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Ownership of Knowledge

Beyond Intellectual Property

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**OWNABILITY, OWNERSHIP, KNOWLEDGE, AND GENETIC
INFORMATION IN THE UNITED STATES**

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Gene patenting and genetic information offer us prime examples of the instability of ownership and knowability in the age of biocapitalism. Starting in the 1970s, the United States Patent and Trademark Office (USPTO) began awarding patents for short sequences of DNA, specifically ones that could be used to search for genes. During the early 1980s, when genes were initially being awarded patents by the USPTO, the Japanese Patent Office, and the European Patent Office, the procedure was to isolate a gene, determine the function of its protein product by biochemical assays, and then patent it. The procedure first required knowability—that is, knowledge of what the gene coded for (i.e., its utility)—before ownership could be granted; one needed to know what one owned.

By the 1990s, that had changed. Broad utility patents were being issued for rather vague statements about a gene's utility. That is to say, one could obtain a patent for a gene that coded for a protein whose precise function remained unknown. In this case, one owned something before one precisely knew what one had. With this change in the relationship between ownability and knowability came a change in expertise. Previously, molecular biologists and their “wet” skills, techniques, and practices had been necessary to define the function of the gene product and therefore its utility. By the last decade of the century, their authority had been controversially usurped by a generation of computer scientists who had invented algorithms to find gene sequences with unprecedented rapidity, and who began to model proteins using computer graphics with a view to finding structural homologies and deducing similar functions. The tools and skills of the computer scientist were now seen as being both necessary and sufficient to ascertain knowability. This transformation in expertise raises a number of interesting questions. Does the sequence or genetic information, specifically the genetic code as it appears in the patent description, trump materiality to convey ownership? Do patent owners forfeit their right to ownership if they patent an incorrect sequence, a practice much more common than one might believe? Is the gene sequence sufficient

to determine protein function? How can a gene become *visible* before it has been sequenced in a “wet” laboratory? How has the disappearance of materiality with the appearance of bioinformatics changed both intellectual property and the discipline of molecular biology?

I have detailed elsewhere the history of the patent portfolio for the CCR5 gene, which codes for a chemokine receptor.¹ The story raised questions regarding the relationship between property and knowability. In 2000 Human Genome Sciences, Inc. (henceforth HGS), which was subsequently bought out by GlaxoSmithKline, obtained a patent for a gene without knowing the precise function of its protein product. The company maintained that describing the sequence was synonymous with knowability. Thus, much along the lines of Bruno Latour’s 2012 work on mapmaking, means of knowing could be understood as description.² Using bioinformatic techniques, which compare the sequence with ones whose protein products are well known, they deduced that their gene coded for a chemokine receptor. Using more traditional molecular biological and biochemical techniques, other laboratories determined independently that the receptor was recognized by HIV-1. The sequence HGS listed in the patent specification contained a number of serious errors; it turned out that it would not code for a protein that HIV-1 would recognize. Luckily for the company, its scientists submitted the gene into a public depository. As a result, their patent was not revoked. The key point here, as with this chapter, is that verified, documented materiality is privileged by the law. HGS could show that they possessed the gene by depositing a physical copy in a depository. The material object trumps the written word. The story of the CCR5 gene patents was, in one important way, rather typical of many gene patents of the 1990s and 2000s: sequencing companies submitted literally tens of thousands of DNA sequence applications hoping that subsequent research would render (an albeit small) percentage of the patent material useful. These patent applications had potential financial value.

This chapter analyzes the main legal theories of ownership that have shaped, and have been shaped by, genetic information. These theories have become particularly relevant now that private genomics companies, such as 23andMe and AncestryDNA (the genetic testing company of Ancestry.com), are sharing their clients’ genetic information with various interested third parties. While one may naïvely think that these customers *own* their DNA, the situation is actually much more complicated and centers around the question, What does it really mean to own something? Whereas having a certain piece of DNA is a property of the human body, which is independent of knowing what precisely that gene does in that body, the genetic information encoded in that piece of gene is ownable. Indeed, ownership is granted to the person or persons who can glean information about what genetic sequence is and what that gene does. As a

result, there is an obvious conflict between possessing a gene and knowing and owning the knowledge of that gene.

This chapter details the ownability of genetic information as property, which can potentially be converted into future financial gain. In short, this chapter demonstrates the *constructedness* and instability of expertise, ownership, ownability, knowability, and privacy.

LEGAL PRECEDENTS AND OWNERSHIP

As any law student in the United States will tell you, property does not necessarily refer to a physical object but rather to an association, or bundle, of rights, which can be—and usually are—enjoyed by more than one person.³ Despite the economic, political, and historical importance of property, the law is vague, as Roberts outlines:

But even within law and the legal academy, we have no clear consensus regarding precisely what property *is* or how property rights should be distributed amongst individuals. . . . Consequently, no single set of rights uniformly applies across all situations to all kinds of property.⁴

Since there are critical definitions between various legal regimes worldwide, it is important to stress that the case I am describing in this chapter applies to the United States. Relationships between ownability and knowability with regard to genetic information might look very different outside the United States.

Likewise, ownability is equally difficult to define legally, since different bundles of rights are associated with different types of property.⁵ For instance, a 1963 lawsuit declared, “Ownership is not a single concrete entity but a bundle of rights and privileges as well as of obligations.”⁶ As is the case with ownership of other entities such as land, the various ways of knowability are unstable at the time of ownership, and utility changes and becomes increasingly complex with time. This chapter addresses several fundamental questions about ownership and ownability. Who owns the genetic information given to personal genetic companies? And what can be done with it? How do theories of ownership and ownability necessitate stricter privacy legislation? Questions about ownership, ownability, and property of genetic information are embedded in larger debates about agency. If body parts are property and can be owned, then they become passive agents and a means to an end.⁷ The sociopolitical and ethical ramifications of the instabilities of ownership, ownability, possession, and knowability are enormous.

