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## 23andMe: Attack of the Clones and Other Concerns

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## 23andMe: Attack of the Clones and Other Concerns

### Cover Page Footnote

Claire M. Amodio graduated from Fordham University School of Law in May of 2020. She would like to thank her parents, Cecilia and Mike, for their unending support. She would also like to thank her advisor, Professor Kimani Paul-Emile, for her guidance throughout this process. Last but not least, she would like to thank Elliott Fink, Sara Mazurek, and the entire IPLJ staff for their help, guidance, and patience in getting this Note to the finish line.

## 23andMe: Attack of the Clones and Other Concerns

Claire M. Amodio\*

*A few years ago, ancestry websites took the world by storm. People were fascinated with their history and heritage and wanted to find out more about where they came from. Then along came 23andMe, which allowed people to not only unearth their familial roots, but also bring to light unknown medical conditions or predispositions to certain medical issues. 23andMe then took the unprecedented step of teaming up with a pharmaceutical company to create drugs with its users' genetic information. After this announcement, some users were caught off guard, having had no idea that their genetic information—something so sensitive and uniquely personal to them—was being used to create drugs. While 23andMe presented this possibility in their Research Consent Document, it is clear that many users either did not read it or simply did not understand the terms of their participation. This begs the question: how do users effectively pull their genetic information from research they did not necessarily intend to participate in?*

*Neither the current American statutory scheme nor property and contract case law provide these users with protection or any way to withdraw from all research they deem unacceptable. Courts have ruled that people who allow their genetic information to be used for research forfeit their property rights to it and that it is not relevant if people did not read the consent form they agreed to, as*

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*long as they were put on notice of additional terms. Since these avenues for legal recourse are essentially blocked for users that want to reclaim their genetic information, they should instead pursue a clearer path. Examining gametic material jurisprudence—a similarly situated but more consumer-friendly area of law which involves disputes over the rights to the genetic information found in eggs, sperm, and embryos—may just reveal that new path.*

*This Note examines the various issues 23andMe’s research program presents for users who wish to fully remove their genetic information from 23andMe’s research given the current American statutory scheme and case law in various American jurisdictions. Under these legal frameworks, the courts do not look to the intent of the parties in deciding who has rights to the genetic material. Rather, courts look to whether there was a forfeiture, consent, and notice of terms. This is in spite of the well-documented fact that people often do not fully read or understand contracts, especially internet contracts, when they agree to them. In contrast, gametic material jurisprudence looks beyond contracts and certain acts to the intent of the donors in deciding who has rights to the gametic material. This legal framework recognizes the reality that people do not necessarily read or understand what they agree to when they allow their genetic material to be used in research and gives those who did not intend to participate in certain kinds of research a way to permanently reclaim their genetic material.*

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#### INTRODUCTION

In 2007, the personal genomics and biotechnology company 23andMe launched.<sup>1</sup> 23andMe enables its users to submit a spit sample to the company, which analyzes it and creates an ancestry, health, or combination report based on the type of kit ordered.<sup>2</sup> 23andMe, and companies like it, have surged in popularity in recent years as technology that can reveal our ancestry and origin has developed at a rapid pace.<sup>3</sup> Users have been drawn to this service because “our DNA is a way to help us paint a story of who we are, understand what that means about our identity, and even dictate how

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<sup>1</sup> Megan Molteni, *23andMe’s Pharma Deals Have Been the Plan All Along*, WIRED (Aug. 3, 2018, 3:28 PM), <https://www.wired.com/story/23andme-glaxosmithkline-pharma-deal/> [https://perma.cc/LQ7Z-UFM2]; *About Us*, 23ANDME, <https://mediacenter.23andme.com/company/about-us/> [https://perma.cc/C3G8-CHGG]; Nicole Wetsman, *23andMe Sold the Rights to a Drug It Developed from Its Genetic Database*, THE VERGE (Jan. 10, 2020, 3:50 PM), <https://www.theverge.com/2020/1/10/21060456/23andme-licensed-drug-developed-genetic-database-autoimmune-psoriasis-almirall> [https://perma.cc/7N7M-7WVC].

<sup>2</sup> *How It Works*, 23ANDME, <https://www.23andme.com/howitworks/> [https://perma.cc/4TV6-44C4].

<sup>3</sup> Sofia Sokolove, *How Did DNA Kits Become So Popular—and What’s Next?*, ALCALDE (June 30, 2018, 2:24 PM), <https://alcalde.texasexes.org/2018/06/how-did-dna-kits-become-so-popular-and-whats-next/> [https://perma.cc/A5R2BY8U].

we should move through the world.”<sup>4</sup> It is not only a somewhat affordable way to learn whether one is predisposed to any diseases or other health problems, but also gives people a look into their—and their family’s—genetic past.<sup>5</sup>

In the midst of its meteoric rise in 2018, 23andMe teamed up with the huge pharmaceutical company GlaxoSmithKline, giving GlaxoSmithKline exclusive rights to 23andMe’s users’ data to create drugs.<sup>6</sup> By 2018, however, 23andMe had already been sharing its users’ personal information with other pharmaceutical companies for three and a half years.<sup>7</sup> Although 23andMe claims that 80% of its roughly 12,000,000 users agree to have their DNA used for research,<sup>8</sup> many reported being “surprised and angry, unaware of what they had already signed (and spat) away.”<sup>9</sup> Some users were also completely unaware that 23andMe retained virtually unfettered access to and control over their genetic information.<sup>10</sup> While 23andMe users must sign terms of service agreements that include information regarding the use of their DNA for various types of research,<sup>11</sup> it is unclear whether they fully understand its ramifications, one of which being that the users cannot profit from any drug development that may result from the use of their DNA.<sup>12</sup>

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<sup>4</sup> *Id.*

<sup>5</sup> *Id.*

<sup>6</sup> Molteni, *supra* note 1.

