

Privacy Perspectives on Direct-to-Consumer Genetic Testing in the Era of Big Data: Role of Blockchain Technology in Genomics

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I. INTRODUCTION

We currently live in the era of Big Data.¹ Digital information is collected, shared, organized, stored, and analyzed on a scale unlike any time before, “allow[ing] analysts, researchers, and business users to make better and faster decisions using data that was previously inaccessible or unusable.”² The amount of digital data generated annually has grown exponentially since 2012 and will continue to increase on an upward and seemingly unbounded trajectory.³ It is estimated that by the end of 2020,

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1. Laurie A. Schintler & Connie L. McNeely, *Encyclopedia of Big Data*, SPRINGER PRESS (2019), <http://link.springer.com/referencework/10.1007/978-3-319-32001-4> (“Technological advancements and other related trends are contributing to the production of an astoundingly large and exponentially increasing collection of data and information, referred to in popular vernacular as ‘Big Data.’”).

2. *Big Data Analytics*, IBM, <http://www.ibm.com/analytics/hadoop/big-data-analytics> (last visited Mar. 16, 2019).

3. Patrick Tucker, *Has Big Data Made Anonymity Impossible?*, MIT TECH. REV. (May 7, 2013), <http://www.technologyreview.com/s/514351/has-big-data-made-anonymity-impossible/>.

the amount of digital data will surpass forty zettabytes, which is equivalent to 5200 gigabytes of data for every single person on the planet.⁴

The plummeting cost of data collection, storage, and processing coupled with new sources of data, “means that we live in a world of near-ubiquitous data collection.”⁵ When used appropriately, “big data analysis can boost economic productivity, drive improved consumer and government services, thwart terrorists, and save lives.”⁶ However, the sheer quantities of data and improvements in analytics have generated unique sets of challenges that affect several sectors and the public at large.⁷ One common denominator across disciplines is the concern that Big Data is diminishing individual privacy protection.

Traditional methods of privacy protection are insufficient when applied to Big Data analytics. For example, unlike physical records and documents that can be permanently destroyed, digital information “can be captured, copied, shared, and transferred at high fidelity and retained indefinitely.”⁸ As a result, data is effectively a permanent, indefatigable resource of information. In addition, “[a]nonymity is also eroded in a big data paradigm.”⁹ Modern research shows that nearly every piece of data can be used to identify the original owner, even if measures are taken to “de-identify” the personally identifiable information.¹⁰ Moreover, Big Data possesses an inherent predictive value that clashes with privacy norms—trends in past data can lead to invasive predictions of the future.¹¹ Privacy issues have profound implications across many disciplines; however, privacy concerns involving genetic data are particularly apropos.¹²

4. *Big Data and the Future of Privacy*, EPIC, <http://epic.org/privacy/big-data/> (last visited Mar. 30, 2019). One zettabyte equals one sextillion bytes or 10^{21} units of information—to put this into perspective, “the 1,250 pages of Leo Tolstoy’s *War and Peace* would fit into a zettabyte 323 trillion times.” EXEC. OFFICE OF THE PRESIDENT, *BIG DATA: SEIZING OPPORTUNITIES, PRESERVING VALUES PRIVACY REPORT* (May 1, 2014), http://obamawhitehouse.archives.gov/sites/default/files/docs/big_data_privacy_report_may_1_2014.pdf.

5. EXEC. OFFICE OF THE PRESIDENT, *supra* note 4 (“[W]ith the rising capabilities of ‘data fusion,’ which brings together disparate sources of data, big data can lead to some remarkable insights.”).

6. *Id.*

7. *See id.*; Tucker, *supra* note 3.

8. EXEC. OFFICE OF THE PRESIDENT, *supra* note 4.

9. *Big Data and the Future of Privacy*, *supra* note 4.

10. *Id.*

11. Researchers using GPS data sets “predicted a person’s approximate location up to 80 weeks into the future, at an accuracy of above 80 percent.” Tucker, *supra* note 3.

12. Yulan Liang & Arpad Kelemen, *Big Data Science and Its Applications in Health and Medical Research: Challenges and Opportunities*, 7 J. BIOMETRICS & BIostat. 1, 1 (2016) (“The

There is nothing more private than your personal genetic information. Although human beings are 99.9% identical in their genetic makeup, the differences coded in the 0.1% contain important markers about disease manifestation and give rise to individual differences in physical features, well-being, and health outcomes.¹³ Genetic testing is a common tool for identifying changes in an individual's genetic composition, whether it is in chromosomes, genes, or proteins.¹⁴

Today, genetic testing is used in a litany of applications ranging from secret paternity testing to genealogy to solving decades-old cold case crimes. Despite the seemingly ubiquitous nature of genetic testing, the ability to sequence a human genome is a relatively recent technological achievement that was first accomplished in 2003 by the Human Genome Project.¹⁵ Since then, a “genomic revolution” has ensued that has become more prolific with the advent of direct-to-consumer (DTC) genetic testing.¹⁶ As a result, tens of millions of individuals have submitted their genetic information for testing and analysis.

The DTC genetic testing industry is not immune to the privacy concerns that plague other Big Data industries. Although fifteen years have passed since the Human Genome Project was completed, the law has been unable to keep pace with the rapid advancements in biotechnology. The reality is that our current legal framework is not equipped to deal with privacy concerns that originate from DTC genetic testing and the databases that store genetic information. As a result, alternative solutions to augmenting individual privacy should be explored.

This Comment explores the history of genome sequencing and the current privacy concerns that have emerged from the technology. Specifically, this Comment will consider the current privacy implications that surround DTC genetic testing and will advocate for the use of blockchain technology to enhance consumer privacy. I argue that blockchain technology serves as an ideal privacy measure allowing researchers access to genomic data, while protecting consumer identity.

healthcare and biomedical sciences have rapidly become data-intensive as investigators are generating and using large, complex, high dimensional, and diverse domain specific datasets.”).

13. *Frequently Asked Questions About Our Genome Science*, NAT'L HUM. GENOME RES. INST. (Sept. 7, 2018), <http://www.genome.gov/19016904/faq-about-genetic-and-genomic-science/>.

14. *What Is Genetic Testing?*, U.S. NAT'L LIBR. MED. (Mar. 19, 2019), <http://ghr.nlm.nih.gov/primer/testing/genetic-testing>.