The influence of capital—in these particular cases, biocapital—dictates the power relations in the biotech sector. The means of production are raw materials, natural entities (such as genes), and legal and technical tools—in this case, intellectual property

law, which results in the commodification of the so-called subjects of labor. These legal and technical tools structure the social relationships of those in the biotech world. People whose DNA sequences have been patented or used to trace their ancestry are alienated from the means of production, as they do not share in the governance of biomedical research, nor do they reap the profits. Historians are obliged to address the unequal power relations between actors in order to illustrate the politics of knowledge ownership. Waiting until closure is reached prevents historians from playing a role in the outcome of a controversy. Precisely because historians are best placed to illustrate that there always have been alternatives and that nothing is inevitable, they should be at the table during decision-making.

So, who owns your genetic information? Several US court cases have set the legal precedent for the behavior of personal genomics companies.⁸ In 1990 the Supreme Court of California ruled that Mr. John Moore of Washington was not entitled to any royalties generated from cells that had been taken from his body. Moore, who was first treated for his hairy cell leukemia by Dr. David W. Golde of UCLA Medical Center back in 1976, had signed a consent form agreeing to have his spleen removed as part of his treatment. For the ensuing seven years, he returned to UCLA for continued treatment, which included the removal of tissue and blood. By August 1979, Golde and Shirley G. Quan had created a cell line from Moore's blood, and seventeen months later the physician and the University of California applied for a patent on the cell line, which was granted by the USPTO on March 20, 1984.⁹ The physician and the university received some \$440,000 as well as stock options from Genetics Institute, which had hired Golde as a paid consultant.¹⁰ Moore became aware of the patent and decided to sue Golde and UCLA.

The key issue under consideration was whether the plaintiff could argue for conversion, or taking with the intent of exercising over the property a form of ownership that is inconsistent with the owner's right of possession. This was predicated on the patient's ownership over excised cells. Two aspects of the California supreme court majority report are particularly germane to this essay. First, California statutory law drastically limits a patient's control over their excised cells. According to Health and Safety Code 7054.4, "Notwithstanding any other provision of law, recognizable anatomical parts, human tissues, anatomical remains, or infectious waste following conclusion of scientific use shall be disposed of by internment, incineration, or any other method determined by scientific department [of health services] to protect the public health and safety."¹¹ Clearly, this statute is about public safety: one may not possess a diseased tissue extracted from one's body and then take it home to show friends and family. The majority report, however, felt that

one cannot escape the conclusion that the statute's practical effect is to limit, drastically, a patient's control over excised cells. By restricting how excised cells may be used and requiring their eventual destruction, the statute eliminates so many of the rights ordinarily attached to property that one cannot simply assume that what is left amounts to "property" or "ownership" for purposes of conversion law.¹²

Second, the California supreme court opined that the patented product had been altered sufficiently such that Moore could no longer claim ownership. "This is because the patented cell line is both factually and legally distinct from the cells taken from Moore's body."¹³ Hence, the majority concluded that "the use of excised human cells in medical research does not amount to a conversion."¹⁴ They felt extending conversion law to biomedical research would drastically restrict access to the necessary raw materials.¹⁵ "The theory of liability that Moore urges us to endorse threatens to destroy the economic incentive to conduct important medical research. If the use of cells in research is a conversion, then with every cell sample a researcher purchases a ticket in a litigation lottery."¹⁶

Judge Allen E. Broussard, who wrote a report agreeing with some aspects of the majority report and disagreeing with others, also maintained that "a patient may not retain any legal interest in a body part after its removal when he has properly consented to its removal and use for scientific purposes."¹⁷ The key for Broussard, who felt that the plaintiff had indeed established a cause of action for conversion, was not whether a patient retains ownership interest in a body part once it is removed, but rather if a patient has a right to determine, before it is removed, the use to which it will be put. He also criticized the majority's stated concern that extending conversion here would restrict access to existing cell lines. Judge Stanley Mosk offered a much stronger rebuttal to the majority report. He criticized the use of the Health and Safety Code section 7054.4 as a precedent to limit Moore's control over his cells.¹⁸ Contra his colleagues, Mosk felt that the concepts of ownership and property were extremely broad in California state law and that "the limitation or prohibition diminishes the bundle of rights that would otherwise attach to the property, yet what remains is still deemed in law to be a protectible property interest."¹⁹ Under his liberal reading of property and ownership, Moore could legally assert an ownership interest in his cells, thereby warranting his sharing in the commercial rewards of their sale.²⁰

The second case relevant to the use and selling of genetic information by personal genomics companies is *Greenberg v. Miami Children's Hospital Research Institute*.²¹ Deborah and Daniel Greenberg had two children who suffered from Canavan disease, a degenerative disorder affecting the nerve cells of the brain. Those afflicted usually die

by the age of eighteen months. During the early to mid-1980s, they and other families with afflicted children, in conjunction with the nonprofit patient advocacy group National Tay-Sachs and Allied Disease Association, offered Dr. Reuben Matalon of the University of Illinois at Chicago tissue samples so that he could try to find the gene. By 1993 he and his lab, which had relocated to Miami's Children Hospital some three years earlier, had identified the gene and the mutations associated with the disease. The plaintiffs argued that they had provided Matalon with the biological samples and confidential familial information "with the understanding and expectation that such samples and information would be used for the specific purpose of researching Canavan disease and identifying mutations in the Canavan gene which could lead to carrier detection within their families and benefit the population."²² Apparently, it was their

understanding that any carrier and prenatal testing developed in connection with the research for which they were providing essential support would be provided on an affordable and accessible basis, and that Matalon's research would remain in the public domain to promote the discovery of more effective prevention techniques and treatments and, eventually, to effectuate a cure for Canavan disease.²³