<sup>7</sup> *Id.*

<sup>8</sup> *About Us*, *supra* note 1.

<sup>9</sup> Molteni, *supra* note 1.

<sup>10</sup> *Id.*

<sup>11</sup> *Id.*; *Terms of Service*, 23ANDME, <https://www.23andMe.com/about/tos/> [<https://perma.cc/4LKS-PF3R>].

<sup>12</sup> Molteni, *supra* note 1; *Research Consent Document*, 23ANDME, <https://www.23andMe.com/about/consent/> [<https://perma.cc/5UYF-AGUN>]; Valerie Gutmann Koch, *Pgtandme: Social Networking-Based Genetic Testing and the Evolving Research Model*, 22 HEALTH MATRIX 33, 71 (2012); Katherine Drabiak, *Caveat Emptor: How the Intersection of Big Data and Consumer Genomics Exponentially Increases Informational Privacy Risks*, 27 HEALTH MATRIX 143 (2017); Anne S.Y. Cheung, *Moving Beyond Consent for Citizen Science in Big Data Health and Medical Research*, 16 NW. J. TECH. & INTELL. PROP. 15, 23–25 (2018); J. Lyn Entrikin, *Family Secrets and Relational Privacy: Protecting Not-So-Personal, Sensitive Information from Public Disclosure*, 74 U. MIAMI L. REV. 781, 867 (2020); JENS OMDAL, THE BATTLE BETWEEN PRIVACY AND PROGRESS: HOW GENOMIC COMPANIES PLAN TO MOVE INTO PERSONALIZED HEALTHCARE AND WHAT IT MEANS FOR YOUR PRIVACY (2020); Matthew Rimmer, *23andMe Inc.: Patent Law and Lifestyle Genetics*, 22(1) J.L. INFO. & SCI. 132, 153–58 (2012).

Indeed, most Americans support human genetics research, believing it to be important for their own and the country's overall health.<sup>13</sup> They are thus willing to "grant broad consent for future use of their genetic information."<sup>14</sup> However, "[o]nce educated on privacy concerns regarding genetic information, individuals are less likely to support public data availability."<sup>15</sup>

Current bodily property jurisprudence offers little protection for unwitting 23andMe users whose DNA has been used for research or drug development as significant deference is given to scientists engaged in these endeavors, particularly with respect to novel genomic drugs and other therapies.<sup>16</sup> This Note argues that because of evolving technological and scientific landscapes and the potential for DNA to be used for much more than drug development, courts should begin giving users more protection and control over their genetic material. This could be achieved by encouraging courts to investigate users' intent upon signing up for the service, determine whether users actually read or understood the service's research contract when they signed it and uploaded their DNA to the site, and to eschew traditional contract jurisprudence in favor of a more nuanced approach.

Part I examines 23andMe's history, its Research Consent Document, and the concerns and controversies surrounding the website's research and storage of genetic information. Part II discusses the different types of internet contracts and how courts treat them, studies that show most internet users do not adequately read or understand internet contracts, and problems the average 23andMe user may encounter as a result. It also examines the legal implications of these problems; mainly that 23andMe users have no legal recourse to correct them. Part III argues that courts should look to the intent of the user and her understanding of the research contract when she signed

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<sup>13</sup> *Americans Strongly Support Human Genetics Research and Potential*, SCI. DAILY (Jan. 29, 2020), <https://www.sciencedaily.com/releases/2020/01/200129091531.htm> [<https://perma.cc/84K9-EGCX>].

<sup>14</sup> Kelsey Russo, *The Digital Life of Henrietta Lacks: Reforming the Regulation of Genetic Material*, 38 J. LEGAL MED. 449, 467 (2018) (internal quotations omitted).

<sup>15</sup> *Id.*

<sup>16</sup> *See generally* Moore v. Regents of Univ. of Cal., 51 Cal. 3d 120, 146 (1990); Greenberg v. Miami Child. Hosp. Rsch. Inst., Inc., 264 F. Supp. 2d 1064 (S.D. Fla. 2003); Wash. Univ. v. Catalona, 490 F.3d 667, 669 (8th Cir. 2007).

up for 23andMe, and further that they should eschew traditional contracts jurisprudence in favor of the user in these cases.

I. 23ANDME'S HISTORY, RESEARCH, AND CONTROVERSIES  
SURROUNDING ITS PRACTICES.

This Part examines statutes and the attendant case law to demonstrate that people do not have control over the disposition of their body parts once relinquished, except under very limited circumstances. Moreover, if they agreed to 23andMe's Research Consent Document, they will most likely be held to it by the courts, leaving 23andMe users with little to no legal recourse to reclaim their genetic information once they have given it to 23andMe and agreed to participate in their research.

A. *Factual Background*

1. The Evolution of 23andMe

Gaining access to one's own genetic information was not always simple or affordable.<sup>17</sup> Once upon a time, unlocking the secrets of one's own genetic material once was quite expensive and required direct access to experts in the field. Now, the evolution of technology and an expanding market has allowed early genomics studies to transform into the current genetic information industry—one that provides users with a complex analysis of their genes through a simple cheek swab and email.<sup>18</sup> Geneticist Michael Hammer conducted one of the first studies and discovered that a subset of Jewish men shared “distinctive genetic traits,” which he published in 1997.<sup>19</sup> Jewish men soon began contacting Hammer to see if they were part of the same subgroup.<sup>20</sup> While initially hesitant, he began taking their cheek swabs to analyze the results and charging them to offset the cost.<sup>21</sup>

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<sup>17</sup> Sokolove, *supra* note 3.