15. *Id.*

16. *Id.* (“Direct-to-consumer genetic testing provides people access to their genetic information without necessarily involving a healthcare provider or health insurance company in the process.”).

Part II provides a comprehensive overview of the Human Genome Project, the genome revolution, and the current state of DTC genetic testing. Part III explores the current privacy implications of genetic testing and the intersection of law and genetic privacy. Lastly, Part IV provides an overview of blockchain technology and argues for its implementation to promote genetic privacy.

II. BACKGROUND

A. *The Human Genome Project*

The entire human genome was first successfully mapped and sequenced in 2003 by the Human Genome Project (HGP)—a thirteen-year-long, international public collaboration among twenty separate institutions.¹⁷ The HGP was launched through a joint effort between the National Institutes of Health (NIH) and the U.S. Department of Energy in 1990.¹⁸ It involved research institutions spanning three continents and is still considered to be the world's largest collaborative biological endeavor.¹⁹

Members of the HGP shared two principal goals. First, the HGP aimed to create a high-quality human “genetic blueprint” by determining the DNA sequences that make up the human genome’s twenty-three chromosome pairs.²⁰ Second, the HGP sought to produce a high-resolution map to illustrate genetic linkages and identify the precise locations of individual genes in the genome.²¹

Researchers hoped the HGP’s genome maps and sequences would “further our basic understanding of human genetics and of the role of various genes in health and disease.”²² Put simply, the results of the HGP were slated to revolutionize our understanding of human development and

17. The HGP was also complemented by private efforts of Celera Genomics. SIMON TRIPP & MARTIN GRUEBER, BATTELLE MEM’L INST., ECONOMIC IMPACT OF THE HUMAN GENOME PROJECT (May 2011), <http://www.battelle.org/docs/default-source/misc/battelle-2011-misc-economic-impact-human-genome-project.pdf>.

18. *Id.*

19. *Id.*

20. *Human Genome Project FAQ*, NAT’L HUM. GENOME RES. INST. (Nov. 12, 2018), <http://www.genome.gov/11006943/human-genome-project-completion-frequently-asked-questions/> (“Sequencing means determining the exact order of the base pairs in a segment of DNA.”).

21. Gene mapping is a technique that identifies the locus of a gene on a particular chromosome and “can offer firm evidence that a disease transmitted from parent to child is linked to one or more genes.” *Genetic Mapping Fact Sheet*, NAT’L HUM. GENOME RES. INST., <http://www.genome.gov/10000715/genetic-mapping-fact-sheet/> (last visited Mar. 17, 2019).

22. Kristin M. Raffone, *The Human Genome Project: Genetic Screening and the Fundamental Right of Privacy*, 26 HOFSTRA L. REV. 503, 511 (1997).

disease etiology. At the time, the endeavor was considered to be the “holy grail” of life, with the imminent results likened to outstanding scientific achievements of humankind such as the lunar landing and invention of the first nuclear weapon.²³

The HGP was declared complete in April 2003 after researchers successfully mapped and sequenced the entire human genome for the first time in history.²⁴ Using DNA from anonymous volunteers, the HGP revealed that a single human genome is composed of approximately three billion DNA base pairs and contains instructions for manufacturing roughly 30,000 genes.²⁵ The maps and sequences were immediately made freely available to the public and are regularly updated as sequencing technology advances.²⁶

B. Genome Revolution

DNA fragments were sequenced in clinical laboratories prior to the HGP; however, sequencing was used judiciously because it was considered expensive and laborious.²⁷ Some companies offered genetic testing services, but they were limited to a few commercial genetic testing and research laboratories.²⁸ Genetic testing was generally cost-prohibitive to most of the population, and insurance companies rarely paid for the testing services.²⁹ Testing was primarily “used to make or confirm a diagnosis of a genetic condition” and to screen newborns for congenital conditions.³⁰

23. *Id.*

24. *Human Genome Project FAQ*, *supra* note 20.

25. *Id.*

26. All human genome sequence information had to be made publicly available within twenty-four hours of its assembly to allow unrestricted access to researchers in academia and private industry. Heidi Chial, *DNA Sequencing Technologies Key to the Human Genome Project*, 1 *NATURE EDUC.* 219, 219 (2008).

27. Jill Hagenkord, *What Has Been the Biggest Advance in Genomics in the Last Five Years?*, *FORBES* (Apr. 4, 2017, 3:09 PM), <http://www.forbes.com/sites/quora/2017/04/04/what-has-been-the-biggest-advance-in-genomics-in-the-last-five-years/#40441ce428d7> (“Turn around times were four months to more than a year.”).

28. NAT’L INST. OF HEALTH, *FACT SHEET: GENETIC TESTING: HOW IT IS USED FOR HEALTHCARE* (June 30, 2018), [http://archives.nih.gov/asites/report/09-09-2019/report.nih.gov/nihfactsheets/Pdfs/GeneticTesting-HowItsUsedForHealthcare\(NHGRI\).pdf](http://archives.nih.gov/asites/report/09-09-2019/report.nih.gov/nihfactsheets/Pdfs/GeneticTesting-HowItsUsedForHealthcare(NHGRI).pdf).

29. Hagenkord, *supra* note 27 (“Genetic testing on affected people was rarely done and preventive genetic testing of healthy people was unheard of.”).

30. NAT’L INST. OF HEALTH, *supra* note 28.

However, the HGP triggered pioneering advancements in medical science and catalyzed a genomic revolution.³¹ Genetic testing is now widely commercially available and is offered by over 500 laboratories worldwide.³² Testing services include diagnostic testing, predictive and pre-symptomatic genetic testing, carrier testing, prenatal testing, pharmacogenetic testing, and research genetic testing.³³ In addition, the HGP made personalized genomic medicine a reality. Today, more clinical decisions are based on genomic information than ever before, and “[s]cientists are developing and using diagnostic tests based on genetics . . . to better predict patients’ responses to targeted therapy.”³⁴ Further, the genomic revolution has impacted disciplines ranging from renewable energy development to agricultural biosciences to homeland security.³⁵

One of the greatest benefits to emerge from the genomic revolution is advancement in the ease and cost of performing genetic sequencing. The HGP required over thirteen years of computing power and more than \$3.7 billion to sequence the first complete human genome.³⁶ Since then, the cost and time necessary to sequence genetic material has experienced a precipitous decline. Advances in genomics have exceeded Moore’s Law—an observation that with time, “[c]omputing would dramatically increase in power, and decrease in relative cost, at an exponential pace.”³⁷ For example, “[s]ince 2000, the cost to sequence a whole human genome has continued to collapse. From \$3.7 billion, it dropped to \$10 million in

31. The HGP ushered in a new age of discovery and has promoted incredible advances in science, technology, and medicine. *Human Genome Project FAQ*, *supra* note 20.