Unbeknownst to the families, in 1994 the hospital applied for a gene patent, which was granted three years later. It was also granted patents on prenatal testing. Once the hospital had found a marketer, it granted that marketer an exclusive license for the genetic test, which was too expensive for the families who had donated the samples. The plaintiffs also alleged that the Miami Children's Hospital had enviously guarded their intellectual property by sending threatening enforcement letters to other centers offering Canavan testing.²⁴ In October 2000 the families, along with the National Tay-Sachs and Allied Disease Association and Dor Yeshorim, a nonprofit organization that offers genetic screening to the Jewish community around the globe, sued the hospital on six grounds: lack of informed consent, breach of fiduciary duty, unjust enrichment, fraudulent concealment, conversion, and misappropriation of trade secrets. Relevant to this chapter once again is the notion of conversion, which is defined by Florida state law as "an unauthorized act which deprives another of his property permanently or for an indefinite time."²⁵ The court ruled that since the body tissue had been donated for research, there was no expectation of return of the physical object and the knowledge derived from it, and therefore conversion was not applicable. They cited *Moore v. Regents of the University of California* as the precedent. In addition, since the Supreme Court of Florida decided not to recognize a property right in the body of another after death, they determined that the property right of the knowledge in blood and tissue samples dissipates once the sample is voluntarily given to a third party. Also taking their cue from that case, they opined that "the patented result of research is 'both

factually and legally distinct' from excised material used in research."²⁶ Finally, much along the lines that the California supreme court had argued, the US District Court for the Southern District of Florida ruled that "if adopted, the expansive theory [of conversion] championed by Plaintiffs would cripple medical research as it would bestow a continuing right for donors to possess the results of any research conducted by the hospital. At the core, these were donations to research without any contemporaneous expectations of return."²⁷

The third and final precedent case for the ownership of biological materials involves the work of Dr. William Catalona, a renowned urologist who, starting in 1983 as an employee of the Washington University Division of Urologic Surgery, created a collection of over thirty thousand prostate tissue samples donated by his own and his colleagues' patients with a view to determining the genetic basis of prostate cancer.²⁸ In 2003 he resigned his position and accepted a new job offer from Northwestern University. He wished to take along his collection of samples, asserting that the informed consent forms he had obtained transferred ownership of the samples from the university to him personally. Approximately six thousand patients who had donated their biological material signed a document requesting that Washington University release their samples to Catalona.²⁹ Citing its intellectual property policy, namely that "all intellectual property (including . . . tangible research property) shall be owned by the university if significant university resources were used or if it is created pursuant to a research project," Washington University insisted that the samples were their property and sued Catalona.³⁰ As the senior district judge stated in the introduction of the opinion, "Central to the several pending summary judgment motions, and preliminary injunction motion(s) is the issue of 'ownership.'"³¹ Later in the decision, the importance of ownership was underscored: "The sole issue determinative of this permanent injunction; in fact of this lawsuit; is the issue of ownership."³² Specifically, the crucial question was whether the research participants retained ownership rights after they had made voluntary donations of their biological samples to a research institution for medical research.

The court turned to the decisions of the two aforementioned cases for their ruling. In March 2006, the US District Court ruled in favor of Washington University. The previous two cases had deemed research participants to be donors who had surrendered their property rights once their biological materials had been excised for research. With that in mind, the Missouri court "finds that W[ashington] U[niversity] has met its burden in establishing ownership of the subject materials and that the R[esearch] P[articipants] have not put forth adequate evidence to challenge WU's ownership claim."³³ The court also ruled that the informed consent forms transferring ownership to Catalona were invalid because they had not received the approval of the university's Human Studies

Committee, nor were they ever submitted to an institutional review board for prior approval.³⁴ Finally, the court agreed with the earlier cases that

medical research can only advance if access to these materials to the scientific community is not thwarted by private agendas. If left unregulated and to the whims of an RP, these highly-prized biological materials would become nothing more than chattel going to the highest bidder. . . . Allowing an RP to choose who can have the sample, where the sample will be stored, and/or how the sample can be used is tantamount to a blood donor being able to dictate that his/her blood can only be transfused into a person of a certain ethnic background, or a donated kidney being transplanted only into a woman or man. This kind of “selectiveness” is repugnant to any ethical code which promotes medical research to help all of mankind.

Hence, the court ruled that Washington University owned all of the biological material and that neither Catalona nor any of the research participants had any ownership or proprietary interest in it.³⁵

PRECISION MEDICINE, PERSONAL GENOMICS COMPANIES, AND THE OWNABILITY AND OWNERSHIP OF KNOWLEDGE

Perhaps the most important advance in medical treatment over the past twenty-five years, precision medicine is a medical model whereby treatment is tailored to an individual patient, based on her/his genetic makeup. It does not intend to create specific drugs or treatments for each individual; however, it does seek to create categories of individuals, or populations, which will respond in the same way to certain medications or treatment regimes. It involves researching the relationship of genetic markers to certain illnesses within various populations which, in the United States, are controversially—some might argue dubiously—often defined by “race” or “ethnicity.”³⁶ The precision medicine market generated \$18 billion in 2017 in the United States alone, and it is expected to be worth nearly \$100 billion by 2024.³⁷ On December 18, 2015, President Barack Obama signed legislation that provided over \$200 million for the Precision Medicine Initiative.³⁸ This initiative unites an impressive array of for-profit, nonprofit, charitable, and federal institutions, such as the Department of Defense, the National Institutes of Health, the Food and Drug Administration, the American Medical Association, Genentech, Pfizer, the Broad Institute, the Bill and Melinda Gates Foundation, Color Genomics, Amazon Web Science, Microsoft, IBM, and the New York Genome Center, to name just a few. The initiative stresses the importance of securing the privacy of the individual from which the data have been collected, on the one hand, while on the other hand ensuring access to the data to all interested biomedical researchers, rather than only those belonging to institutions that are willing and able to pay for such access.

