Introduction of BiDil,” *Target Market News*, December 14, 2005, <http://www.targetmarketnews.com/storyid12150501.htm> (accessed Mar. 25, 2008).
63. The *New York Times* reported, in part: “Recognizing racial controversy as a potential deterrent to BiDil’s approval, NitroMed reached out to African-American politicians and physicians,

including the Association of Black Cardiologists. After considerable debate, the heart doctors agreed to be co-sponsors of BiDil's clinical trial, embracing the drug as a way to redress years of inequality in medical care, starkly symbolized by the Tuskegee syphilis study that began in the 1930's, in which black men were denied lifesaving treatment. By the time they got to us, they had made presentations to the Congressional Black Caucus and the N.A.A.C.P.," said B. Wayne Kong, the cardiologist group's executive director. "I'm sure they were aware of the political fallout if they did not have African-American participation. And that was a wise decision." NitroMed paid Dr. Kong's group \$200,000 for its assistance with the BiDil trial, Dr. Kong said." Stephanie Saul, "U.S. to Review Drug Intended For One Race," *New York Times*, June 13, 2005, <http://query.nytimes.com/gst/fullpage.html?res=9B05E0D61E38F930A25755C0A9639C8B63&sec=health&spone=&pagewanted=all> (accessed Mar. 25, 2008).

64. Andrew Gumbel, "Color Coded," *Los Angeles City Beat*, June 30, 2005, <http://www.lacitybeat.com/cms/story/detail?id=2279&IssueNum=108> (accessed Mar. 25, 2008).
65. Stephanie Saul, "U.S. to Review Drug Intended For One Race," *New York Times*, June 13, 2005, <http://query.nytimes.com/gst/fullpage.html?res=9B05E0D61E38F930A25755C0A9639C8B63&sec=health&spone=&pagewanted=all> (accessed March 25, 2008).
66. Kirsten Bibbins-Domingo and Alicia Fernandez, "Focus on the Right Health Fight," *San Francisco Chronicle*, March 5, 2007, <http://www.sfgate.com/cgi-bin/article.cgi?file=/c/a/2007/03/05/EDG8JO-EJ4A1.DTL> (accessed Mar. 25, 2008). See also, Angela Stewart, "Heart Drug's Racial Focus Proves a Liability Rather Than Asset," *Newark Star Ledger*, May 31, 2008, http://www.nj.com/business/index.ssf/2008/05/heart_drugs_racial_focus_prove.html (accessed Jun. 9 2008).
67. "NitroMed Suspends Marketing of Heart Drug BiDil, Cuts Staff," *Target Market News*, January 16, 2008, <http://www.targetmarketnews.com/story-id01310802.htm> (accessed Mar. 25, 2008).
68. See Rebecca Zacks, "NitroMed Sells Off Its Only Product, A Controversial Heart Pill for African-Americans," *Xconomy*, October 23, 2008, available at <http://www.xconomy.com/boston/2008/10/23/nitromed-sells-off-its-only-product-a-controversial-heart-pill-for-african-americans/>.
69. Troy Duster, "Race and Reification in Science," *Science*, Vol. 37, February 18, 2005, 1050–1051.
70. Gould writes, "Linnaeus divided the species *Homo sapiens* into four basic varieties, defined primarily by geography and, interestingly, not in

the ranked order favored by most Europeans in the racist tradition—Americanus, Europaeus, Asiaticus, and Afer, or African. (He also alluded to two other fanciful categories: ferus for "wild boys," occasionally discovered in the woods and possibly raised by animals—most turned out to be retarded or mentally ill youngsters abandoned by their parents—and monstrosus for hairy men with tails, and other travelers' confabulations.) In so doing, Linnaeus presented nothing original; he merely mapped humans onto the four geographic regions of conventional cartography.

Linnaeus then characterized each of these groups by noting color, humor, and posture, in that order. Again, none of these categories explicitly implies ranking by worth. Once again, Linnaeus was simply bowing to classical taxonomic theories in making these decisions. For example, his use of the four humors reflects the ancient and medieval theory that a person's temperament arises from a balance of four fluids (humor is Latin for "moisture")—blood, phlegm, cholera (yellow bile), and melancholy (black bile). Depending on which of the four substances dominated, a person would be sanguine (the cheerful realm of blood), phlegmatic (sluggish), choleric (prone to anger), or melancholic (sad). Four geographic regions, four humors, four races.

For the American variety, Linnaeus wrote "rufus, cholericus, rectus" (red, choleric, upright); for the European, "albus, sanguineus, torosus" (white, sanguine, muscular); for the Asian, "luridus, melancholicus, rigidus" (pale yellow, melancholy, stiff); and for the African, "niger, phlegmaticus, latus" (black, phlegmatic, relaxed), Stephen Jay Gould, *The Mismeasure of Man* (New York: W.W. Norton & Company, Inc., 1996) 403–404.

71. Darwin wrote "Although the existing races of man differ in many respects, as in colour, hair, shape of skull, proportions of the body, &c., yet if their whole structure be taken into consideration they are found to resemble each other closely in a multitude of points. Many of these are of so unimportant or of so singular a nature, that it is extremely improbable that they should have been independently acquired by aboriginally distinct species or races. The same remark holds good with equal or greater force with respect to the numerous points of mental similarity between the most distinct races of man. The American aborigines, Negroes and Europeans are as different from each other in mind as any three races that can be named; yet I was incessantly struck, whilst living with the Feugians on board the "Beagle," with the many little traits of character, shewing how similar their minds were to ours; and so it was with a full-

blooded negro with whom I happened once to be intimate.

“He who will read Mr. Tylor’s and Sir J. Lubbock’s interesting works can hardly fail to be deeply impressed with the close similarity between the men of all races in tastes, dispositions and habits. This is shown by the pleasure which they all take in dancing, rude music, acting, painting, tattooing, and otherwise decorating themselves; in their mutual comprehension of gesture-language, by the same expression in their features, and by the same inarticulate cries, when excited by the same emotions. This similarity, or rather identity, is striking, when contrasted with the different expressions and cries made by distinct species of monkeys. There is good evidence that the art of shooting with bows and arrows has not been handed down from any common progenitor of mankind, yet as Westropp and Nilsson have remarked, the stone arrow-heads, brought from the most distant parts of the world, and manufactured at the most remote periods, are almost identical; and this fact can only be accounted for by the various races having similar inventive or mental powers. The same observation has been made by archeologists with respect to certain widely-prevalent ornaments, such as zig-zags, &c.; and with respect to various simple beliefs and customs, such as the burying of the dead under megalithic structures. I remember observing in South America, that there, as in so many other parts of the world, men have generally chosen the summits of lofty hills, to throw up piles of stones, either as a record of some remarkable event, or for burying their dead.

“Now, when naturalists observe a close agreement in numerous small details of habits, tastes, and dispositions between two or more domestic races, or between nearly-allied natural forms, they use this fact as an argument that they are descended from a common progenitor who was thus endowed; and consequently that all should be classed under the same species. The same argument may be applied with much force to the races of man.

“As it is improbable that the numerous and unimportant points of resemblance between the several races of man in bodily structure and mental faculties (I do not here refer to similar customs) should all have been independently acquired, they must have been inherited from pro-

genitors who had these same characters.” Darwin, *The Descent of Man*, 224–225 (1871), quoted in Stephen Jay Gould, *The Mismeasure of Man* (New York: W.W. Norton & Company, Inc., 1981): 421.

72. Tukufu Zuberi writes “Historically, eugenics has been characterized by three principles: the unchangeable biological basis of class and race; the assumption that “like begets like,” or the hereditary basis of physical, mental, moral, and behavioral human characteristics, qualities, and defects; and the biological evolution and the superiority of a particular race. I use the term *eugenics* to refer to its original intent and definition as biologically based explanations and justifications of racial stratification. In 1883 Francis Galton (1822–1911), the movement’s founder and intellectual champion, coined the term *eugenics* from the Greek *eugenes*, meaning “well born” or “noble hereditary.” Galton described the science of eugenics as “giving the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable” . . . “in his book *Hereditary Genius*, Francis Galton presented intelligence as the most important human trait and one around which society should be organized. He believed it was biologically inherited and that Africans and other people of color were inferior in intelligence to the lighter skinned Europeans. Critical to his ideas of eugenics was the notion that the less intelligent population were reproducing at a more rapid rate than the more intelligent ones and this process would ultimately reduce the intelligence of humanity.” Tukufu Zuberi, *Thicker Than Blood: How Racial Statistics Lie* (Minneapolis: University of Minnesota Press 2001), 34, 54.
73. Francis Galton, The [London] *Times*, June 5 1873; available at galton.org. Galton went on to say “My proposal is to make the encouragement of the Chinese settlements at one or more suitable places on the East Coast of Africa a part of our national policy, in the belief that the Chinese immigrants would not only maintain their position, but that they would multiply and their descendants supplant the inferior Negro race. I should expect the large part of the African seaboard, now sparsely occupied by lazy, palavering savages living under the nominal sovereignty of the Zanzibar, or Portugal, might in a few years be tenanted by industrious, order loving Chinese, living either as a

- semi-detached dependency of China, or else in perfect freedom under their own law.” Ibid.
74. Robert Temple and Norman Stockbridge, “BiDil for Heart Failure in Black Patients: The U.S. Food and Drug Administration Perspective,” *Annals of Internal Medicine* 146:1 (January 2, 2007) 57.
 75. “Cohn . . . says he believes it probably will be effective in patients who aren’t black. In fact, he says, he prescribes the generic drugs that make up BiDil for the 25% of his white patients who don’t do well on other drugs. ‘I actually think everybody should be using it,’ Cohn said.” Denise Gellene, “Heart Pill Intended Only for Blacks Sparks Debate,” *Los Angeles Times*, June 16, 2005, <http://articles.latimes.com/2005/jun/16/business/fi-bidil16>.
 76. Jonathan Kahn, “From Difference to Disparity: How Race Specific Medicines May Undermine Policies To Address Inequalities in Health Care,” 15 *Southern California Interdisciplinary Law Journal* 105, 106 (2006).
 77. Francis S. Collins, “What We Do and Don’t Know About ‘Race,’ ‘Ethnicity,’ Genetics and Health At the Dawn of the Genome Era,” 36 *Nature Genetics Supplement* S13 (2004).
 78. Sarah K. Tate and David B. Goldstein, “Will Tomorrow’s Medicines Work For Everyone?” *Nature Genetics Supplement*, 36:11 (November 2004) S34. They go on to note that “these claims are universally controversial and there is no consensus on how important race or ethnicity is in determining drug response.”
 79. Andrew Pollack, “F.D.A. Restricts Access to Cancer Drug, Citing Ineffectiveness,” *New York Times*, June 18, 2005, <http://www.nytimes.com/2005/06/18/business/18drug.html>.
 80. “Targeted Therapy—A Groundbreaking Therapy Triggering Spark of Hope,” AstraZeneca China Website, <http://en.astrazeneca.com.cn/Article/516066.aspx> (accessed Mar. 25, 2008).
 81. “Crestor Significantly Helps Hispanic Patients With Elevated Cholesterol, Large Scale Study,” *Medical News Today*, March 27, 2006, <http://www.medicalnewstoday.com/articles/40309.php> (accessed Mar. 25, 2008).
 82. FDA Public Health Advisory on Crestor (rosuvastatin), March 2, 2005, http://www.fda.gov/CDER/Drug/advisory/crestor_3_2005.htm (accessed Mar. 25, 2008).
 83. David R. Baker, “Vaccine Has No Impact, AIDS-VAX’s Failure a Blow to Treatment,” *San Francisco Chronicle*, November 13, 2003, <http://www.sfgate.com/cgi-bin/article.cgi?f=/c/a/2003/11/13/BUGLE30GIF1.DTL&hw=AIDSVAX&sn=003&sc=794> (accessed Mar. 25, 2008).
 84. PhRMA, “Nearly 700 Medicines in the Pipeline Offer Hope for Closing the Health Gap for African Americans,” December 2007, http://www.phrma.org/news_room/press_releases/new_report_offers_hope_for_african_americans_shows_nearly_700_medicines_in_pipeline/ (accessed June 25, 2008).
 85. A recent report by the Robert Wood Johnson Foundation notes that “factors such as income and education, and how they play out in housing and neighborhood, directly exert a powerful influence on health disparities in the United States—“potentially as powerful as medical care or genetics.” Robert Wood Johnson Foundation, “Overcoming Obstacles to Health: Stories, Facts and Findings,” (February 2008): 3. Another report by the John D. And Catherine T. Macarthur Foundation finds that “Societies are structured like ladders. The rungs of the ladder represent the resources that determine whether people can live a good life—prosperous, healthy, and secure—or a life plagued by difficulties—insufficient income, poor health, and vulnerability. People standing on the top rungs are the best educated, have the most respected jobs, ample savings, and comfortable housing. On the bottom rungs are people who are poorly educated, experience long bouts of unemployment or low wage jobs, have nothing to fall back on in the way of savings, and live in substandard homes. The people in the middle have more resources to rely on than do people at the bottom, but far less than people on the top. In reaching for health, every step up makes a difference. Of all the outcomes determined by your position on the ladder, none is more fundamental than this: it predicts how long you live and how healthy you are during your lifetime. This is a surprising finding because we tend to think of health as something that is fixed by our genetic heritage. But genes are only part of the picture. It turns out that the more advantaged our lives are, the longer we live and the healthier we are from birth to old age.” The John D. and Catherine T. Macarthur Foundation, “Reaching for a Healthier Life: Facts on Socioeconomic Status and Health in the U.S.” (2007): 4. For a vivid documentary demonstration of the effect of social determinants on health outcomes, see Larry Adelman, *Unnatural Causes: Is Inequality Making Us Sick?* California Newsreel, 2008.
 86. To describe this dynamic, Dorothy Nelkin and Susan Lindee write, “In the public debates over human differences—for example the meaning of gender, race, and sexual orientation—genetic images are strategically employed in an effort to delineate boundaries, justify rights or legitimate inequalities. Genes can be understood in this debate

