BEYOND PROTECTING GENETIC PRIVACY: UNDERSTANDING GENETIC DISCRIMINATION THROUGH ITS DISPARATE IMPACT ON RACIAL MINORITIES

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At the very end of the last century, scientists produced the first draft of the whole human genetic sequence. But that was just the first step; the hard work of the first few decades of this century will be to learn more about how to apply genetic information to improve health. As the pace of technological development accelerates and we learn more about what genetic variations mean about individual human characteristics and health risks, so too does the risk and consequences of the misuse of such information become more significant. The principal answer to this challenge has been to safeguard privacy by constructing legal and technical barriers that conceal and anonymize genetic information. While it may be a worthwhile objective, ultimately privacy protections will likely fail in practice. If this is so, how can we prevent genetic information from being used to categorize, stigmatize, and subordinate? This Note approaches this problem by analyzing the African American experience with genetic discrimination in the United States. African Americans have confronted the adverse consequences of genetic research in ways that can serve as a foundation to understand future threats posed to racial minorities and everyone in society, as genetic testing increases in prevalence and the privacy of genetic information is unable to be protected. Studying the real history of genetic discrimination, rather than merely speculating about what may happen, can point toward policy solutions that go beyond "genetic privacy." As genetic information becomes more plentiful and valuable, policies to prevent the misuse of that information will benefit everyone, regardless of race or ethnicity.

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INTRODUCTION

Science in the twenty-first century has been defined in large part by the successful completion of the Human Genome Project. As scientific understanding of the human genome increases, it will shape society as well. The human genome represents a source of information that is uniquely both universal and personal in nature. The composition and ordering of the chemical constituents of DNA determine what molecules are synthesized by all living cells and how living cells adapt to change and stress.[1] As members of the same species, we share more than ninety-nine percent of our DNA sequence with each other, as we all share the same cells, tissues, and organs, all with virtually indistinguishable functions.[2]

Yet each of us can be easily distinguished and identified by the information contained in what individual variation remains. Indeed, this tiny fraction of the genome is correlated with differences in disease risk, subtle differences in metabolism, physical characteristics, and all kinds of other hereditary factors that make us different from one another—possibly even behavioral propensities and personality. The promise of using these genetic differences to help tailor diagnostic tools, drug design, and treatment planning to maximize therapy and minimize side-effects at the individual level rather than the traditional "one-size-fits-all" approach has led to widespread excitement and investment around the concept of "personalized medicine."[3] Along with the promise of its benefits, genetic information poses considerable

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[1] Genetic information is encoded by the specific ordering of the four DNA "bases," which are typically identified by their first initials (Adenine, Thymine, Cytosine, and Guanine). This ordering is called the "sequence" of DNA. A fragment of DNA sequence is typically represented as a string of initials representing the bases along one strand of the DNA double-helix, *e.g.* ATCATGACCTGGA. "Genes" are the regions of DNA that encode proteins (the molecules that form the structure and perform the functions of living cells). The word "genome" denotes the entire DNA sequence of an organism, *i.e.* the human genome is all the DNA sequence on all the chromosomes combined, including all 25,000+ genes, regulatory sequences, and "junk" DNA for which no function has yet been discovered. Because new technologies make it so easy to rapidly generate DNA sequence information across large portions of the genome, scientists often use the words "DNA sequence," "genetic sequence," and "genomic sequence" interchangeably. *See, e.g.*, *Online Education Kit: Understanding the Human Genome Project*, NAT'L HUM. GENOME RESEARCH INST., http://www.genome.gov/25019879 (last visited Mar. 17, 2012).

[2] NAT'L HUM. GENOME RESEARCH INST., A GUIDE TO YOUR GENOME 1, *available at* http://www.genome.gov/Pages/Education/AllAbouttheHumanGenomeProject/GuidetoYourGenome07.pdf (last visited May 5, 2012).

[3] *See generally* Mara G. Aspinall & Richard G. Hamermesh, *Realizing the Promise of Personalized Medicine*, 85 HARV. BUS. REV. 108 (2007) (describing business models for personalized medicine in the pharmaceutical industry). There is

risks as well, with the potential of "personalized" stereotyping, stigmatization, and discrimination based on the carriage of "undesirable traits."

These risks underscore the importance of preserving the privacy of genetic information. Formal legal protections for medical patients and genetic research study participants in the United States are based on protecting privacy interests primarily through anonymization.[4] Privately, biobanks and other data collectors also use informed consent covering disclosure risks that may occur despite formally mandated protections.[5] Recently, federal legislation has been passed in the form of the Genetic Information Nondiscrimination Act ("GINA"), which generally prohibits the acquisition and use of genetic information by health insurance providers and employers.[6] While it includes anti-discrimination provisions, GINA is fundamentally based on privacy and the nondisclosure of genetic information, and prohibits the use of genetic testing by employers.

For most Americans, GINA addresses the fantastical problems seen in science fiction movies, not real-world problems they experience themselves. However, genetic discrimination already has a history in the United States, particularly targeting African Americans within the contexts of employment, medical research, and forensic DNA databases used in criminal investigation. In general, genetic testing presents racial minorities with the prospect of racial difference being seen as the pre-World War II paradigm of fixed biological grounds based on hereditary genetic information, rather than a social construction that can be challenged, reformed, and eventually eliminated. This Note analyzes the disparate incidence of genetic discrimination against racial minorities, in particular African Americans, as exemplified by the past experience of discriminatory genetic testing and present occurrence of genetic discrimination in the context of medical research and forensic DNA databases. Looking at genetic discrimination through this lens reveals that an approach based on ensuring privacy and focusing on individual consent will not work. Rather, policy solutions must be developed that target the specific problems generated by the availability of genetic information.

The first part of this Note reviews privacy risks specific to DNA sequence data, including the practical reasons why anonymity fails. The second part discusses specific risks of genetic information misuse, highlighting issues particularly significant for African American and other minority communities. Importantly, not only does genetic information misuse cause specific harms, its prevalence has resulted in a fear of participation in the next generation of genetic medicine among already disadvantaged minorities. The final part describes potential solutions for protecting research participants and others from misuse of their genetic information, based on the need to go beyond a practically obsolete privacy-based framework. While this Note focuses on the African American experience with genetic discrimination, this experience demonstrates that genetic testing poses real threats that exist now and will affect a larger population as genetic testing becomes more common. Responding to the specific concerns of African Americans—which arise from misuse of genetic testing in the medical context, from the categorization and stigmatization of individuals on the basis of genetic disease, and from the risks of the use of genetic information by law enforcement—will benefit everyone, regardless of race or ethnicity.

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tremendous interest in the field—simply entering "personalized medicine" as a search string in the National Institutes of Health's PubMed literature yields well over 1000 articles.

[4] *See infra* notes 19–24 and accompanying text.

[5] *See infra* note 148 and accompanying text.

[6] Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (2008) [hereinafter GINA].

I. LIMITS TO PRIVACY AS A PROTECTIVE MEASURE

A. Practical Limitations on Genetic Anonymity as a Basis for Privacy

The principal mechanism used to prevent privacy risks, both in medical research and in other applications, is the separation of personally identifiable information from accompanying DNA.[7] The de-identification or anonymization of data is the only requirement that is actually mandated by federal regulations for federally funded research and data associated with medical records.[8] Many states supplement federal law with additional regulations.[9] One of the main concerns of these state regulations is to ensure consent for subsequent independent research projects that use preserved samples, which otherwise would no longer be under the control of the donor in the absence of a specific contractual obligation.[10]

The two primary means for regulating research data are the Privacy Rule of the Health Insurance Portability and Accountability Act ("HIPAA")[11] and the federal regulation for Protection of Human Subjects,[12] known as the Common Rule.[13] The Common Rule applies to all research involving human subjects that is "conducted, supported, or otherwise subject to regulation"[14] by the federal government. This rule applies broadly to all federally funded research, research that takes place using federally funded facilities, and private research that is federally regulated, such as clinical trials used to generate data for FDA approvals. The HIPAA Privacy Rule applies to "covered entities," including health plans,

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[7] *See, e.g.*, Stephen J. O'Brien, Stewardship *of Human Biospecimens, DNA, Genotype, and Clinical Data in the GWAS Era*, 10 ANN. REV. GENOMICS & HUM. GENETICS 193, 201–02 (2009).

[8] *See, e.g.*, Mark A. Rothstein, *Expanding the Ethical Analysis of Biobanks*, 33 J.L. MED. & ETHICS 89, 91–92 (2005) (describing ethical issues regarding DNA biobanks, in particular informed consent, and the legal protections for privacy in the United States).

[9] *See generally Genetic Privacy Laws*, NAT'L CONF. OF ST. LEGISLATORS, http://www.ncsl.org/issues-research/health/genetic-privacy-laws.aspx (last updated Jan. 2008) (surveying the status of state genetic privacy laws). For example, Arizona has legislation that requires "specific informed written consent" for a genetic test unless otherwise specifically authorized by state law (*i.e.* for forensic DNA databases), as well as "expressed consent" of the test subject for the release of the results to any party. ARIZ. REV. STAT. ANN. § 20-448.02 (2012). Louisiana's genetic privacy provision makes genetic tests part of the test subject's medical record, and thus confidential without "express written consent." LA. REV. STAT. ANN. § 40:1299.6 (2011). Louisiana also has a statutory provision for the collection of genetic information by health insurers that defines the insured's genetic information as the "property" of the insurer and prohibiting its retention by any parties except for criminal and death investigations, and for paternity determination. LA. REV. STAT. ANN. § 22:1023(E) (2011). The federal GINA statute would now supersede this provision.

[10] *See* Katherine Drabiak-Syed, *State Codification of Federal Regulatory Ambiguities in Biobanking and Genetic Research*, 30 J. LEGAL MED. 299, 305 (2009) (noting that of the approximately two-thirds of states that have supplemented federal regulations, only a few limit third-party release, and only another few address the collection, storage, and future use of biological specimens).

[11] Standards for Privacy of Individually Identifiable Information, 45 C.F.R. pts. 160, 164 (2012).

[12] HHS Protection of Human Subjects Rule, 45 C.F.R § 46 (2012); FDA Institutional Review Boards Rule, 21 C.F.R § 56 (2012).

[13] *See generally* Mark A. Rothstein, *Research Privacy Under HIPAA and the Common Rule*, 33 J.L. MED. & ETHICS 154 (2005) (discussing the relationship between the HIPAA and the Common Rule in regulating the privacy of information obtained in the course of experimental studies).

[14] 45 C.F.R. § 46.101(a) (2012).

healthcare clearinghouses (*e.g.* billing services), and healthcare providers that use any kind of electronic records.[15]

In practice, much other research takes place under the same terms as the HIPAA Privacy Rule, even if it does not formally comply, in part because the administrative load on the researching entity is not substantially different.[16] The Common Rule does not apply to data collected on an anonymous basis, while HIPAA may apply if such data are collected on a form that constitutes an applicable medical record.[17] If such data were collected from an individual whose identity was then removed from the data (*i.e.* de-identified or anonymized data), then the Common Rule and its requirements for informed consent would apply.[18]

The HIPAA Privacy Rule sharply restricts the use and disclosure of "protected health information," which is any "individually identifiable health information" held by a covered entity.[19] However, there are no restrictions on the use or disclosure of de-identified health information.[20] Health information is considered de-identified in two ways. First, a qualified statistician may make a formal determination that the information has been de-identified.[21] Second, specified identifiers of the individual and relatives, household members, and employers, may be removed and the covered entity has no actual knowledge that the remaining information could be used to identify the individual.[22] This is the HIPAA "Safe Harbor," and examples of such data include names, telephone numbers, email addresses, any geographical information except for the first three digits of a zip code (subject to population restriction provisions), Social Security numbers, all kinds of account and driver's license information, any identifying visual information (such as full-face photographs), and any biometrics (like fingerprints).[23] Notably, the covered entity may still retain a code that can be used to re-identify the individual, provided the code is adequately protected from decryption and is securely held.[24]

The use of anonymity to protect genome data thus follows the precedent set by decades of other kinds of biomedical research, in which the privacy of patients and clinical trial participants is preserved by stripping data of personal identifiers in compliance with HIPAA and Common Rule provisions described above. The post-genome era of medical research challenges this traditional privacy-based

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[15] 45 C.F.R. § 160.103 (2012).

[16] *See, e.g.*, Sarah Fendrick, *The Role of Privacy Law in Genetic Research*, 4 I/S: J.L. & POL'Y FOR INFO. SOC'Y 803 (2008). For example, one difference is that the Common Rule only applies to living research participants, but the HIPAA applies to the deceased as well.

[17] *See, e.g.*, Appendix F of the Report of the Secretary's Advisory Committee on Human Research Protections (SACHRP), HHS OFC. FOR HUM. RES. PROTECTIONS, *available at* http://www.hhs.gov/ohrp/sachrp/appendixf.html (last visited Feb. 28, 2011).

[18] *Id.*

[19] 45 C.F.R. § 160.102 (2012).

[20] 45 C.F.R. § 160.502(d) (2012) (assuming the information required to reestablish re-identification is not included in the disclosure).

[21] 45 C.F.R. § 164.514(b)(1) (2012).