<sup>18</sup> *Id.*

<sup>19</sup> *Id.*

<sup>20</sup> *Id.*

<sup>21</sup> *Id.*



In 2003, Spencer Wells, an adjunct professor at the University of Texas, released the documentary *Journey of Man* with National Geographic and PBS; it showcased how he researched human migration patterns using the Y chromosome.<sup>22</sup> People were intrigued.<sup>23</sup> In 2005, Wells launched the first direct-to-consumer genetic testing kit with The Genographic Project, which sequenced users' DNA and gave them "deep ancestry insights."<sup>24</sup> The company sold 10,000 kits on the first day.<sup>25</sup>

Due to the success of The Genographic Project, 23andMe launched in 2006.<sup>26</sup> The company initially charged users \$1,000 per kit, which proved to be prohibitively expensive for many potential customers.<sup>27</sup> However, after the company lowered its prices, its share of the market increased dramatically.<sup>28</sup> In 2012, Ancestry.com launched its own genomics company with AncestryDNA.<sup>29</sup> By 2015, 23andMe and Ancestry had tested over one million people; by 2016, they reached over two million.<sup>30</sup> In 2017, Illumina, the company that makes direct-to-consumer genetics technology for 23andme and others, estimated that 7,000,000 people had been tested in that year alone.<sup>31</sup>

Today, 23andMe is a powerhouse—it has penetrated pop culture and boasts millions of users, many of which describe having profound experiences.<sup>32</sup> 23andMe posts stories to its blog about people who have learned more about themselves, their ancestry, and their health through its services.<sup>33</sup> In one blog post, 23andMe interviewed Jeremiah, an African-American man, who could not accurately trace

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<sup>22</sup> *Id.*

<sup>23</sup> *Id.*

<sup>24</sup> *Id.*; *The Genographic Project Geno 2.0 Next Generation Helix Product Privacy Policy*, NAT'L GEOGRAPHIC, <https://www.nationalgeographic.com/legal/privacy/genographic/> [<https://perma.cc/BM3W-K8JP>].

<sup>25</sup> Sokolove, *supra* note 3.

<sup>26</sup> *Id.*; *About Us*, *supra* note 1.

<sup>27</sup> Sokolove, *supra* note 3.

<sup>28</sup> *Id.*

<sup>29</sup> *Id.*

<sup>30</sup> *Id.*

<sup>31</sup> *Id.*

<sup>32</sup> *See generally* 23ANDME BLOG, <https://blog.23andme.com/> [<https://perma.cc/F27L-FZTU>].

<sup>33</sup> *Id.*

back his ancestry due to slavery.<sup>34</sup> Once he took a 23andMe test, however, he was able to trace his roots back to Ghana, Nigeria, the Congo, and other parts of Africa.<sup>35</sup> He told 23andMe that “[i]n that one moment, he felt connected.”<sup>36</sup> In another blog post, Jessica Algazi wrote how she used 23andMe and discovered she was carrying the BRCA1 gene, which greatly increases one’s chances of developing breast or ovarian cancer.<sup>37</sup> Jessica recounted how she “dodged a bullet” and that there are “many women walking around with this risk, who, like me, would have never known of their own risk but for this test from 23andMe.”<sup>38</sup> Powerful stories such as these may prompt anyone with difficulty tracing back through their ancestry or family’s medical history to use 23andMe to get a better picture of themselves and any possible health risks they may carry.

In order for 23andMe users to have these profound experiences, they must first purchase a kit, collect a sample of their DNA, and send it back to receive their results. 23andMe offers various kits for users to choose from that differ based on price and services provided. One kit, for example, simply offers ancestry information, while another offers both ancestry information *and* health data.<sup>39</sup> Whatever the user chooses, 23andMe will have access to her DNA and genetic history once she sends in her spit swab.<sup>40</sup>

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<sup>34</sup> *Learning About Yourself with 23andMe*, 23ANDME (Feb. 18, 2020), <https://blog.23andMe.com/23andMe-customer-stories/learning-about-yourself-with23andMe/> [<https://perma.cc/UF6R-M8BM>].

<sup>35</sup> *Id.*

<sup>36</sup> *Id.*

<sup>37</sup> Jessica Algazi, *23andMe Alerted Me to My BRCA1 Variant*, 23ANDME (Dec. 6, 2019), <https://blog.23andMe.com/23andMe-customer-stories/23andMe-alerted-me-to-my-brca1-variant/> [<https://perma.cc/7VF8-X3G7>].

<sup>38</sup> *Id.*

<sup>39</sup> There are two kinds of kits: (1) Ancestry + Traits Kit and (2) Health + Ancestry Service Kit. The Ancestry + Traits Kit is \$99 and provides the user with an ancestry report including Ancestry Percentages (to the 0.1%), Automatic Family Tree Builder, 30+ Trait Reports, and DNA Relative Finder. The Health + Ancestry Service is \$199 and includes everything in the Ancestry + Traits Kit plus 10+ Health Predisposition Reports, 5+ Wellness Reports, and 40+ Carrier Status Reports. Users can choose which kit is best for them based on their budget and what they are looking for out of 23andMe. *Compare Our Services*, 23ANDME, <https://www.23andMe.com/compare-dna-tests/> [<https://perma.cc/J3WC-ERMU>].

<sup>40</sup> *See id.*

## 2. 23andMe's Research Consent Document

When a user signs up for a free 23andMe account, even if she did not provide her genetic information to the website, she automatically agrees to both the Privacy Statement and the Terms of Service.<sup>41</sup> These state that the user completely waives her property rights in any research, products that result from research on her DNA, or any information the user provides to the site; the document also indemnifies 23andMe from any liability resulting from the use or disclosure of her genetic information.<sup>42</sup> 23andMe also provides users with a Research Consent Document, where the user allows 23andMe to use her genetic information in research that supposedly aims to “[d]iscover genetic factors behind diseases and traits, [u]ncover connections among diseases and traits, [l]earn about human migration and population history through genetics, [and] [u]nderstand how people react to their personal genetic information.”<sup>43</sup>

In order for her DNA to be included in research, the 23andMe user must first agree to the Research Consent Document (the “Document”).<sup>44</sup> 23andMe contends that about 80% of its users consent to research, which is roughly 9,600,000 people.<sup>45</sup> It is unclear whether people consent because they want to help others or because they did not in fact read the Document before signing, or some mixture of both. It should be noted that the Document is ten pages when printed.