as rhetorical devices that can be utilized in many different ways. They have been used to identify biological differences and to give them social meaning—by those, for example, who believe education will make no difference in the social status of black Americans. . . . Biological narratives do not inherently oppress. But we argue that they are dangerous precisely because of the cultural importance attached to DNA. These narratives, attributing social differences to genetic differences, are especially problematic in a society that tends to overstate the powers of the gene. Charged with cultural meaning as the essence of the person, the gene appears to be powerful, deterministic, and fundamental entity. And genetic explanations—of gender, race, or sexual orientation—construct differences as central to identity, definitive of the self. Such explanations thereby amplify the differences that divide society. . . . The gene, as an apparently determinist force has transformed public debate about the source of social problems. . . . [This transformation is part of our culture's growing] emphasis on individual responsibility [which] effectively deflects attention from the broad social and economic forces within which individuals act. If society is simply a collection of autonomous individuals, then responsibility for social progress and problems lies not with political organizations, not with group actions, but with the individual—whether pathological, admirable, deviant, courageous or dysfunctional. And if individuals are not malleable—and in the political imagination a genetic trait is a trait that cannot be affected by environmental forces—then efforts to change the social environment may be irrelevant. People with problems become, in effect, problem people. This implies that the government can “only do so much” to help those who are “programmed” to be the way they are, since there are severe limits to the efficacy of social intervention.” Dorothy Nelkin and M. Susan Lindee, *The DNA Mystique: The Gene as a Cultural Icon* (New York: W. H. Freeman, 1995), 124, 126, 128–129.

87. See generally, Ruth Hubbard and Elijah Wald, *Exploding the Gene Myth*, (2nd ed.) Boston (1999); Dorothy Nelkin and M. Susan Lindee, *The DNA Mystique: The Gene as a Cultural Icon* (1995).
88. “It is unlikely that the intense selective pressure for electrolyte conservation proposed by [the slavery hypothesis,] although a significant constraint during the Middle Passage, can be shown to have persisted as a consistent feature of the more recent post–Middle Passage environments of African Americans. Once the survivors were deposited in the Americas, they faced a diversity of new physical and biological challenges in various ecological settings. Under these non-uniform conditions, the descendents of these Africans not only survived but continued to evolve. The result has been an expansion of their collective genetic variability after the Middle Passage rather than a continued constriction of heterogeneity.” Fatimah Linda Collier Jackson, “An Evolutionary Perspective on Salt Hypertension and Human Genetic Variability,” *Hypertension* 17:1, January 1991, 1–132.
89. See Osagie Obasogie, “Hypertension: What Oprah Doesn’t Know,” *Los Angeles Times*, May 17, 2007, <http://www.latimes.com/news/opinion/la-oe-obasogie17may17,0,7566670.story?coll=la-opinion-righttrail> (accessed Mar. 25, 2008).
90. S. William Tam et. al., “Lack of Bioequivalence Between Different Formulations of Isosorbide Dinitrate and Hydralazine and the Fixed-Dose Combination of Isosorbide Dinitrate/Hydralazine: The V-HeFT Paradox,” *Clinical Pharmacokinetics* 46(10):885–895, 2007.
91. D. Winickoff and O. Obasogie, “Race-specific Drugs: Regulatory Trends and Public Policy,” *Trends in Pharmacological Science*, 29:6, 277–279 (2008).
92. Osagie K. Obasogie, “Beyond Best Practices: Strict Scrutiny As A Regulatory Model for Race Specific Medicines,” *Journal of Law, Medicine, and Ethics*, Vol. 36, No. 3 (September 2008) 491–497.
93. Bolnick et al, “Science and Business of Genetic Ancestry Testing,” *Science* 318:5859, 399–400 (2007).
94. Henry Louis Gates, Jr., *African American Lives*, (PBS Home Video) 2005.
95. Henry Louis Gates, Jr., *African American Lives*, (PBS Home Video) 2005.
96. *Indian Country Today*, September 22, 2004, quoted in Kim Tallbear, “Native American DNA.com: In Search of Native American Race and Tribe,” in *Revisiting Race in a Genomic Age* (Barbara Koenig, Sandra Soo-jin Lee, Sarah Richardson eds.) 350 (2008).
97. *Ibid.* at 350.
98. Kim Tallbear and Deborah Bolnick, “Native American DNA Tests: What are the Risks to

- Tribes?" *The Native Voice*, December 3, 2004, D2. See also, James C. McKinley, Jr., "No Prison for 'Indian Chief' in Scheme for Catskills Casino," *New York Times*, June 18, 2004, <http://query.nytimes.com/gst/fullpage.html?res=9403E7DD1739F93BA25755C0A9629C8B63&n=Top/Reference/Times%20Topics/Subjects/G/Gambling> (accessed June 23, 2008).
99. The *New York Times*' Amy Harmon writes, "Alan Moldawer's adopted twins, Matt and Andrew, had always thought of themselves as white. But when it came time for them to apply to college last year, Mr. Moldawer thought it might be worth investigating the origins of their slightly tan-tinted skin, with a new DNA kit that he had heard could determine an individual's genetic ancestry. The results, designating the boys 9 percent Native American and 11 percent northern African, arrived too late for the admissions process. But Mr. Moldawer, a business executive in Silver Spring, Md., says they could be useful in obtaining financial aid. 'Naturally when you're applying to college you're looking at how your genetic status might help you,' said Mr. Moldawer, who knows that the twins' birth parents are white, but has little information about their extended family. 'I have three kids going now, and you can bet that any advantage we can take we will.' Genetic tests, once obscure tools for scientists, have begun to influence everyday lives in many ways. The tests are reshaping people's sense of themselves—where they came from, why they behave as they do, what disease might be coming their way. It may be only natural then that ethnic ancestry tests, one of the first commercial products to emerge from the genetic revolution, are spurring a thorough exploration of the question, What is in it for me? Amy Harmon, "Seeking Ancestry in DNA Ties Uncovered by Tests," *New York Times*, April 12, 2006, <http://www.nytimes.com/2006/04/12/us/12genes.html> (accessed August 13, 2008).
100. Kim Tallbear and Deborah Bolnick, "Native American DNA Tests: What are the Risks to Tribes?" *The Native Voice*, December 3, 2004, D2.
101. See, for example, the Genetic Identity Ancestry Testing webpage, http://www.genetic-identity.com/Ancestry_Testing/ancestry_testing.html (accessed Mar. 25, 2008).
102. Stephen Jay Gould, *The Mismeasure of Man*, (New York: W.W. Norton & Company, Inc., 1996).
103. H. H. Goddard, "Mental Tests and the Immigrant," *2 Journal of Delinquency*, 243 (1917), quoted in Stephen Jay Gould, *The Mismeasure of Man* (New York: W.W. Norton & Company, Inc., 1996) 196.
104. R. M. Yerkes, "Psychological Examining in the United States Army," in *15 Memoirs of the National Academy of Sciences*, 1921, quoted in Stephen Jay Gould, *The Mismeasure of Man*, (New York: W.W. Norton & Company, Inc., 1996) 227.
105. Charlotte Hunt-Grubbe, "The Elementary DNA of Dr Watson," *The Sunday Times* [London], October 14, 2007, http://entertainment.timesonline.co.uk/tol/arts_and_entertainment/books/article2630748.ece (accessed Mar. 25, 2008).
106. For a fairly comprehensive collection of Watson's most offensive remarks, see Center for Genetics and Society, "James Watson's Legacy," October 22, 2007, <http://biopoliticaltimes.org/article.php?id=3723> (accessed Mar. 25, 2008).
107. Watson said "To all those who have drawn the inference from my words that Africa, as a continent, is somehow genetically inferior, I can only apologize unreservedly. That is not what I meant. More importantly from my point of view, there is no scientific basis for such a belief." "DNA Pioneer James Watson Says He is 'Mortified' by Race Comments," Associated Press, October 18, 2007, <http://www.iht.com/articles/ap/2007/10/18/europe/EU-GEN-Britain-US-Scientist-Racism.php> (accessed Mar. 25, 2008).
108. For example, *Slate* columnist William Saletan wrote, "James Watson, the legendary biologist, was condemned and forced into retirement after claiming that African intelligence wasn't 'the same as ours.' 'Racist, vicious and unsupported by science,' said the Federation of American Scientists. 'Utterly unsupported by scientific evidence,' declared the U.S. government's supervisor of genetic research. The *New York Times* told readers that when Watson implied 'that black Africans are less intelligent than whites, he hadn't a scientific leg to stand on. . . . I wish these assurances were true. They aren't. Tests do show an IQ deficit, not just for Africans relative to Europeans, but for Europeans relative to Asians. Economic and cultural theories have failed to explain most of the pattern, and there's strong preliminary evidence that part of it is genetic. It's time to prepare for the possibility that equality of intelligence, in the sense of racial averages on tests, will turn out not to be true." William Saletan, "Created Equal," *Slate*, November 18, 2007, <http://www.slate.com/id/2178122/entry/2178123/> (accessed Mar. 25, 2008). Also see the trio of editorials in the *Journal Medical Hypothesis* passionately defending Watson's statements: J. Philippe Rush-ton and Arthur R. Jensen, "James Watson's Most

- Inconvenient Truth: Race Realism and the Moral Fallacy,” *Medical Hypotheses* 71:5 (2008) 629–640; Bruce G. Charlton, “First a Hero of Science and Now a Martyr to Science: The James Watson Affair—Political Correctness Crushes Free Scientific Communication,” *Medical Hypotheses*, 70:6 (2008) 1077–1080; Jason Malloy, “James Watson Tells the Inconvenient Truth: Faces the Consequences,” *Medical Hypotheses* 70:6 (2008) 1081–1091.
109. “James Watson, the DNA pioneer who claimed Africans are less intelligent than whites, has been found to have 16 times more genes of black origin than the average white European. An analysis of his genome shows that 16% of his genes are likely to have come from a black ancestor of African descent. By contrast, most people of European descent would have no more than 1%. The study was made possible when he allowed his genome—the map of all his genes—to be published on the internet in the interests of science. ‘This level is what you would expect in someone who had a great-grandparent who was African,’ said Kari Stefansson of deCODE Genetics, whose company carried out the analysis. ‘It was very surprising to get this result for Jim.’” Jonathan Leake, “DNA pioneer James Watson is Blacker Than he Thought,” *The Sunday Times* [London], December 9, 2007, <http://www.timesonline.co.uk/tol/news/uk/science/article3022190.ece> (accessed June 13, 2008).
110. Cavalli-Sforza noted, “the populations that can tell us the most about our evolutionary past are those that have been isolated for some time, are likely to be linguistically and culturally distinct, and are often surrounded by geographic barriers. Isolate human populations contain much more informative genetic markers than more recent urban ones. Such isolated human populations are being rapidly merged with their neighbors, however, destroying irrevocably the information needed to reconstruct our evolutionary history. Population growth, famine, war, and improvements in transportation and communication are encroaching on once stable populations. It would be tragically ironic if, during the same decade that biological tools for understanding how our species were created, major opportunities for applying them were squandered.” L.L. Cavalli-Sforza et. al, “Call for a Worldwide Survey of Human Genetic Diversity: A Vanishing Opportunity for the Human Genome Project,” 11 *Genomics* 490 (1991).
111. “The Human Genome Diversity project provides a resource that is aimed at promoting worldwide research on human genetic diversity, with the ultimate goal of understanding how and when patterns of diversity were formed.” L. Luca Cavalli-Sforza, “The Human Genome Diversity Project: Past, Present, and Future,” 6 *Nature Reviews Genetics*, 333 (April 2005). See also: Jenny Reardon, *Race to the Finish: Identity and Governance in an Age of Genomics* (2005); Henry Greely, “Human Genome Diversity: What About the Other Human Genome Project,” 2 *Nature Reviews Genetics*, 222 (March 2001).
112. The International HapMap Consortium, “Integrating Ethics and Science in the International HapMap Project,” 5 *Nature Reviews Genetics* 467 (June 2004).
113. “The Genographic Project, in important ways, aims to do what the Diversity Project—hampered by controversy—failed to do. And there are ties between the two projects. For example, [Genographic project leader Spencer] Wells did a post-doctoral fellowship with the Stanford University population geneticist, Luca Cavalli-Sforza, who founded the Diversity Project and is chair of Genographic’s advisory board. Furthermore, both the Diversity Project and Genographic consist of teams of scientists from around the world who collect DNA samples, mostly from indigenous peoples, to build large DNA databases—up to 100,000 samples in the Genographic’s case. Thus, Genographic’s ultimate goal is synonymous with that of the Diversity Project: to greatly increase the size of the existing data base in order to produce a more detailed story about human migratory history and the deep historical genetic relationships between different peoples of the world. Finally, the two projects employ the trope, the ‘vanishing indigene,’ to give a sense of urgency of the need to collect blood, especially from those who are isolated both genetically and culturally. On the other hand, Genographic consistently, but diplomatically, distances itself from the Diversity Project. Clearly conscious of Diversity Project history, Genographic disclaims medically relevant research as a motive. Diversity Project organizers attempted to ward off indige-

nous criticism with claims about potential health benefits of their research—e.g. greater understanding of human genetic variation could eventually inform studies of disease that plague indigenous peoples. But critics were not convinced. They felt indigenous peoples had been duped before into supposedly health related genetic research that actually had nothing to do with their pressing health issues.” Kim Tallbear, “Narratives of Race and Indigeneity in the Genographic Project,” 35 *Journal of Law, Medicine, and Ethics* 412, 412–413 (2007).