[22] 45 C.F.R. § 164.514(b)(2) (2012).

[23] 45 C.F.R. § 164.514(b)(2)(i)(B) (2012).

[24] 45 C.F.R. § 164.514(c) (2012).

approach to medical information. In the past decade since the draft human genome sequence was released, it has been clear that the functional consequences of individual genetic variation occurs in many different genes throughout the whole human genome, as well as in regions of DNA that are not associated with known genes.[25] At the same time, advances in DNA sequencing technology have made it feasible to cheaply and rapidly obtain a large amount of genomic data from a minute sample of biological material, such as from approximately a milliliter of blood or saliva, or even from a cheek swab.[26] Moreover, human genetic research has advanced at the same time as innovation in computation and communication technologies. These innovations not only provide the means for storing and analyzing massive data sets for individuals, but they also allow the sharing of data sets and their integration to learn more about how to interpret the genome.

This combination of technological advances enables the key experimental tool for human genetic research as it moves beyond the culmination of the Human Genome Project and publication of the first full human DNA sequence into the "post-genome" era: the Genome-Wide Association Study ("GWAS").[27] To conduct an effective GWAS requires enrolling as many subjects from as diverse a population as possible.[28] To this end, the concept of national "biobanks" has been developed to contain a combination of DNA sequence information and as much data for potential phenotypes[29] about what are eventually to be hundreds of thousands of enrolled volunteers. National biobanks have been established in Iceland, Japan, the United Kingdom, Estonia, Canada, Sweden, and China, among others, and one has been proposed for the United States as well, which are even larger than those currently being developed by non-profit research organizations and private pharmaceutical firms.[30] In addition, a

[25] *See* 1000 Genomes Project Consortium et al., *A Map of Human Genome Variation from Population-Scale Sequencing*, 467 NATURE 1061 (2010) (describing the location of 15 million sites of base variation found in a dataset of fully sequenced genomes from 1000 individuals, which is likely to represent over ninety-five percent of variation found in the whole human population).

[26] *See, e.g.*, Chunsun Zhang & Da Xing, *Miniaturized PCR Chips for Nucleic Acid Amplification and Analysis: Latest Advances and Future Trends*, 35 NUCLEIC ACIDS RES. 4223 (2007) (describing chip-based DNA amplification methods that can work with sample volumes of as little as 3 μL).

[27] *See* Teri A. Manolio, *Genomewide Association Studies and Assessment of the Risk of Disease*, 363 NEW ENG. J. MED. 166 (2010) (providing an overview of technical challenges related to GWAS and summarizing and linking to over 600 GWAS publications). Typically in a GWAS, human test subjects are grouped according to some observable variable, for example whether they have a particular disease or not, or whether a drug has the desired effect or not, etc. Statistical techniques are used to determine all the DNA sequence features that correlate with differences between the groups.

[28] There may be several hundred thousand to millions of genetic features that are compared across whole genomes. One of the key principles in statistics is that reliable correlations require that the number of observations exceeds the number of variables, which would imply that millions of people have to be enrolled in a GWAS for it to be useful. Costs and other practical considerations have meant that most studies only involve thousands or even hundreds of participants, and sophisticated statistical methods are used to analyze the data. *See* John P.A. Ioannidis, *A Compendium of Genome-Wide Associations for Cancer: Critical Synopsis and Reappraisal*, 102 J. NAT'L CANCER INST. 846 (2010) (using statistical analysis as a basis to criticize and reassess the findings of cancer gene risk in most GWAS).

[29] A potential phenotype in this context refers to any variable that could potentially be correlated to some set of genetic factors. This can be any imaginable human characteristic, from height, to risk of developing breast cancer by the age of 65, to narcotic addiction, to ability to metabolize tryptophan, propensity to be arrested for a crime, and so on. While it is more precise to use the word "phenotype" in an actual sense where the genetic link has been established, the term is used ambiguously in the genetic literature. *See, e.g.*, O'Brien, *supra* note 7.

[30] *See, e.g.*, OECD, CREATION AND GOVERNANCE OF HUMAN GENETIC RESEARCH DATABASES (2006). A list of biobanks around the world that are currently members can be found at the Confederation of Cancer Biobanks website. *Current Members*, CONFEDERATION OF CANCER BIOBANKS, http://www.ncri.org.uk/ccb/currentmembers.html (last visited May 6, 2012).

growing number of private "personal genomics" firms are now producing genome sequence information for a fee.[31] At least one such service, 23andMe, is using the data it collects from its customers to perform a progressively more comprehensive GWAS.[32] Another emerging venue for GWAS is in the workplace. Employees may enroll in health and wellness programs, as well as research into potential occupational health hazards, which may have a comprehensive genetic testing component.[33]

Because GWAS research necessarily means large-scale disclosure of individual genomic data, preserving informational privacy is a major challenge. As GWAS participation proliferates, three trends emerge that compound the risk of inadvertent disclosure of a person's identity associated with DNA sequence data: first, more databases are being established that store large genomic data sets from more people; second, individual data sets from more people are being combined together and associated with more detailed phenotype information; and third, data may be obtained from the same individual in multiple studies, which means that their genomic data may be stored in multiple databases. Open data sharing is critical for progress in human genome research, because so much data are required to interpret complex individual variations occurring over large populations with any statistical significance. The National Institutes of Health ("NIH") has formally established a policy for public release of data from federally funded GWAS, stating that "the NIH believes that the full value of GWAS to the public can be realized only if the genotype and phenotype datasets are made available as rapidly as possible to a wide range of scientific investigators," in particular due to "extraordinary opportunities for making comparisons across multiple studies."[34] Restrictions on data openness to preserve privacy have been sharply criticized by scientists as potentially limiting the future of genetic research.[35]

Data security methods have practical limitations as well. Measures that try to tweak simple anonymization to better obscure the association between personal identity and genomic data have practical limitations. In other applications, complex data sets with private information are protected by some kind of statistical transformation that reduces its identifiability.[36] One possible way of doing this with DNA sequence data would be to introduce "noise" into the data set, for example by randomly

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[31] Katherine Harmon, *Genome Sequencing for the Rest of Us*, SCI. AM. (June 28, 2010), http://www.scientificamerican.com/article.cfm?id=personal-genome-sequencing.

[32] Nicholas Eriksson et al., *Web-Based, Participant-Driven Studies Yield Novel Genetic Associations for Common Traits*, 6 PLOS GENETICS e1000993 (2010).

[33] The text of the Genetic Information Nondiscrimination Act (GINA) (2008) and regulations promulgated by the U.S. Equal Employment Opportunity Commission (EEOC) to implement it explicitly anticipate this possibility. For example, GINA sets out as an exception to the prohibition and allows employers to request, require, or purchase genetic information where "health or genetic services are offered by the employer, including such services offered as part of a wellness program." GINA § 202(b)(2)(A), 42 U.S.C. § 2000ff-1 (2012). There is also an exemption to the disclosure prohibition "to an occupational or other health researcher if the research is conducted in compliance with the regulations and protections provided for under part 46 of title 45, Code of Federal Regulations." GINA §206(b)(2), 42 U.S.C. § 2000ff-5 (2012).

[34] *Policy for Sharing of Data Obtained in NIH Supported or Conducted Genome-Wide Association Studies (GWAS)*, NIH Notice NOT-OD-07-088, NAT'L INST. OF HEALTH (Aug. 28, 2007), http://grants.nih.gov/grants/guide/notice-files/NOT-OD-07-088.html [hereinafter NIH NOTICE].

[35] Dov Greenbaum et al., *Genomics and Privacy: Implications of the New Reality of Closed Data for the Field*, 7 PLOS COMP BIOLOGY e1002278 (2011).

[36] *See, e.g.*, A. D. Marks & K. K. Steinberg, *The Ethics of Access to Online Genetic Databases: Private or Public?*, 2 AM. J. PHARMACOGENOMICS 207 (2002) (describing the ethical consequences of private versus public genome sequencing projects, including the issue of public research projects releasing data freely to the public).

changing some of the bases in the sequence of a particular individual.[37] While this would certainly reduce identifiability, it would have a severely adverse impact on the utility of the data. This is because most genetic variation between different individuals is in fact in single base sites, so any errors or deliberate noise introduced into the data would make it impossible to correlate these variations with any physical or disease-related manifestation. It could be possible to use these noise-generating techniques to obscure associated personal demographic information or clinical information, but again there would be similar costs in terms of the ability to interpret the impact of genetic variation. In addition, researchers have suggested ways in which sophisticated cyber-attacks may compromise noising schemes to reveal protected data.[38]

An alternative is to encrypt the data and rely on computer and network security mechanisms to restrict access and make it harder for someone to employ re-identification techniques. This is the approach taken by NIH in putting its public genome databases behind a controlled access firewall (and mandating that researchers do so as well).[39] This, however, is still an imperfect solution. Many research groups will still have access to the data because they need to use it,[40] and as a result, the system relies on maintaining effective access control to a relatively open network. For the system to succeed and not overly inhibit research work by legitimate users, the credentialing process for eligible researchers must balance the need for openness and a wide diversity of research users with the need to keep things confidential. This means holes will necessarily be left open for unscrupulous exploitation.[41]

The preceding discussion has focused primarily on genetic information collected in the course of GWAS. Other DNA sequence data are being collected and stored online, leading to the same issues regardless of whether information is accessed by hackers or disclosed voluntarily. The latter is not an unrealistic possibility. For example, in the future, people may add genetic data to the information they share in online social networks. Even today, some of the people who have used commercial genome sequencing technology have released their data to the public under their own names.[42] It only costs a few hundred dollars now to obtain DNA data on hundreds of thousands of single base variations that are associated with disease risk and ancestry. The cost of a whole personal genome sequence is now under $20,000, and prices are dropping exponentially. In a legal and regulatory regime that requires preserving anonymity as a theoretically effective means of preserving genetic privacy, practically speaking, the anonymity approach is facing increasing challenges by the continuous and rapid expansion of access to cheap genome sequencing, computation, and communications technology.

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[37] *See, e.g.*, Bee-Chung Chen et al., *Privacy-Preserving Data Publishing*, 2 FOUND. & TRENDS IN DATABASES 1, 15 (2009).

[38] *Id.* at 117–19.

[39] NIH NOTICE, *supra* note 34.

[40] *Id.* "Investigators and institutions seeking data from the NIH GWAS data repository will be expected to meet data security measures (such as physical security, information technology security, and user training) and will be asked to submit a data access request, including a Data Use Certification, that is co-signed by the investigator and the designated Institutional Official(s). Data access requests should include a brief description of the proposed research use of the requested GWAS dataset(s)."

[41] For example, not only would principal investigators have access to data, but also a variety of graduate students, postdoctoral researchers, staff technicians, and casual labor such as undergraduate students.

[42] *See, e.g.*, *Data/Code*, GENOMES UNZIPPED, *available at* www.genomesunzipped.org/data (last visited May 6, 2012) (providing links to the genetic sequence data of Genomes Unzipped consortium members).

B. Limited Legal Protections on Genetic Privacy

The Fourth Amendment of the United States Constitution prohibits unreasonable searches and seizures, placing a significant limitation on privacy invasion. This limitation presupposes an expectation of privacy: specifically, both an individual's actual, subjective expectation of privacy and an objectively reasonable one.[43] A requirement of an objectively reasonable expectation of privacy has important consequences for genetic information privacy because of how the Fourth Amendment deals with "abandoned property."[44] The Supreme Court has held that Fourth Amendment protection does not extend to property that is abandoned or voluntarily discarded.[45] Thus, there is a question about whether DNA obtained from discarded property would pose any constitutional issues.

This question has played out in different ways. In one recent case, *United States v. Davis*, the defendant was first admitted to a hospital for a gunshot wound, at which point his clothing was searched and subsequently confiscated by the police after marijuana was found.[46] Then, during a later murder investigation, DNA on the clothing was tested and the sample was retained. In a second murder investigation, the DNA sample was used to identify the defendant, who then moved to suppress the evidence as the product of an illegal search.[47] During its analysis of the objectively reasonable expectation of privacy, the federal district court noted,

> Nor does the Court necessarily agree that conscious disposal of an item, or unconscious shedding of hair, saliva, or dermal cells, reasonably supports the conclusion that an individual has manifested an intent to abandon one's privacy interest in the information that can be gleaned from that item or tissue by DNA analysis. . . . A colorable argument could certainly be made that a reasonable societal expectation exists that law enforcement officials will not follow individuals around, waiting for an opportunity to collect and analyze their DNA without their knowledge or consent.[48]

As a result, the court moved onto a Fourth Amendment analysis, and found that in the "totality of circumstances," the search was lawful—though it did fall under constitutional jurisdiction.[49]

However, most courts do not consider abandoned DNA to fall under Fourth Amendment protection at all. For example, in *Williamson v. State*, the Maryland Court of Appeals, the state's highest court, considered the circumstances in which the defendant, while under arrest for unrelated charges, was brought a meal from McDonald's. The cup he discarded from the meal was tested for a DNA match to two rapes that he was suspected of perpetrating.[50] The court held that the cup had been abandoned

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[43] *See generally* Katz v. United States, 389 U.S. 347 (1967).