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<sup>41</sup> *Terms of Service*, *supra* note 11.

<sup>42</sup> *Id.*

<sup>43</sup> *Research Consent Document*, *supra* note 12.

<sup>44</sup> *Privacy Policy*, 23ANDME, <https://www.23andMe.com/en-int/about/privacy/> [<https://perma.cc/AG3B-ZM69>]; *Research Consent Document*, *supra* note 12.

<sup>45</sup> *About Us*, *supra* note 1; Wetsman, *supra* note 1.

The Document can be found on 23andMe's website before creating an account. The "key points" of the Document are listed before the rest of the agreement, presumably so users can quickly read what they are consenting to before they scroll to the bottom of the page and accept. Importantly, none of the key points mention anything about drug research.<sup>46</sup>

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## Research Consent Document

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### Consent Document - Key Points

23andMe aims to make and support scientific discoveries and publish those discoveries in scientific journals. We invite you to take part in this project, which we call **23andMe Research**. To get started you must agree to the terms in our full consent document (below). Here are key points of that document:

#### How do I take part in 23andMe Research?

- Take surveys or otherwise enter information about yourself into the 23andMe website. You choose which surveys to take and which questions to answer.

#### Can my child take part in 23andMe Research?

- Your child may take part in 23andMe Research if they give assent to participate and a parent or legal guardian authorizes 23andMe to use their Genetic & Self-Reported Information for research.
- [Here are some talking points](#) to help you discuss 23andMe Research with your child.

#### Which of my personal information is used for research?

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<sup>46</sup> *Research Consent Document, supra* note 12.

- [Here are some talking points](#) to help you discuss 23andMe Research with your child.

#### Which of my personal information is used for research?

- Your genetic data and any other personal information you enter into the website, except for your Registration Information (name, contact information, and credit card information), may be analyzed in the research.
- Your name and contact information may be used to communicate with you but are not analyzed in combination with your genetic and other personal information.

#### Who gets to see my personal information?

- 23andMe's privacy statement outlines who does and does not get access to the personal information of 23andMe customers; here we list the additional individuals who will get access if you consent to take part in research.
- *Within 23andMe:* 23andMe researchers who conduct analyses will have access to your genetic and other personal information, but not to your name, contact, or credit card information. 23andMe researchers who contact you will have access to names and contact information, but only to very limited genetic or other personal information.
- *Outside of 23andMe:* 23andMe may share some data with external research partners and in scientific publications. These data will be summarized across enough customers to minimize the chance that your personal information will be exposed. 23andMe may need to share the information with other agencies as required by law.

#### How will I benefit from this research?

- By taking surveys you may learn about 23andMe's research findings, including how your answers compare with those of others and new discoveries made by 23andMe's research program.
- Sometime in the future you or your family may benefit indirectly from research discoveries made by 23andMe or its research partners.

#### What are the risks of taking part in this research?

- There is a very small chance that someone with access to the research data or results could expose personal information about you. 23andMe has policies and practices in place to minimize the chance of such an event.

#### Can I stop taking part in 23andMe Research?

- Yes, you can withdraw from 23andMe Research at any time. Any of your data that have already been entered into a study cannot be withdrawn, but your data will not be included in studies that start more than 30 days after you withdraw (it may take up to 30 days to withdraw your information after you withdraw your consent).

#### Full Consent Document

One of 23andMe's missions is to make and support meaningful scientific discoveries by enabling its customers to participate directly in research. 23andMe has enrolled hundreds of thousands of participants from among its customers in this project, which we call **23andMe Research**. Specifically, 23andMe Research refers to research aimed at publication in peer-reviewed journals and research funded by the federal government (such as the National Institutes of Health - NIH). The

When the user agrees to participate, she agrees to allow 23andMe researchers to use her genetic and self-reported information in research and that she will, at her election, enter inform-

ation about herself into the 23andMe features on its website.<sup>47</sup> The 23andMe research features include “surveys, individual questions, and other features” where the user enters information about herself.<sup>48</sup> The Document provides that if the user does not feel comfortable providing certain information, she may elect not to answer that question and she can choose to take part in “all, some, or none of the surveys.”<sup>49</sup>

Halfway through the Document, 23andMe informs the user of the kind of research it will be performing with her DNA.<sup>50</sup> The Document provides that the user’s genetic and self-reported information may be used to research:

[L]inks between genetic markers, non-genetic markers, traits, diseases, behaviors and other characteristics; human migrations or population history; or to assess how people respond to personal genetic information. *Discoveries made as a result of this research could be used to understand the basic causes of disease, develop drugs or other treatments and/or preventive measures, or predict a 'person's risk of disease.* The topics to be studied span a wide range of traits and conditions, from common to rare. The topics include simple traits such as hair color or freckles, serious diseases such as Parkinson’s disease or diabetes, and less serious conditions such as migraine headaches or response to over-the-counter drugs. Some of these studies may be sponsored by or conducted on behalf of third parties, such as non-profit foundations, academic institutions or *pharmaceutical companies.*<sup>51</sup>

The Document also provides information on the myriad of risks that can arise from allowing DNA to be used in research, but only

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<sup>47</sup> *Id.*; see also Drabiak, *supra* note 12, at 155–59.

<sup>48</sup> *Research Consent Document, supra* note 12.

<sup>49</sup> *Id.*

<sup>50</sup> *Id.*

<sup>51</sup> *Id.* (emphasis added).

starting on page seven.<sup>52</sup> The risks vary in severity.<sup>53</sup> Moreover, it states that if the user does consent to participate in research, she can choose not to take certain surveys.<sup>54</sup> This gives users the choice to participate passively in research by just providing their genetic information or more actively by answering questions that might provide more insight to researchers.