114. <https://www3.nationalgeographic.com/genographic/about.html> (accessed May 6th, 2008).

115. *Ibid.*

116. “United Nations Recommends Halt to Genographic Project,” Press Release from the Indigenous Peoples Council on Biocolonialism, May 26, 2006, http://www.ipcb.org/issues/human_genetics/htmls/unpfii_rec.html (accessed May 6th, 2008).

117. Steve Olson writes, “In 1991 Cavalli-Sforza and a group of colleagues proposed a comprehensive study of human genetic differences, which they called the Human Genome Diversity Project. The study would involve gathering cells from several thousand people around the world, “immortalizing” the cells by converting them into laboratory cell lines, and using the cells’ DNA to reconstruct human evolution and history. For Cavalli-Sforza, the Human Genome Diversity Project was to be the culmination of a lifetime of work. The proposal loosed a flood of controversy. Aboriginal groups in the United States, New Guinea, and other countries accused the HGDP of stealing their genes, destroying their culture, and even contributing to genocide. Academic critics claimed that the project could encourage racist thinking, by oversimplifying issues of great complexity. “The idea of studying human genetic diversity is a good one,” says one outspoken critic, Jonathan Marks, an anthropologist at the University of North Carolina at Charlotte. “But the way that Cavalli-Sforza has conceptualized it has problems at all levels.” . . . For almost a decade Cavalli-Sforza has been trapped in the paradox at the heart of human genetics: The only way to understand how similar we are is to learn how we differ. Yet any study of human differences seems to play into the hands of those who would accentuate those differences. Researchers might claim that the genetic differences they identify among groups have no biological significance. Yet simply by dividing human beings into categories—whether sub-Saharan Africans, Jews, Germans, or Australian aborigines—they reinforce the dis-

tinctions they would seek to minimize. How to resolve this dilemma is quickly becoming one of the most difficult problems facing the study of human genetics. . . . In 1993 an odd-looking document appeared on the desks of the Human Genome Diversity Project’s organizers. Under the heading “RAFI communiqué” it was titled “Patents, Indigenous Peoples, and Human Genetic Diversity.” An artful combination of analysis and innuendo, the document was unambiguous in its conclusion: “The Human Genome Diversity Project should immediately halt any collection efforts.” The campaign against the HGDP marked the first foray into human genetics for RAFI—the Rural Advancement Foundation International. A small organization based in Canada, RAFI had previously targeted corporations that removed indigenous plants from developing countries, repackaged their genetic material in hybrid seeds, and then offered the seeds to Third World farmers for exorbitant prices. Now it accused the HGDP of a similar form of “biopiracy.” The DNA of indigenous people would be mined for valuable information. Pharmaceutical companies would then use this information to make drugs far too expensive for Third World people to buy. The actions of the U.S. government seemed to bear out RAFI’s claims. Federal agencies had applied for patents on cell lines containing DNA from several Third World groups. The patent applications, which were all aimed at medical uses, had nothing to do with the HGDP, and the project repeatedly dissociated itself from them. But opponents eagerly conflated the uproar over the patents with what they called the “vampire project.” Many Native Americans were especially critical of the HGDP. “The benefits for Native people are elusive or nonexistent, and the risks are tremendous,” says Debra Harry, a member of the Northern Paiute Nation and the director of an organization called the Indigenous Peoples Council on Biocolonialism. Native American creation stories say that Native Americans have always lived in the Americas, Harry observes, not that their ancestors migrated across the Bering land bridge sometime before the arrival of Europeans. Furthermore, many Native American cultures hold that biological materials are sacred. “DNA is not ours to manipulate, alter, own, or sell,” Harry says. “It was passed on from our ancestors and should be passed on to our children and future generations with its full integrity.” Native Americans and many other groups were also quick to raise the specter of biological warfare. What would stop a government from developing lethal microbes tailored to particular groups? This criticism especially galls geneticists,

- who say that it is too far-fetched to take seriously. Even if it were possible someday to devise a genetically based weapon, it would simply kill varying percentages of the people in different groups.” Steve Olson, “The Genetic Archaeology of Race,” *The Atlantic*, April 2001, <http://www.theatlantic.com/doc/200104/olson>. For further background, see <http://www.etcgroup.org/en/issues/biopiracy.html> and <http://www.ipcb.org/>.
118. Quoted in “The Human Genome Diversity Project” *GenEthics News*, Issue 10, 1996, <http://www.hgalert.org/topics/personalInfo/hgdp.htm>.
119. As an example, Jay McGown writes, “Sometimes pharmaceutical companies admit that there are traditional uses for plants that they seek to patent, but almost always they allege that the “new” use claimed in their patent application is different than the “old” use employed by indigenous peoples or traditional medical practitioners. Rare are the cases in which the patent applicant openly admits to appropriating traditional knowledge. Few are as clear as the words in US patent 6,350,478 (issued 26 February 2002), which belongs to Phytopharm plc of Cambridge, UK. The patent covers the use of extracts of *Artemisia judaica*, a North African medicinal plant, for the treatment of diabetes. The patent could not make the origin of Phytopharm’s treatment any clearer: “*Artemisia judaica is used in Libyan traditional medicine as an infusion for the treatment of “wasting disease”, almost certain diabetes mellitus [sic].*” The last clause of the sentence should obviously read “*almost certainly diabetes mellitus*”. In other words, Phytopharm admits that Libyans have used the plant that the company wishes to patent for the same use that the patent application claims as an “invention”. Scientific literature reveals that the plant is also used in Egypt and other North African countries. Despite this explicit declaration of a lack of novelty, the US Patent Office granted the patent. So, a British company discerned a traditional Libyan treatment for diabetes and then successfully claimed that treatment as its own invention in the US, where the patent office apparently did not notice (or care) that the “invention” was—by the company’s own admission—not novel.” Jay McGown, *Out of Africa: Mysteries of Access and Benefit Sharing*, Edmonds Institute & African Centre for Biosafety, 2006, <http://www.edmonds-institute.org/outofafrica.pdf>.
120. See for example Gillian N. Rattray, “The Enola Bean Patent Controversy: Biopiracy, Novelty and Fish-and-Chips,” 2002 *Duke L. & Tech. Rev.* 0008. See also: Vandana Shiva, “The Neem Tree—a case history of biopiracy,” Third World Network, n.d., <http://www.twinside.org.sg/title/pir-ch.htm>; Trade Environment Database (TED) Case Study: Basmati, <http://www.american.edu/ted/basmati.htm>.
121. See N. Zamel, “In search of the genes of asthma on the island of Tristan da Cunha,” *Canadian Respiratory Journal* 1995;2(1):18–22. The ETC Group was severely critical of this project, noting “In recent months, RAFI has learned that scientists and their corporate partners are collecting DNA samples from remote island populations in the South Atlantic, Micronesia and the east China Sea. These are just a few examples of the people who are being targets in the race to identify and patent human disease genes. . . . No matter how socially desirable the goal may seem at first glance, genomic companies and scientists are committing acts of genetic biopiracy and, in the process, violating the fundamental human rights of the people from whom DNA samples are taken. In all likelihood, the people who are targeted by scientists and corporate gene hunters are giving DNA samples (blood, hair, tissue) willingly under standard regulations of “informed consent.” Most of them do so with general understanding that they are making a contribution to science that someday improve human condition. They are NOT informed that products derived from their DNA, or information gleaned from it, will be patented and commercialized, nor that they will lose control of their genetic material once it is removed from their bodies. Consider the following study: In September, 1994 Sequana Therapeutics, a genomic company based in California, announced that DNA samples extracted from nearly all of the 300 inhabitants of an isolated island in the South Atlantic may give the company the information they need to locate, identify and eventually patent the gene or genes that predispose people to asthma. In 1991, researchers from the University Of Toronto’s Genetics Of Asthma Research Group first proposed to take blood samples from all the residents of Tristan Cunha. But the islanders were not eager to participate. According to the University of

Toronto researcher, Patricia Mclean, it took two years for the researchers to convince the island's inhabitants to participate in the programme. After being subjects of scientific inquiry in England nearly 30 years ago, "they wanted no part of being guinea pigs again," McLean told Biotech Business. It was the island's resident physician, provided by the British government, who finally convinced the people of Tristan to participate in the study. Permission was granted by the Tristan's Island Council. . . . If Sequana is successful in identifying the mutant gene or genes, it will file for patent claims immediately. According to Salka, any patent application filed by company would be made in Sequanas name, with sharing of economic benefits with the Lunenfield Institute in Canada. Will inhabitants of Tristan da Cunha benefit from the asthma gene? University of Toronto scientist, Patricia McClean, explains that the Canadian researchers made an agreement to leave their lung functioning equipment on the island following their departure. This gives the islanders the technology they need to assess their asthmatic condition before treatment. The people of Tristan da Cunha represent only one of many populations that have been targeted or who have already provided raw material for human DNA research. RAFI Report, "Gene Hunters in Search of 'Disease Genes' Collect Human DNA from Remote Island Populations," Etc Group, http://www.etcgroup.org/en/materials/publications.html?pub_id=477 (accessed Mar. 25, 2008).

122. J. Brock with Anne Green, "Chief Islander Sets the Record Straight," *Tristan Times*, November 19, 2004, <http://www.tristantimes.com/art.php?cat=56>.
123. See Amy Harmon, "DNA Gatherers Hit Snag: Tribes Don't Trust Them," *New York Times*, December 10, 2006, <http://www.nytimes.com/2006/12/10/us/10dna.html> (accessed Mar. 25, 2008).
124. Roger Lewin, "Genes From a Disappearing World," *New Scientist*, May 29, 1993.
125. The guidelines for referring to the populations sampled in the HapMap project reflect this sensibility. For example, they note: "The way that a population is named in studies of genetic variation, such as the HapMap, has important ramifications scientifically, culturally, and ethically. From a scientific standpoint, precision in describing the population from which the samples were collected is an essential component of sound study design; the source of the data must be accurately described in order for the data to be interpreted correctly. From a cultural stand-

point, precision in labeling reflects acknowledgment of and respect for the local norms of the communities that have agreed to participate in the research. From an ethical standpoint, precision is part of the obligation of researchers to participants, and helps to ensure that the research findings are neither under-generalized nor over-generalized inappropriately. The use of careless and inconsistent terminology when describing the populations represents a failure in all three of these areas. The populations included in the HapMap should not be named in such a way that they single out small, discrete communities of individuals and imply that those communities are somehow genetically unique, of special interest, or very different from their close neighbors. Labels that are too specific could also invade the privacy interests of communities (or even, conceivably, of individual sample donors). On the other hand, describing the populations in terms that are too broad could result in inappropriate over-generalization. This could erroneously lead those who interpret HapMap data to equate geography (the basis on which populations were defined for the HapMap) with race (an imprecise and mostly socially constructed category). This, in turn, could reinforce social and historical stereotypes, and lead to group stigmatization and discrimination in places where members of the named populations or of closely related populations are minorities." Guidelines for Referring to the HapMap Populations in Publications and Presentations, <http://www.hapmap.org/citinghapmap.html>.