Taking their legal cue from the rulings in the aforementioned three decisions, personal genomics companies share their clients' genetic information with third parties such as Big Pharma.³⁹ Anyone living in the United States would have noticed a significant increase in the number of television commercials for personal genomics companies such as AncestryDNA, some of which are quite comical, while others are serious attempts to encourage the notion of biological identity.⁴⁰ Some, such as 23andMe, offer both ethnic ancestry and medical testing.⁴¹ Others, such as AncestryDNA, focus exclusively on ethnic ancestry. Thanks in large part to the Food and Drug Administration (FDA)'s decision in 1985 to permit direct-to-consumer advertising, these companies have joined pharmaceutical companies in advertising their wares to a nation hungry to find out where their ancestors hailed from or what medical ailments might await them in the future.⁴² Their use of clients' genetic information has recently made headlines, which illustrates how these companies' practices highlight the instability of the legal notions of ownership and privacy.

Personal genomics companies refer to hundreds of thousands of genetic markers known as single nucleotide polymorphisms (SNPs), from populations in Asia, the Americas, Africa, and Europe. SNPs are singular differences of DNA at specific spots along the chromosomes. They occur approximately once in approximately every three hundred base pairs. Hence, there are circa ten million SNPs in the human genome. Since they are passed down from generation to generation, different populations have different SNPs. SNPs that possess markedly different frequencies between populations are referred to as ancestry informative markers (AIMs), which are used to determine a person's ancestry. By comparing their client's DNA with previously collected samples from around the globe stored in their proprietary databanks, these companies offer customers profiles of their genetic heritage for a cost of anywhere between \$49.99 and \$199. For example, 23andMe's v4 chip, introduced in December 2013, tested for some 602,000 SNPs from 2,329 Y chromosomes and 19,487 X chromosomes, and 3,154 SNPs from mitochondrial DNA. Their newest v5 chip, which was introduced in late 2017, added approximately fifty thousand more SNPs of custom content. As of November 2017, 23andMe was using twenty-four reference populations around the globe in order to report thirty-one population labels.⁴³ The technology is rapidly changing and—according to the companies—improving. 23andMe boasts that its “innovative machine learning technology under the hood gets better and more precise as we add new customers and refine our technology.”⁴⁴ This is, after all, the age of bioinformatics. Customers who have used both the v4 and v5 versions have blogged that the percentages of ethnicities, particularly those from East Asia, were wildly different, and that the results from the v5 chip corresponded much more closely with their family history.⁴⁵ AncestryDNA tests

for some 700,000 SNPs from 885 Y chromosomes and 17,604 X chromosomes. They boast an accuracy rate of 90 percent without actually defining how one measures that, and claim that clients can find out their ancestry going back to the sixteenth century.⁴⁶

For those whose ancestors originate from parts of the world where few samples have been taken, the tests tend to be inaccurate. A number of my students who independently decided to have their DNA tested by both 23andMe and AncestryDNA, and who were from regions of the globe where there is limited genetic information testing, informed me that the results they obtained from the two companies were different—not necessarily in the ethnicities, but in the corresponding percentages. Apparently, this is a common complaint. “People have sent their DNA to several of these companies and found differences in the results—though not necessarily radical differences. So you have to look at the percentages you receive back with skepticism.”⁴⁷ As Sheldon Krimsky has pointed out, the companies doing the testing do not share their data with other personal genomics companies, their methods have not been tested by any independent group of scientists, and there are no generally accepted standards of accuracy.⁴⁸

While these companies do profit from these tests, other sources of income come from third parties, such as Big Pharma, which are very interested in the genetic information of various human populations. The white male is no longer used to represent all of humankind. We need medical information on women and people of color, as required by the National Institutes of Health Revitalization Act of 1993.⁴⁹ In an age of precision medicine, where one size no longer fits all, Big Pharma has a vested interest in ascertaining which populations will respond best to certain medications. And, as mentioned above, many of them have controversially used race as a proxy for human diversity and populations.

Intellectual property is, of course, critical to the survival of these personal genomics companies. Access to data is granted in the likelihood of potential future payoff, and Big Pharma is willing to take that chance. Personal genomics companies own the data, which become scientifically relevant and knowable once their algorithms determine the data's importance. While gene patents seemed to be the best financial way forward for a number of early sequencing companies of the 1990s, including Incyte Genomics, Human Genome Sciences, and Millennium Pharmaceuticals,⁵⁰ nowadays personalized genomics companies are far more interested in protecting the patents of their algorithms. For example, 23andMe has patented algorithms related to providing displays with graphic-user interfaces, summarizing an individual's aggregate contribution to a genetic characteristic, processing data from genotyping chips, finding relatives in a database, identifying matrilineal or patrilineal relatives, processing data from genotyping chips, genome sharing, making genetic comparisons between grandparents and

grandchildren, trio-based phasing using a dynamic Bayesian network, and correcting errors in ancestry classification.⁵¹ Their patent portfolio more closely resembles a computer information company than a traditional wet-biomedical research company. By and large, they do not seem all that interested in patenting specific gene sequences, perhaps as a result of the USPTO's decision to make it substantially more difficult to patent products of nature after the US Supreme Court ruled in June 2013 to disallow gene patents based on DNA that was merely excised from the genome.⁵² One notable exception is the patenting of genetic polymorphisms, which give rise to a particular disease, such as Parkinson's.⁵³ Similarly, Ancestry.com DNA LLC, the subsidiary of Ancestry.com, owns patents as well, most of which are for algorithms for, for example, identifying ancestral relationships using a continuous stream input, discovering population structure from patterns of identity by descent, identifying family networks using combinations of DNA analysis and genealogical information, a method and system for displaying genetic and genealogical data, and a method for molecular genealogical research. They have also applied for a patent for the computational methods needed to reconstruct the chromosomes and genomes of ancestors based on genetic data.⁵⁴