[44] *See generally* Elizabeth E. Joh, *Reclaiming "Abandoned" DNA: The Fourth Amendment and Genetic Privacy*, 100 NW. U. L. REV. 857 (2006). The opinions discussed here cite to the Joh article.

[45] Abel v. United States, 362 U.S. 217, 241 (1960).

[46] 657 F. Supp. 2d 630, 634 (D. Md. 2009).

[47] *Id.*

[48] *Id.* at 649–50.

[49] *Id.* at 650.

[50] 993 A.2d 626, 634 (Md. 2010), *cert. denied*, 131 S. Ct. 419 (2010).

and thus the Fourth Amendment did not apply.[51] The court noted the *Davis* result, but it cited only to the part of the opinion distinguishing clothing from other cases of abandoned property, ignoring the passage quoted above.[52]

Courts have also acknowledged the sensitivity of genomic information in an area in which they have endorsed the mandatory collection of genetic data: forensic DNA databases. In allowing the collection of DNA for such databases, courts have carefully underlined the fact that such databases contain only a limited amount of genetic information required to determine identity.[53] Courts analogize the DNA in such databases to fingerprints and other means of identification that are not loaded with the kind of personal information that a whole sequence would entail, thus limiting the intrusive nature of DNA retention.[54] But, importantly, while permitting the collection of DNA, these courts have in some cases acknowledged that other information can be included in these databases.[55] Also, the majorities have ignored criticism from dissenters pointing to the possibility that future scientific research may reveal that those sequences do contain more information.[56] Thus, there is a broad judicial consensus at the state and federal levels encouraging the expansion of forensic DNA use and storage beyond just those convicted of felonies to those arrested for many kinds of misdemeanors and convicted of any crime.[57]

The key limitation on genetic privacy protection is reliance on the reasonable expectation of privacy. And, as society becomes more accustomed to routine genetic testing, this expectation is rapidly diminishing. As the *Davis* court suggested once it turned to its Fourth Amendment analysis and balancing the defendant's privacy interest, "In this day and age, where DNA testing is referenced almost daily in the news and on popular television series such as 'CSI' and 'NCIS,' this certainly should have put Davis on notice that his DNA *could* someday be tested."[58] Thus, there is arguably no reasonable expectation of privacy left in genetic information as it pertains to identification.

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[51] *Id.* at 635.

[52] *Id.* at 641.

[53] *See, e.g.*, United States v. Kincade, 379 F.3d 813, 818 (9th Cir. 2004) ("Through the use of short tandem repeat technology ('STR'), the Bureau analyzes the presence of various alleles located at 13 markers (or loci) on DNA present in the specimen. These STR loci are each found on so-called 'junk DNA'—that is, non-genic stretches of DNA not presently recognized as being responsible for trait coding—and were purposely selected because they are not associated with any known physical or medical characteristics.").

[54] *See*, *e.g.*, Nicholas v. Goord, 430 F.3d 652, 671 (2d Cir. 2005) ("[W]e see the intrusion on privacy . . . as similar to the intrusion wrought by the maintenance of fingerprint records.").

[55] The *Kincade* court, for example, acknowledges that the DNA profiles may identify race or sex. 379 F.3d at 818.

[56] *See*, *e.g.*, *id.* at 850 (Reinhardt, J., dissenting). *See also* the Second Circuit's tacit acknowledgment of scientific uncertainty in *Nicholas*: "DNA databases like New York's utilize 'junk DNA,' which does not (*as far as we know*) contain genetic information." 430 F.3d at 656, n.3 (emphasis added).

[57] *See, e.g.*, Dean G. Skelos, *Senate Passes DNA Databank Expansion Bill* (Jan. 31, 2012), www.nysenate.gov/press-release/senate-passes-dna-databank-expansion-bill (describing the New York State Senate's passage of legislation supported by Governor Cuomo to require those convicted of all felonies, and misdemeanors in the penal law, to supply DNA samples).

[58] United States v. Davis, 657 F. Supp. 2d 630, 651–52 (D. Md. 2009) (emphasis in original).

The Fourth Amendment analysis on the reasonable expectation of privacy also applies to state action. However, even where at the state level there is constitutional privacy protection that does not require state action, as in under the California constitution, courts have analyzed the privacy right the same way by requiring a "reasonable expectation of privacy in the circumstance."[59] There is the additional possibility that privacy tort law could provide an alternative mechanism for preventing the use of information that could be obtained from abandoned DNA. Such an action would be based on the publication of information about a person without consent.

Privacy tort actions may be brought when a matter regarding private life is publicized, such that it "(a) would be highly offensive to a reasonable person, and (b) is not of legitimate concern to the public."[60] In some cases, the fact of an invasion of privacy is non-controversial; in particular, "facts related to an individual's sexual relations, or 'unpleasant or disgraceful' illnesses, are considered private in nature and the disclosure of such facts constitutes an invasion of the individual's right of privacy."[61] An example would be a person's positive HIV status.[62] However, not all nonconsensual revelations of genetic information constitute a tortious invasion of privacy. Genetic information may be negative for disease risk, or it could be relatively benign information such as eye color. Thus, a successful privacy tort action brought for genetic information would likely be limited to cases in which real harm occurs, such as through discrimination or stigmatization.

Even beyond this caveat, the privacy tort is sharply limited by free speech rights.[63] Genetic information may be published if it is already in the public record[64] or if it is "newsworthy," a broad description that includes even such deeply private information as the names of rape victims[65] or the homosexuality of public figures.[66] Indeed, there is precedent from wiretapping law suggesting that even

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[59] The California state constitution includes the provision, amended by referendum, "All people are by nature free and independent and have inalienable rights. Among these are enjoying and defending life and liberty, acquiring, possessing, and protecting property, and pursuing and obtaining safety, happiness, and *privacy*." CALIF. CONST. ART. 1 § 1 (emphasis added). The California Supreme Court has held that the provision requires "that a plaintiff alleging an invasion of privacy in violation of the state constitutional right to privacy must establish each of the following: (1) a legally protected privacy interest; (2) a reasonable expectation of privacy in the circumstances; and (3) conduct by defendant constituting a serious invasion of privacy." Hill v. Nat'l Collegiate Athletic Ass'n., 865 P.2d 633, 657 (Cal. 1994). *See also* Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260, 1271 (9th Cir. 1998) (interpreting the California constitutional claim by following its Fourth Amendment balancing of "reasonable expectation" and government interests).

[60] RESTATEMENT (SECOND) OF TORTS, § 652D (1977).

[61] Robert C. Ozer, P.C. v. Borquez, 940 P.2d 371, 377 (Colo. 1997).

[62] *See, e.g.*, Urbaniak v. Newton, 226 Cal. App. 3d 1128, 1140 (Cal. Ct. App. 1991).

[63] *See generally* Eugene Volokh, *Freedom of Speech and Information Privacy: The Troubling Implications of A Right to Stop People from Speaking About You*, 52 STAN. L. REV. 1049 (2000) (arguing that almost any privacy protection that would allow someone to unilaterally limit another's expression rights necessarily would be unconstitutional).

[64] Cox Broad. Corp. v. Cohn, 420 U.S. 469, 494 (1975) ("[E]ven the prevailing law of invasion of privacy generally recognizes that the interests in privacy fade when the information involved already appears on the public record.").

[65] Florida Star v. B.J.F., 491 U.S. 524 (1989).

[66] Sipple v. Chron. Publ'g Co., 154 Cal. App. 3d 1040 (Cal. App. Ct. 1984) (finding that the homosexuality of a plaintiff who had intervened to grab the arm of a man attempting to assassinate President Gerald Ford was newsworthy and could thus be publicized).

if genetic information were to be obtained through unlawful means and then turned over to the media, the information may be broadcast.[67] In general, while there may be some scope for statutory or common law mechanisms to prevent the publication of genetic information without consent, it will be limited by the First Amendment. It is unclear how privacy laws based on the reasonable expectation of privacy will translate to a future of ubiquitous genetic information.

II. PAST AND CONTINUING GENETIC DISCRIMINATION TARGETING RACIAL MINORITIES

A. Racially Targeted Genetic Testing

While genetic testing is increasingly a fact of life for all Americans, African Americans have had a longer and more problematic history of adverse consequences and controversial applications of testing for hereditary conditions. This is exemplified by the legislative findings supporting GINA. Since Congress crafted GINA following the framework of other antidiscrimination legislation, the Act contains findings that include a history of genetic discrimination, but in doing so, GINA's drafters were limited by genetic testing's necessarily limited history.[68] The specific examples that are in the Act arise from testing that targeted African Americans in particular. The Findings describe screening for carriers of sickle cell anemia, a disease that mostly affects African Americans. The screening, which began in the 1970's, was imposed on African Americans specifically to determine health insurance coverage, to decide whether they had the qualifications to join and remain in the military, for permission to play high school athletics, and as a condition for employment.[69] Eventually, sickle cell disease testing was actually mandated by state legislatures.[70] GINA's Findings also refer to *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*[71], a case about sickle cell testing that represents the only appellate decision about pre-employment genetic screening from the era prior to GINA's passage.

The laboratory, which was run by a federal contractor, collected blood and urine samples from all employees, and plaintiffs sued for invasion of privacy due to syphilis, pregnancy, and sickle cell testing that was done on the samples without informing employees.[72] The latter genetic test for sickle cell

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[67] *See* Bartnicki v. Vopper, 532 U.S. 514 (2001) (holding that even though the information in question was known to have been obtained through an illegal wiretap, the media could report it because it was newsworthy).

[68] *See generally* Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439 (2010) (discussing evidence supporting and detracting from a history of genetic discrimination and detailing GINA proponents' concession of the Act's "preemptive" and anticipatory nature).

[69] Diane Beeson & Troy Duster, *African American Perspectives on Genetic Testing*, *in* THE DOUBLE-EDGED HELIX: SOCIAL IMPLICATIONS OF GENETICS IN A DIVERSE SOCIETY 152, 154 (Joseph S. Alper et al. eds., 2002).

[70] GINA, Pub. L. 110-233, § 2(3), 122 Stat. 881 (2008). Congress did pass the National Sickle Cell Anemia Control Act in 1972, which withheld federal funding from states with mandatory screening programs, and broad screening programs led to the first state anti-discriminatory laws. Pub. L. 92-294, 86 Stat. 136 (1972).

[71] GINA § 2(4), referring to *Norman-Bloodsaw v. Lawrence Berkeley Laboratory,* 135 F.3d 1260 (9th Cir. 1998). *See also* Elizabeth Pendo, *Race, Sex, and Genes at Work: Uncovering the Lessons of Norman-Bloodsaw*, 10 HOUS. J. HEALTH L. & POL'Y 227 (2010) (describing in detail the history of the case with a particular focus on aspects related to race and gender that are often neglected in favor of discussing personal privacy issues). Another case on record regarding sickle cell disease testing is *Jones v. Inter-County Imaging Centers*, 889 F. Supp. 741 (S.D.N.Y. 1995) (denying defendants' motion for summary judgment on the ADA claim, but publishing no details of the opinion).

[72] *Norman-Bloodsaw*, 135 F.3d at 1265. The University of California had a contract with the United States Department of Energy to run this particular laboratory.

disease was done only on samples from black employees, and it continued through June 1995.[73] The Ninth Circuit determined that the Fourth Amendment applied, rejecting the lower court's determination that testing was "de minimis" and thus no violation of privacy occurred "in light of (1) the 'large overlap' between the subjects covered by the medical questionnaire and the three tests and (2) the 'overall intrusiveness' of 'a full-scale physical examination.'"[74] Moreover, the court recognized that the non-consensual screening for sickle cell disease raised a potentially valid Title VII claim, since only black employees were affected.[75] Although the court did not make note of it, despite sickle cell anemia's association with Africa, it is found in members of other ethnicities as well, merely at lower—but non-negligible—rates.[76]

After the *Norman-Bloodsaw* case, genetics and race continue to interact in medical research. This is in part because of physicians' entrenched beliefs that race and ethnicity affect medical risk. For example, in a recent study of pediatricians on the issue of mandatory sickle cell genetic screening for student-athletes, a much higher percentage supported screening targeted by race and ethnicity than supported universal screening.[77] Presumably, such attitudes might be seen as changing over time.

Contrary to such expectations, however, contemporary genetic research threatens to result in the "reification of race," where biological language reenters the discourse of racial differences that are otherwise considered to be social categories.[78] This may seem counter-intuitive. Since the advent of DNA sequencing, it has been clear that interracial genetic diversity is a small fraction of total individual diversity (itself the mere <1% of variation cited above).[79] This science-based challenge to the biological

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[73] *Id.* The testing program ended, in fact, because African American adults had almost all been tested at birth at that time. The testing of African Americans for the sickle cell trait of course implicates substantial issues of racial discrimination, and it motivated much of the legislative concern over genetic information privacy in the United States prior to the Human Genome Project's inception in the early 1990s. Indeed, it may account for why many states had genetic information privacy laws on the books long before such statutes were developed in other countries (though at the federal level, GINA was not passed until 2008).

[74] *Id.* at 1269.

[75] *Id.* at 1272.