126. Jenny Reardon, *Race to The Finish: Identity and Governance in an Age of Genomics*, 32 (2005). Reardon continues by saying "The typological approach drew upon a natural classification system that dated back to Plato and Aristotle. According to this classification system, organisms in the natural world come packaged in discrete, static groups that increase in complexity as one moves 'up' the 'great chain of beings.'" Ibid. at 33.
127. "Historians of race and science draw upon five dichotomies to distinguish an ideological typological approach from a scientifically sound population: race/population; race/culture; classificatory/empirical; history/natural selection; phenotype/genotype." Jenny Reardon, *Race to the Finish: Identity and Governance in an Age of Genomics*, 33 (2005).
128. In describing the anti-racism that is often presumed to have been ushered in with a population focus, Gannett writes "The typological-population distinction is fundamentally a conceptual one. "Population thinkers" are considered to be

- averse to the imposition of artificial and arbitrary” typologies” on heterogeneous biological nature. For this reason, they are supposed to be open to recognizing the . . . empirical evidence that genetic variability is distributed statistically across the species, and thus the invalidation of classification schemes that attempt to categorize each and every human being as belonging to a discrete racial kind or “type” that is homogeneous for certain characteristics. “Population thinkers” appreciate that two individuals from different groups can be genetically more similar than two individuals from the same group because of the extent to which allele frequency distributions in populations are overlapping. On the conventional accounts, “population thinking” is considered to be inherently anti-racist because it subverts and helps to dispel the “typological” thinking that supports racial prejudice that is associated with stereotypes.” Lisa Gannett, “Racism and Human Genome Research: The Ethical Limits of ‘Population Thinking,’” 68 *Philosophy of Science* S479, S489 (2001).
129. For a definitive account of the shift (or lack thereof) between typological and populations accounts of race in science, see generally, Jenny Reardon, *Race to the Finish: Identity and Governance in an Age of Genomics*, 17–44 (2005).
130. “Human genome diversity research might be claimed to be non-racist because human population geneticists and biological anthropologists study DNA differences that, for the most part, are distributed across the species even if they vary quantitatively among groups. Human genome diversity research might also be claimed to be non-racist because the DNA differences investigated are objective, in the sense of being context-independent and value-neutral. *But this is not so.* DNA differences are conceptualized and categorized within particular contexts of investigation and these contexts of investigation are themselves historically, socially, and culturally situated. Historical, social, and cultural contingencies inform the theoretical and practical interests that constitute the various pragmatic contexts in which genetic explanations for physiological and behavioral differences among humans, and groups of humans, are sought. It is not nature that determines distinctions like that between “fundamental” and “superficial” characteristics; it is not nature that encourages biologists to relegate non-genetic causal factors to the necessary background context against which genes exert their effects; it is not nature that leads geneticists to investigate DNA differences associated with some physiological or behavioral differences and not others, nor to represent these as quantitative group differences rather than individual differences. The persistence of racist structures in society means not only that “facts” about group DNA differences can be “misused” to racist ends but that such ‘facts’ will incorporate those cultural meanings that attach to human difference.” Lisa Gannett, “Racism and Human Genome Research: The Ethical Limits of ‘Population Thinking,’” 68 *Philosophy of Science* S488–S489, S489 (2001).
131. Jenny Reardon, *Race to the Finish: Identity and Governance in an Age of Genomics*, 42, 44 (2005).
132. American Anthropological Association, *Race—Are We So Different?* available at http://www.understandingrace.org/humvar/race_humvar.html.
133. Esteban Gonzalez et. al., “The Importance of Race and Ethnic Background in Biomedical Research and Clinical Practice,” 12 *N Engl J. Med* 348 (March 20 2003).
134. Steven Epstein, *Inclusion: The Politics of Difference in Medical Research* (Chicago: University of Chicago Press, 2007) 212.
135. Deborah Bolnick, “Individual Ancestry Inference and the Reification of Race as a Biological Phenomenon,” in *Revisiting Race in a Genomic Age* (Barbara Koenig et. al eds.), forthcoming, Rutgers University Press, p. 2. Manuscript on File with author.
136. The Church of Latter-Day Saints (e.g. Mormons) has been a leader in genealogy. See Helen Schatvet Ullmann, “What Is the IGI (aka International Genealogy Index)?” <http://www.livgenmi.com/fhcigi.htm> (accessed Mar. 25, 2008).
137. “Ancestry.com Parent Sold for \$300 Million,” Reuters, October 17, 2007, <http://www.reuters.com/article/technologyNews/idUSN1729430020071017?sp=true> (accessed Mar. 25, 2008).
138. “Ancestry.com Offers Unprecedented Look Into Lives of Once-Enslaved Ancestors With Largest Online Collection of African-American Historical Records,” Press Release, February 7, 2008,

<http://myfamily.mediaroom.com/index.php?s=43&item=118> (accessed Mar. 25, 2008).

139. Jesse Reynolds, "Google Wants to Track Your Medical History—And Your Genome," *AlterNet*, September 20, 2007, <http://www.alternet.org/healthwellness/62847> (accessed Mar. 25, 2008).
140. Kristen Philipkoski, "Genetics Scandal Inflames Iceland," *Wired*, March 20, 2000, <http://www.wired.com/politics/law/news/2000/03/35024> (accessed Mar. 25, 2008).

Nicholas Wade, "Company Offers Genome Assessments," *New York Times*, November 16, 2007, <http://www.nytimes.com/2007/11/16/science/17gene.html> (accessed Mar. 25, 2008).
141. Andrew Pollack, "Broader Financial Turmoil Threatens Biotech's Innovation and Cash," *New York Times*, 28 October, 2008; <http://www.nytimes.com/2008/10/29/business/29biotech.html>.
142. The International Society of Genetic Genealogy (isogg.org) has useful comparison charts.
143. African Ancestry promotes its service on its website by saying, in part, "African Ancestry is the only company that traces your ancestry back to a specific present-day African country of origin and often to a specific African ethnic group when African ancestry is found. Most companies can only tell you what continent you originated from, but not what country. They tell you what haplogroup you belong to and whether that haplogroup is African. However, you are left to analyze this information yourself. African Ancestry provides a comprehensive analysis. We do the work for you and go beyond the generic haplogroup jargon. Using our African Lineage Database, we compare your genetic sequence against 25,000 indigenous African samples to connect your roots back to a specific African country(ies) and ethnic group(s) when possible." African Ancestry company website, <http://www.africanancestry.com/benefits.html> (accessed Mar. 25, 2008).
144. This emphasis on Native and indigenous populations is apparent on the company's website: "DNA Tribes Genetic Ancestry Analysis is a service that uses genetic material inherited from both maternal and paternal ancestors to measure your genetic connections to individual ethnic groups and major world regions. Your top ranked results indicate places where your blend of ancestry is most frequent and where your genetic ancestors left the strongest traces. DNA Tribes® analysis identifies the peoples and places where your geographical genetic ancestry is most strongly represented. DNA Tribes is the only personal genetic analysis that compares your genetic profile to a population database that includes

over 250,000 individuals from 826 populations around the world, including 593 indigenous populations. Each person's ranked population results are divided into Native and Global Population Match. Native Population Match results include indigenous populations with minimal admixture in the past 500 years, such as Native Amazonians, Scottish, Egyptians or Japanese. Global Population Match includes these indigenous populations as well as modern Diaspora ethnic groups such as African-Americans, European-Americans or Asian-Americans. Modern Diaspora populations are descended from immigrants who have recently moved from their homelands to live around the world, often blending with other peoples." DNA Tribes company website, <http://www.dnatribes.com/faq.html> (accessed Mar. 25, 2008).

145. See DNAPrint Genomics Website on admixture mapping at <http://www.ancestrybydna.com/welcome/productsandservices/ancestrybydna/accuracyandprecision/>.
146. "Mitochondria are structures within cells that convert the energy from food into a form that cells can use. Although most DNA is packaged in chromosomes within the nucleus, mitochondria also have a small amount of their own DNA. This genetic material is known as mitochondrial DNA or mtDNA. In humans, mitochondrial DNA spans about 16,500 DNA building blocks (base pairs), representing a fraction of the total DNA in cells. Mitochondrial DNA contains 37 genes, all of which are essential for normal mitochondrial function. Thirteen of these genes provide instructions for making enzymes involved in oxidative phosphorylation. Oxidative phosphorylation is a process that uses oxygen and simple sugars to create adenosine triphosphate (ATP), the cell's main energy source. The remaining genes provide instructions for making molecules called transfer RNAs (tRNAs) and ribosomal RNAs (rRNAs), which are chemical cousins of DNA. These types of RNA help assemble protein building blocks (amino acids) into functioning proteins." U.S. National Library of Medicine, Genetics Home Reference, <http://ghr.nlm.nih.gov/chromosome=MT> (accessed Mar. 25, 2008).
147. See generally, U.S. National Library of Medicine, Genetics Home Reference, <http://ghr.nlm.nih.gov/chromosome=Y> (accessed Mar. 25, 2008).
148. An exchange between correspondent Lesley Stahl, geneticist Rick Kittles, and Stanford Law Professor Hank Greely on *60 Minutes* highlights this issue. Stahl notes: "Geneticist Rick Kittles runs a company called African Ancestry that specializes in DNA testing for black Americans. He says a full one

- third of the men he tests find out they have a white male relative somewhere back in time. How do people who find this out react? “Some black men get upset and say, ‘Look, I’m black. Look at me, I’m black.’ And you know and I say, ‘Yeah, you are. But this small segment of your DNA doesn’t go back to Africa but to Europe,’” Kittles says. “We are a mosaic of many different ancestors. We can go back several generations and there are hundreds of people who, thousands of people who actually contributed to our DNA.” And that’s the rub. This business of genetic genealogy is fraught with limitations. For one thing, it can only provide information about a tiny fraction of our ancestry. Because we get half our DNA from our mothers and half from our fathers, almost all of our DNA gets shuffled and remixed every generation, making it impossible to trace what comes from whom. There are just two bits of DNA that remain pure—the “Y” chromosome, which passes directly from father to son, and something called mitochondrial DNA, which passes unchanged from mother to child. Hank Greely, a law professor at Stanford University, has studied this new field. He worries that people don’t realize just how many ancestors they actually have. “Eight generations ago both you and I had 256 great-great-great-great-great-great grandparents,” Greely points out. “It doubles every generation. So you’ve got two parents. You have four grandparents. You have eight great grandparents. Sixteen great-great grandparents. And it adds up fast. It adds up so fast in fact that if you go back 20 generations you’ve got over a million grandparents.” 1,048,576 to be exact. And in each generation, DNA testing can provide information about only two of them. “So you could be Peruvian on your mother’s mother’s mother’s side, Japanese on your father’s father’s father’s side. Swedish on everything else,” Greely explains. “And you’ll never know?” Stahl asks. “And you’ll never know the Swedish from the ‘Y’ chromosome or the mitochondrial DNA,” Greely says.” CBS News, “Rebuilding The Family Tree: Lesley Stahl Reports On The Hopes And Limitations Of Genetic Genealogy,” *60 Minutes*, June 29, 2008, <http://www.cbsnews.com/stories/2007/10/05/60minutes/main3334427.shtml>.
149. Tony N. Frudakis, *Molecular Photofitting: Predicting Ancestry and Phenotype Using DNA*, p. 44 (2008).
150. Deborah Bolnick, “Individual Ancestry Inference and the Reification of Race As A Biological Phenomenon,” in *Revisiting Race in a Genomic Age* (B. Koenig et. al. eds) (2008).
151. “Even though there is little evidence that four biologically discrete groups of humans ever existed, the AncestryBYDNA [admixture] test creates the appearance of genetically distinct populations by relying on ‘ancestry informative markers’ (AIMs). AIMs are SNPs or other markers that show relatively large (30to 50%) frequency differences between population samples. The AncestryBYDNA test examines AIMS selected to differentiate between four ‘parental’ populations (Africans, Europeans, East Asians, and Native Americans). However, these AIMs are not found in all peoples who would be classed together as a given ‘parental’ population. The AIMs that characterize ‘Africans,’ for example, were chosen on the basis of a sample of West Africans. Dark skinned East Africans might be omitted from the AIMs reference panel of ‘Africans’ because they exhibit different gene variants. Furthermore, some of the most ‘informative’ AIMs involve loci that have undergone strong selection, which makes it unclear whether these markers indicate shared ancestry or parallel selective pressures (such as similar environmental exposures in different geographic regions) or both.” Deborah A. Bolnick, et. al., “The Science and Business of Genetic Ancestry Testing,” 318 *Science* 399 (October 19, 2007).
152. Duana Fullwiley, “Can DNA Witness Race? Forensic Uses of An Imperfect Ancestry Testing Technology,” *GeneWatch* (forthcoming; paper on file with author, p. 15). Fullwiley provides an illuminating discussion of how the assumptions behind the construction of AIMs as markers drives the findings of individuals ancestry in a manner that reflects a distinctively American understanding of racial typology: “The complexity of how both ‘geography’ and ‘time’ have born out human variation has been drastically simplified . . . [in a manner] that makes the AIMs technology increasingly appealing to the wide range of lay, scientific, and law enforcement clients who are now using it. While the girth of the globe has been flattened to a small area of West Africa, sporadic points in North and South American, and even sparser points of Europe [as the places

where DNAPrint Genomics conducted its sampling to act as reference points to deduce individual ancestry], time has been collapsed into a world history that pivots on the year 1492 with Columbus's arrival in Latin America. Although certain researchers who use AIMs in the biomedical field acknowledge that 15th century Spain consisted of 'Celts, Greeks, Romans, Sephardic Jews, Arabs, Gypsies, and other groups,' the AIMs model permits them to gloss over this complexity with a general 'European' label. This 'old' vs. 'new' world terminology holds for African ancestry as well. As a clear example of what social epidemiologist Nancy Krieger has termed 'the politics of time,' it is assumed that, for instance, present day Yoruba and Mende people are older than African-Americans, Puerto Ricans, and the more than few whites with African Ancestry. In both instances it is taken for granted that those in the 'new world' with 'African' or 'European' ancestry, detected by the test, have actually inherited the ancestral (Yoruba, Mende, Valencian, etc.) genotypes denoted by AIMs." Ibid. at 12.