These algorithm patents are critical for the viability of these companies, as witnessed by the lawsuit 23andMe filed against Ancestry.com DNA LLC on May 11, 2018, in the Northern District of California. In this, 23andMe alleges that Ancestry.com DNA LLC has infringed on the patent for algorithms it uses to find relatives in a database that share a common ancestor (known as "identity by descent," or IBD) within a certain number of generations. The patent claims to determine the IBD by obtaining DNA sequence information of first and second users stored in a database of many users, and to ascertain a degree of relative relationship based on the number of generations within which the two users share a common ancestor. The lawsuit also claims trademark infringements by Ancestry.com DNA LLC by using the word *ancestry* in the company's advertisement.⁵⁵ Ancestry.com DNA LLC is banking on the hope that 23andMe's patent on the algorithm for IBD will not hold up in a court of law. The theory behind IBD dates back some seventy years to the pioneering research of the French mathematician Gustave Malécot, and the IBD method has been used by hundreds of scientists over the past decade. On October 29, 2008, the first computational framework for analyzing IBD was published as an open-source software program, GERMLINE. 23andMe filed its patent on the following December 31.⁵⁶ As is the case with many patents on algorithms, this patent might not hold up, as it may fail the novelty criterion of patentability.⁵⁷ In short, while these companies still depend on traditional forms of intellectual property protection, such as patents and copyright, it turns out that more of their income involves their clients' genetic information, as I will discuss later. Interestingly, these

companies do not know the relevance of certain bits of the data until their patented algorithms tell them which ones are scientifically—and therefore commercially—relevant. Ownership precedes knowing exactly what they have.

So, do personal genomics companies *really* own the genetic information of their clients? Well, it depends on what you mean by “own.” Over the past several years, the instability of the legal notion of ownership—and the related notion of privacy—has been the subject of legal concerns. When a customer accepts 23andMe’s terms of service, they are agreeing to the company’s waiver of property rights, which states that “you specifically understand that you will not receive compensation for any research or commercial products that include or result from your Genetic Information or Self-Reported Information.”⁵⁸ The client does not own any part of the services, which include the genetic information determined by the company’s tests and provided by 23andMe. It is important to note that the terms of service refer specifically to “genetic information” and not to the actual DNA material, which will always belong to the donor:

You acknowledge and agree that 23andMe (or 23andMe’s licensors, as applicable) own all legal right, title, and interest in and to the Services, including any intellectual property rights (including but not limited to patents) which subsist in the Services (whether those rights happen to be registered or not, and wherever in the world those rights may exist).⁵⁹

23andMe actually grants their customers a “limited license” to copy and distribute their genetic information freely for noncommercial purposes. The terms of service go on to say that if a customer has granted permission to 23andMe Research to do so, the company may share anonymized and aggregate genetic and self-reported information with third parties who are interested in publishing articles in peer-reviewed journals. Moreover, “23andMe may also include your information in Aggregated Genetic and Self-Reported Information disclosed to third-party non-profit and/or commercial research partners who will not publish that information in a peer-reviewed scientific journal.”⁶⁰ If you withdraw from 23andMe Research, your data that have already been used in studies cannot be withdrawn, and you must give the company thirty days to withdraw your information.⁶¹ In addition, if you do not give consent to 23andMe Research, “your Genetic Information and Self-Reported Information may still be used for other purposes, as described in our Privacy Statement.”⁶²

While the company’s CEO, Anne Wojcicki, has stressed that 23andMe does not work with insurance companies,⁶³ the company’s terms of service does convey a chilling warning:

Currently, very few businesses or insurance companies request genetic information, but this could change in the future. While the Genetic Information Nondiscrimination Act [GINA]

was signed into law in the United States in 2008, its protection against discrimination by employers and health insurance companies for employment and coverage issues has not been clearly established. In addition, GINA does not cover life, long-term care, or disability insurance providers. Some, but not all, states and other jurisdictions have laws that protect individuals with regard to their Genetic Information. You may want to consult a lawyer to understand the extent of legal protection of your Genetic Information before you share it with anybody.⁶⁴

However, a number of legal scholars have complained that GINA provides too little consumer protection.⁶⁵ Furthermore, the genetic information that you do choose to share with your physician or other healthcare providers may become part of your medical record and, through that route, be accessible to other healthcare providers and/or insurance companies in the future. Genetic information that you share with family, friends, or employers may be used against your interests. Even if you share genetic information that has no or limited meaning today, that information could have greater impact in the future as new discoveries are made. If you are asked by an insurance company whether you have learned genetic information about health conditions and you do not disclose this to them, this may be considered to be fraud.⁶⁶

AncestryDNA's terms and conditions were recently a source of contention. They originally stated that "you grant AncestryDNA and the Ancestry Group Companies a perpetual, royalty-free, world-wide, transferable license to use your DNA . . . to use, host, sublicense and distribute the resulting analysis to the extent and in the form or context we deem appropriate on or through any media and medium and with any technology or devices now known or hereafter developed or discovered."⁶⁷

In May 2017, Joel Winston, a consumer protection lawyer and former deputy attorney general of New Jersey, published a blog entry that sharply criticized AncestryDNA's practices, claiming that "according to its privacy policies Ancestry.com takes ownership of your DNA forever. Your ownership of your DNA, on the other hand, is limited in years."⁶⁸ Thus, Winston highlighted how your genetic information can be used, and can be seen, as a form of ownership by means of a proprietary license. The terms and conditions (TaC) go on to say that a client has no right to any commercial gain from their sample.⁶⁹ Consumers may, of course, withdraw consent; however, just as is the case with 23andMe, the company can continue to use your information for thirty days from the date of your request. In addition, any research, including research published online, that already uses your data cannot be withdrawn. The terms and conditions insist that Ancestry.com "will not share your Genetic Information with insurance companies, employers, or third-party marketers *without* your express consent."⁷⁰ While DNA as a material substance is being replicated and translated into mRNA to produce

proteins within a person's body, it still remains owned by that person. The information encoded in someone's DNA, however, can be licensed to, and therefore owned by, another entity. Recall that under US law, property is a bundle of rights, which can be owned by numerous entities simultaneously.