32. NAT’L INST. OF HEALTH, *supra* note 28.

33. *Id.*

34. Margaret A. Hamburg & Francis S. Collins, *The Path to Personalized Medicine*, 363 *NEW ENG. J. MED.* 301, 303-04 (2010). Personal genomics can improve health care “by providing personalized risk information about diseases such as cancer, diabetes, heart disease and obesity, and about how individuals metabolize drugs, whether they are carriers for certain diseases and even what personality traits they are likely to have.” Simone Vernez & Sandra Soo-Jin Lee, *Making Sense of the Genomic Revolution*, 99 *AM. SCIENTIST* 266, 266 (2011); Joanna Lynne Kelley, *The Genomics Revolution*, *HUFFINGTON POST* (Jan. 19, 2013), http://www.huffingtonpost.com/joanna-lynn-kelley/genomics_b_2161232.html.

35. Several additional applications for manipulating genome structure and function are on the imminent horizon. Charles A. Gersbach, *Genome Engineering: The Next Genomic Revolution*, 11 *NATURE METHODS* 1009, 1009-11 (2014); TRIPP & GRUEBER, *supra* note 17.

36. James Bannon, *Heading for \$100: The Declining Costs of Genome Sequencing & the Consequences*, *ARK INVEST* (Aug. 21, 2014), <http://ark-invest.com/research/genome-sequencing>.

37. *Over 50 Years of Moore’s Law*, *INTEL*, <http://www.intel.com/content/www/us/en/silicon-innovations/moores-law-technology.html> (last visited Mar. 17, 2019).

2006, and to \$5,000 in 2012” and to \$1000 in 2014.³⁸ Most recently, whole genome sequencing was offered for \$199 and some estimate that “the \$99 genome will be here in three to five years.”³⁹ Simultaneously, the time necessary to sequence a human genome has also decreased dramatically. Current DNA sequencers can decode the entire human genome on a time scale ranging from minutes to a couple of days.⁴⁰ The ease and affordability of genetic sequencing has allowed genetic testing to flourish and become embedded in our vernacular and society.

C. *Direct-to-Consumer (DTC) Genetic Testing*⁴¹

In the past, genetic tests were administered by health care providers that would “determine which test is needed, order the test from a laboratory, collect and send the DNA sample, interpret the test results, and share the results with the patient.”⁴² DTC genetic testing varies from classical genetic testing in several respects: DTC tests are marketed directly to the consumer, tests can be bought online or in a store, customers submit a saliva sample, customers receive results directly from a secure website or upload their raw genetic data to a third-party site, and health care provider participation is not necessary.⁴³ Popular testing companies include 23andMe, Ancestry, and MyHeritage DNA.⁴⁴ DTC genetic testing companies offer an array of genetic tests including:

[N]utrigenomic testing (regarding the body’s processing of different nutrients), pharmacogenomic testing (regarding the sensitivity to particular substances or medications), disease susceptibility testing (regarding disease risk factors), ancestry testing (regarding racial and ethnic genomic identifies), athletic dispositions testing, matchmaking on the basis of genetic factors, and comprehensive whole exome sequencing (sequencing of those

38. Bannon, *supra* note 36; see *The Cost of Sequencing a Human Genome*, NAT’L HUM. GENOME RES. INST. (July 6, 2016), <http://www.genome.gov/sequencingcosts>.

39. Megan Molteni, *Now You Can Sequence Your Whole Genome for Just \$200*, WIRED (Nov. 19, 2018, 8:00 AM), <http://www.wired.com/story/whole-genome-sequencing-cost-200-dollars/>.

40. Matthew Harper, *Illumina Promises to Sequence Human Genome for \$100—but Not Quite Yet*, FORBES (Jan. 9, 2017), <http://www.forbes.com/sites/matthewherper/2017/01/09/illumina-promises-to-sequence-human-genome-for-100-but-not-quite-yet/#40090140386d>.

41. Direct-to-consumer genetic testing is also referred to as direct-access genetic testing, at-home genetic testing, and home DNA testing. *What Is Direct-to-Consumer Genetic Testing?*, U.S. NAT’L LIBR. MED. (Mar. 12, 2019), <http://ghr.nlm.nih.gov/primer/dtcgeneticstesting/directoconsumer>.

42. *Id.*

43. *Id.*

44. Antonio Regalado, *More than 26 Million People Have Taken an at-Home Ancestry Test*, MIT TECH. REV. (Feb. 11, 2019), <http://www.technologyreview.com/s/612880/more-than-26-million-people-have-taken-an-at-home-ancestry-test/>.

parts of the genome that code for proteins) or whole genome sequencing (sequencing of the entire genome).⁴⁵

However, the majority of consumers use DTC tests for recreational purposes out of curiosity about their genetic make-up.⁴⁶

Advocates of DTC genetic testing argue that at-home tests confer several benefits to consumers and society. Benefits include empowerment, the ability to make better-informed health decisions, and enhanced public awareness about genetic diseases.⁴⁷ In addition, DTC genetic tests are cheaper than a genetic test obtained through a health care provider and do not require preapproval from a physician or insurance company.⁴⁸ There are, however, several risks and limitations associated with DTC genetic testing. For example, many courts reject the use of DTC genetic tests to establish proof of paternity.⁴⁹ Moreover, unproven or invalid DTC tests may be misleading, there is little oversight or regulation of testing companies, information may be stressful or upsetting, and individuals may make life-altering decisions based on inaccurate or misunderstood information.⁵⁰

Of note, the lack of DTC genetic testing regulation and percentage of false positives has particular significance. Consumers may be exposed to nebulous and exaggerated claims because most genetic tests are unregulated and enter the commercial market without any independent analysis to verify their accuracy.⁵¹ For example, when 23andMe first launched, it operated with little federal oversight.⁵² At the time, 23andMe

45. Heike Felzmann, *'Just a Bit of Fun': How Recreational Is Direct-to-Customer Genetic Testing?*, 21 *NEW BIOETHICS* 20, 21 (2015).