153. Frudakis, Tony N., et al., "Compositions and methods for inferring ancestry," Patent application 20040229231, November 18, 2004.
154. Deborah Bolnick et. al., "The Science and Business of Genetic Ancestry Testing," 318 *Science* 399, 400 (2007).
155. Rick Kittles and 60 *Minutes'* Lesley Stahl discuss this point: "We don't oversell. I mean, we just say, 'Look, we provide a service.' If you're interested in exploring a tiny bit of your DNA and trace it's ancestry we can do that," Kittles says. "When you say it's a tiny little amount . . ." Stahl says. "It's less than point one percent," Kittles explains. "That's pretty teeny," Stahl remarks. "Yeah, but for people who know nothing about any of them, I think it's very important," Kittles says. Kittles' company has amassed the largest database of DNA sequences from countries in Africa, particularly those from which slaves were taken. His goal is to help American blacks trace their ancestry back to Africa, a history totally lost to them." CBS News, "Rebuilding The Family Tree: Lesley Stahl Reports On The Hopes And Limitations Of Genetic Genealogy," 60 *Minutes*, June 29, 2008.
156. "For example, genetic ancestry testing can identify some of the groups and locations around the world where a test-taker's haplotypes or autosomal markers are found, but it is unlikely to identify all of them. Such inferences depend on the samples in a company's database, and even databases with 10,000 to 20,000 samples may fail to capture the full array of human genetic diversity in a particular population or region." Deborah A. Bolnick, et. al., "The Science and Business of Genetic Ancestry Testing," 318 *Science* 399 (October 19, 2007).
157. Ron Nixon, "DNA Tests Find Branches But Few Roots," *New York Times*, November 25, 2007, <http://www.nytimes.com/2007/11/25/business/25dna.html> (accessed Mar. 25, 2008).
158. Genetic Testing Laboratories website, https://www.gtdna.net/earth_origins_dna_ancestry.html?source=google&gclid=CNaAu7nj-I4CFQqZg-godJxLL-A (accessed Mar. 25, 2008).
159. Deborah A. Bolnick, et. al., "The Science and Business of Genetic Ancestry Testing," 318 *Science* 399, 400 (October 19, 2007).
160. "Consumers often purchase these tests to learn about their race or ethnicity, but there is no clear-cut connection between an individual's DNA and his or her racial or ethnic affiliation. Worldwide patterns of human genetic diversity are weakly correlated with racial and ethnic categories because both are partially correlated with geography. Current understandings of race and ethnicity reflect more than genetic relatedness, though, having been defined in particular sociohistorical contexts (i.e., European and American colonialism). In addition, social relationships and life experiences have been as important as biological ancestry in shaping individual identity and group membership. Many genetic ancestry tests also claim to tell consumers where their ancestral lineage originated and the social group to which their ancestors belonged. However, present-day patterns of residence are rarely identical to what existed in the past, and social groups have changed over time, in name and composition. Databases of present-day samples may therefore provide false leads." Deborah A. Bolnick, et. al., "The Science and Business of Genetic Ancestry Testing," *Science* Volume 318, Issue 5849 (October 19, 2007): 399, 400.
161. See Determigen website, DNA Ancestry Testing & DNA Parentage Testing, http://www.determigen.com/detail_ancestry.asp (accessed Mar. 25, 2008).
162. Editors, *Science*, December 21, 2007, <http://www.sciencemag.org/sciext/btoy2007/> (accessed Mar. 25, 2008).
163. "Such premature attempts at popularizing genetic testing seem to neglect key aspects of the established multifaceted evaluation of genetic tests for clinical applications. First, there is the question of a test's analytic validity, "its ability to accurately and reliably measure the genotype of interest." Although appropriate monitoring and oversight of the analytic validity of genetic tests remain

largely unaddressed, most researchers report that the analytic validity of these platforms is very high. It is likely that sample-handling errors are a greater threat to the validity of results than are genotypic misclassification errors. Yet even very small error rates per SNP, magnified across the genome, can result in hundreds of misclassified variants for any individual patient. Without transparent quality-control monitoring and proficiency testing, the real-world performance of these platforms is uncertain. Second, one must consider clinical validity, or the ability of the test to detect or predict the associated disorder. Components of clinical validity include the test's sensitivity, specificity, and positive and negative predictive value. This is the area in which the data are in the greatest flux, and even the ardent proponents of genomic susceptibility testing would agree that for most diseases, we are still at the early stages of identifying the full list of susceptibility-associated variants. Most of the diseases listed by the direct-to-consumer testing companies (e.g., diabetes, various cancers, and heart disease) are so-called complex diseases thought to be caused by multiple gene variants, interactions among these variants, and interactions between variants and environmental factors. Thus, a full accounting of disease susceptibility awaits the identification of these multiple variants and their interactions in well-designed studies. What we have now is recognition of a limited number of variants associated with relative risks of diseases on the order of 1.5 or lower. Risk factors with this level of relative risk clearly do a poor job of distinguishing people who will develop these diseases from those who will not. Finally, there is the issue of the test's clinical utility, or the balance of its associated risks and benefits if it were to be introduced into clinical practice. Measures of utility address the question at the heart of the clinical application of a test: If a patient is found to be at risk for a disease, what can be done about it? This is the arena in which there are virtually no data available on the health impact of genomewide analysis. There are very few observational studies and almost no clinical trials that demonstrate the risks and benefits associated with screening for individual gene variants—let alone testing for many hundreds of thousands of variants. Thus, any claim to clinical utility currently rests on the

assumption that interventions that have proven successful in the general population will behave the same way in a genetically at-risk population.

Many of these interventions—such as smoking cessation, weight loss, increased physical activity, and control of blood pressure—are likely to be broadly beneficial in relation to many diseases, regardless of a person's genetic susceptibility to a specific disease." David J. Hunter et. al., "Letting the Genome out of the Bottle—Will We Get our Wish?" *New England Journal of Medicine* 358:2, 105–107.

164. Andrew Pollack, "Gene Testing Questioned By Regulators," *New York Times*, June 26, 2008, <http://query.nytimes.com/gst/fullpage.html?res=9501E1DB1238F935A15755C0A96E9C8B63&scp=4&sq=Andrew+Pollack&st=nyt>
165. Michael Mann writes: "The 'CSI effect' has entered the lexicon as one of the most popular television shows in America, catching the imagination of audiences and indoctrinating the American public to believe that scientific evidence is available and irrefutable in every criminal proceeding. . . . Prosecutors who bear surprising negative verdicts, credit the primetime success of CSI with causing jurors to have heightened expectations of what they will see when they enter a courtroom. Rarely do television prosecutors lack the evidence needed to convict a defendant, which leaves real-life jurors scratching their heads looking for the same definitive evidence seen on television—the deoxyribose nucleic acid (DNA), ballistics and fingerprints—even when such evidence simply is not available. But are unrealistic expectations held by jurors as a result of watching CSI and other crime dramas such as Dick Wolf's Law and Order, marginalizing actual criminal investigations? Undoubtedly, forensic science is paramount to public perceptions of guilt and innocence. Witnesses no longer play a large role in crimes because human can be fallible or simple lie. This premise has helped the greater science community teach perspective jurors from a young age that the only reliable proof is scientific evidence. When the murder is committed, investigators 'need only to look at the body, as it is now through science, the dead can appear on behalf of the prosecution.'" Michael D. Mann, "The 'CSI Effect': Better Jurors through Television and Science?" *Buffalo Public Interest Law Journal*, 2006.

166. Innocence Project, Special Report: *200 Exonerated, Too Many Wrongfully Convicted*, http://www.innocenceproject.org/Images/751/ip_200.pdf.
167. “The list of first-generation forensic analysts and laboratories caught up in scandals of one variety or another is both well documented and long. The worst stories are of methodologies seemingly concocted from thin air, such as the ‘Cinderella’ expert who purported to match foot and shoe impressions based on a method developed by and known only to her. On the other end of the spectrum are techniques such as fingerprinting, which have long been embraced in the absence of any scientific validation even though such validation seems at least possible to attain. But even setting aside the validity of a particular methodology, the ignominious past of the first generation includes tales of fabrication and improper handling of evidence, falsification of results and reports, rogue or incompetent analyses, and corrupt or misleading testimony.” Erin Murphy, “The New Forensics: Criminal Justice, False Certainty, and the Second Generation of Scientific Evidence,” 95 *Cal. L. Rev.* 721, 745 (2007).
168. Richard Willing, “Police Dupe Suspects Into Giving Up DNA,” *USA Today*, September 10, 2003, http://www.usatoday.com/news/nation/2003-09-10-dna-dupes_x.htm (accessed Mar. 25, 2008). Willing notes that “Police across the nation increasingly are turning to such clever—and, critics say, legally questionable—ploys to get DNA from suspects without obtaining court orders. In the past four years, cops seeking DNA samples have created a phony dating service in Boston and have impersonated a public health worker in New York City. They have portrayed a rape counselor in Iowa City, a Taco Bell worker in Brea, Calif., and a diner at a Wendy’s restaurant in Upstate New York. . . . In each instance, police had a suspect in mind but lacked enough evidence to get a court order requiring the suspect to give a DNA sample. So they simply took it, from skin cells that become stuck in saliva nearly every time the mouth or tongue touches another object. Then the police matched the genetic code in the samples to that from DNA taken from blood, semen or other evidence at the scenes of unsolved crimes.”
169. *State of Washington v. Athan*, 160 Wn. 2d 354 (2007).
170. See e.g. Electronic Privacy Information Center, “Kohler v. Englade: The Unsuccessful Use of DNA Dragnets to Fight Crime,” <http://epic.org/privacy/kohler/> (accessed Mar. 25, 2008).
171. Henry T. Greely et. al., “Family Ties: The Use of DNA Offender Databases to Catch Offenders’ Kin,” 34 *Journal of Law, Medicine, & Ethics* 249 (2006).
172. Hank Greely writes: “In the United States, crime laboratories typically use a set of thirteen STRs, known as the ‘CODIS markers,’ named after the FBI’s Combined DNA Information System. These STRs are spread over twelve chromosomes. Each individual has two copies of each of the thirteen STRs. On average, one of the CODIS markers has twelve different lengths, or alleles, found in significant numbers of the population, but the least variable CODIS marker has seven alleles and the most variable has twenty-three. One person might have two copies of the first marker that are four and eight repeats long, copies of the second that are eleven and twenty-three copies long, copies of the third that are three and ten copies long, and so on through all thirteen markers. That person—someone, possibly the perpetrator, who left DNA at a crime scene; someone who left DNA on some important evidence to a crime; or an unidentified person whose remains have been found—can thus be identified as thirteen pairs of numbers, one pair for each of the thirteen STRs. Those numbers constitute a “genotype” of the individual for those STRs (based on the alleles they have of those STRs). The odds that an unrelated person shares the same set of thirteen pairs are normally infinitesimal—at most one in several hundred billion, compared with a total of 6.3 billion living humans.” Henry T. Greely et. al., “Family Ties: The Use of DNA Offender Databases to Catch Offenders’ Kin,” 34 *Journal of Law, Medicine, & Ethics* 250 (2006).
173. For a more complete discussion of the various techniques, see Frederick Bieber, “Science and Technology of Forensic DNA Profiling: Current Use and Future Directions,” in *DNA and the Criminal Justice System: The Technology of Justice* (David Lazer ed.) 2004.
174. Frederick Bieber, “Science and Technology of Forensic DNA Profiling: Current Use and Future Directions,” in *DNA and the Criminal Justice System: The Technology of Justice* (David Lazer ed.) 29 (2004).
175. “In 1997, Timothy Durham of Tulsa, Oklahoma, was released from prison after serving four years for a rape that he could not have committed. At his trial, he was able to produce 11 alibi witnesses who placed him in another state at the time of the crime, but he was still convicted of raping an 11-year-old girl and sentenced to 3,000 years in prison. The prosecution’s case rested on three pieces of evidence: he was identified by the victim; a hair found at the crime scene was shown to be similar to his; and a DNA test showed that