Winston's blog entry ignited a firestorm on the internet. Ancestry.com's chief privacy officer Eric Hearsh called Winston's remarks "inflammatory and inaccurate."⁷¹ His defense of his company's policies was based in large part on the fuzziness of the legal concept of ownership:

The consumer maintains ownership of their data. This is actually why we need a license in order to conduct our analysis, display their results, and so on. Not only do they own their own data, but we allow them to download their raw data and they can ask us to destroy the data at any time.⁷²

Winston countered by differentiating between various legal notions of ownership:

A license is a contractual form of ownership. At its most basic, a license is defined as "a permit from an authority to own or use something." Ancestry.com does not have "exclusive ownership" because customers still retain ownership of their own DNA. Ancestry.com does not have "absolute ownership" because customers can revoke the license. But, Ancestry.com irrefutably takes ownership of customers' genetic data by contractual license granted in the Terms and Conditions.⁷³

Personal genomics companies do not own your DNA—the physical, material object—and it would not be in their interest to argue that they do. An Ancestry.com spokesperson was adamant about that, and the terms and conditions explicitly state that. In addition, the terms and conditions make it clear that "you always maintain ownership of your data." The company immediately continues by explaining, "but we need the ability to use your data for the purposes set out in our Privacy Statement and these Terms, and, if you agree to it, in our Informed Consent to Research."⁷⁴ The same spokesperson did concede that it is "broadly correct" that the license allows the company the privileges of ownership: "We couldn't send samples to the lab to be analyzed, transmit the results, etc. if we didn't have a license."⁷⁵ Ancestry.com decided to alter its terms and conditions slightly in 2017 in direct response to Winston's critiques. The company dropped the word *perpetual* to describe the license, and removed the phrase "to the extent and in the form and context we deem appropriate."⁷⁶

Finally, AncestryDNA.com also warns its customers that their DNA may be used against them or a genetic relative in a court of law. This might seem farfetched, but it has already happened in the United States. On April 24, 2018, Joseph James DeAngelo was arrested in Sacramento on suspicion of being the so-called Golden State Killer, accused of murdering a dozen people, raping at least fifty women, and committing

over a hundred burglaries from 1974 to 1986. The case had gone cold decades ago. Then in 2017 Paul Holes, who had previously been an investigator with the California's Contra Costa County District Attorney's Office, took the genetic information that had been left at one of the crime scenes and entered it into GEDmatch, a small DNA analysis company that possesses an online database filled with genetic information. This Florida-based website pools raw genetic data from anyone who uploads their genetic information online, often those who have their genetic profiles determined by 23andMe and AncestryDNA. Since they are publicly shared, no court order was necessary. More than a hundred users had corresponding matches at specific SNPs, possibly representing distant cousins. Holes contacted "one or two people," which subsequently led to DeAngelo's arrest. Curtis Rogers, the cocreator and operator of GEDmatch, was quick to point out that

it has always been GEDmatch's policy to inform users that the database could be used for other uses, as set forth in the site policy. While the database was created for genealogical research, it is important that GEDmatch participants understand the possible uses of their DNA, including identification of relatives that have committed crimes or were victims of crimes.⁷⁷

Less than two months later, Gary Hartman of Tacoma, Washington, was arrested and charged with raping and murdering a twelve-year-old girl some thirty-two years earlier. DNA evidence from a discarded restaurant napkin was used in identifying the suspect. In 2016 police began working with a genetic genealogist who was able to track down two brothers, using the DNA databases on the internet. They were then put under surveillance, and the police collected the napkin and sent it to the Washington State Patrol Crime Laboratory, where the sample was found to be a match.⁷⁸

And on July 17, 2018, John D. Miller was arrested in Indiana for the abduction, rape, and murder of eight-year-old April Tinsley in 1988. Comparing the DNA from the scene of the crime with the DNA in a genealogical database, police found matches with the sequences which led them to two men, Miller and his brother. DNA found in the Millers' garbage led to John's arrest and confession.⁷⁹ In mid-October 2018, an article in the *New York Times* warned its readers that "already, 60% of Americans of Northern European descent—the primary group using these sites—can be identified through databases whether or not they've joined one themselves." Researchers say it will soon be possible [within two to three years] to identify up to 90 percent of white Americans from genealogical databases.⁸⁰ Privacy, it turns out, is just as unstable as ownership and property.

In addition, there is always the threat of data breaches, and such a case occurred in the summer of 2020. The DNA analysis site used to catch the Golden State Killer, GEDmatch, was the victim of hackers on July 19 and 10. The DNA profile data of over one million clients could be viewed by law enforcement agencies, even though many had opted not to have their data made available.⁸¹

The importance of ownership over genetic information for biotech companies became evident in the 1990s in Oregon, which was the first state to enact a law relevant to such information.⁸² In 1995 Senate Bill 276, sponsored by then state senator Neil Bryant, declared that genetic information was the property of the individual from which it was obtained. While the bill was passed, it was revised six years later. In 1997 SmithKline Beecham (now GlaxoSmithKline) sponsored a bill that would repeal the property provision; the company feared that if individuals owned their genetic information, then the company would have to share the royalties generated by gene patents or, even worse, the transfer of rights to their biomedical researchers might not be enforceable. During this time, Oregon wanted to lure biotech companies to the Greater Portland area. After much debate over the ensuing four years, in 2001 the Oregon legislature overhauled its genetic privacy law. It deleted the provision that genetic information and DNA samples are the property of the individual, and in exchange, tightened up the privacy requirements surrounding such information.⁸³

Despite Oregon's valiant efforts to create more stringent privacy laws, many feel that more needs to be done, as preexisting federal privacy laws as stipulated by GINA are considered insufficient. A number of politicians have recently expressed concerns that tighter restrictions should be placed on personal genomics companies. For example, in late November 2017, Democratic US senator from New York, Chuck Schumer, warned that "many consumers don't realize that their sensitive information can end up in the hands of unknown third-party companies. There are no prohibitions, and many companies say that they can still sell your information to other companies."⁸⁴ He called on the Federal Trade Commission to "take a serious look at this relatively new kind of service and ensure that these companies can have clear, fair privacy policies."⁸⁵