[76] *See, e.g.*, Eugene F. Roth, Jr. et al., *Sickle Cell Disease in Sicily*, 17 J. MED. GENETICS 34 (1980).

[77] Joy Koopmans et al., *Sickle Cell Trait Screening in Athletes: Pediatricians' Attitudes and Concerns*, 128 PEDIATRICS 477, 477 (2011). The study was based on activities pursuant to a rule of the National Collegiate Athletic Association (NCAA) requiring mandatory sickle cell genetic testing of student athletes in Division I programs to take place in the first season during which they are eligible to compete. The mandatory testing rule was enacted in 2010 as part of a settlement between the NCAA and the family of Dale Lloyd II, a nineteen-year-old Rice University football player whose death in 2006 after a practice was attributed to sickle cell trait. Vence L. Bonham et al., *Screening Student Athletes for Sickle Cell Trait—A Social and Clinical Experiment*, 363 NEW. ENG. J. MED. 997, 997 (2010).

[78] *See generally* GUY P. HARRISON, RACE AND REALITY: WHAT EVERYONE SHOULD KNOW ABOUT OUR BIOLOGICAL DIVERSITY (2009); AUDREY SMEDLEY, RACE IN NORTH AMERICA: ORIGIN AND EVOLUTION OF A WORLDVIEW (3d ed. 2007); Troy Duster, *Race and Reification in Science*, 307 Sci. 1050 (2005); William M. Richman, Genetic *Residues of Ancient Migrations: An End to Biological Essentialism and the Reification of Race*, 68 U. PITT. L. REV. 387 (2006).

[79] *See, e.g.*, Richard C. Lewontin, *The Apportionment of Human Diversity*, 6 EVOLUTIONARY BIOLOGY 381 (1972) (the first study of inter-racial variation using samples obtained from blood cells); P.C. Ng et al., *Individual Genomes Instead of Race for Personalized Medicine*, 84 CLINICAL PHARMACOLOGY THERAPY 306 (2008) (the first study of inter-individual and inter-racial genetic variation using the whole DNA sequence).

concept of race was advanced by the human genome project's government sponsors.[80] In celebrating the culmination of the project, President Clinton stated: "In genetic terms all human beings, regardless of race, are more than 99.9 percent the same. . . . Modern science has confirmed what we first learned from ancient faiths. The most important fact of life on this earth is our common humanity."[81]

This rhetoric nevertheless conceals a paradox arising from the length and complexity of DNA sequence. Even a small fraction of total variation represents enough information to distinguish between groups of people that correlate with ancestry, and thus, roughly, with race.[82] The significance of ethnicity-based (if not outright race-based) medical research is underscored by the pharmaceutical giant GlaxoSmithKline's investment in assembling a DNA database resource with information from almost 6,000 people from explicitly African American, East Asian, South Asian, Mexican, and European origins.[83] Scientists investigating racial disparities in health outcomes have also used genetic testing to verify the degree of African ancestry in study participants.[84]

The interweaving of race and genetic medicine was made even more explicit with the FDA's 2005 approval of BiDil, a combination drug for use specifically in African Americans to treat congestive heart failure.[85] The FDA initially rejected BiDil, but after re-analyzing the data from the failed clinical trial, the drug's developers found a potentially beneficial effect among African American patients enrolled in the trial.[86] This led the researchers to design an FDA-approved clinical trial to study the drug in an exclusive African American population, in which they found a statistically significant impact.[87] The

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[80] *Human Genome Project Information: Minorities, Race, and Genomics*, U.S. DEP'T OF ENERGY, http://www.ornl.gov/sci/techresources/Human_Genome/elsi/minorities.shtml (last visited Aug. 31, 2007).

[81] Nicholas Wade, *Now, the Hard Part: Putting the Genome to Work*, N.Y. TIMES, June 27, 2000, http://partners.nytimes.com/library/national/science/062700sci-genome-future.html.

[82] As one example of many such studies, a 2008 paper published in the journal *SCIENCE* profiled 938 unrelated individuals based on 650,000 features of DNA sequence, drawn from fifty-one populations. The authors were able to blindly categorize the individuals into categories that exactly mapped onto groups corresponding to origin in Africa, East Asia, Oceania, the Americas, the Middle East, Europe, and South/Central Asia using only on average five percent of inter-individual DNA variation. J.Z. Li et al., *Worldwide Human Relationships Inferred from Genome-Wide Patterns of Variation*, 319 SCI. 1100 (2008). *See generally* C.W.K. Chiang et al., *Rapid Assessment of Genetic Ancestry in Populations of Unknown Origin by Genome-Wide Genotyping of Pooled Samples*, 6 PLOS GENETICS e1000866 (2010) (categorizing the individuals in their study into African American, Nigerian, European, and Native American groups), R. Yaeger et al., *Comparing Genetic Ancestry and Self-Described Race in African Americans Born in the United States and Africa*, 17 CANCER EPIDEMIOLOGY BIOMARKERS PREV. 1329 (2008); K. Brye et al. *Genome-Wide Patterns of Population Structure and Admixture in West Africans and African Americans*, 107 PROC. NAT'L ACAD. SCI. U.S.A. 786 (2010) (describing studies that identified groups according to African American or proximate West African descent).

[83] M. R. Nelson et al., *The Population Reference Sample, POPRES: A Resource for Population, Disease, and Pharmacological Genetics Research*, 83 AM. J. HUM. GENETICS 347 (2008).

[84] Yaeger, *supra* note 82 (comparing African ancestry as referenced to a West African and African American database versus self-identification survey results).

[85] Andrew Pollack, *Drug Approved for Heart Failure in Black Patients*, N.Y. TIMES, July 20, 2004, at C1. BiDil is the trade name for isosorbide dinitrate/hydralazine, a combination vasoldilator and antihypertensive. Both drugs had already been approved for treatment individually, so only the combination was novel.

[86] *Id. See also* Jay N. Cohn, *The Vasodilator-Heart Failure Trials (V-HeFT): Mechanistic Data from the VA Cooperative Studies*, 87 CIRCULATION VI-1-4 (1993).

[87] Anne L. Taylor et al., *The African-American Heart Failure Trial: Background, Rationale and Significance*, 94 J. NAT'L MED. ASS'N 762 (2002).

FDA subsequently approved BiDil as a drug for the "treatment of heart failure as an adjunct to standard therapy in self-identified black patients to improve survival, to prolong time to hospitalization for heart failure, and to improve patient-reported functional status."[88] BiDil's approval led to substantial debate on scientific, political, and ethical grounds, and it continues to be prominently highlighted in discussions surrounding genetic medicine generally.[89] One of the principal scientific grounds for the critique of BiDil was that the data emphasized by the drug maker and the FDA was very controversial. It purported to show dramatically higher African American mortality rates due to heart failure.[90] However, some studies have shown that disparities in hypertension among African American men are highly correlated with socioeconomic status, overwhelming any measurable genetic difference even if one exists.[91]

The debate over BiDil exemplifies the problems associated with incorporating the analysis of genetic information into the study of racial disparities in medicine.[92] It is true that genetic differences along ethnic lines may merely reflect the natural genetic similarity that results from shared ancestry and geographic origin.[93] And, indeed, there are geographical concentrations of phenotype that may be due to shared ancestry and consequent genetic similarities, such as the prevalence of hereditary sickle cell disease in Africa;[94] the inability to metabolize alcohol in parts of Asia;[95] and beta thalassemia, otherwise

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[88] BiDil Package Insert - Final Draft, U.S. FOOD & DRUG ADMIN. (June 23, 2005),*available at* http://www.accessdata.fda.gov/drugsatfda_docs/label/2005/020727lbl.pdf. This is the label approved on June 23, 2005 by the FDA. Approved Drug Products, BIDIL, NDA 020727, U.S. FOOD AND DRUG ADMINISTRATION, http://www.accessdata.fda.gov/scripts/cder/drugsatfda/index.cfm?fuseaction=Search.DrugDetails#.T5re00QNDvk (search "Bidil") (last visited May 5, 2012).

[89] *See, e.g.*, Amanda Tessmer, *Pharmacogenomics and the Genetic Information Nondiscrimination Act of 2008: Legislation Limitations and Its Impact on PGX Research and Clinical Opportunity*, 3 ST. LOUIS U. J. HEALTH & POL'Y 153, 164–68, 177–81 (2008) (discussing racial issues as being a prominent factor in limiting the progress of pharmacogenomic research); Troy Duster, *Medicalisation of Race*, 369 LANCET 702, 703 (2007) (critiquing assumptions of disproportionate African American mortality rates due to heart failure and BiDil's manufacturer's interest in receiving a patent extension for the novel race-based use of the drug); G.T.H. Ellison et al., *Flaws in the U.S. Food and Drug Administration's Rationale for Supporting the Development and Approval of BiDil as a Treatment for Heart Failure Only in Black Patients*, 36 J.L. MED. ETHICS 449, 449-57 (2008) (disputing the statistical significance of the observed difference between Black and White patients in the trial). *But see also* Britt M. Rusert & Charmaine D. M. Royal, *Grassroots Marketing in a Global Era: More Lessons from BiDil*, 39 J.L. MED & ETHICS 79, 84–86 (2011) (describing support within the African-American community and outreach by BiDil's manufacturer targeting community organizations).

[90] Duster, *supra* note 89, at 703 (discussing how the mortality discrepancies appear entirely based on age effects in the cohort, in which a disproportionate number of people aged forty-five to sixty-four dying but representing only six percent of the total population distorting the final results in a statistically insignificant manner).

[91] Michael J. Klag et al., *The Association of Skin Color with Blood Pressure in US Blacks with Low Socioeconomic Status*, 265 J. AM. MED. ASS'N 599, 599-602 (1991) (showing that pigmentation intensity correlates with hypertension, but that this correlation is well-explained by differences in socioeconomic status); *see also* Richard S. Cooper et al., *An International Comparison Study of Blood Pressure in Populations of European vs. African descent*, 3 BMC MED. 22 (2005).

[92] This debate is not limited to African Americans, nor is it limited to the positive effects of drugs. For example, in 2005, the FDA issued a Public Health Advisory for the cholesterol-lowering drug Crestor targeted to Asian Americans specifically. Public Health Advisory for Crestor (rosuvastatin), U.S. FOOD & DRUG ADMIN. (Mar. 2, 2005), http://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/DrugSafetyInformationforHeathcareProfessionals/PublicHealthAdvisories/ucm051756.htm.

[93] Nelson et al., *supra* note 83.

[94] *See, e.g.*, A. P. Gelpi, *Migrant Populations and the Diffusion of the Sickle-Cell Gene*, 79 ANNALS INTERNAL MED. 258, 258-64 (1973).

known as "Mediterranean" anemia.[96] Thus, some inter-group biological differences are genetic; but these are differences between ethnicities, not necessarily the social constructs of race that have developed in the American context. There may even still be pragmatic utility in using "African American" and "Hispanic American" as racial groupings in medical genetics research; for example, it may be a way to ensure that members of minority communities are adequately represented in genetic studies.[97]

That said, many scholars reject the notion that racial classifications are biologically meaningful and instead propose that not only should health disparity research be focused on environmental and socioeconomic considerations, but also that any association of race with biological outcomes is harmful.[98] For example, a study that classifies African Americans as a group more likely to develop lung cancer as a result of cigarette smoking due to presence of a particular genetic mutation will be reported in such a way that it ignores the large minority of non-African Americans who share the same mutation and have a higher rate of smoking.[99] The study thus overlooks the alternative conclusion that economic factors, social context, or environmental factors like pollution might make African Americans more likely to develop nicotine addiction or suffer from lung cancer.[100] Indeed, at least one study that carefully compared head and neck cancer outcomes among patients who self-declared their race and their genetically-identified ancestry revealed that health outcomes were correlated with self-declared social conceptions of race, as opposed to "biological" ancestry.[101] Where such an approach has not been used, the outcome of research intended to solve the problem of racial disparities in health outcomes may only

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[95] *See, e.g.*, Hui Li et al., *Refined Geographic Distribution of the Oriental ALDH2*504Lys (nee 487Lys) Variant*, 73ANNALS HUM. GENETICS 335, 335-45 (2009).

[96] *See, e.g.*, Roshan Colah et al., *Global Burden, Distribution and Prevention of ß-thalassemias and Hemoglobin E Disorders*, 3 EXPERT REV. HEMATOLOGY 103 (2010).

[97] *See generally* Michael J. Malinowski, *Dealing with the Realities of Race and Ethnicity: A Bioethics-Centered Argument in Favor of Race-Based Genetics Research*, 45 HOUS. L. REV. 1415 (2009) (arguing that cautious deployment of genetic studies is warranted given existing ethnic and racial divisions in society, the need for access to those groups to address health disparities, and the possible targeting of treatments to particular genetic factors).

[98] Dorothy E. Roberts, *Legal Constraints on the Use of Race and Ethnicity in Biomedical Research: Toward a Social Justice Framework*, 34 J.L. MED. & ETHICS 526, 531–32 (2006) (advocating a strong presumption *against* the use of racial categories in scientific publications, research funding proposals, and other medical research and clinic contexts). *But cf.* Clarence C. Gravlee, *How Race Becomes Biology: Embodiment of Social Inequality*, 139 AM. J. PHYS. ANTHRO. 47 (2009) (presenting a more moderate view that scientists and public health workers should continue to consider race to show how health differences arise from social inequality between racial groups while discounting genetics as scientifically valid causative factor).