- his profile matched that of the semen recovered from the girl. A repeat DNA test later revealed that the initial result was a false positive that had arisen because of errors in interpreting a mixed sample. The lab had failed to completely separate the male and female DNA and the combination of STRs from the two sources produced a profile that could have included Durham's." Kristina Staley, "The Police National DNA Database: Balancing Crime Detection, Human Rights and Privacy," *Genewatch UK*, 22 (January 2005), <http://www.genewatch.org/pub-492774> (accessed Mar. 25, 2008).
176. "Advances in second generation sciences do not just encourage the substitution of cases with a forensic evidence component for those without such a component. They also allow for the identification of perpetrators even in the absence of any other evidence. That is, second generation sciences introduce into the criminal justice system an entirely new kind of case: one in which the only evidence is scientific." Erin Murphy, "The New Forensics: Criminal Justice, False Certainty, and the Second Generation of Scientific Evidence," 95 *Cal. L. Rev.* 721, 738 (2007).
177. Adam Liptak, "The Nation; You Think DNA Evidence Is Foolproof? Try Again," *New York Times*, March 16, 2003.
178. "Legal experts say the laboratory (Houston Police Department Crime Lab) is the worst in the country, but troubles there are also seen in other crime laboratories. Standards are often lax or nonexistent, technicians are poorly trained and defense lawyers often have no money to hire their own experts. Questions about the work of laboratories and their technicians in Oklahoma City, Montana and Washington State and elsewhere have led to similar reviews. But the possible problems in Houston are much greater. More defendants from Harris County, of which Houston is a part, have been executed than from any other county in the country." Adam Liptak, "Worst Crime Lab in the Country: Or is Houston Typical?" *New York Times*, March 11, 2003.
179. "The Harris County District Attorney's Office for years ignored its obligation to inform defense lawyers about accusations that Houston crime lab analysts had falsified drug test results, attorneys said this week. Evidence in thousands of drug cases during the past seven years might have received closer scrutiny, the attorneys said, if they had been informed that two Police Department analysts were suspected of 'drylabbing'—concocting results without performing tests." Roma Khanna and Steve McVicker, "Prosecutors Accused of Withholding Drug Test Suspicions From Defenders: Defense Lawyers Say that Being Kept in the Dark May Have Damaged Their Clients' Cases," *Houston Chronicle*, June 30, 2005, <http://www.chron.com/disp/story.mpl/special/crimelab/3247023.html> (accessed Mar. 25, 2008).
180. Michael R. Bromwich, *Summary of Recommendations of the Independent Investigator for the HPD Crime Lab and Property Room*, August 8, 2007, <http://www.hpdlabinvestigation.org> (accessed Mar. 25, 2008).
181. "One unresolved DNA case, highlighted in Bromwich's final report on the investigation as 'the most troubling,' is the one against Lewis. An 18-year-old Jones High School student in 1991, Lewis was accused in the slaying of bank teller Alexandra Rendon. After an outside lab analyzed evidence, an HPD analyst reported that Lewis and his co-defendant could have contributed to biological samples from the crime. Facing a capital murder charge and possible death sentence, Lewis pleaded guilty to murder. A decade later, his case received new attention when errors in HPD's DNA testing came to light. The state Department of Public Safety retested the evidence, confirming the possibility that the co-defendant's DNA was present on the samples but finding no evidence of Lewis', according to Bromwich's final report. 'The Lewis case is troubling and . . . is among those that we recommend be reviewed to determine whether additional DNA testing would be appropriate,' the investigative team wrote. . . . Among the cases in which HPD's work was deemed unreliable is Cantrell's, which the Bromwich report describes as 'very troubling.' In August 2002, Cantrell was sentenced to six years in prison after pleading guilty to aggravated sexual assault of an 8-year-old neighbor. Cantrell says he confessed to avoid a lengthier sentence after his original attorney told him that the prosecutor claimed DNA evidence conclusively identified him as the attacker. Cantrell had an earlier deferred adjudication for indecency with a minor. In May 2003, retesting by a private

- lab failed to confirm the original HPD results. It also questioned whether semen had been found on the girl's shirt, as reported by HPD." Roma Khanna and Steve McVicker, "'Troubling' Cases Surface in Report on HPD Crime Lab: 1991 Conviction for Rape, Murder Has Drawn the Most Concern," *Houston Chronicle*, June 17, 2007, <http://www.chron.com/dispatch/story.mpl/special/crimelab/4896367.html> (accessed Mar. 25, 2008).
182. Roma Khanna and Steve McVicker, "'Troubling' Cases Surface in Report on HPD Crime Lab: 1991 Conviction for Rape, Murder Has Drawn the Most Concern," *Houston Chronicle*, June 17, 2007, <http://www.chron.com/dispatch/story.mpl/special/crimelab/4896367.html> (accessed Mar. 25, 2008).
183. See, for example: Kristina Staley, "The Police National DNA Database: Balancing Crime Detection, Human Rights and Privacy," *GeneWatch UK*, 22 (January 2005), <http://www.gene-watch.org/pub-492774> (accessed Mar. 25, 2008); Tania Simoncelli, "Retreating Justice: Proposed Expansion of Federal DNA Database Threatens Civil Liberties," 17 *GeneWatch* 3 (April 2004) <http://www.gene-watch.org/genewatch/articles/17-2Simoncelli.html> (accessed Mar. 25, 2008).
184. "Mandatory DNA database rejected," BBC, February 23, 2008, http://news.bbc.co.uk/2/hi/uk_news/7260164.stm (accessed Mar. 25, 2008); Professor Jon Silverman, "Has our DNA database gone too far?" BBC, September 5, 2007 <http://news.bbc.co.uk/2/hi/uk_news/6979165.stm> (accessed Mar. 25, 2008).
185. "The DNA of a seven-month-old baby girl has been added to the police's national database designed to identify criminals. . . . It was revealed this year that more than 100,000 DNA samples had been taken from children, aged ten to 16, who have never been charged or convicted of any crime. Now the news that a baby's genetic profile is stored on the system saw leading campaigners react with horror and disgust. She is one of 47 children under ten whose DNA has been recorded and will be retained by the police until after their deaths. Civil liberties organization Liberty said the baby girl's case was 'a chilling example of how out of control the DNA database has become.' Children can be added to the register only with their parents' agreement, but Liberty director Shami Chakrabarti said: 'This baby has not given her consent to be on this criminal database. Who knows the circumstances that led to her parent or guardian agreeing to put her profile on the system?'" Jason Lewis, "Outrage as DNA profile of seven-month-old baby is added to register," *Daily Mail* [UK], September 15, 2007, http://www.dailymail.co.uk/pages/live/articles/news/news.html?in_article_id=481997&in_page_id=1770 (accessed Mar. 25, 2008).
186. The Innocence Project notes on their website's factsheet: "There have been 218 post-conviction DNA exonerations in the United States. Mistaken eyewitness identification testimony was a factor in 77 percent of post-conviction DNA exoneration cases in the U.S., making it the leading cause of these wrongful convictions. Of that 77 percent, 48 percent of cases where race is known involved cross-racial eyewitness identification. Studies have shown that people are less able to recognize faces of a different race than their own. . . . Lab error and junk science have played a role in 65 percent of wrongful convictions. In over half of DNA exonerations, the misapplication of forensic disciplines—such as blood type testing, hair analysis, fingerprint analysis, bite mark analysis, and more—has played a role in convicting the innocent. In these cases, forensic scientists and prosecutors presented fraudulent, exaggerated, or otherwise tainted evidence to the judge or jury which led to the wrongful conviction. Three cases have even involved erroneous testimony about DNA test results. . . . False confessions and incriminating statements lead to wrongful convictions in 25 percent of cases. More than 350 jurisdictions now record interrogations. False confessions are another leading cause of wrongful convictions. Twenty-five percent of cases involve a false confession or incriminating statement made by the defendant. Of those cases, 35 percent were 18 or under and/or developmentally disabled. . . . [With regards to the 218 exonerees' race, there have been] 134 African Americans, 59 Caucasians, 19 Latinos, 1 Asian American, [and] 5 whose race is unknown." Innocence Project, "Facts on Post-Conviction DNA Exonerations," <http://www.innocenceproject.org/Content/351.php> (accessed August 16, 2008).
187. Robert Matthews, "The Informer in Your Blood," *First Post*, 20 March, 2008, <http://www.thefirstpost.co.uk/?menuID=2&subID=1066> (accessed Mar. 25, 2008).
188. Robert Matthews, "The Informer in Your Blood," *First Post*, 20 March, 2008, <http://www.thefirstpost.co.uk/?menuID=2&subID=1066> (accessed Mar. 25, 2008).
189. "Tandem repeat DNA in the human genome remained elusive at first, and the research went down several blind routes. The answer came from a totally different project in Professor Jeffrey's lab which was searching for the human copy of the myoglobin gene, which produces the

- oxygen carrying protein in muscle. The group decided to look for the myoglobin gene first in grey seals (as seals produce lots of myoglobin, and have high levels of myoglobin mRNA, which makes it easy to clone a cDNA), then use the seal gene to isolate its human counterpart. “The true story of DNA fingerprinting starts at the headquarters of the British Antarctic Survey in Cambridge,” says Professor Jeffreys. ‘I collected a big lump of seal meat from their lock-up freezer and, to cut a long story short, we got the seal myoglobin gene, had a look at human myoglobin gene and there, inside an intron in that gene was tandem repeat DNA—a minisatellite.’ This minisatellite was to prove the key to the rest of the genome, for while it was not variable itself, its sequence was similar to the very few minisatellites that had been described previously. Using the myoglobin minisatellite as a ‘hook’, the team could then identify more minisatellites and to their surprise discovered a core sequence—a piece of DNA that is similar in many different minisatellites. ‘Using the core sequence, we made a probe that should latch onto lots of these minisatellites at the same time,’ says Professor Jeffreys, ‘and, to test out the system, we hybridised the probe to a blot with DNA from several different people.’ On a Monday morning in September 1984, the X-ray of the blot was developed in the Leicester University darkroom. ‘I took one look, thought ‘what a complicated mess’, then suddenly realised we had patterns,’ says Professor Jeffreys. ‘There was a level of individual specificity that was light years beyond anything that had been seen before. It was a ‘eureka!’ moment. Standing in front of this picture in the darkroom, my life took a complete turn. We could immediately see the potential for forensic investigations and paternity, and my wife pointed out that very evening that it could be used to resolve immigration disputes by clarifying family relationships.’” Giles Newton, “Discovering DNA Fingerprinting,” Wellcome Trust website, February 4, 2004, http://genome.wellcome.ac.uk/doc_wtd020877.html (accessed Mar. 25, 2008).
190. Robert Matthews, “The Informer in Your Blood,” *First Post*, March 20, 2008, <http://www.thefirstpost.co.uk/?menuID=2&subID=1066> (accessed March 25, 2008).
191. Iain Haddow, “Debating Ethics of DNA Database,” BBC, January 9, 2008, <http://news.bbc.co.uk/1/hi/uk/7177152.stm> (accessed Mar. 25, 2008).
192. “Privacy Fears Over DNA Database,” BBC, September 12, 2002, http://news.bbc.co.uk/1/hi/in_depth/sci_tech/2002/leicester_2002/2252782.stm (accessed Mar. 25, 2008).
193. For example, Simoncelli and Krimsky write: “The trend to collect and bank the DNA from innocent persons including newborns, schoolchildren, suspects and arrestees is highly problematic. First, it marks a fundamental shift in the purpose and intent of what have been termed ‘criminal’ databanks. The routine trawling of these databases by law enforcement renders the people whose personal data are included as suspects for any and all future crimes even though they have not actually been deemed suspects by any method. Requiring persons convicted of a crime to forfeit certain rights of bodily integrity and privacy while under authority of the penal system has been ruled defensible. However, subjecting those who have *never* been suspected of a crime, let alone convicted of one, to this treatment potentially undermines the presumption of innocence. Adding the DNA data from millions of innocent persons to these databanks alters their purpose from one of criminal investigation to population surveillance, subverting our deepest notions of a free and autonomous citizenry. Furthermore, there is no reason to assume that biological samples and DNA data in the hands of the government would be safe from misuse, or that all purposes for which it may be used will be either appropriately law-enforcement related or benign. The privacy concerns associated with potential misuse of DNA information are driven by current laboratory practice, where the individual’s biological sample is retained along with the generated profile. Since all of our genetic information is encoded in each and every one of our cells, the risk of abuse remains real as long as the biological samples remain on file. Only one state—Wisconsin—mandates the destruction of the individual offender’s biological sample after a DNA profile is generated, although to date, none has been destroyed. Twenty-nine states specifically require retention of the offender samples.” Tania Simoncelli and Sheldon Krimsky, “A New Era of DNA Collections: At What Cost to Civil Liberties?” *The American Constitution Society*,

August 2007, p. 8, <http://www.acslaw.org/node/5338> (accessed Mar. 25, 2008).