CONCLUSION

In conclusion, this chapter has discussed an example of the related constructedness and instabilities of genetic information, ownership, knowability, expertise, and privacy. The sharing with third parties of genetic information that companies hold on their clients—who are seeking to gain an understanding of their ancestry and genetic predispositions—illustrates the legally contentious notion of ownership. The expertise of such ancestry testing is also being questioned, as the results are often inconsistent. Yet, the data do give these companies a good idea of the possible afflictions from which certain populations suffer. Big Pharma can now focus their efforts on treating certain genetic ailments of these groups, while insurance companies potentially can gauge how to move forward in setting their premiums. On July 25, 2018, GlaxoSmithKline (GSK) announced that they had just entered into a four-year

collaboration with 23andMe to develop novel forms of medicine. GSK issued a statement in an attempt to assuage any fears of people who had had their DNA sequenced by 23andMe:

23andMe customers are in control of their data. Participating in 23andMe's research is always voluntary and requires customers to affirmatively consent to participate. For those who do consent, their information will be de-identified, so no individual will be identifiable to GSK. The continued protection of customers' data and privacy is the highest priority for both GSK and 23andMe. Both companies have stringent security protections in place when it comes to collecting, storing and transferring information about research participants. 23andMe employs software, hardware and physical security measures to protect the computers where data is stored and information will only be transferred using encryption to offer maximum security.⁸⁶

The press release—tellingly, and wisely—did not mention ownership.

Intellectual property still plays a major role in biomedical research. With some notable exceptions, gene patents are not now considered to be as profitable as they used to be. The intellectual property portfolios of personal genomics companies are instead filled with patents on algorithms, which make their databases both knowable and scientifically and economically relevant. That said, there seems to be a trend among private companies in the biotech sector to increase their financial viability by means of their proprietary databases. This chapter has explored the instability of ownership and knowability of genetic information and the moral implications of such instability. Going forward, it is clear that renewed efforts to ensure privacy are critical during an age when our most intimate data, and our very identities, are becoming a coveted financial entity.

Notes

1. For the complete story, see Myles W. Jackson, *The Genealogy of a Gene: Race, Patents, and HIV/AIDS* (Cambridge, MA: MIT Press, 2015). For a recent work on patenting biological materials in general, see Shobita Parthasarathy, *Patent Politics: Life Forms, Markets, and the Public Interest in the United States and Europe* (Chicago: University of Chicago Press, 2017).
2. I would like to thank the anonymous reader for pointing this out to me.
3. For the classic study on property, see Tony M. Honoré, "Ownership," in *Oxford Essays in Jurisprudence*, ed. Anthony G. Guest (New York: Oxford University Press, 1961). See also Pilar N. Ossorio, "Property Rights and Human Bodies," in *Who Owns Life?*, ed. David Magnus, Arthur Caplan, and Glenn McGee (New York: Prometheus Books, 2002), 224–225.
4. Jessica L. Roberts, "Theories of Genetic Ownership" (working paper, September 9, 2015), 8–9, accessed February 14, 2019, http://petrieflom.law.harvard.edu/assets/publications/Roberts_Genetic_Ownership_Draft.pdf.

5. Ossorio, "Property Rights," 225.
6. *Union Oil Co. v. State Board of Equal.*, 60 Cal.2d 441, 447 (Cal. 1963), <https://www.courtlistener.com/opinion/1165762/union-oil-co-v-state-bd-of-equal/>.
7. Ossorio, "Property Rights," 226.
8. Christopher Heaney et al., "The Perils of Taking Property Too Far," *Stanford Journal of Law and Science Policy* 46, no. 1 (2009): 46–64. See also Linda L. McCabe and Edward R. B. McCabe, "Gene Patents: Perspective from the Clinic and the Laboratory," in "Gene Patents," ed. Myles W. Jackson, special issue, *Perspectives on Science* 23, no. 1 (2015): 67–69; Lori Andrews and Dorothy Nelkin, "Propriety and Property: The Tissue Market Meets the Courts," in *Who Owns Life?*, ed. David Magnus, Arthur L. Caplan, and Glenn McGee (New York: Prometheus Books, 2002), 200–201; and Margaret Everett, "The Social Life of Genes: Privacy, Property and the New Genetics," in *Information Ethics: Privacy, Property, and Power*, ed. Adam D. Moore (Seattle: University of Washington Press, 2005), 233–234.
9. *Moore v. Regents of the University of California*, 51 Cal.3d 120, 127–128 (Cal. 1990); 271 Cal. Repr. 146; 793 P.2d 479.
10. *Moore*, 51 Cal.3d at 128–129.
11. *Moore*, 51 Cal.3d at 141.
12. *Moore*, 51 Cal.3d at 141–142.
13. *Moore*, 51 Cal.3d at 137, 141. See also McCabe and McCabe, "Gene Patents," 67–69; Andrews and Nelkin, "Propriety and Property," 200–201; and Everett, "Social Life of Genes," 233–234.
14. *Moore*, 51 Cal.3d at 144.
15. *Moore*, 51 Cal.3d at 145–146.
16. *Moore*, 51 Cal.3d at 147.
17. *Moore*, 51 Cal.3d at 152. Please note the gendered language in the quotation. Women have also had bodily cells and tissues removed for scientific research.
18. *Moore*, 51 Cal.3d at 164.
19. *Moore*, 51 Cal.3d at 167.
20. *Moore*, 51 Cal.3d at 170.
21. *Greenberg v. Miami Children's Hospital Research Institute*, 208 F. Supp. 2d 918 (2002). The ruling of the Florida district court, which was final, can be found at *Greenberg v. Miami Children's Hospital Research Institute*, 264 F. Supp. 2d 1064 (2003).
22. *Greenberg*, 208 F. Supp. 2d at 922.
23. *Greenberg*, 208 F. Supp. 2d at 922.
24. *Greenberg*, 208 F. Supp. 2d at 922.