46. Recreational genomics is "used to distinguish genetic testing for ancestry or other non-health concerns from genetic testing for health factors." *Id.* at 22; see J. Scott Roberts & Jenny Ostergren, *Direct-to-Consumer Genetic Testing and Personal Genomics Services: A Review of Recent Empirical Studies*, 1 *CURRENT GENETIC MED. REP.* 182 (2013).

47. See Pascal Su, *Direct-to-Consumer Genetic Testing: A Comprehensive View*, 20 *YALE J. BIOL. MED.* 359 (2013).

48. *What Are the Benefits and Risks of Direct-to-Consumer Genetic Testing?*, U.S. NAT'L LIBR. MED. (Mar. 19, 2019), <http://ghr.nlm.nih.gov/primer/dtcgeneticstesting/dtcrisksbenefits>.

49. *Ashby v. Mortimer*, 329 F.R.D. 650, 655 (D. Idaho) ("The Ancestry.com test does not provide conclusive proof of paternity because, *inter alia*, there is no documented chain of custody.").

50. For example, Ancestry's privacy statement warns, "You may discover unexpected facts about yourself or your family . . . [o]nce discoveries are made, we can't undo them." Regalado, *supra* note 44; see *What Are the Benefits and Risks of Direct-to-Consumer Genetic Testing?*, *supra* note 48.

51. *Regulation of Genetic Tests*, NAT'L HUM. GENOME RES. INST. (Jan. 17, 2018), <http://www.genome.gov/10002335/regulation-of-genetic-tests/>.

52. Francie Diep, *The FDA Aims to Relax Regulation on Genetic Tests*, PAC. STANDARD (Nov. 6, 2017), <http://psmag.com/news/fda-aims-to-relax-regulation-on-genetic-tests>.

appeared to be a fun, nascent technology that provided personal insight into ancestry, genealogy, and inherited traits.⁵³ However, 23andMe soon began marketing their genetic testing kits as a way to detect and mitigate health problems.⁵⁴ In 2013, the Food and Drug Administration (FDA) sent a warning letter to 23andMe that stated, “[Y]ou are marketing the 23andMe Saliva Collection Kit and Personal Genome Service (PGS) without market clearance or approval in violation of the Federal Food, Drug, and Cosmetic Act.”⁵⁵ The FDA ordered 23andMe to stop disclosing carrier status, health risks, drug response, and any information that would enable customers to take steps towards mitigating serious diseases.⁵⁶ 23andMe temporarily stopped providing health-related results in its genetic tests; however, several class-action legal proceedings commenced against 23andMe alleging *inter alia*:

23andMe falsely represented in advertising that the personal genome service would give consumers knowledge about their health conditions and their status as carriers of genetic disorders; the results actually provided were inaccurate and incomplete; 23andMe misled consumers into believing that the personal genome service had received government approval; and 23andMe did not disclose to consumers that their genetic information would be used to create a database that 23andMe could market to physicians and pharmaceutical companies.⁵⁷

23andMe later gained FDA approval to send results for gene variants associated with ten diseases, marking the first time a federal agency approved this type of DTC genetic test.⁵⁸

The FDA prohibits most DTC companies from offering diagnostic tests, but consumers can still obtain their raw genetic data. However, “[i]t is challenging to interpret raw genotype data on your own. To help with this, several online ‘third-party interpretation’ services offer analysis and

53. Charles Seife, *23andMe Is Terrifying, but Not for the Reasons the FDA Thinks*, SCI. AM. (Nov. 27, 2013), <http://www.scientificamerican.com/article/23andme-is-terrifying-but-not-for-the-reasons-the-fda-thinks/> (“The FDA had little problem with [23andMe] telling you why you had dry ear wax or whether you’re likely to sneeze when you look at a bright light.”).

54. *Id.*

55. According to federal law, 23andMe’s kits were now considered a “medical device” and required FDA approval because they were intended to cure, mitigate, treat, prevent, or diagnose a disease. Dep’t of Health & Human Servs., Pub. Health Serv., Doc. No. GEN1300666, Warning Letter (2013).

56. *Id.*

57. *Ironshore Specialty Ins. Co. v. 23andMe, Inc.*, No. 14-cv-03286-BLF, 2016 U.S. Dist. LEXIS 96079, at *3-4 (N.D. Cal. 2016).

58. Diep, *supra* note 52.

interpretation of the raw data collected by another company.”⁵⁹ Yet, “[t]here is little regulation of third-party interpretation services.”⁶⁰ A recent study revealed 40% of gene variants reported in DTC raw data were false positives.⁶¹ In addition, some gene variants classified as conferring risk for a condition were actually benign.⁶² Furthermore, a report by the U.S. Government Accountability Office found that “identical DNA samples yield[ed] contradictory results” when interpreted by four different companies.⁶³ In totality, these findings highlight the inaccuracies of DTC genetic tests and underscore the importance of consulting clinical professionals to ensure appropriate test interpretation and intervention.

DTC genetic testing has continued to surge in popularity despite lack of federal regulation, risks of false positives, and inherent privacy concerns (see Part III below). DTC genetic testing has expanded into pet-DNA markets, music streaming services, DNA-tailored cosmetics, and artificial intelligence weight-loss coaching services.⁶⁴ In response to DTC popularity, one DTC genetic services company translated its website into forty-two languages.⁶⁵ Moreover, the global genomics market is estimated to reach \$27.6 billion by 2025.⁶⁶ Of note, more people took ancestry tests in 2017 than in all previous years combined.⁶⁷ According to recent

59. *What Can Raw Data from a Direct-to-Consumer Genetic Test Tell Me?*, U.S. NAT'L LIBR. MED. (Feb. 26, 2019), <http://ghr.nlm.nih.gov/primer/dtcgeneticstesting/dtcrawdata>.

60. *Id.*

61. See Stephany Tandy-Connor et al., *False-Positive Results Released by Direct-to-Consumer Genetic Tests Highlight the Importance of Clinical Confirmation Testing for Appropriate Patient Care*, 20 GENETICS MED. 1515 (2018).