194. Robin McKie, "Meet the DNA Genius Who Fears the Dark Side of His Discovery," *The Observer* [London], August 8, 2004, <http://www.guardian.co.uk/politics/2004/aug/08/idcards.genetics> (accessed Mar. 25, 2008).
195. Seth Axelrod, *Survey of State DNA Database Statutes*, ASLME Report, http://www.aslme.org/dna_04/grid/guide.pdf (accessed Mar. 25, 2008).
196. Ellen Nakishima and Spencer Hsu, "U.S. To Expand Collection of Crime Suspects' DNA," *Washington Post*, April 17, 2008, <http://www.washingtonpost.com/wp-dyn/content/article/2008/04/16/AR2008041602729.html?hpid%3Dtopnews&sub=AR> (accessed June 11, 2008).
197. "The Justice Department is completing rules to allow the collection of DNA from most people arrested or detained by federal authorities, a vast expansion of DNA gathering that will include hundreds of thousands of illegal immigrants, by far the largest group affected. The new forensic DNA sampling was authorized by Congress in a little-noticed amendment to a January 2006 renewal of the Violence Against Women Act, which provides protections and assistance for victims of sexual crimes. The amendment permits DNA collecting from anyone under criminal arrest by federal authorities, and also from illegal immigrants detained by federal agents. Over the last year, the Justice Department has been conducting an internal review and consulting with other agencies to prepare regulations to carry out the law. The goal, justice officials said, is to make the practice of DNA sampling as routine as fingerprinting for anyone detained by federal agents, including illegal immigrants. Until now, federal authorities have taken DNA samples only from convicted felons. The law has strong support from crime victims' organizations and some women's groups, who say it will help law enforcement identify sexual predators and also detect dangerous criminals among illegal immigrants. . . The 2006 amendment was sponsored by two border state Republicans, Senator Jon Kyl of Arizona and Senator John Cornyn of Texas. In an interview, Mr. Kyl said the measure was broadly drawn to encompass illegal immigrants as well as Americans arrested for federal crimes. He said that 13 percent of illegal immigrants detained in Arizona last year had criminal records. 'Some of these are very bad people,' Mr. Kyl said. 'The number of sexual assaults committed by illegal immigrants is astonishing. Right now there is a fingerprint system in use, but it is not as thorough as it could be.' . . . Immigration lawyers noted that most immigration violations, including those committed when people enter the country illegally, are civil, not criminal, offenses. They warned that the new law would make it difficult for immigrants to remove their DNA profiles from the federal database, even if they were never found to have committed any serious violation or crime. Under the new law, DNA samples would be taken from any illegal immigrants who are detained and would normally be fingerprinted, justice officials said. Last year federal customs, Border Patrol and immigration agents detained more than 1.2 million immigrants, the majority of them at the border with Mexico. About 238,000 of those immigrants were detained in immigration enforcement investigations. A great majority of all immigration detainees were fingerprinted, immigration officials said. About 102,000 people were arrested on federal charges not related to immigration in 2005." Julie Preston, "U.S. Set to Begin a Vast Expansion of DNA Sampling," *New York Times*, February 5, 2007, http://www.nytimes.com/2007/02/05/washington/05dna.html?_r=3&hp&ex=1170651600&en=a2a71de54d113c56&ei=5094&partner=homepage&oref=slogin&oref=slogin&oref=slogin (accessed Mar. 25, 2008).
198. Julia Preston, "U.S. Set to Begin a Vast Expansion of DNA Sampling," *New York Times*, February 5, 2007.
199. Erin Murphy, "The New Forensics: Criminal Justice, False Certainty, and the Second Generation of Scientific Evidence," 95 *Cal. L. Rev.* 721, 740 (2007). Murphy goes on to note: "From a cold hit, the government either develops further facts to implicate the suspect, or else brings the case on the basis of this evidence alone. To be sure, in the majority of cases, the government will endeavor to collect additional evidence beyond the forensic proof. For instance, in one case, the government established a cold hit and, after identifying a suspect, found two witnesses who claimed to recall the suspect having a cut on his finger the day of the murder that corresponded to a wound inflicted by the victim. But in some cases, the government may proceed on the sole basis of genetic evidence or marginally probative additional evidence, such as the suspect's proximity to the scene of the offense. In some cases, the offense occurred long before genetic typing was available—sometimes as far back as twenty or thirty years." *Ibid.* at 740–741.
200. Erin Murphy, "The New Forensics: Criminal Justice, False Certainty, and the Second Generation of Scientific Evidence," 95 *Cal. L. Rev.* 721, 740 (2007).

201. *The Wire*, episode 46, Know Your Place, see <http://www.hbo.com/thewire/episode/season4/episode46.shtml>.
202. “In the end, jurors said they found the 1-in-1.1 million general population statistic [the prosecutor] emphasized to have been the most ‘credible’ and ‘conservative.’ It was what allowed [the jury] to reach a unanimous verdict. ‘I don’t think we’d be here if it wasn’t for the DNA,’ said Joe Deluca, a 35 year old martial arts instructor. Asked whether the jury might have reached a different verdict if it had been given the 1 in 3 number, Deluca didn’t hesitate. ‘Of course it would have changed things,’ he said. ‘It would have changed a lot of things.’” Jason Felch and Maura Dolan, “DNA Matches Aren’t Always a Lock,” *Los Angeles Times*, May 3, 2008, <http://www.latimes.com/news/local/la-me-dna4-2008may04,0,6156934,full.story>.
203. Some have disagreed with how the *Los Angeles Times* presented the probabilities in this case. See Eugene Volokh, “DNA Matches and Statistics,” *The Volokh Conspiracy*, May 5, 2008, <http://volokh.com/posts/1210019406.shtml>.
204. Jason Felch and Maura Dolan, “DNA Matches Aren’t Always a Lock,” *Los Angeles Times*, May 3, 2008, <http://www.latimes.com/news/local/la-me-dna4-2008may04,0,6156934,full.story>.
205. FBI DNA Advisory Board, “Statistical and Population Genetics Issues Affecting the Evaluation of the Frequency of Occurrence of DNA Profiles Calculated From Pertinent Population Databases(s),” *Forensic Science Communications*, Vol. 2, Issue 3 (July 2000), <http://www.fbi.gov/hq/lab/fsc/backissu/july2000/dnastat.htm#Database%20Search>.
206. Recommendation 5.1 from this report states: “When the suspect is found by a search of DNA databases, the random-match probability should be multiplied by N, the number of persons in the database.” National Research Council, “The Evaluation of Forensic DNA Evidence: Commission on DNA Forensic Science: An Update,” *National Academy Press* Washington, D.C., 1996, <http://www.nap.edu/html/DNA/index.html#sum> (accessed on July 15, 2008).
207. “A partial match at 9 loci, for instance, would be a pair of individuals who match at 9 CODIS loci out of the 13.” Laurence D. Mueller, “Can Simple Population Genetic Models Reconcile Partial Match Frequencies Observed in Large Forensic Databases?” *Journal of Genetics*, 87:2 (July 8, 2008) 100–108.
208. William C. Thompson, “The Potential for Error in Forensic DNA Testing (and How That Complicates the Use of DNA Databases for Criminal Identification),” *GeneWatch* (forthcoming; manuscript on file with author, p. 18).
209. Jon Jefferson, “Cold Hits Meet Cold Facts: Are DNA Matches Infallible?” 40 *Transcript* 29–33 (2008). Barlow’s efforts to shed light on this issue have been repeatedly hindered. See generally, A.C. Thompson, “Weird Science: Why is S.F.’s Crime Lab Resisting Scrutiny by Defense Attorneys?” *San Francisco Bay Guardian*, April 6, 2005.
210. Bruce S. Weir, “The Rarity of DNA Profiles,” *Annals of Applied Statistics*, 1:2 2007, 358–370.
211. William C. Thompson, “The Potential for Error in Forensic DNA Testing (and How That Complicates the Use of DNA Databases for Criminal Identification),” *GeneWatch* (forthcoming; manuscript on file with author, p. 9).
212. See generally, William C. Thompson and Edward L. Schumann, “Interpretation of Statistical Evidence in Criminal Trials,” 11 *Law and Human Behavior* 167 (1987).
213. Jon Jefferson, “Cold Hits Meet Cold Facts: Are DNA Matches Infallible?” 40 *Transcript* 29–33 (2008).
214. For an overview of state and federal governments’ responses to alleged statistical mischaracterizations in calculating the odds of matching DNA database profiles, see Jason Felch and Maura Dolan, “How Reliable is DNA in Identifying Suspects?” *Los Angeles Times*, July 19, 2008.
215. Jon Jefferson, “Cold Hits Meet Cold Facts: Are DNA Matches Infallible?” 40 *Transcript* 29–33 (2008).
216. Pew Center on the States, “1 in 100: Behind Bars in America,” (March 2008), <http://www.pewcenteronthestates.org/uploadedFiles/One%20in%20100.pdf> (accessed Mar. 25, 2008).
217. “The United States incarcerates more people than any country in the world, including the far more populous nation of China. At the start of the new year, the American penal system held more than 2.3 million adults. China was second, with 1.5 million people behind bars, and Russia was a dis-

tant third with 890,000 inmates, according to the latest available figures. Beyond the sheer number of inmates, America also is the global leader in the rate at which it incarcerates its citizenry, outpacing nations like South Africa and Iran. In Germany, 93 people are in prison for every 100,000 adults and children. In the U.S, the rate is roughly eight times that, or 750 per 100,000. (See Appendix A-7 for additional international analysis.) To produce a fresh portrait of incarceration levels at the start of 2008, Pew conducted a survey of inmate counts from the states and the federal government. Our finding: the U.S. prison population rose by more than 25,000 inmates in 2007—a 1.6 percent rate of growth that brought the national prison census to 1,596,127.

Although the 2007 expansion didn't match the 3.1 percent hike during 2006, the growth tracks projections and continues a pattern of steady expansion that has characterized the U.S. penal system for more than 30 years. The consequences of that upward trend are many, but few can rival this: more than 1 in 100 adults is now locked up in America. With 1,596,127 in state or federal prison custody, and another 723,131 in local jails, the total adult inmate count at the beginning of 2008 stood at 2,319,258. With the number of adults just shy of 230 million, the actual incarceration rate is 1 in every 99.1 adults. That statistic masks far higher incarceration rates by race, age and gender. A separate analysis of midyear 2006 data from the U.S. Department of Justice shows that for Hispanic and black men, for instance, imprisonment is a far more prevalent reality than it is for white men. The young, meanwhile, are disproportionately more likely to wind up in prison than their elders. While one in every 15 black males aged 18 or older is in prison or jail, for black men over 55, the rate is one in 115." Pew Center on the States, "One in 100: Behind Bars in America," (March 2008), p. 5, <http://www.pewcenteronthestates.org/uploadedFiles/One%20in%20100.pdf> (accessed June 25, 2008).