[99] *See, e.g.*, *Lung Cancer Genetics Different in Black Patients: Study*, WASH. POST, Nov. 14, 2008, http://www.washingtonpost.com/wp-dyn/content/article/2008/11/14/AR2008111403130.html. However, the difference is only in the probability of finding mutations in different populations. Rom S. Leidner et al., *Genetic Abnormalities of the*EGFR *Pathway*, 27 J. CLINICAL ONCOLOGY 5620, 5622 (2009). Moreover, a later study of samples from more African American patients revealed no racial difference in the prevalence of mutations. *See* J. Matthew Reinersman et al., *Frequency of* EGFR *and* KRAS*Mutations in Lung Adenocarcinomas in African Americans*, 6 J. THORACIC ONCOLOGY 28, 30-31 (2011).

[100] *See* Reanne Frank, *What to Make of It? The (Re)emergence of a Biological Conceptualization of Race in Health Disparities Research*, 65 SOC. SCI. & MED. 1977, 1980–81 (2007) (citing Neil Risch, *Dissecting Racial and Ethnic Differences*, 354 NEW ENG. J. MED. 408 (2006) (describing an editorial following a 2005 epidemiological study on differential rates of lung cancer among African Americans urging the use of genetic admixture methods to identify potential genetic factors related to the disparity)

[101] Maria J. Worsham et al., *Race as a Social Construct in Head and Neck Cancer Outcomes*, 144 OTOLARYNGOLOGY – HEAD & NECK SURGERY 381 (2011).

reinforce the social inequality that caused the disparities in the first place, by purportedly confirming old stereotypes or introducing new ones.[102]

B. Disparate Racial Impact of Forensic DNA Databases

Many of the aforementioned negative consequences of race-based genetic research depend on whether scientists continue to conduct such studies. However, substantial racial disparity already exists in the use of DNA to identify criminal suspects. Forensic applications of DNA are almost as old as the development of technology to detect areas of specific inter-individual variation. In 1985, Alec Jeffreys, the inventor of "DNA fingerprinting" technology, employed his then year-old method to resolve an immigration case.[103] Shortly thereafter, the technology was used to identify the perpetrator of a double homicide.[104] In the United States, the DNA Identification Act of 1994 funded national DNA analysis laboratory facilities and gave the FBI the authority to establish a nationwide database of DNA records.[105] Subsequent legislation expanded the scope of what DNA could be acquired and retained. The most recent of which is the Adam Walsh Child Protection and Safety Act of 2006,[106] which authorizes DNA sample collection from all individuals arrested, facing charges, or convicted under the authority of the United States.[107] This federal legislation is similar to several state mandates, including California, Maryland, and New Jersey, to collect DNA of persons with multiple felony arrests, and all fifty states collect DNA from all state offenders.[108]

Because virtually everyone in the state and federal DNA databases (between which information is shared) was at one point either arrested or convicted of a crime, the racial distribution of samples within the databases generally reflect the overall racial disparity in arrests and convictions.[109] For example, in Maryland, which tracks the demographics of the population from whom DNA samples are collected, 60.9% of those sampled were African American, whereas 35.0% who were White.[110] Among

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[102] *See, e.g.*, Vence L. Bonham et al., *Community-Based Dialogue: Engaging Communities of Color in the United States' Genetics Policy Conversation*, 34 J. HEALTH POL., POL'Y & L. 325, 326 (2009) (highlighting the role of public misunderstanding of genetics and the perpetuation of stigmatization after publication of experimental data).

[103] Alec J. Jeffreys et al., *Positive Identification of an Immigration Test-Case Using Human DNA Fingerprints*, 317 NATURE 818 (1985).

[104] J. Gitschier, *The Eureka Moment: An Interview with Sir Alec Jeffreys*, 5 PLOS GENETICS e1000765 (2009), *available at* http://dx.doi.org/10.1371/journal.pgen.1000765 (Jeffreys describes the police as also conducting the first "DNA dragnet," when after testing of individual suspects failed to find a match, 500 samples were taken from throughout the local community).

[105] Pub. L. No. 103-322, 108 Stat. 2065 (1994) (codified as amended at 42 U.S.C. § 14131–14134).

[106] Pub. L. No. 109-248, 120 Stat. 587 (2006).

[107] 42 U.S.C. § 14135A(a)(1)(A) (2012).

[108] Paul M. Monteleoni, *DNA Databases, Universality, and the Fourth Amendment*, 89 N.Y.U. L. REV. 247, 252 (2007).

[109] *See, e.g.*, D.H. Kaye & Michael E. Smith, *DNA Identification Databases: Legality, Legitimacy, and the Case for Population-Wide Coverage*, 2003 WIS. L. REV. 413, 452–54 (2003).

[110] These percentages were calculated from: FORENSIC SCIENCES DIV., MD. STATE POLICE, STATEWIDE DNA DATABASE REPORT: 2009 ANNUAL REPORT (2010), *available at* http://cdm15029.contentdm.oclc.org/cdm/ref/collection/p266901coll7/id/2894.

the state population as a whole, 63.0% are White and 29.7% are African American.[111] In the United States as a whole, an estimated 28.3% of those arrested in 2009 were African American,[112] as compared to 12.9% of the general population.[113]

While this overwhelming racial disparity in individual DNA samples in the database raises troubling questions on its own,[114] it becomes particularly salient in view of new approaches that go beyond the model of a database restricted to those actively convicted or even arrested of crimes.[115] Where no match was found in the existing database, DNA samples have been used to attempt to predict a suspect's racial or ethnic origin.[116] This explicitly racial use of forensic DNA analysis echoes the race-based medical research questions discussed above and raises important issues regarding racial profiling and the potential for reinforcing stereotypes associated with criminal behavior—or perhaps the use of more insidious categories, such as those associated with genetic traits thought to be explicitly predictive of behavior.[117]

Of more immediate applicability is the growing interest in kinship or familial DNA searches for forensic use. In these kinds of database searches, when no exact match to a database is found, a near match is correlated with a suspect's family member whose genetic information is available to law enforcement.[118] Based on theoretical models, scientists have predicted that using familial DNA searches could increase the "cold-hit" rate (match between a sample obtained at the crime scene and an entry already in the database) by as much as forty percent.[119] This technique is already being used. For

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[111] *Maryland QuickFacts*, U.S. CENSUS BUREAU, http://quickfacts.census.gov/qfd/states/24000.html (last visited April 27, 2012).

[112] *Crime in the United States 2009: Arrests by Race*, FBI, http://www2.fbi.gov/ucr/cius2009/data/table_43.html (the data represent arrest records covering approximately 80% of the total U.S. population) (last visited April 27, 2012).

[113] *U.S.A. QuickFacts*, U.S. CENSUS BUREAU, http://quickfacts.census.gov/qfd/states/00000.html (last visited May 6, 2012).

[114] *See generally* Michael T. Risher, *Racial Disparities in Databanking of DNA Profiles*, 22 GENEWATCH 22 (2009), *available at* http://www.councilforresponsiblegenetics.org/GeneWatch/GeneWatchPage.aspx?pageId=204 (describing racial skew in the database influences what crimes go unsolved and what crimes go solved).

[115] Notably, there have also been problems with expunging the newly expanded databases of wrongfully collected genetic information. *See, e.g.*, Solomon Moore, *F.B.I. and States Vastly Expand DNA Databases*, N.Y. TIMES, Apr. 19, 2009, at A1 (describing how a public defender had spent weeks trying to expunge the profile erroneously taken from a fourteen year old boy guilty of assault and bicycle theft).

[116] Duana Fullwiley, *Can DNA "Witness" Race?*, 21 GENEWATCH 12 (2008), *available at* http://genocommunity.org/editoruploads/file/Crime%20and%20DNA%20readings/can%20DNA%20witness%20race.pdf (describing the case of Derrick Todd Lee, who was convicted in 2004 for serial murder and rape cases committed in the early 2000's). This case is referred to in the promotional material of DNAPrint Genomics, the now-defunct company that conducted the analysis. In general, these methods use genetic signatures based on those particular aspects of DNA sequence that are associated with race, ethnicity, and common geographical origin. *See* sources and accompanying text, *supra* note 82.

[117] *See, e.g.*, Bert-Jaap Koops & Maurice Schellekens, *Forensic DNA Phenotyping: Regulatory Issues*, 9 COLUM. SCI. & TECH. L. REV. 158, 164 (2008).

[118] *See, e.g.*, Eva Steinberger & Gary Sims, *Finding Criminals Through the DNA of Their Relatives: Familial Searching of the California Offender DNA Database*, 31 PROSECUTOR'S BRIEF 28, 31 (2008) (describing the statistical technique used to analyze a familial hit in a forensic DNA database).

[119] Frederick R. Bieber et al., *Finding Criminals Through DNA of Their Relatives*, 312 SCI. 1315 (2006).

example, police investigators in California recently identified the suspected "Grim Sleeper" serial murderer by first obtaining a close DNA match to an individual in a forensic database, and then using familial relationship data found in public records to identify the suspect himself.[120] Scholars have questioned the ethical issues regarding privacy in familial DNA searching, which include violating the privacy of the individual whose sample is in the DNA database already, as well as violating the privacy of a potentially large pool of possible relatives.[121] Moreover, familial DNA searches may unexpectedly reveal hits and misses that disrupt family structure, by finding a genetic link where one was previously unknown or revealing the absence of such a link that was thought to exist.[122]

There is also a high potential for the use of familial DNA searching to increase the already racially disparate impact of forensic DNA testing. Given that African Americans and increasingly other minority populations are dramatically overrepresented in forensic DNA databases, the number of their relatives who will be potentially captured through familial searching will be even more exponentially overrepresented.[123] It has been suggested that if proper precautions are taken, such as ensuring the destruction of DNA samples associated with innocent family members, kinship searches may not be as problematic as claimed since they can be used equally well to demonstrate innocence.[124] However, as other commentators have pointed out, familial matches inherently produce only partial matches, which would be of limited exoneration value.[125] Any such benefit is outweighed by the risk that a minority community overrepresented in the forensic database would find itself potentially cast entirely within the net of the database supplemented by kinship searches.[126] Thus, while there is no "universal" DNA database of all Americans, there may soon be effectively such a database for African Americans, and increasingly, other minorities that share common genetic ancestry.

C. Skepticism About DNA Testing among Minority Communities

Racial minorities, in particular African Americans, are massively underrepresented in genetic studies. As of August 2009, 320 of 373 publicly known GWAS were entirely made up of European

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[120] Jennifer Steinhauer, *"Grim Sleeper" Arrest Fans Debate on DNA Use*, N.Y. TIMES, July 9, 2010, at A14.

[121] Erica Haimes, *Social and Ethical Issues in the Use of Familial Searching in Forensic Investigations: Insight from Family and Kinship Studies*, 34 J.L. MED. ETHICS 263, 264 (2006).

[122] *Id.* at 268–70.

[123] *See, e.g.*, Jennifer Mnookin, *Devil in the DNA Database*, L.A. TIMES, Apr. 5, 2007, at A23; Henry T. Greely et al., *Family Ties: The Use of DNA Offender Databases to Catch Offenders' Kin*, 34 J.L. MED. & ETHICS 248, 259 (2006). *See also* Daniel J. Grimm, *The Demographics of Genetic Surveillance: Familial DNA Testing and the Hispanic Community*, 107 COLUM. L. REV. 1164, 1184 (2007) (theoretically predicting higher rates of kinship matches among Hispanic families that tend to be larger and thus include more immediate relatives).

[124] Jules Epstein, *"Genetic Surveillance"—The Bogeyman Response to Familial DNA Investigations*, 2009 U. ILL. J.L. TECH. & POL'Y 141, 170–72 (2009).

[125] *See, e.g.*, *Erin Murphy, Relative Doubt: Familial Searches of DNA Databases*, 109 MICH. L. REV. 291, 311–13 (2010).

[126] Greely, *supra* note 122. One estimate from 2006, when there were far fewer samples in DNA databases under more restrictive sample collection laws predicted that given 1.1 million African Americans in the database, using a ballpark figure of five first-degree relatives, there would be 5.5 million who would be "searchable"—in total accounting for seventeen percent of the total African American population. By comparison, given that 1.65 million U.S. Caucasians were in the database, the using the same ballpark figure of five living first-degree relatives, the total "searchable" population would make up only four percent of the total U.S. Caucasian population.

ancestry, with over 1.5 million participants.[127] There were no studies of only African Americans, and of just eleven studies with mixed populations, the average size of the African American population (crucial to get statistically meaningful results) was just 682, as opposed to 8403 for populations with European ancestry.[128] Given the issues raised in the previous sections, one might hypothesize that racial minorities, and African Americans in particular, would have concerns about the potential risks of genetic testing. After all, as discussed previously, African Americans have a concrete experience with many of the kinds of misuse of genetic information that are otherwise hypothetical to majority populations, such as profiling for forensic investigation, misuse of genetic testing in the employment context, and use of genetic information to reify socioeconomic differences as reflecting physical distinction in the medical context.