62. *Id.*

63. Jessica Cussins, *Direct-to-Consumer Genetic Tests Should Come with a Health Warning*, PHARMA. J. (Jan. 15, 2015), <http://www.pharmaceutical-journal.com/opinion/comment/direct-to-consumer-genetic-tests-should-come-with-a-health-warning/20067564.article?firstPass=false>.

64. Kristen V. Brown, *23andMe Will Add Weight-Loss Advice to Its DNA-Testing Services*, BLOOMBERG (Jan. 8, 2019, 10:00 AM), <http://www.bloomberg.com/news/articles/2019-01-08/23andme-will-add-weight-loss-advice-to-its-dna-testing-services>; Jennifer Peltz, *Dog DNA Under the Microscope as Genetic Testing Takes Off*, CHI. SUN TIMES (Feb. 11, 2019, 10:13 AM), <http://chicago.suntimes.com/entertainment/dog-dna-under-the-microscope-as-genetic-testing-takes-off/>; Rob Thubron, *Spotify and Ancestry Team Up to Create Music Playlists Based on Your DNA*, TECH SPOT (Sept. 25, 2018, 7:12 AM), <http://www.techspot.com/news/76603-spotify-ancestry-team-up-create-playlists-based-dna.html>; see Susanne B. Haga, *Genome Policy Considerations for Genomic Medicine*, in ESSENTIALS OF GENOMIC AND PERSONALIZED MEDICINE 209 (Geoffrey S. Ginsburg & Huntington F. Willard eds., 2010).

65. Regalado, *supra* note 44.

66. *Genomics Market Size Worth USD 27.6 Billion by 2025*, GRAND VIEW RES. (June 2019), <http://www.grandviewresearch.com/press-release/genomics-market-analysis>.

67. Antonio Regalado, *2017 Was the Year Consumer DNA Testing Blew Up*, MIT TECH. REV. (Feb. 12, 2018), <http://www.technologyreview.com/s/610233/2017-was-the-year-consumer-dna-testing-blew-up/>.

estimates, more than 26 million consumers have taken an at-home genetic test.⁶⁸ At this current pace, it is expected that more than 100 million people will undergo genetic testing by 2021.

III. PRIVACY IMPLICATIONS OF DTC GENETIC TESTING

The proliferation of DTC genetic testing has generated a host of legal, ethical, moral, and regulatory implications; however, none are more paramount than the issue of privacy. Privacy implications emerge in the context of consent agreements, third-party access to data and use in scientific/clinical research settings, and criminal cases. For example, the majority of DTC genetic testing company privacy statements are long, vague, and written at a college reading level.⁶⁹ Companies that sufficiently disclose their privacy policies are an exception, rather than a rule. A recent study revealed that most privacy statements do not comply with international transparency guidelines related to “confidentiality, privacy, and data use.”⁷⁰ It can be challenging to navigate the contours of the privacy statements because each company maintains divergent policies regarding how long DNA samples and data may be stored, the process for deleting data, and opting into research projects.⁷¹ Moreover, most consent forms do not delineate how, when, and where data will be used.⁷² As a result, many consumers fail to understand and exercise their genetic privacy rights.

Opaque privacy policies also generate a maelstrom of concerns in the research sector. Almost every major DTC genetic company, such as 23andMe and Ancestry, shares anonymized genetic data with external research institutions.⁷³ Companies must obtain each consumer’s informed consent before their data can be used in research; however, “subsequent researchers may want to use genetic data for future investigations, making

68. Regalado, *supra* note 44.

69. Cassie Martin, *Privacy and Consumer Genetic Testing Don’t Always Mix*, SCI. NEWS (June 5, 2018, 7:00 AM), <http://www.sciencenews.org/blog/science-public/privacy-and-consumer-genetic-testing-dont-always-mix>.

70. *Id.*

71. Erin Brodwin, *How to Delete Your DNA Data from Genetics Companies Like 23andMe and Ancestry*, BUS. INSIDER (May 4, 2018, 7:37 AM), <http://www.businessinsider.com/how-to-delete-dna-genetic-data-2018-5>.

72. Jamie Ducharme, *A Major Drug Company Now Has Access to 23andMe’s Genetic Data. Should You be Concerned?*, TIME (July 26, 2018), <http://time.com/5349896/23andme-glaxo-smith-kline/>.

73. Kim Hart, *Genetic Testing Firms Share Your DNA Data More than You Think*, AXIOS (Feb. 25, 2019), <http://www.axios.com/dna-test-results-privacy-genetic-data-sharing-4687b1a0-f527-425c-ac51-b5288b0c0293.html>.

it difficult to keep participants abreast of the various uses of the genetic data.”⁷⁴ In addition, “DNA testing services don’t have to tell their consumers every time their data has been stripped of their identity, combined with others’ genetic information, combed for insights, then turned into statistics, and perhaps shared with a third party for further analysis.”⁷⁵ Furthermore, although most companies strive to provide their customers with control over their genetic data, it is unlikely consumers can revoke their data if it is already in use by researchers.⁷⁶

Privacy issues also emerge when data is sold to third parties. 23andMe recently announced that pharmaceutical industry behemoth GlaxoSmithKline purchased a \$300 million stake in the company.⁷⁷ 23andMe’s CEO touted the new collaboration as a way to make “novel treatments and cures a reality.”⁷⁸ However, privacy experts are skeptical that customers fully comprehended what they signed up for when they offered their genetic information to research studies. “If people are concerned about their social security numbers being stolen, they should be concerned about their genetic information being misused. This information is never 100% safe. The risk is magnified when one organization shares it with a second organization.”⁷⁹ When companies share genomic information with third parties, “DNA sequences are usually stripped of personal information and encrypted, identifiable only by a bar code.”⁸⁰ Although genetic data is presumably anonymized, the ability to reidentify anonymized genetic data has already been shown.⁸¹

For example, current DTC genetic databases are relatively homogenous and lack diversity. According to a recent survey, 85% of DTC

74. *Id.* Eighty percent of 23andMe customers have opted in to share their genomic data for research purposes. On average, each individual’s data contributes to more than 200 different studies. Kristen Hovet, *Your Genetic Data Is the New Oil. These Startups Will Pay to Rent It*, LEAPS MAG. (Sept. 21, 2018), <http://leapsmag.com/your-genetic-data-is-the-new-oil-these-startups-will-pay-to-rent-it>.