If users originally consented to research but have since changed their minds, the Document provides that they may withdraw all or some of their genetic and self-reported information from 23andMe research at any time, but if:

[Y]ou withdraw all or some of your Genetic & Self-Reported Information, 23andMe will prevent that information from being used in new 23andMe Research initiated after 30 days from receipt of your request (it may take up to 30 days to withdraw your information after you withdraw your consent). *Any research on your data that has been performed or published prior to this date will not be reversed, undone, or withdrawn.*<sup>55</sup>

In other words, if the user originally consented to participate in research and then changes her mind, her information will only be removed from being considered for use in future research and will not be taken out of research that has begun before the 30-day period or that has already finished.<sup>56</sup>

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<sup>52</sup> *Id.*

<sup>53</sup> *Research Consent Document*, *supra* note 12; *see also* Drabiak, *supra* note 12; Sarah Washburn, *Controlling Your DNA: Privacy Concerns in Genomic Testing and the Uncertainty of Federal Regulation and Legislation*, 18 DEPAUL J. HEALTH CARE L. 1, 22 (2016); Eunice Park, *Objects, Places and Cyber-Spaces Post-Carpenter: Extending the Third-Party Doctrine Beyond CSLI: A Consideration of IoT and DNA*, 21 YALE J. L. & TECH. 1, 44 (2019).

<sup>54</sup> *Research Consent Document*, *supra* note 12.

<sup>55</sup> *Id.* (emphasis added).

<sup>56</sup> *See* Drabiak, *supra* note 12.

## B. *Legal Background*

### 1. GINA

The Genetic Information Nondiscrimination Act (“GINA”) prohibits employers from using genetic information to make employment decisions “such as hiring, firing, advancement, compensation, and other terms, conditions, and privileges of employment.”<sup>57</sup> There are no exceptions.<sup>58</sup> Under GINA, genetic information includes: information about a person’s genetic tests; information about a family members’ genetic test; family medical history; requests for and receipt of genetic services by a person or a family member; and the genetic information of a fetus or embryo carried or legally held by a family member or other individual.<sup>59</sup> According to the Equal Employment Opportunity Commission (“EEOC”), an example of an employer illegally using genetic information would be “for an employer to reassign an employee from a job it believes is too stressful after learning of his family medical history of heart disease.”<sup>60</sup>

23andMe mentions GINA in its Terms of Service when it warns users to be careful about sharing their genetic information with other people.<sup>61</sup> The company states that few businesses or insurance companies ask people for their genetic information, but as with anything, this could always change.<sup>62</sup> Importantly, the company notes that while GINA has been in effect in the United States since 2008, “its protection against discrimination by employers and health insurance companies for employment and coverage issues *has not been clearly established*” and “does not cover life, long-term care,

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<sup>57</sup> U.S. EQUAL EMP. OPPORTUNITY COMM’N, EEOC-NVTA-0000-4, FACT SHEET: GENETIC INFORMATION NONDISCRIMINATION ACT (2014), <https://www.eeoc.gov/laws/guidance/fact-sheet-genetic-information-nondiscrimination-act> [<https://perma.cc/WL37-L97S>]; 42 U.S.C. § 2000ff.

<sup>58</sup> U.S. EQUAL EMP. OPPORTUNITY COMM’N, EEOC-NVTA-0000-4, FACT SHEET: GENETIC INFORMATION NONDISCRIMINATION ACT (2014), available at <https://www.eeoc.gov/laws/guidance/fact-sheet-genetic-information-nondiscrimination-act> [<https://perma.cc/WL37-L97S>].

<sup>59</sup> *Id.*

<sup>60</sup> *Id.*

<sup>61</sup> *Terms of Service*, *supra* note 11.

<sup>62</sup> *Id.*



or disability insurance providers.”<sup>63</sup> 23andMe further notes that while some states have laws protecting people’s genetic information, many do not and suggests that the user consult a lawyer to fully understand the scope of the legal protection over her genetic information in her jurisdiction.<sup>64</sup>

Further, 23andMe maintains that any genetic information users choose to share with their doctors may become part of their medical records and “through that route be accessible to *other* health care providers and/or insurance companies in the future.”<sup>65</sup> Likewise, it advises that any genetic information the user shares with anyone may be against her interest and “[e]ven if you share Genetic Information that has no or limited meaning today, *that information could have greater meaning in the future as new discoveries are made.*”<sup>66</sup> 23andMe also advises that it may be considered fraud if the user’s insurance company asks if the user is aware of any health conditions from her genetic information and she does not disclose them.<sup>67</sup>

23andMe’s specific mention of GINA in its Terms of Service is important for multiple reasons. First, it acknowledges that sharing genetic information can be risky and that, in the future, businesses and insurance companies could start asking for the user’s genetic information. Second, it acknowledges that while GINA is good law, its protection is not “clearly established” and it does not cover all types of insurance.<sup>68</sup> 23andMe is essentially warning its users that their genetic information may be used against them at a later date for insurance purposes and its protection cannot be guaranteed. In fact, the company goes on to recommend speaking to a lawyer to understand how the user’s genetic information may be protected in their jurisdiction.<sup>69</sup> These sections of the Terms of Service are parti-

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<sup>63</sup> *Id.* (emphasis added); see also Leslie E. Wolf et al., *The Web of Legal Protections for Participants in Genomic Research*, 29 HEALTH MATRIX 1, 35–36 (2019); Josef A. Mejido, *Personalized Genomics: A Need for a Fiduciary Duty Remains*, 37 RUTGERS COMPUT. & TECH. L.J. 281, 294 (2011); Kristi Harbord, *Genetic Data Privacy Solutions in the GDPR*, 7 TEX. A&M L. REV. 269, 279 (2019).