Indeed, while survey data are not unanimous, the trend of several studies clearly supports this hypothesis, in addition to showing mistrust of genetic information misuse in other minority populations, among whom studies have been more limited.[129] African American attitudes toward genetic testing may also be influenced by more prevalent mistrust of medical research and health care. For example, in one survey of African American patients, respondents, as compared to White respondents, were (1) more likely than White respondents not to trust that their physician would fully explain research participation, (2) less likely to believe that they could freely ask their physician questions, (3) more likely to disagree that their physician would not ask them to participate in research the physician thought would harm them, (4) more likely to believe that someone like them could be used in a genetic study without consent, and (5) much more likely to believe that physicians often prescribed medication as a way of experimenting on people without consent and that even their own physicians had given treatment as part of an experiment without consent.[130] To explain this repeatedly observed phenomenon of medical mistrust, most authors immediately bring up the specific experience of the Tuskegee Syphilis Study as a principal reason why African Americans have a mistrust of the system.[131] However, studies that have specifically investigated the actual significance of Tuskegee in explaining attitudes have suggested that it is not the sole trigger for mistrust.[132]

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[127] Anna C. Need & David B. Goldstein, *Next Generation Disparities in Human Genomics: Concerns and Remedies*, 25 TRENDS GENETICS 489, 490 (2009).

[128] *Id.*

[129] *See infra* notes 131–36 and accompanying text.

[130] *See, e.g.*, C. H. Herbert, *Racial Differences in Medical Mistrust Among Men Diagnosed With Prostate Cancer*, 115 CANCER 2553 (2009); G. Corbie-Smith et al., *Distrust, Race, and Research*, 162 ARCH. INTERNAL MED. 2458, 2459 (2002).

[131] *See, e.g.*, S. B. Thomas & S. C. Quinn, *The Tuskegee Syphilis Study, 1932 to 1972: Implications for HIV Education and AIDS Risk Education programs in the Black Community*, 81 AM. J. PUB. HEALTH 1498 (1991).

[132] *See, e.g.*, Dwayne T. Brandon, Lydia A. Isaac & Thomas A. LaVeist, *The Legacy of Tuskegee and Trust in Medical Care: Is Tuskegee Responsible for Race Differences in Mistrust of Medical Care?*, 97 J. NAT'L MED. ASS'N 951 (2005); Darcell P. Scharff et al., *More than Tuskegee: Understanding Mistrust about Research Participation*, 21 J. HEALTH CARE POOR UNDERSERVED 879 (2010); *See also* Beeson & Duster, *supra* note 69, at 162 (In describing interviews with African Americans regarding attitudes to pre-natal testing for sickle cell disease, beyond just the Tuskegee study, the authors state, "Their narratives are saturated with references to medicine as an instrument of domination and control."). On the other hand, the impact of popular portrayals of the Tuskegee Study should not be underestimated, as evinced by the 1997 film *Miss Evers' Boys*, which, while a fictionalized account, according to at least one study directly worked to shape attitudes regarding medical research. Vicki S. Freimuth et al., *African Americans' Views on Research and the Tuskegee Syphilis Study*, 52 SOC. SCI. & MED. 797, 800, 804-807 (2001) (discussing the impact of *Miss Evers' Boys* specifically on black perceptions of medical research). While studies do point to the role of the Tuskegee Study as a factor determining perceptions of research, it is important to note that questions have been raised by historians and survivors regarding the

Suspicion of health care professionals and the history of medical research adverse to African Americans is not the only reason why they do not trust genetic research. For example, African Americans and other minority communities have also had a history and have an ongoing present experience of discrimination at the hands of law enforcement, which provides a reinforcing context enhancing the concerns expressed within these communities concerning racial disparities in the forensic DNA databases and the risk of selective investigation.[133] As the studies described in this section demonstrate, the fear of potential misuse of genetic information, motivated by all of the reasons described above, plays a significant role in making African Americans hesitate to participate in genetic studies and worry about the outcomes of such research.

For example, a study of nurses attending the 2006 Annual Conference of the National Black Nurses Association found that while a majority were interested in genetic testing and were willing to participate in genetic education, more than seventy-five percent believed that genetic tests could be used to discriminate against minorities.[134] Supporting this view was a recent focus group on attitudes towards personalized medicine which showed that African Americans simultaneously encouraged by the development of genetic testing for personalized medicine and suspicious of the use of race to tailor medicine, with BiDil as a specific example.[135] In a study of consent to a large-scale genetic study, while African American participants consented to the immediate study at similar levels to others, they were the least likely, by a statistically significant margin, to consent to save blood samples long term.[136]

In a 2004 study of attitudes towards breast cancer gene testing, study participants had a positive view of the likely applications of genetic tests for medicine and research that was uniform across all racial categories. After adjustment for age, gender, and educational level, however, African Americans were more likely to believe that the government "would use genetic tests to label groups as inferior, and less likely to endorse the potential health benefits of testing."[137] In 2008, a team studying participants in a GWAS on colon cancer risks compared the response to open-ended questions about genetic testing: African Americans proved as likely as other groups to express willingness to participate in future studies.[138] But, once prompted by closed-ended question with specific examples of negative

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accuracy of popular portrayals of the Study. *See generally* FRED D. GRAY, THE TUSKEGEE SYPHILLIS STUDY: THE REAL STORY AND BEYOND (1998).

[133] Troy Duster, *Explaining Differential Trust of DNA Forensic Technology: Grounded Assessment or Inexplicable Paranoia?*, 293 J.L. MED. ETHICS 294, 294–95 (2006).

[134] I. Spruill et al., *Knowledge, Beliefs and Practices of African-American Nurses Regarding Genetics/Genomics*, 20 J. NAT'L BLACK NURSES ASS'N 20 (2009) (noting that despite the heightened interest in genetic testing, 56% self-reported their knowledge of genetics as fair or poor).

[135] M. De Marco et al., *Views on Personalized Medicine: Do the Attitudes of African American and White Prescription Drug Consumers Differ?*, 13 PUBLIC HEALTH GENOMICS 276, 281 (2010). For BiDil, see *supra* notes 85–91 and accompanying text.

[136] G. M. McQuillan et al., *Consent for Genetic Research in a General Population: the NHANES Experience*, 5 GENETICS MED. 35, 38 (2003).

[137] Nikki Peters, Abigail Rose & Katrina Armstrong, *The Association between Race and Attitudes about Predictive Genetic Testing*, 13 CANCER EPIDEMIOLOGY BIOMARKERS PREVENTION 361, 363 (2004) (the result described in the text held even when the sample was reduced to only those who had heard of genetic testing prior to the study).

[138] Jada Bussey-Jones et al., *Asking the Right Questions: Views on Genetic Variation Research Among Black and White Research Participants*, 24 J. GEN. INTERNAL MED. 299, 302 (2008) (some of the specific concerns that were expressed by significantly higher levels of African American participants about genetic research in general included the likelihood that it would result in higher insurance costs, not benefit minorities, reinforce racism, and "use minorities as guinea pigs.").

consequences, they were less likely to feel very positive about genetic variation research generally and were more likely to express concerns than other study participants.[139]

These results only represent a sample of many studies of African American and other minority community participation and attitudes towards genetic testing.[140] Although the trend is not unanimous, two themes seem to frequently recur: African Americans (and in fewer studies, Hispanic participants) are generally as enthusiastic as other study participants about the potential benefits of genetic testing, while simultaneously they are much more cautious or even pessimistic about potential risks. This accords with the hypothesis one might draw of African American reluctance to participate in genetic testing based on history and experience with genetic testing in the past, as well as concrete fears about genetics reinforcing racial inequality.

Besides the significance of this analysis in understanding attitudes toward genetic testing generally, there is a real practical concern with the reluctance to participate in genetic studies demonstrated by African Americans and underrepresented minorities. For example, while the important breast cancer risk genes *BRCA1* and *BRCA2* were identified in 1990 in a study of women of European origin, until recently there had been no study of breast cancer genetic epidemiology within an African American population.[141] Many genetic variants connected to disease risk are rare in the population taken as a whole, so they may be missed if the people who have the variant happen to be members of minority groups who do not want to participate in studies. This affects everyone, since, as discussed above in the context of the sickle cell trait, even if such a variant is found more frequently within a racial minority, it can certainly still be present in the majority as well.[142] Alternatively, a variant that is found in only in a small number of people may still be the basis for developing a new therapeutic drug with broader benefits.[143] Thus, effective genetic research requires broad participation. The perception that

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[139] *Id.* at 302.

[140] Sandra Suther & Gebre-Egziabher Kiros, *Barriers to the Use of Genetic Testing: A Study of Racial and Ethnic Disparities*, 11 GENETICS MED. 655 (2009) (discussing study conducted in 2000 showing that thirty four percent of blacks, twenty eight percent of Latinos, and twenty percent of non-Hispanic whites agree with the statement "Information from genetic tests is likely to be misused"); Richard K. Zimmerman et al., *Racial Differences in Beliefs about Genetic Screening among Patients at Inner-City Neighborhood Health Centers*, 98 J. NAT'L MED. ASS'N 370, 373 (2006) (finding that, in a sample of older adult patients from four inner-city health centers, African Americans were significantly more likely than Caucasians to believe that genetic testing will lead to racial discrimination); Hayley S. Thompson et al., *Perceived Disadvantages and Concerns about Abuses of Genetic Testing for Cancer Risk: Differences across African American, Latina and Caucasian Women*, 51 PATIENT EDUC. & COUNSELING 217, 221 (2003) (African American women and Latina participants were significantly more likely to agree that genetic testing "is used to show that their ethnic group is not as good as others," a result accompanied by higher medical mistrust scores); *but see* Charles R. Jonassaint et al., *Regional Differences in Awareness and Attitudes Regarding Genetic Testing for Disease Risk and Ancestry*, 128 HUMAN GENETICS 249 (2010) (claiming that inter-regional variation in attitudes is more substantial than inter-racial variation, but with only 452 adults, of whom only seventy two percent reported ethnicity, and which consisted of mostly White adults spread across four sites, the statistical significance of these results is limited); Eleanor J. Murphy et al., *Racial and Ethnic Differences in Willingness to Participate in Psychiatric Genetic Research*, 19 PSYCHIATRIC GENETICS 186, 189–90 (2009) (the study found no significant differences between racial groups on willingness to participate in genetic research, but Blacks and Hispanics were more likely to endorse negative reactions, *e.g.* mistrust and wariness, stigma, participation only for incentives, while willingness to participate among Whites was only correlated with benefits to the individual with society and importance for furthering education and knowledge).

[141] Heather M. Ochs-Balcom et al., Establishing a Community Partnership to Optimize Recruitment of African American Pedigrees for a Genetic Epidemiology Study, 2 J. CMTY. GENETICS 223, 224 (2011).

[142] *See generally* Roth, *supra* note 76.

[143] *See, e.g.*, Victor Acuña-Alonzo et al., *A Functional ABCA1 Gene Variant is Associated with Low HDL-Cholesterol Levels and Shows Evidence of Positive Selection in Native Americans*, 19 HUM. MOLECULAR GENETICS 2877, 2878 (2010)

participation increases the risk of adverse effects of genetic discrimination will therefore substantially hinder the effort to use the discoveries of the Human Genome Project to improve human health.=

III. BEYOND PRIVACY: EXPLICITLY PROHIBITING MISUSE OF GENETIC INFORMATION

A. New Challenges Presented by Genetic Information

In the context of the kind of medical research applications that are the focus of this Note, it is natural to identify genetic data as medical information. So, it is natural to first think of protecting genetic information in the same way as we protect other medical records: by restricting disclosure of records associated with personal identifiers. However, genetic sequences are not like typical medical information at all. First, any large sets of combinatorial data can be identifiable, as described for clinical data and as has been demonstrated in the case of consumer records, most notably in a recent controversial contest run by Netflix.[144] However, even more so than such data sets, a genetic sequence is identifiable on its own, as an individual record. Consider this paradox: the HIPAA Privacy Rule permits the disclosure of genetic information provided it is stripped of personal identifiers—but included on the list of prohibited identifiers are "[b]iometric identifiers, including finger and voice prints."[145] Even a small fraction of DNA sequence information is more personally identifiable than a fingerprint, which depends at least somewhat on human interpretation.[146] In addition, a solution that would restrict the amount of genetic data in a record, or modify data to prevent identification, would necessarily also conflict with the medical usefulness of the data.

There is another important way in which DNA sequence is unlike any other medical information: physical samples containing DNA can be easily stored without significant degradation,[147] and even more unlike other biological specimens, actual DNA material needs to be kept intact and whole to retain the entirety of the information it contains. This makes it difficult to employ sample destruction, another conventionally employed solution for maintaining privacy. Even if all the tissue obtained in the course of an experiment is lost, all the information within a DNA sequence can remain stored on a computer disk or easily transmitted across the Internet. The deletion of the sequence data may be

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(describing a genetic variant associated with low levels of obesity and type 2 diabetes in people of Native South American ancestry, which has not yet been found in studies of other populations).