75. Tony Romm & Drew Harwell, *Ancestry, 23andMe and Others Say They Will Follow These Rules When Giving DNA Data to Businesses or Police*, WASH. POST (July 31, 2018), http://www.washingtonpost.com/technology/2018/07/31/ancestry-andme-others-say-they-will-follow-these-rules-when-giving-dna-data-businesses-or-police/?noredirect=on&utm_term=.c3baedc4a543.

76. *Id.*

77. Ducharme, *supra* note 72.

78. *Id.*

79. *Id.*

80. Martin, *supra* note 69.

81. Megan Molteni, *Genome Hackers Show No One’s DNA Is Anonymous Anymore*, WIRED (Oct. 11, 2018, 2:04 PM), <http://www.wired.com/story/genome-hackers-show-no-ones-dna-is-anonymous-anymore/>.

genetic test participants were white.⁸² While this presents an inherent hurdle for personalized medicine, the lack of heterogeneity among participants has huge privacy implications.⁸³ A homogenous commercial DNA database means most white Americans can be identified, even if they never submitted their DNA for testing.⁸⁴ In a recent study, researchers discovered that “if you live in the United States and are of European ancestry, there’s a 60% chance you have a third cousin or closer relative in the database” that can lead to your identification.⁸⁵ The study showed if a genetic database includes roughly 2% of adults in a given ethnic population, a match of a third cousin or closer is expected for almost any person of interest.⁸⁶ Moreover, a separate research group was able to identify personal genomes by surname inference.⁸⁷ The researchers recovered surnames by profiling certain DNA sequences, querying a public, recreational genetic genealogy database, and following up with an Internet search.⁸⁸ These advancements in reidentification warrant serious attention to the privacy implications of granting data access to third-party commercial companies.

Moreover, DNA sequencing technology has had a profound effect on the criminal justice system and police investigative practices. “There is the growing practice, at all levels of law enforcement, of collecting genetic data from suspects when they are arrested and storing the information in a database for later reference.”⁸⁹ In *Maryland v. King*, the Supreme Court held in a 5-4 decision that DNA collection from suspects who have been

82. Gollust et al., *Consumer Perspectives on Access to Direct-to-Consumer Genetic Testing: Role of Demographic Factors and the Testing Experience*, 95 MILBANK Q. 291, 301 (2017).

83. The majority of predictions are based on individuals mostly of European descent, and studies show the genetic risk of disease varies between different ethnic groups. Emily Singer, *23andMe Offers Free Genetic Tests to African Americans*, MIT TECH. REV. (Aug. 8, 2011), <http://www.technologyreview.com/s/424943/23andme-offers-free-genetic-tests-to-african-americans/> (“Growing evidence suggests that the results of these [DTC] studies, which encompass hundreds of thousands of people, may be less relevant or even irrelevant to those in other groups.”).

84. Jocelyn Kaiser, *We Will Find You: DNA Search Used to Nab Golden State Killer Can Home in on About 60% of White Americans*, SCIENCE (Oct. 11, 2018, 2:00 PM), <http://www.sciencemag.org/news/2018/10/we-will-find-you-dna-search-used-nab-golden-state-killer-can-home-about-60-white>.

85. *Id.*

86. Yaniv Erlich et al., *Identity Inference of Genomic Data Using Long-Range Familial Searches*, 362 SCIENCE 690, 690-94 (2018).

87. Melissa Gymrek et al., *Identifying Personal Genomes by Surname Inference*, 339 SCIENCE 321, 321 (2013).

88. *Id.*

89. *Genetic Information Privacy*, ELECTRONIC FRONTIER FOUND., <http://www EFF.ORG/issues/genetic-information-privacy> (last visited Mar. 31, 2019).

arrested for a crime is reasonable under the Fourth Amendment.⁹⁰ The dissent was troubled by the privacy implications, with Justice Scalia stating, “Make no mistake about it: As an entirely predictable consequence of today’s decision, your DNA can be taken and entered into a national DNA database if you are ever arrested, rightly or wrongly, and for whatever reason.”⁹¹ The Ninth Circuit Court of Appeals recently upheld a California law that requires all individuals arrested for or charged with any felony (or attempted felony) to submit DNA samples for inclusion in various law enforcement databases.⁹² The court compared the California statute to the Maryland law in *King* and found no Fourth Amendment violations.⁹³

The United States maintains the world’s largest databases of criminal DNA profiles.⁹⁴ The databases are composed of DNA from criminals, criminal suspects, parolees, probationers, and individuals who were arrested.⁹⁵ Offender databases contain the DNA of roughly 17 million people and are heavily skewed towards African-American and Hispanic populations.⁹⁶ Of note, forensic genetic tests vary greatly from medical and DTC genetic tests. “Law enforcement only collects and analyzes highly variable non-coding portions of the genome, counting up the number of times these ‘junk’ sequences repeat.”⁹⁷ The junk sequences are highly unique to each individual but do not reveal any personally identifiable information (e.g., hair color, eye color, ethnicity, etc.).⁹⁸ In contrast, medical and DTC genetic testing involve full genome sequencing or sequencing at particular gene locations.⁹⁹

However, researchers are already crossing forensic databases with biomedical and genealogical databases to identify persons of interest. Studies have shown forensic genetic records can be matched to a set of nonoverlapping genetic markers in an entirely different database.¹⁰⁰ Specifically, more than 30% of individuals in a forensic database can be

90. The Court found DNA sampling is analogous to taking fingerprints or a photo. *See Maryland v. King*, 569 U.S. 435 (2013).

91. *Id.* at 481.

92. *Haskell v. Harris*, 745 F.3d 1269, 1271 (9th Cir. 2013).

93. *Id.*

94. *Genetic Information Privacy*, *supra* note 89.

95. *Id.*

96. *Molteni*, *supra* note 81.