<sup>64</sup> *Terms of Service*, *supra* note 11.

<sup>65</sup> *Id.* (emphasis added).

<sup>66</sup> *Id.* (emphasis added).

<sup>67</sup> *Id.*

<sup>68</sup> *Id.*

<sup>69</sup> *Id.*

cularly significant because 23andMe acknowledges that the user's genetic information may not be protected by law and that, even if it is, only a lawyer would be able to properly explain how or to what extent.<sup>70</sup> Finally, while GINA offers some protection in the employment and insurance contexts, it does not offer any protection for research misuse.<sup>71</sup>

## 2. HIPAA

Generally, the Health Insurance Portability and Accountability Act (“HIPAA”) provides fairly limited protection of genetic information.<sup>72</sup> Congress enacted HIPAA in 1996 and “included two provisions that restricted group health insurers’ use of health-related information in making coverage decisions and setting premiums.”<sup>73</sup> Under HIPAA, genetic information cannot be used to make coverage decisions or to set premiums if it is “maintained by a health provider or health plan covered by [HIPAA].”<sup>74</sup> Likewise, HIPAA definitively states that “genetic information in the absence of a diagnosis cannot be considered a pre-existing condition.”<sup>75</sup>

However, given the technological advancements since the passing of HIPAA and the rise of companies like 23andMe, which have started teaming up with drug companies, it is clear that HIPAA is not as expansive as necessary.<sup>76</sup> Specifically, HIPAA does not forbid insurance companies from requesting genetic information from

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<sup>70</sup> *See id.*

<sup>71</sup> *See generally* Dustin W. Massie, 23, *My Employer & Me on Genetic Testing, Privacy, and Employment*, 74-DEC BENCH & B. MINN. 12 (2017); Stephanie Bair, *Direct-to-Consumer Genetic Testing: Learning from the Past and Looking Toward the Future*, 67 FOOD & DRUG L.J. 413, 425–26 (2012); Colin McFerrin, *DNA, Genetic Material, and a Look at Property Rights: Why You May Be Your Brother's Keeper*, 19 TEX. WESLEYAN L. REV. 967, 984–85 (2013); Eriq Gardner, *Gene Swipe: Few DNA Labs Know Whether Chromosomes Are Yours or If You Stole Them*, ABA (Aug. 1, 2011, 8:40 AM), [https://www.abajournal.com/magazine/article/gene\\_swipe\\_few\\_dna\\_labs\\_know\\_whether\\_chromosomes\\_are\\_yours\\_or\\_if\\_you\\_stole](https://www.abajournal.com/magazine/article/gene_swipe_few_dna_labs_know_whether_chromosomes_are_yours_or_if_you_stole) [<https://perma.cc/K57E-QTPE>].

<sup>72</sup> McFerrin, *supra* note 71, at 983.

<sup>73</sup> Louise Slaughter, *Genetic Information Non-Discrimination Act*, 50 HARV. J. ON LEG. 41, 48 (2013); 42 U.S.C. § 1320d-6.

<sup>74</sup> Slaughter, *supra* note 73, at 48.

<sup>75</sup> *Id.*

<sup>76</sup> *See Genetic Information Privacy*, ELEC. FRONTIER FOUND., <https://www EFF.ORG/issues/genetic-information-privacy> [<https://perma.cc/4AJE-Z339>].

people they already insure or “using genetic information during the insurance underwriting process.”<sup>77</sup> Likewise, HIPAA forbids health insurance companies from charging higher premiums “of an individual within a group plan based on genetic makeup, [but] it allows insurers to charge the entire group a higher rate.”<sup>78</sup> Perhaps most importantly, HIPAA does not limit the disclosure of genetic information from third parties to insurance companies.<sup>79</sup>

Given these facts, one might reasonably wonder—is it legal under federal law for an insurance company to request a different person’s genetic information from one of their insured.<sup>80</sup> It would certainly be legal for insurance companies to use a 23andMe user’s genetic information to charge her more as long as the insurance companies charge the group with which she shares certain genetic characteristics more.<sup>81</sup> Additionally, HIPAA doesn’t appear to restrict 23andMe from sending genetic information to insurance companies.<sup>82</sup> Finally, HIPAA offers no protection for research misuse.<sup>83</sup>

### 3. Case Law Regarding Control and Ownership Over Body Parts

Courts have held that, generally, people do not have property rights in their own body parts once they give them up.<sup>84</sup> In *Moore v. Regents of University of California*,<sup>85</sup> Moore underwent treatment for hairy-cell leukemia at UCLA Medical Center and then underwent a splenectomy at the advice of his doctor, Golde.<sup>86</sup> He continued to go to UCLA and receive treatment—there, Golde withdrew blood, skin, bone marrow, and sperm samples from him.<sup>87</sup> During this time, Golde performed research using Moore’s samples and

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<sup>77</sup> Slaughter, *supra* note 73, at 48.

<sup>78</sup> *Id.*

<sup>79</sup> *Id.*; see also Wolf et al., *supra* note 63, at 76–77.

<sup>80</sup> See Slaughter, *supra* note 73, at 48.

<sup>81</sup> See *id.*

<sup>82</sup> See *id.*

<sup>83</sup> See Wolf et al., *supra* note 63, at 77; McFerrin, *supra* note 71, at 983.

<sup>84</sup> See *Moore v. Regents of Univ. of Cal.*, 51 Cal. 3d 120 (1990); *Greenberg v. Miami Child.’s Hosp. Rsch. Inst., Inc.*, 264 F. Supp. 2d 1064 (S.D. Fla. 2003); *Wash. Univ. v. Catalona*, 490 F.3d 667, 669 (8th Cir. 2007).

<sup>85</sup> *Moore*, 51 Cal. 3d.