[144] Ryan Singel, *Netflix Spilled Your* Brokeback Mountain *Secret, Lawsuit Claims*, WIRED, Dec. 17, 2009, http://www.wired.com/threatlevel/2009/12/netflix-privacy-lawsuit/ (describing a lawsuit filed alleging that Netflix had violated privacy laws as a result of a competition in which Netflix had released what it believed were de-identified customer data to the public to develop new customer recommendation algorithms).

[145] 45 C.F.R § 165.514(b)(2)(P) (2012).

[146] Michael Cherry & Edward Imwinkelreid, *How We Can Improve the Reliability of Fingerprint Identification*, 90 JUDICATURE 55, 55–57 (2006). However, many courts have taken the view that fingerprint identification is *more* reliable, because monozygotic (i.e. "identical") twins share the same DNA sequence but not the same fingerprint. *See, e.g.*, United States v. Mitchell, 681 F. Supp. 2d 597, 608 (W.D. Pa. 2009) (notably, despite finding DNA to be less identifiable, the court held on other grounds that DNA collected at the point of arrest was unconstitutional because DNA sequence could potentially contain medical or other personal genetic information).

[147] Jong Soo Park et al., *Haloarcheal diversity in 23, 121 and 419 MYA salts*, 7 GEOBIOLOGY 515 (2009) (describing DNA extracted from salt crystals formed 419 million years ago). This is an extreme example; however, while the samples were highly degraded, enough DNA sequence data was obtained to successfully analyze evolutionary similarity with modern organisms.

mandated, as is done now for expunging DNA records maintained by law enforcement agencies.[148] However, mandating this approach for proliferating public and privacy DNA databases is limited by practical limits on auditing procedures needed to ensure that all files and copies thereof are in fact removed.

Even if genetic records could be effectively controlled and reliably destroyed, in many cases the utility of DNA information is such that it can be stored indefinitely. A forensic DNA database is useful for law enforcement because it allows matching samples taken from future crime scenes. The information contained within a research biobank should be accessible by future researchers. Biobanks are also intended to be dynamic, with new participants being continuously added along with clinical information taken throughout their lifespans that allow correlations to future disease risk as participants in the study age.

B. Proposed Consent-Based Solutions

Given that the research application of DNA information collides with expectations for medical privacy, one solution might be to expand the scope of informed consent by ensuring that study participants fully understand the risks of disclosure and consent to how much individual control they may exert over the continued storage of genetic information and use of the information in future research. Informed consent procedures are also practically appealing in that they do not require significant legislative efforts. One example of this approach is the extensive consent form used by the personal genomics service, 23andMe, for the studies it performs on data submitted by its customers, which includes specific information (either directly or following hyperlinks) on the uses of the data, benefits, risks, and data protection mechanisms.[149]

One prominent genetic scientist, George Church, has proposed a more general solution along these lines. It takes advantage of open access, communal regulatory frameworks that have emerged in the Internet, the "Creative Commons Universal Waiver."[150] This approach, which is used by the Personal Genomics Project,[151] tries to involve the community as broadly as possible, recognizing that individualized consent is limited by the risk posed to relatives who do not consent. The goal is a dynamically evolving framework for consent that adapts to changing technology and public understanding. The enhanced consent strategy employs comprehension tests as a means to ensure that the consenter understands the complex scientific and ethical issues within the information accompanying the consent interface. Some have argued that this approach would help integrate genetic information across multiple studies, which is otherwise hampered by limited consent procedures and HIPAA restrictions, but would greatly enhance the ability to gain medical insight from the data.[152]

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[148] *See, e.g.*, N.Y. COMP. CODES, R. & Regs. § 6193.4(a)(4) (2012) (describing how in New York both documents related to subject's DNA databank record are destroyed along with the subject's DNA sample).

[149] *See supra* note 32. The consent information for this study is described at *Consent Document*, 23ANDME, https://www.23andme.com/about/consent (last visited Feb. 4, 2011). Notably, as a completely private service, 23andMe is not obliged to follow the Common Rule regulations on informed consent.

[150] George Church et al., *Public Access to Genome-Wide Data: Five Views on Balancing Research with Privacy and Protection*, 5 PLOS GENETICS e1000665 (2009).

[151] PERSONAL GENOMES PROJECT, http://www.personalgenomes.org (last visited May 6, 2012).

[152] Michael Tomasson, *Legal, Ethical, and Conceptual Bottlenecks to the Development of Useful Genomic Tests*, 18 ANNALS OF HEALTH L. 231, 237 (2009) (arguing also that 23andMe and Google get competitive advantages because they are not limited by HIPAA and the Common Rule).

An even more radical proposal is to recruit "information altruists" who would fully comprehend all the risks of research but voluntarily contribute their sequences for the advancement of medical research.[153] These could indeed be the same individuals who voluntarily disclose their sequence information in public anyway. Some people may not mind such public disclosure, as they recognize that DNA sequence information is at most probabilistic, and that environment is most important for determining future disease or other sensitive characteristics, such as behavior or intelligence. Information altruists may also be required to obtain consent from immediate family members, which would at least mitigate the problem of any individual-based consent scheme in that it may lead to the unwanted de-identification of DNA sequence information from close relatives.

Nevertheless, voluntary information altruists would still risk having the data used to identify them in other contexts, such as in the course of a civil or criminal investigation, or as part of a medical study in which they have been diagnosed with a disease they wish to keep private. A study was recently undertaken to determine the effect of education prior to consent in a GWAS. The authors found that 84% of participants chose public data release, with anonymization, prior to learning about re-identification risks. After receiving such education, only 53% chose public release, 33% chose restricted access in a password-protected database, and 14% opted out of data sharing.[154] It is quite likely that such numbers would drop even more once there are cases of misuse of genetic data, which would actualize those risks that are only hypothetical and speculative today, unless one has shared in the experience of racial minorities as outlined above in Part III. Many people may also believe that there would be legal protections over their informational privacy even in light of the identification of their sequence, which as discussed in Part II.B may not necessarily be true.

In general, informed consent arises from the belief that as people have more knowledge about genetic technology and its potential risks, participation in research and disclosure of genetic information will be encouraged. But, what if fears of genetic information disclosure are not associated with education about genetic technology? As discussed in Part III.C, surveys of African Americans have consistently shown pervasive concerns about the risks of genetic research. These concerns exist even alongside the enthusiasm about the benefits of genetic research.[155] Significantly, African Americans are confronted with their disparate experience with forensic DNA databases and the risk of being caught in the genetic "dragnets" of familial searching, as discussed in Part III.B. Given that no appellate court has prevented genetic identification based on abandoned DNA in criminal investigations, confidence in an informed consent regime that could not be pierced by a criminal investigation with limited legal protection is unlikely. Because consent-based solutions are focused on the problem of medical research trial participation, without considering other uses of genetic data, they would not address the actual concerns African Americans have with the consequences of genetic research.

C. Alternative Problem-Specific Strategies

Any problems that appear more threatening among racial minorities are likely to affect members of the majority as well. The attitudes that African Americans express about genetic testing, discussed in Section III, are salient beyond their community. African Americans have a particular experience with sickle cell disease carrier screening and overrepresentation in forensic DNA databases, along with the

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[153] *See generally* Isaac S. Kohane & Russ B. Altman, *Health Information Altruists—A Potentially Critical Resource*, 353 NEW ENG. J. MED. 2074 (2005).

[154] Amy L. McGuire et al., *To Share or Not to Share: A Randomized Trial of Consent for Data Sharing in Genome Research*, 13 GENETICS MED. 948, 952 (2011).

[155] *See supra* notes 131–37 and accompanying text.

fear of reification of racial inequality as a result of genetic research in medicine. In these ways, they have had to face the reality of problems that, for the majority, are largely in the domain of science fiction. Given that genetic information (even in the limited sense of sickle cell disease carrier status) has already been misused, and that it is currently being misused in the case of kinship searching, there is a concrete basis for identifying at least some of the problems that must be addressed now. This is significant not just for protecting African Americans as a discrete group, but also in attempting to minimize harms for everyone as genetic research expands in the future.

Many commentators have criticized efforts to develop ethical frameworks, rules, and legislation that deal specifically with DNA and genetic information as "genetic exceptionalism."[156] In this view, genetic information is parallel to information that we already have about family history and ancestry, so it poses no additional threats to privacy or discrimination based on stigmatizing characteristics. One problem with such arguments is that genetic information is different. While it contains probabilistic information and not certainties, the result suggests more than what manifested conditions would reveal. For example, even if there are only a few manifested cases of breast cancer in a person's family history, that person may still have a significantly above-average risk of developing breast cancer in their own lives, depending on the toxins to which they may be exposed, or just because of chance alone. Or, while a person may not express symptoms of stigmatizing conditions as alcoholism[157] or schizophrenia,[158]they may possess genes linked to all these issues. Genetics may also be used to infer behavioral propensities even when tied to less significant conditions, such as attention deficit hyperactivity disorder (ADHD).[159]

Thus, the anti-"exceptionalism" view does not address real problems associated with genetic information where current solutions are inadequate or do not explicitly cover genetic information. The alternative is to just rely on existing legal protections for health information. But these may not be robust enough, given how comprehensive genetic information can be—including as it does all of ancestry, disease risk, and potentially even behavioral propensities combined. For example, Fourth Amendment protections on the acquisition of genetic information obtained from medical research by law enforcement agencies may not apply if a subpoena is used to obtain the information, if it is voluntarily submitted upon request (e.g., as a condition of a consent form) or acquired from a public data source.[160]

Thoughtfully developing detailed policy responses to the problems that we see emerge from this discussion is outside the scope of this Note, but I will briefly outline the key issues. First, the use of kinship searching by law enforcement leads to increased racial disparities in the criminal justice system, while also challenging one of the core principles governing the use of DNA in forensics: that only those

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[156] *See, e.g.,* Mark A. Rothstein, *Genetic Exceptionalism and Legislative Pragmatism*, 35 J.L. MED. & ETHICS 59, 61–64 (2007) (describing the fixation of legislatures on DNA information, specifically risks obscuring the broader issue of the use of predictive health information generally, not all of which takes the place of DNA); Sonia M. Suter, *The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?*, 79 WASH. U. L.Q. 669 (2001) (claiming that legislation about genetic discrimination ignores the real issues which are race and gender discrimination along with social inequality); Lainie Friedman Ross, *Genetic Exceptionalism vs. Paradigm Shift: Lessons from HIV*, 29 J.L. MED. & ETHICS 141 (2001) (reviewing reasons why genetic information poses the same kinds of issues as that of disease status, such as stigma, effect on families, identifiability, etc.).

[157] *See, e.g.*, Howard J. Edenberg & Tatiana Foroud, *The Genetics of Alcoholism: Identifying Specific Genes Through Family Studies*, 11 ADDICTION BIOLOGY 386 (2006).

[158] *See, e.g.*, P.V. Gejman et al., *Genetics of Schizophrenia: New Findings and Challenges*, 12 ANN. REV. GENOMICS HUM. GENETICS 121 (2011).

[159] *See, e.g.*, B. Franke et al., *Genome-wide Association Studies in ADHD*, 126 HUM. GENETICS 13 (2009).

[160] *See, e.g.*, David H. Kaye, *DNA Typing: Emerging or Neglected Issues*, 76 WASH. L. REV. 413, 433–35 (2001).

who are criminals or suspected with probable cause of criminal activity should be targeted by this scheme. This principle needs to have a statutory basis, since constitutional challenges against the racial disparities presented by the use of forensic DNA databases are likely to fail, as courts have been unfriendly towards similar challenges to criminal sentencing disparities.[161] This principle animates the legislature's refusal to extend DNA typing to the population as a whole and in many cases mandate expungement of samples from those who are cleared of charges.

Whether this principle should be changed is a question that should be decided at the political level, rather than through the discretion of law enforcement agencies or government officials with authority over law enforcement.[162] This is especially necessary given the high level of mistrust that minority communities have towards law enforcement, which as outlined above is a likely contributor to their reluctance to embrace genetic technologies that can be used for criminal investigations.[163] An alternative proposal that has been raised is that racial disparities can be best addressed without losing the benefits of DNA searches for crime by expanding the database to include all Americans, without regard to status within the criminal justice system.[164] If such an approach were to gain political support in the future, it may still not serve to alleviate concerns among minority communities that criminal investigations are not uniformly targeted. But at least they could potentially have the positive benefit of not exposing minority populations to disproportionate effects due to the capture of family members in database searches, with the accompanying problematic ethical issues. However, such benefits would potentially come with costs. The effective conduct of investigations may be inhibited due to the potential for spurious hits to a rise in property crimes, the added risk of "framing" innocent people for crimes by planting their DNA (which is a potential problem currently, but could become more practical with a greater population in the database), and the costs of creating and maintaining such a large database, especially given the existing backlog in DNA testing.[165]

Second, prohibitions against the use of genetic information as a basis for genetic discrimination should be strengthened. The application of sickle cell carrier disease screening is in one sense an "easy problem," since it fell under the purview of existing civil rights legislation, as exemplified by the decision in *Norman-Bloodsaw*.[166] Genetic testing was explicitly conditioned on race, and medical testing overall on race and gender; consequently, existing laws were adequate to the protection of individuals who faced the misuse of their genetic information. Sickle cell anemia was a stigmatizing disease that was associated with racism in a clearly understandable way: in *Norman-Bloodsaw* and other workplaces and schools, African Americans were selected for testing, as the disease was considered to be restricted to them as a

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[161] *See, e.g.*, McCleskey v. Kemp, 481 U.S. 279 (1987) (holding that mere statistical racial disparity in the application of the death penalty was not sufficient to find civil rights violations in the absence of conscious and deliberate bias); United States v. Clary, 34 F.3d 709 (8th Cir. 1994) (rejecting a challenge to federal sentencing guidelines for crack cocaine on similar grounds).