97. *Id.*

98. *Id.*

99. *Id.*

100. *See Jaehee Kim et al., Statistical Detection of Relatives Typed with Disjoint Forensic and Biomedical Loci*, 175 *CELL* 848 (2018).

linked to a family member (e.g., sibling, parent, or child) in a consumer database.¹⁰¹ This creates profound privacy implications, especially as it pertains to Fourth Amendment rights because “all the Supreme Court decisions about why existing offender databases don’t violate Fourth Amendment rights are all premised on the presumption that nothing personal can be gleaned from this junk DNA.”¹⁰² It is clear that forensic DNA profiles contain more information than previously considered and exploitation of further advancements in sequencing technology could violate the Fourth Amendment.¹⁰³

Genetic sequencing continues to be a transformative tool in the legal system, albeit a controversial one. 23andMe recently offered to genetically test undocumented migrant children in an effort to reunite them with their families.¹⁰⁴ However, privacy advocates argued that the genetic information could be used for nefarious purposes beyond reuniting migrant families seeking asylum.¹⁰⁵ Moreover, in 2018, law enforcement officials used public genealogy databases to arrest the Golden State Killer—a California man responsible for a series of rapes and murders dating back as early as 1979.¹⁰⁶ Investigators uploaded the unknown assailant’s DNA data to GEDmatch, a free, open-source online genealogy database where individuals share their raw data from consumer DNA testing companies.¹⁰⁷ A search revealed the crime scene DNA partially matched the DNA of a relative on GEDmatch.¹⁰⁸ “Other information such as genealogical records, approximate age, and crime locations then allowed the sleuths to hone in on a single person.”¹⁰⁹ Since then, more than

101. *Id.*

102. Molteni, *supra* note 81.

103. Kaiser, *supra* note 84 (“The linked consumer DNA profile could also reveal physical appearance or medical information for a criminal or their relatives, such as genes for eye color or a disease, even though the forensic databases aren’t supposed to contain that kind of information.”).

104. Dan Robitzski, *By Turning Down 23andMe, Immigration Activists Are Actually Being Responsible About Genetic Privacy*, FUTURISM (June 25, 2018), <http://futurism.com/23andme-immigration-activists-data-privacy>.

105. *Id.* (“Collecting this genetic information would give these companies—and the government, if the records were subpoenaed—the ability to trace these families for purposes far beyond reuniting parents with children. It would create a store of private information about migrants that could be devastating if leaked or sold.”).

106. Kaiser, *supra* note 84.

107. *Id.*

108. Sarah Zhang, *How a Genealogy Website Led to the Alleged Golden State Killer*, ATLANTIC (Apr. 27, 2018), <http://www.theatlantic.com/science/archive/2018/04/golden-state-killer-east-area-rape-dna-genealogy/559070/>.

109. Kaiser, *supra* note 84.

thirty rapists, killers, and victim's bodies have been identified using the same methods.¹¹⁰

Of concern, the ability of law enforcement to upload DNA data to public databases is entirely unregulated and remains an open question. After the Golden State Killer was arrested, four major DTC testing companies vowed to never share their information with law enforcement unless served with a warrant. Yet, weeks after the announcement, Family Tree DNA allowed the FBI to upload DNA samples for comparison against their private customer database.¹¹¹ This policy change was both unilateral and secret.¹¹² Shortly thereafter, the Federal Trade Commission launched an investigation into how DTC genetic testing companies were handling personal information and genetic data and how that information was shared with third parties.¹¹³

IV. USING BLOCKCHAIN TECHNOLOGY TO PROTECT PRIVACY

Unlike other forms of personal data, genetic information deserves a higher level of protection. As one expert phrased it, "Once your DNA has been compromised, you cannot change it. It's not like a credit card that you can cancel and receive a new one. Your genetic code is with you for all of your life Once it's been compromised, there's no way back."¹¹⁴ Around the world, "[t]here is a general trend towards more control by the individual that has very deep implications to companies and sites that collect and aggregate data."¹¹⁵ In the era of Big Data, blockchain technology has emerged as a powerful tool and provides users with augmented privacy and security.

In general terms, blockchain is a data storage technology that contains a "distributed and immutable database, shared and automatically synchronized among all participants."¹¹⁶ Blockchain allows digital pieces of information to be distributed, but not copied.¹¹⁷ Importantly, blockchain

110. Regalado, *supra* note 44.

111. *Id.*

112. *Id.*

113. Marcus Baram, *The FTC Is Investigating DNA Firms Like 23andMe and Ancestry over Privacy*, FAST COMPANY (June 5, 2018), <http://www.fastcompany.com/40580364/the-ftc-is-investigating-dna-firms-like-23andme-and-ancestry-over-privacy>.

114. Marie Huillet, *Life's Code: Blockchain and the Future of Genomics*, COINTELEGRAPH (Sept. 3, 2018), <http://cointelegraph.com/news/lifes-code-blockchain-and-the-future-of-genomics>.

115. Hovet, *supra* note 74.

116. Ozercan et al., *Realizing the Potential of Blockchain Technologies in Genomics*, 28 GENOME RES. 1255, 1256 (2018).

117. Paul Dughi, *A Simple Explanation of How Blockchain Works*, MEDIUM (Feb. 3, 2018), <http://medium.com/the-mission/a-simple-explanation-on-how-blockchain-works-e52f75da6e9a>.

allows new data to be shared in a protected and anonymous way.¹¹⁸ The critical components of blockchain technology are “(1) decentralization (i.e., a single entity cannot control the database), (2) immutability (i.e., no past record can be altered), and (3) security (i.e., accounts are protected by enhanced cryptographic methods).”¹¹⁹ One of the most common uses of blockchain is cryptocurrency—a digital currency that “uses encryption techniques to control the creation of monetary units and verify the transfer of funds.”¹²⁰

Harnessing genetic information is key to scientific and medical advancements; however, “[u]nderstanding the complex relationship between genetics and disease requires powerful statistical tests.”¹²¹ In other words, researchers need data—the bigger the database, the better the statistical power, and the more informative the results. Accessible data is the cornerstone of scientific development and is essential for analysis and reproducibility; however, research achievements should not come at the expense of privacy.¹²²

Blockchain technologies are ideally situated at the nexus between anonymity and dissemination of information—“[t]he vision is to incentivize consumers to share their genomic data and empower researchers to make new breakthroughs.”¹²³ Blockchain-based marketplaces can give individuals control over their encrypted DNA data and the ability to sell their DNA for a profit. “If these sequencing companies truly promote ownership by the individual of their genome, that’s a great segue to owning all your medical data.”¹²⁴ “By sequencing and then securely storing full genome sequences using blockchain technology, industries . . . will be able to query an individual’s DNA data

118. Helen Albert, *How Blockchain Companies Are Helping Us Protect Our Genomic Data*, LABIOTECH (June 6, 2019), <http://labiotech.eu/features/blockchain-control-genomic-data/>.