<sup>86</sup> *Id.* at 125–26.

<sup>87</sup> *Id.* at 126.

eventually created a cell-line, which he patented.<sup>88</sup> Moore sued Golde and the Regents of California for conversion, which is a tort under property law “that protects against interference with possessory and ownership interests in personal property.”<sup>89</sup>

The court found, first, that there was no reported precedent supporting Moore’s claim that he had an ownership right or a sufficient interest in his cells to warrant a conversion claim “either directly or by close analogy.”<sup>90</sup> Next, the court found that California statutes severely limit “any continuing interest of a patient in excised cells”<sup>91</sup> and, finally, that UCLA’s patented cell-line and the products derived from it “cannot be Moore’s property.”<sup>92</sup>

The court found that the cell-line and any products that derived from it could not be Moore’s property because they are “both factually and legally distinct from the cells taken from Moore’s body” and that federal law only permits patenting products of human ingenuity, not naturally occurring organisms such as cells taken from a body.<sup>93</sup> Moreover, the Court refused to extend conversion to cover body parts because this may “hinder research by restricting access to the necessary raw materials.”<sup>94</sup> *Regents* was the first in a string of decisions which held that people do not have property interests in their own body parts because it is unprecedented and granting such interests may ultimately harm productive research.<sup>95</sup>

Years later, in *Greenberg v. Miami Children’s Hospital Research Institute, Inc.*, a court found that people “have no cognizable property interest in body tissue and genetic matter donated for research under a theory of conversion” and therefore have no rights to a patent that resulted therefrom.<sup>96</sup> The court also refused to extend the informed consent doctrine to cover disclosure of researchers’

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<sup>88</sup> *Id.* at 168 (Mosk, J., dissenting).

<sup>89</sup> *Id.* at 37.

<sup>90</sup> *Id.*

<sup>91</sup> *Id.*

<sup>92</sup> *Id.*

<sup>93</sup> *Id.* at 141–42.

<sup>94</sup> *Id.* at 144.

<sup>95</sup> *See generally id.*; *Greenberg v. Miami Child.’s Hosp. Rsch. Inst., Inc.*, 264 F. Supp. 2d 1064 (S.D. Fla. 2003); *Wash. Univ. v. Catalona*, 490 F.3d 667 (8th Cir. 2007).

<sup>96</sup> *Greenberg*, 264 F. Supp. 2d at 1074.

economic interests in their own research because it “would have pernicious effects over medical research, as it would give each donor complete control over how medical research is used and who benefits from that research.”<sup>97</sup> Here, the court made a point of stating that not only do people not have property rights in their own body parts, but that research subjects do not have to be informed of researchers’ economic interests in the research they are conducting.<sup>98</sup> The court was concerned about disclosure to research subjects primarily because of the possibility that the subjects may refuse to partake in research or try to exert more control over the research. The court expressed concern that this could potentially hinder scientific progress without acknowledging that the subjects may have an interest in the disposition of their bodily materials.<sup>99</sup>

In another seminal case, *Washington Univ. v. Catalona*, the Court found that people who make “an informed decision to contribute their biological materials voluntarily to a particular research institution for the purpose of medical research [do not] retain an ownership interest allowing the individuals to direct or authorize the transfer of such materials to a third party.”<sup>100</sup> Here, the Court once again emphasized that people who give their body parts to research do not have any ownership interest in those body parts.

Washington University claimed that the research subjects made an *inter-vivos* gift to them which, under the law, requires that the proponent present the donor’s intent to make a gift the donor’s delivery of the property to the donee; and the donee’s acceptance and automatic ownership of the gift.<sup>101</sup> The Court found that the individuals did intend to make a gift to the university because they signed a consent form which “emphasized the voluntariness” of their participation, described how they could decline to participate or “withdraw consent at any time,”<sup>102</sup> and because they were given brochures that said they would be making “gifts” to the University.<sup>103</sup>

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<sup>97</sup> *Id.* at 1070.

<sup>98</sup> *Id.* at 1070–71.

<sup>99</sup> *Id.*

<sup>100</sup> *Catalona*, 490 F.3d at 673.

<sup>101</sup> *Id.* at 674.

<sup>102</sup> *Id.*

<sup>103</sup> *Id.* at 671.

The Court also found that since the brochures described that the bodily materials donated by participants could be shared with researchers outside of Washington University—without needing additional consent from the participants—this in turn sufficiently informed the participants that they were abandoning “the right to designate the particular destination of their biological materials” when they agreed to participate in the research.<sup>104</sup> Further, the court found that the language in the brochure coupled with the consent form, could not “reasonably be characterized as reflecting the [participants’] intention either to entrust their samples solely to Dr. Catalona or to transfer the samples in some legal form other than a gift.”<sup>105</sup> The Court also found that the second and third elements were met.<sup>106</sup>

### C. *Internet Contracts Jurisprudence*

Contract law also plays a part in 23andMe’s users experiences and possible legal recourse. Courts consistently find internet contracts to be enforceable where users are put on notice of the contracts’ terms. There are primarily four kinds of internet contracts: browsewrap, clickwrap, scrollwrap, and sign-in-wrap.<sup>107</sup> Browsewrap is a type of contract where the website determines that a user assents “merely by using the site.”<sup>108</sup> A clickwrap contract is where the user “must click ‘I agree,’ but [does] not necessarily view the contract to which she is assenting.”<sup>109</sup> In a scrollwrap contract, the user must “physically scroll through an internet agreement and click on a separate ‘I agree’ button in order to assent to the terms and conditions of the host website.”<sup>110</sup> Finally, Sign-in-wrap is a type of contract where the user essentially assents to the terms of the website by “signing up for use of the site’s services.”<sup>111</sup> 23andMe’s Research Consent Document falls under the scrollwrap definition

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<sup>104</sup> *Id.* at 674–75.

<sup>105</sup> *Id.* at 675.