[162] In California, the then-Attorney General has said that familial DNA searching would be used to investigate serious sexual assaults and murder cases, but in general, the California Department of Justice reviews requests to use familial DNA searching and has refused to rule out approving them for other crimes as its program expands. Maura Dolan, *State to Double Crime Searches Using Family DNA*, L.A. TIMES, May 9, 2011, http://articles.latimes.com/2011/may/09/local/la-me-familial-dna-20110509.

[163] *See* Spruill, *supra* note 133.

[164] *See* Kaye & Smith, *supra* note 108.

[165] Tania Simoncelli, *Dangerous Excursions: The Case Against Expanding Forensic DNA Databases to Innocent Persons*, 34 J.L. MED. & ETHICS 390, 392–94 (2006).

[166] *See* Pendo, *supra* note 71.

definable racial group. Irrespective of whether an individual tested positive for sickle cell, the testing was itself an instance of racial discrimination.

However, future applications of screening will present subtle ways in which genetic information will be used to discriminate against groups. Stigma may no longer attach to easily identifiable categories like race, gender, national origin, or even disability (where genetic differences have not yet manifested in physical or mental impairment), and existing laws that are narrowly protective of these kinds of groups will be ineffective for the next generation of social categorization. GINA is a first step toward eliminating the threat of discrimination, but it must be strengthened. This can be done by adding a private right of action and enhancing damage provisions to prevent misuse of genetic information. Further, GINA should be expanded beyond a narrow construction of genetic information to include other kinds of differences in molecular biology, which are being discovered at an increasingly rapid pace.[167]

Third, the application of genetic research to racial reification must be barred to prevent the kind of statistical discrimination that we might start seeing otherwise (the above point). To this end, we should prevent the use of "race" as one of the categories in which medical research is reported for genetic studies.[168] One approach that has been suggested by a leading medical journal is to replace ancestry, ethnicity, and racial information with the genetic markers that represent the categories of different individuals who are identified in a genetic study. The commonality may or may not be correlated with a "racial" category, but it would not be labeled with words that would identify it as such.[169] Alternatively, tables in articles may explicitly be headed with words that explicitly indicate that race or ethnicity is being used merely as a "category" and not a biological reality, or that it is "self-identified" where the category is significant for studying health disparities.[170]

However, it is important to note the limits of this approach, since ancestry information may be easily obtained from GWAS databases by identifying the kinds of markers that have been used for ancestry identification to the DNA sequence data that is stored in databases, using the same kind of techniques described above for the re-identification of personal data. Also, if particular DNA sequence features are in fact associated with particular ethnic heritage because of shared ancestry, then studying their significance to disease risk will be difficult unless enough individuals with that ancestry are recruited into the study, which requires identification of study participants as part of the research process.[171] Moreover, simply removing racial categories in their totality from all medical research risks concealing

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[167] *See* Roberts, *supra* note 68 (describing gaps in GINA in particular due to an overemphasis on the antisubordination concept of genetic discrimination); Mark A. Rothstein, Yu Cai & Gary E. Marchant, *Ethical Implications of Epigenetics Research*, 10 NAT'L REV. GENETICS 224 (2009) (describing legal and ethical challenges posed by epigenetic information, which consists of molecular changes to DNA that are not associated with changes in the A-C-T-G base sequence that would be protected by GINA).

[168] *See* Roberts, *supra* note 98.

[169] Editorial, *Genes, Drug and Race*, 29 NATURE GENETICS 239, 239–40 (2001).

[170] Judith B. Kaplan & Trude Bennett, *Use of Race and Ethnicity in Biomedical Publication*, 289 J. AM. MED. ASS'N. 2709, 2714 (2007).

[171] *See* Esteban González Burchard et al., *The Importance of Race and Ethnic Background in Biomedical Research and Clinical Practice*, 348 N. ENGL. J. MED. 1170 (2003); Carlos D. Bustamante et al., *Genomics for the World*, 475 NATURE 163, 164 (2011).

legitimate racial disparities in medical care, disease risk, and health outcomes that arise from socioeconomic disparities.[172]

Overall, the goal should be to direct the scientific community to develop research norms that critique the use of genetic correlations that involve race and ethnicity. Achieving this will involve specific legislative and regulatory changes that are targeted toward policies promulgated by the groups that in practice govern the kind of information that is produced as a result of biomedical research: public funding agencies, predominately the National Institutes of Health, which support and guide the work done by academic investigators, regulators of medical research institutions where most privately-funded research takes place, such as by a reformation of HIPAA rules and the Food and Drug Administration, which regulates the use of genetic information by the pharmaceutical and diagnostic industries when they use it to develop products.

Ultimately, though, the most powerful policy measures will be those that actually target the outcome of the misappropriation and misuse of genetic information, beyond just taking a privacy-based or anti-discrimination framework, which fails to account for what genetic information actually means. It is true that genetic information does not necessarily indicate that any disease or other characteristic will actually manifest and appear in reality. The DNA sequence is at most a probabilistic blueprint for potential interaction with the environment. Seen this way, the core principle of genetic policy ought to ensure that genetic information will not be used as a basis for discrimination or stigmatization, a concept that Harris and Sulston have called "genetic equity."[173]

GINA is based on the anticlassification principle, with its analogue the "colorblindness" paradigm for racial discrimination, in which it is the categorization based on genetic information that is the harm that the statute seeks to avoid—explicitly so in its provisions keeping the employer as "blind" to the employee's genetic information as possible. [174] This would seem to deal with the stigmatization problem, but it ignores the fact that genetic information does indicate the *potential* for something real to manifest, such as the potential risk for physical disability upon environmental exposure. For example, what if an employee's genetic information indicated that they were at greater risk of carpal tunnel syndrome unless there were accommodations made in their job?[175] Because GINA forces employers to be deliberately "blind" to the information about risk, and there is no physically manifested disability that triggers the reasonable accommodation requirement in the American Disabilities Act ("ADA"), then the

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[172] *See* Mildred K. Cho, *Racial and Ethnic Categories in Biomedical Research: There is no Baby in the Bathwater*, 34 J.L. MED. & ETHICS 497, 499 (2006) ("Because social perceptions of the meaning of race and ethnicity are extremely fluid, basing research findings on these categories or applying scientific findings based on perceived race or ethnicity is fraught with problems.").

[173] John Harris & John Sulston, *Genetic Equity*, 5 NATURE 796, 798 (2004).

[174] *See* Jessica L. Roberts, *Genetic Information Nondiscrimination Act as an Antidiscrimination Law*, 86 NOTRE DAME L. REV. 597, 632–34 (2011) (describing the construction of GINA's provisions as being based on the anticlassification theory of antidiscrimination).

[175] Prior to GINA, the EEOC settled a lawsuit under the ADA with Burlington Northern Santa Fe Railway (BNSF) to end genetic testing of employees who filed claims for injuries based on carpal tunnel syndrome. BNSF sought to investigate whether the employees possessed a rare genetic variant that could itself cause carpal tunnel syndrome. *See* E.E.O.C. v. Burlington Northern & Santa Fe Ry. Co., No. 02-C-0456, 2002 WL 32155386 (E.D. Wis. May 8, 2002). This testing would certainly be disallowed under GINA, as would testing to see if employees were susceptible to carpal tunnel syndrome—even if the outcome would not be to fire those employees, but rather to reassign them or otherwise accommodate them.

employee will fall through the cracks.[176] Thus, while GINA may represent an important first step, it is important to ensure that antidiscrimination in the genetic information context does not follow the anticlassification paradigm that fails to recognize the existence of any harm associated with discrimination other than the mere social and emotional stigma of categorization.

The example of the United Nations Convention on the Rights of Persons with Disabilities ("UNCRPD") may be instructive. The UNCRPD considers the importance of social rights, such as the rights to health care, income assistance, education, and other critical social services needed by a person with a disability given their particular circumstances.[177] Similarly, genetic information manifests itself as an *anticipated* need for additional social services based on genetic risk, such as medical care. Consequently, there ought to be an analogous consideration of social rights in addition to basic civil rights. At the present time, while they are a part of the European Union's Charter of Fundamental Rights, social rights seem to be outside the realm of American constitutional law, at least as it is currently being interpreted by the Supreme Court and understood by legislators and the public. [178]

However, it is likely that much of the American attitude towards social rights is based on the ideal of individualism, which eschews collective responsibility for what is believed to be under individual control, or for problems that only affect "other people." The reality of genetic information is that *everyone* has DNA sequences that suggest the potential for acquiring a disease and manifesting a disability. That means that our genomes teach us that we are all at risk of being left out of the social mainstream, regardless of our racial, ethnic, gender, or economic classification at the present time. Even if exactly how far we are left out of the mainstream will depend on where we start from, we all risk something in the absence of a collective safety net and a society that does not concern itself with the accommodation of physical and psychological variations from what is assumed to be "normal." It is possible that one consequence of widespread DNA sequencing will be the recognition of a need for a social charter as a measure that protects everyone, regardless of one's own perceived present social status. This goal will certainly not be reached if genetic information is used to reinforce the divisions that exist within society by validating regressive attitudes about the biological reality of racial and ethnic difference.

CONCLUSION

Applying the science of genomics will be like no other technological advancement. There is not just one single human genome to discover. What we call the "genome" is the collective of all our

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[176] *See* Mark A. Rothstein, *GINA, the ADA and Genetic Discrimination in Employment*, 36 J.L. MED. & ETHICS 837, 839 (2008) ("Under the ADA, an individual with a mild, temporary, or presymptomatic condition does not come within the statutory definition of an individual with a disability. Similarly, under GINA, an individual with a genetically based, biologically determinable difference beyond genotypic variation but short of phenotypic variation is unlikely to be protected."). The BNSF case, described *supra* in note 174, would seem to suggest that there could be ADA coverage, but as Rothstein's article notes, the Supreme Court had subsequently reduced the scope of the ADA prior to the ADA Amendments Act of 2008. Even after the Amendments, reasonable accommodations are only required for actual disability.

[177] United Nations Convention on the Rights of Persons with Disabilities, U.N. Doc. A/61/611 (Dec. 6, 2006). *See generally* Sandra Fredman, *Disability Equality: A Challenge to the Existing Anti-Discrimination Paradigm*, *in* DISABILITY RIGHTS IN EUROPE: FROM THEORY TO PRACTICE 199, 199–218 (Anna Lawson & Caroline Gooding eds., 2005); Janet E. Lord & Rebecca Brown, *The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities: The UN Convention on the Rights of Persons with Disabilities*, *in* CRITICAL PERSPECTIVES ON HUMAN RIGHTS AND DISABILITY LAW 273–307 (Marcia H. Rioux et al. eds., 2011).

[178] *See generally* Stephen P. Marks, *The Past and Future of the Separation of Human Rights into Categories*, 24 MD. J. INT'L. L. 209 (2009).

personal DNA sequences, each of which contains unique information that is particular to each of us as individuals. Thus, there is a dilemma between the universal and the individual, in which individual interests must be protected if information is disclosed to achieve universal benefits in medical research. It will be insufficient to merely attempt to ensure genetic privacy, especially through the current protections based on de-identification and anonymization of personal data in genome-wide association studies.

As detailed in this note, genetic information is not like other kinds of medical or other personally identifiable information. Genetic information is hard to destroy, especially once it has been translated to computer code. Once anonymized, it easily may be re-identified. Most important of all, while its import in determining intelligence or behavior is controversial, there is no doubt that an individual's DNA sequence contains a large amount of sensitive medical information. Most critically, compromises to genetic privacy affect family members as much as they do the individual who has either consented to the release of their genetic information or participated in a study that releases genetic information. As the Fourth Amendment experience with forensic DNA testing demonstrates, trying to fit genetic information into our existing legal system for privacy protection runs into practical problems. Consequently, the development of new policies that target genetic information differently will not be mere "genetic exceptionalism," but rather, necessary responses to real problems that already affect people.

These issues have all been discussed from the perspective of African Americans and other racial and ethnic minorities within the United States because the problem currently exists in that part of the population. Because genetic discrimination compounds existing racial discrimination and social disadvantage, it is important to take the current disparate impact of genetic discrimination on African Americans into account in establishing strong protections over misuse of genetic information gained through studies to encourage their confidence in medical research and ensure that they do not continue to be underrepresented as the next generation of medicine emerges. More broadly, we can also consider the African American experience with sickle cell disease carrier screening and forensic DNA databases as a kind of "canary in the coal mine" which anticipates the potential risks for the population as a whole as genetic studies become more pervasive. From this perspective, developing robust measures to present misuse of personal genetic information should be a critical goal for everyone, irrespective of race.