25. *Greenberg*, 264 F. Supp. 2d at 1075.
26. *Greenberg*, 264 F. Supp. 2d at 1075.
27. *Greenberg*, 264 F. Supp. 2d at 1076.
28. *Washington University v. William J. Catalona, M.D.*, 437 F. Supp. 2d 985 (8th Cir. 2006).
29. *Catalona*, 437 F. Supp. 2d at 993.
30. *Catalona*, 437 F. Supp. 2d at 990.
31. *Catalona*, 437 F. Supp. 2d at 988.
32. *Catalona*, 437 F. Supp. 2d at 994.
33. *Catalona*, 437 F. Supp. 2d at 997.
34. *Catalona*, 437 F. Supp. 2d at 997 and 1001.
35. *Catalona*, 437 F. Supp. 2d at 1002.
36. Biomedical researchers often use these terms interchangeably.
37. "Precision Medicine Will Surpass USD 96600 Million by 2024," Pharmaphorum (website), April 30, 2019, <https://pharmaphorum.com/partner-content/precision-medicine-market-will-surpass-usd-96600-million-by-2024/>.
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39. It should be noted that FamilyTreeDNA has not sold its customers' DNA or data to third parties.
40. See, for example, "23andMe TV Commercials," iSpot.tv, accessed February 7, 2019, <https://www.ispot.tv/brands/Ias/23andme>; and "Ancestry TV Commercials," iSpot.tv, accessed February 7, 2019, <https://www.ispot.tv/brands/dhv/ancestry>.
41. As of November 2017, 23andMe's database had 2 million users, Ancestry's had 5 million users, FamilyTreeDNA's had 1.5 million users, African Ancestry had 33,000 lineages across 43 African nations, and National Geographic had a database of 830,000 users. See Natasha Stokes, "What You Need to Know Before Buying a Home DNA Test," Techlicious, November 7, 2017, <https://www.techlicious.com/guide/dna-home-test-kit-what-you-should-know-our-picks/>. Here are some of those commercials, which have been aired in the US: Ancestry, "Testimonial: Kyle," 2015, commercial, accessed October 15, 2020, <https://www.ispot.tv/ad/wppp/ancestrydna-testimonial-kyle>; Ancestry, "Ancestry Stories: Anthem," 2018, commercial, accessed October 15, 2020, <https://www.ispot.tv/ad/dwkp/ancestry-ancestry-stories-anthem>; 23andMe, "Getting to Know You," 2018, commercial, accessed October 15, 2020, <https://www.ispot.tv/ad/wvMS/23andme-getting-to-know-you>; and Ancestry, "Lyn Discovers Her Ethnicity Discoveries," 2016, commercial, accessed October 15, 2020, https://www.youtube.com/watch?v=0I0_ttMidII.

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47. Genevieve Rajewski, “Pulling Back the Curtain on DNA Ancestry Tests,” *Tufts Now*, January 26, 2018, <https://now.tufts.edu/articles/pulling-back-curtain-dna-ancestry-tests>.
48. Rajewski.
49. Steven Epstein, *Inclusion: The Politics of Difference in Medical Research* (Chicago: University of Chicago Press, 2007), 95–122.
50. Note that these companies are not the same as personal genomics companies.
51. “Patent Information,” 23andMe, accessed January 22, 2019, <https://www.23andme.com/patents/>.
52. *Association for Molecular Pathology v. Myriad Genetics, Inc.*, 569 U.S. 576 (2013). For the USPTO’s requirements for patent eligibility of objects of nature, see “2105 Patent Eligible Subject Matter—Living Subject Matter,” United States Patent and Trademark Office, accessed January 22, 2019, <https://www.uspto.gov/web/offices/pac/mpep/s2105.html>. It should be noted that the United States Supreme Court’s decision did not outright prohibit the patenting of products of nature; it insisted that patented products of nature have attributes that distinguish them for their naturally occurring homologs. See Jackson, *Genealogy of a Gene*, 175–187.
53. See, for example, 23andMe’s US Patent 8197811: “The application provides nucleic acid sequences that may be used to determine the presence or absence of nucleotides at polymorphic sites in an individual’s RNA or genomic DNA that are associated with susceptibility to or protection from P[arkinson’s] D[isease]. In another aspect, the application provides a method for identifying a human subject having an increased or decreased susceptibility to PD.” 23andMe, *Polymorphisms Associated with Parkinson’s Disease*, US Patent 8197811, filed November 30, 2010, issued May 29, 2012, <https://patents.google.com/patent/US8187811>.
54. “Patents Assigned to Ancestry.com DNA LLC,” *Justia Patents*, accessed January 23, 2019, <https://patents.justia.com/assignee/ancestry-com-dna-llc>.
55. Steve Brachmann, “23andMe Sues Ancestry.com over DNA Genetic Testing Kits,” *IPWatchdog.com*, May 15, 2018, <https://www.ipwatchdog.com/2018/05/15/23andme-sues-ancestry-com-dna-genetic-testing-kits/id=97269/>.

56. Megan Molteni, "23andMe Is Suing Ancestry over Some Pretty Ancient IP," *Wired*, May 30, 2018, <https://www.wired.com/story/23andme-sues-ancestry/>.
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71. Dan MacGuill, "Can Ancestry.com Take Ownership of Your DNA Data? An Experienced Attorney's Blog Post Has Caused Widespread Concern," *Snopes*, May 22, 2017, <https://www.snopes.com/fact-check/ancestry-dna-steal-own/>.
72. MacGuill.
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74. Ancestry, "Ancestry Terms and Conditions." See also Brown, "DNA Testing Companies' Privacy Policies."
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