218. *The Vortex: The Concentrated Impact of Drug Imprisonment and the Characteristics of Punitive Counties*, Justice Policy Institute, December 4, 2007, <http://www.justicepolicy.org> (accessed Mar. 25, 2008).
219. Ibid.
220. Ibid. at 7, citing the 2002 *National Survey on Drug Use and Health*, and the 2006 *Sourcebook on Federal Sentencing Statistics* from the U.S. Sentencing Commission.
221. Pew Center on the States, "1 in 100: Behind Bars in America," (March 2008) [\[teronthestates.org/uploadedFiles/One%20in%20100.pdf\]\(http://www.pewcenteronthestates.org/uploadedFiles/One%20in%20100.pdf\) \(accessed Mar. 25, 2008\).](http://www.pewcen-</div><div data-bbox=)

222. Pew Center on the States, "1 in 100: Behind Bars in America," (March 2008) <http://www.pewcenteronthestates.org/uploadedFiles/One%20in%20100.pdf> (accessed Mar. 25, 2008).
223. David Cole writes: "There are few available statistics on the racial breakdown of police stops. Where reported cases discuss bus and train sweeps, however, the defendants are virtually always Black or Hispanic. A search of all reported federal bus and train sweep cases from January 1, 1993, to August 22, 1995, found that, of fifty-five cases in which the defendant's race could be identified, thirty-six were black, eleven were Hispanic, one was Asian, one was Filipino, and six were white. As Justice Thurgood Marshall stated in dissent in *Bostick*, "the basis of the decision to single out particular passengers during a suspicionless sweep is less likely to be inarticulable than unspeakable." Thus, although doctrine leaves the police free to target whomever they please, the targets will not be random; by and large they will be young black men. All relevant data—from arrest rates to conviction rates to victim reporting—suggest that young people are more likely to commit crime than old people, men more likely than women, and black people more likely than white people. The disproportionate numbers of young black men in prison and jail—disparities that cannot be explained by discriminatory policing or prosecuting alone—suggest that if police are going to be guided not by individualized suspicion but by more general characteristics, the odds of discovering evidence of crime will be greater if they stop young black men. By permitting the police to use what is actually quite coercive behavior without any articulable basis for individualized suspicion, the Court's standard encourages the police to act on race-based judgments." David Cole, *No Equal Justice: Race and Class in the American Criminal Justice System* (1999).
224. "In an average year, over forty percent of people convicted of felonies in the United States are African-American. As a result, the set of individuals in the Offender Index is not racially neutral with regard to the American population. Although we have not been able to find confirmation of this, we assume, based on the felony conviction statistics, that African-Americans make up at least forty percent of the CODIS Offender Index, or roughly 1.1 million people out of 2.75 million." Henry T. Greeley, Daniel P. Riordan, Nanibaa' A Garrison, & Joanna L. Mountain, "Family Ties: The Use of DNA Offender Databases to Catch Offenders"

- Kin," 34 *Journal of Law, Medicine, and Ethics* 248, 258 (2007).
225. D.H. Kaye & Michael E. Smith, "DNA Identification Databases: Legality, Legitimacy, and the Case for Population Wide Coverage," 2003 *Wis. L. Rev.* 413, 452–453 (2003).
226. D.H. Kaye & Michael E. Smith, "DNA Identification Databases: Legality, Legitimacy, and the Case for Population Wide Coverage," 2003 *Wis. L. Rev.* 413, 452–453 (2003).
227. Tania Simoncelli and Sheldon Krinsky, "A New Era of DNA Collections: At What Cost to Civil Liberties?" *The American Constitution Society*, August 2007, p. 3, <http://www.acslaw.org/node/5338> (accessed Mar. 25, 2008).
228. See: "The Sins of the Fathers," *The Economist*, April 22, 2004, http://www.economist.com/world/britain/displaystory.cfm?story_id=E1_NGTTTTPR (accessed Mar. 25, 2008); "Killer Caught by Relative's DNA," BBC News, April 19, 2004, <http://news.bbc.co.uk/1/hi/england/3640199.stm> (accessed Mar. 25, 2008).
229. Frederick R. Bieber et. al., "Finding Criminals Through Their DNA," *Science Policy Forum*, June 2, 2006.
230. Henry T. Greely et. al., "Family Ties: The Use of DNA Offender Databases to Catch Offenders' Kin," 34 *Journal of Law, Medicine, & Ethics* 251–252 (2006).
231. James Randerson, "DNA of 37% of Black Men Held by Police," *Guardian* [UK], January 5, 2006, <http://www.guardian.co.uk/world/2006/jan/05/race.ukcrime>.
232. Ibid.
233. Henry T. Greely, Daniel P. Riordan, Nanibaa' A Garrison, & Joanna L. Mountain, "Family Ties: The Use of DNA Offender Databases to Catch Offenders' Kin," 34 *Journal of Law, Medicine, and Ethics* 248, 259 (2007).
234. Simon Cole, "How Much Justice Can Technology Afford? The Impact of DNA Technology on Equal Criminal Justice," 34 *Science and Public Policy* 95, 102 (2007).
235. "The past fifteen years has seen an enormous upsurge in the number of publications purporting to demonstrate a significant genetic basis for many human personality traits and social behaviors. Chief among these are manic depression, schizophrenia, alcoholism, shyness, homosexual-

ity, risk-taking, general personality factors, including 'religiosity,' intelligence, especially its racial distribution and, of course, criminality and its associated trait of 'violence.' A significant amount of both public and private money has been devoted to funding research on the supposed genetic basis of these complex human behaviors. Thus funding has been made available, and applications for proposals have been 'invited.' Funding has been dramatically increased in the past decade by the NIH among others, raising questions about the socio-political, as well as scientific reasons behind the support. The often preliminary results of this research have been reported to the general reading public through newspaper and magazine articles, television reports, and highly advertised books. The overwhelming conclusion of this literature is that a gene or genes have been demonstrated to cause, or at least strongly to predispose individuals toward specific social behaviors and personality traits. In conjunction with media hype surrounding the human genome project (the 'code of codes' and the 'holy grail' of modern research), and advances in neuroscience during the 'decade of the brain,' the general message is that science has at last begun to provide answers to humanity's most persistent, and seemingly most intractable social problems: the presence in civil society of sociopathic traits. A centerpiece among the recent hereditarian claims is that violent and criminal behavior has a strong genetic or neuro-genetic basis. Government programs have provided funds to study the genetics of violence and 'anti-social' behavior. The federally organized 'Violence Initiative,' which first came to the fore amid a howl of public protest in 1992, contains significant funds for genetic and neuropharmacological research on the origins of violence among inner city youth. In his presidential address to the Behavior Genetics Association (BGA) in June 1995, Glayde Whitney of Florida State University claimed that crime among blacks could have a genetic basis. Physical science seemed poised to provide answers to problems traditionally within the province of the social sciences." Garland, Allen E., "The biological basis of crime: An historical and methodological study," *Historical Studies in the Physical and Biological Sciences* (2001) Vol. 31, No. 2, 183–222.

236. Troy Duster, "Selective Arrests, an Ever-Expanding DNA Forensic Database and the Specter of an Early 21st Century Equivalent of Phrenology," in *DNA and the Criminal Justice System: The Technology of Justice* (David Lazer ed) 331 (2004).
237. For an overview of Gall's work, see S. Zola-Morgan, "Localization of Brain Function: The Legacy of Franz Joseph Gall (1758–1828)," *Ann. Rev. Neurosci* 18:359–383 (1995).
238. Vernellia Randall, "Slavery, Segregation, and Racism: The Health Care System Ain't Always Easy, An African American Perspective on Bioethics," 15 *St. Louis U. Pub. L. Rev.* 191, 227 (1995).
239. Frederick K. Goodwin, "Conduct Disorder as A Precursor to Adult Violence and Substance Abuse: Can the Progression be Halted," address to the American Psychiatric Association, May 5, 1992, quoted in Garland E. Allen, "Modern Biological Determinism: The Violence Initiative, the Human Genome Project, and the New Eugenics," in *The Practices of Human Genetics* (Michael Fortun and Everett Mendelsohn eds.) 1999.
240. Nicole Hahn Rafter, *Creating Born Criminals* (1997)
241. Allen writes that the at risk children that were of the most interest to the Violence Initiative came "predominantly from what Goodwin calls 'high impact urban areas.' Goodwin claims that targeted groups would include those in the inner city, families in which parents (or other custodial adults) have a low income and a low educational level, or female-headed households—all synonyms, of course, for poor, urban, African American (or in some areas, Hispanic-American) populations." Garland E. Allen, "Modern Biological Determinism: The Violence Initiative, the Human Genome Project, and the New Eugenics," in *The Practices of Human Genetics* (Michael Fortun and Everett Mendelsohn eds.) 1999.
242. From DNAGenomics website, <http://www.dnapi.com/welcome/productsandservices/forensics/> (accessed Mar. 25, 2008).
243. Image from Genome News Network, "Genome Test Nets Suspected Serial Killer," http://www.genomenewsnetwork.org/articles/06_03/serial.shtml (accessed Mar. 25, 2008).
244. Tony Frudakis, *Molecular Photofitting: Predicting Ancestry and Phenotype Using DNA*, p. 16 (2008).
245. DNAGenomics, Products and Services, <http://www.dnapi.com/welcome/productsandservices/forensics/> (accessed Mar. 25, 2008).
246. Duster provides a broader historical context from which to understand the dynamics of the function creep: "Social Security in the United

States was originally intended only as a federal retirement programme. The entire scheme was vigorously debated in the 1930s, and some members of Congress argued vehemently that the Social Security identification card should not be a national identification card. The vote in the Congress was close. However, the Internal Revenue Service (IRS) soon began using the Social Security number to track citizens for tax collection purposes. It was later used by many public services as a required personal identification number and, still later, private institutions began to demand it for identification purposes. This process is called 'function creep': the process by which the original function may remain, but newer uses expand into ever-widening spheres. Since it is the state that is primarily involved in criminal law enforcement, there have been state-by-state variations in the use of DNA databanks and storage. Fifteen years ago, most states were only collecting DNA samples from sexual offenders. Now, seven states require the DNA data banking of all felons, including those involved in white-collar felonies. When Governor Pataki proposed such a scheme for New York state, the state legislature forced him to jettison the idea. Louisiana was the first state to pass a law mandating the collection of DNA samples from anyone arrested for a felony but, in the past five years, it has been joined by Virginia and several other states. That is, just like 'function creep' with regard to Social Security identification numbers, the use by states of DNA databanks is rapidly expanding. Today, thirty-eight states store samples from varying categories of lawbreakers in a DNA databank. Twenty-nine states now require that tissue samples be retained in their DNA databanks after profiling is complete. Only one state, Wisconsin, requires the destruction of tissue samples once profiling is complete. What started as a tool for dealing with sex offenders has now 'crept' into a way to deal with lawbreakers and those merely arrested. Twenty states authorize the use of databanks for research on forensic techniques. Based on the statutory language in several of those states, this could easily mean assaying genes or loci that contain predictive information, even though current usage is restricted to analyzing portions of the DNA that are only useful as identifying markers. Since most states retain the full DNA (and every cell contains all the DNA information), it is a small step to using these DNA banks for other purposes. The original purpose has long been pushed to the background, and the 'creep' extends not only to crimes other than sexual offenses, but to misdemeanors and even arrestees." Troy Duster,

- “The Molecular Reinscription of Race: Unanticipated Issues in Biotechnology and Forensic Science,” 40 *Patterns of Prejudice* 427, 437–438 (2006).
247. William C. Thompson, “The Potential for Error in Forensic DNA Testing (and How That Complicates the Use of DNA Databases for Criminal Identification),” *GeneWatch* (forthcoming; paper on file with author), p. 2.
248. Sandra Soo-Jin Lee et al., “The Ethics of Characterizing Difference: Guiding Principles on Using Racial Categories in Human Genetics,” *Genome Biology* 9:404 (2008).
249. Devin Powell, “Ten Commandments of Race and Genetics Issued,” *New Scientist*, July 18, 2008, http://www.newscientist.com/channel/life/genetics/dn14345-ten-commandments-of-race-and-genetics-issued.html?feedId=genetics_rss20.
250. While an examination of health impact assessments is most relevant for the purposes of this discussion, it is important to acknowledge that health impact assessments have “much in common with and builds on “environmental impact assessment” and also has less recognized but salient links with the field of “health and human rights” and the concept of “human rights impact assessment.” Nancy Krieger et. al., “Assessing Health Impact Assessment: Multidisciplinary and International Perspectives,” *J Epidemiol Community Health* 2003;57:659–662.
251. World Health Organisation, Regional Office for Europe, “Technical briefing: Health impact assessment—a tool to include health on the agenda of other sectors.” 52nd session, Copenhagen, September 16–19, 2002, www.euro.who.int/document/rc52/ebd3.pdf.
252. John Kemm, “Perspectives on Health Impact Assessment,” *Bulletin of the World Health Organization*, 81(6) 387 (2003).
253. Racial impact statements or assessments have been proposed in other contexts such as mitigating sentencing disparities. See e.g., Marc Mauer, “Racial Impact Statements As a Means of Reducing Unwarranted Sentencing Disparities,” 5 *Ohio State Journal of Criminal Law* 19 (2007).
254. Nancy Krieger et. al., “Assessing Health Impact Assessment: Multidisciplinary and International Perspectives,” *J Epidemiol Community Health* 2003;57:659–662.

About the Center for Genetics and Society

The Center for Genetics and Society is a non-profit public affairs organization working to encourage responsible uses and effective societal governance of the human biotechnologies. We believe that these technologies hold great potential for advancing knowledge and treating disease, but that if abused they could undermine social justice and human rights, and create new forms of social discrimination and division.

CGS works in a context of support for the equitable provision of health technologies domestically and internationally; for women's health and reproductive rights; for the protection of our children; for the rights of the disabled; and for precaution in the use of technologies that could alter the

fundamental processes of the natural world. CGS is one of the few organizations looking seriously at how human biotechnology affects people of color.

CGS is a project of the Tides Center.

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