119. Ozercan et al., *supra* note 116.

120. *Bitcoin, Cryptocurrency, Blockchain . . . So What Does It All Mean?*, PWC, <http://www.pwc.com/us/en/industries/financial-services/fintech/bitcoin-blockchain-cryptocurrency.html> (last visited Mar. 7, 2019).

121. Caitlin Curtis & James Hereward, *New Cryptocurrencies Could Let You Control and Sell Access to Your DNA Data*, CONVERSATION (Jan. 22, 2018, 2:08 PM), <http://theconversation.com/new-cryptocurrencies-could-let-you-control-and-sell-access-to-your-dna-data-89499>.

122. Hovet, *supra* note 74 (“In the right hands, [genetic information] has the potential to save lives and reduce suffering.”); *see* Ozercan et al., *supra* note 116, at 1261.

123. Hovet, *supra* note 74.

124. Adam Rogers, *Solve Genomics with the Blockchain? Why the Hell Not*, WIRED (Feb. 21, 2018, 7:00 AM), <http://www.wired.com/story/solve-genomics-with-blockchain/>.

and reimburse those who should decide to share their information.”¹²⁵ In other words, “consumers . . . will have a direct say regarding which organizations can ‘rent’ their data, and will be able to negotiate the amount they receive in exchange.”¹²⁶ Potential buyers can filter data based on self-reported health conditions, ethnicity, age, and other physical characteristics.¹²⁷ In exchange for selling encrypted genomic data, individuals receive tokens, which can be cashed out, exchanged for Bitcoin, or used to buy additional tests that further interpret DNA.¹²⁸ Some companies offer a share in their company in exchange for DNA data.¹²⁹ Regardless, every transaction would be securely recorded on the blockchain.

Using blockchain technology to store and share genomic data will eschew several of the current privacy concerns, while allowing researchers unfettered access to millions of individuals’ genetic information. For example, blockchain’s decentralized features and peer-to-peer networks means it will become near impossible to reidentify anonymized data using available methods. Consumers who voluntarily share or sell their genetic information will retain greater control over their information and will no longer have to worry whether their personal identity is discoverable. Moreover, this will likely reduce the amount of cross-database inferences and identifications because public database information is stored in a safer, more anonymous way.

Before the potential of genomic blockchain-based markets can be fully realized and utilized, the field must overcome several hurdles. As a proof of principle, a genetics blockchain company successfully transferred a complete Y chromosome using Ethereum blockchain technology.¹³⁰ However, the sheer size of genomic data is a considerable limiting factor in using blockchain technology. “The size of the diploid human genome is

125. Gemma Milne, *Blockchain Genomics Startup Wants to Make You Money with Your DNA*, FORBES (Sept. 26, 2018, 1:56 AM), <http://www.forbes.com/sites/genmamilne/2018/09/26/blockchain-genomics-startup-allows-you-to-make-money-with-your-dna/#bcd18374b955>.

126. Hovet, *supra* note 74.

127. Molteni, *supra* note 81.

128. An average genomic data set sells for less than ten dollars. Molteni, *supra* note 81; Curtis & Hereward, *supra* note 121.

129. Kristen V. Brown, *As Genetic Testing Blossoms, Companies Search for a Killer App*, BLOOMBERG (Jan. 18, 2019, 4:00 AM), <http://www.bloomberg.com/news/articles/2019-01-18/as-genetic-testing-blossoms-companies-search-for-a-killer-app>.

130. Press Release, DNAtix, DNAtix Successfully Transferred Craig Venter’s Y Chromosome Using IBM Blockchain (June 29, 2018, 3:01 PM), <http://www.globenewswire.com/news-release/2018/06/29/1531531/0/en/DNAtix-Successfully-Transferred-Craig-Venter-s-Y-Chromosome-Using-IBM-Blockchain.html>.

1.5 Gigabytes, so it will require compression tools to significantly reduce DNA size; a must if one desires to use blockchain technologies. For reference, the average size of a transaction over the Ethereum blockchain is approximately less than 500 bytes.”¹³¹ In addition, one obstacle to implementing blockchain genomics is that it is not “widely supported, or even well-understood, by the public at large.”¹³² Thus, more individuals must become familiar and comfortable with the technology before it can gain traction. Moreover, a majority of the new genomic blockchain companies do not have exchangeable operating platforms and most “aren’t on the same kind of network as [B]itcoin.”¹³³ To facilitate convenient, secure exchanges of genomic information, companies will be forced to adopt interoperable platforms.

Blockchain technology will not eliminate all of the privacy concerns surrounding genomic testing in the era of Big Data. However, it is an available technology that is already being tailored to meet the needs of the health care industry and is likely to gain prominence as more individuals exploit the beneficial properties that blockchain technology confers.

V. CONCLUSION

We live in an ever-expanding data-driven world that is reflected by technology that is “moving from gigabytes to terabytes to petabytes and beyond.”¹³⁴ Decoding the first human genome took over a decade. Now, the same analysis can be achieved in a few days. Although direct-to-consumer genetic testing is beset by several privacy problems, DTC genetic tests will continue to grow in popularity. With this expansive trove of genetic data, researchers expect to make rapid advancements in the field of personal genomic medicine and gain critical insight into the role of genes and disease etiology. However, an inherent tension exists between ubiquitous information sharing and privacy protection. Legislators have already been asked to address how civil rights, equity, and equal opportunity will be preserved as the digital ecosystem continues to grow and evolve.¹³⁵ However, blockchain technology is a viable solution that can be implemented now. Further investigations should be conducted to

131. *Id.*

132. Some companies are reaching out to the cryptocurrency community, which is on average more educated about data privacy. Rogers, *supra* note 124; see Hovet, *supra* note 74.

133. Rogers, *supra* note 124.

134. Schintler & McNeely, *supra* note 1.

135. This includes abuse of high-tech profiling, ensuring automated decisions are fair, preserving constitutional principles, increasing individual control of data, and protecting people from misinformed data. *Big Data and the Future of Privacy*, *supra* note 4.

examine the feasibility, convenience, and accessibility of incorporating blockchain technology into genomics to ensure an individual's most personal and immutable information remains secure and anonymized.