<sup>106</sup> *Id.*

<sup>107</sup> *Berkson v. Gogo LLC*, 97 F. Supp. 3d 359, 394 (E.D.N.Y. 2015).

<sup>108</sup> *Applebaum v. Lyft, Inc.*, 263 F. Supp. 3d 454, 465 (S.D.N.Y. 2017) (quoting *Berkson*, 97 F. Supp. 3d at 394–95).

<sup>109</sup> *Id.*

<sup>110</sup> *Id.*

<sup>111</sup> *Id.*

because it requires the user to scroll all the way to the end of the agreement and click “I agree” to consent to the terms.

Courts almost always find that scrollwrap agreements, which require the user to scroll down through the contract and click “I agree” to assent to its terms,<sup>112</sup> to be enforceable “because they present the consumer with a ‘realistic opportunity’ to review the terms of the contract and they require a physical manifestation of assent.”<sup>113</sup> For example, in *Applebaum v. Lyft Inc.*, the court found that the user assented to Lyft’s arbitration agreement through a scrollwrap agreement because he had the “realistic opportunity” to view the terms and consented.<sup>114</sup> On the other hand, courts are skeptical of clickwrap agreements, where the user has to click “I agree” but does not necessarily see the contract to which she is agreeing,<sup>115</sup> because they do “not require the user to review the terms of the proposed agreement.”<sup>116</sup> However, even in these circumstances courts still generally find them enforceable because “[b]y requiring a physical manifestation of assent, a user is said to be put on inquiry notice of the terms assented to.”<sup>117</sup> Significantly, the Ninth Circuit found the mandatory arbitration clause in 23andMe’s Terms of Service, which is a clickwrap agreement, to be enforceable.<sup>118</sup> Traditionally, courts have found that the person agreeing to a contract does not necessarily need to read its terms to be bound. The courts rely on this contracts jurisprudence in finding that, for internet contracts, to “be bound, an internet user *need not actually read the terms and conditions* or click on a hyperlink that makes them available *as long as she has notice of their existence.*”<sup>119</sup>

Internet contracts jurisprudence is significant because courts will find online contracts enforceable—sometimes even if the terms are not readily apparent—because users are put on some form of

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<sup>112</sup> *Id.*

<sup>113</sup> *Id.* (internal citations omitted).

<sup>114</sup> *Id.* at 465.

<sup>115</sup> *Id.* at 465 (quoting *Berkson v. Gogo LLC*, 97 F. Supp. 3d 359, 394–95 (E.D.N.Y. 2015)).

<sup>116</sup> *Id.* (internal citations omitted).

<sup>117</sup> *Id.*

<sup>118</sup> *Tompkins v. 23andMe, Inc.*, 840 F.3d 1016, 1020 (9th Cir. 2016).

<sup>119</sup> *Nicosia v. Amazon.com, Inc.*, 834 F.3d 220, 232 (2d Cir. 2016) (emphasis added); *Entrikin*, *supra* note 12, at 861.

notice of the terms and must assent to them.<sup>120</sup> Additionally, and even more significantly, courts will find users bound by the contract they agreed to, even if they did not read or fully understand its terms, as long as they were on notice that there were terms to which they were agreeing.<sup>121</sup> This means that hundreds of thousands of internet users will be bound to the terms of the contracts they assented to online, even if they did not read or actually understand them, simply because they were put “on notice” of the terms.<sup>122</sup>

However, courts have noted that determining the classification of a contract—such as a scrollwrap or clickwrap agreement, for example—or whether the user clicked a box does not end the inquiry of whether the user assented to the contract, for [a] court “cannot presume that a person who clicks on a box that appears on a . . . screen has notice of all contents not only of that page but of other content that requires further action (scrolling, following a link, etc.).”<sup>123</sup> Importantly, the “presentation of the online agreement matters” in determining whether the user was actually on notice of the existence of additional terms and “depends heavily on whether the design and content of that webpage rendered the existence of terms *reasonably conspicuous*” to the user.<sup>124</sup> Indeed, the “[c]larity and conspicuousness” of the terms are crucial in determining whether the website secured the user’s informed assent.<sup>125</sup>

In other words, courts cannot presume the user is on notice of terms that may require scrolling, for example, and should look to the presentation of the website to see if extra terms are reasonably conspicuous to the user.<sup>126</sup> This gives courts some leeway to find that a clickwrap or scrollwrap agreement is not valid, especially if all of the terms are not reasonably conspicuous to the user. However, this tends to be a rare occurrence with internet contracts.

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<sup>120</sup> *Applebaum v. Lyft, Inc.*, 263 F. Supp. 3d 454, 465 (S.D.N.Y. 2017) (internal citations omitted).

<sup>121</sup> *Nicosia*, 834 F.3d at 232.

<sup>122</sup> *Id.*

<sup>123</sup> *Applebaum*, 263 F. Supp. 3d at 466 (internal quotations omitted).

<sup>124</sup> *Id.* (quoting *Nicosia*, 834 F.3d at 233).

<sup>125</sup> *Id.* (internal citations omitted).

<sup>126</sup> *Id.*



Current legislation and case law do not recognize or protect people's property rights in their own genetic material. GINA, which specifically references genetic material, is a narrow statute, which protects people from employment discrimination based on their genetic information.<sup>127</sup> It does not protect against other forms of discrimination based on genetic information or give people any remedies if their genetic information is misused. HIPAA protects people from insurance companies charging higher premiums based on what is found in their genetic information but does not protect them in the event that their genetic information is misused in another way. Case law offers no protection either. Courts have repeatedly refused to recognize people's property rights over their own body parts.<sup>128</sup> Moreover, courts repeatedly find that if users were put on notice of additional terms, they will be held to the internet contracts to which they agreed, even if they did not totally understand to what they were agreeing.<sup>129</sup> However, some courts have taken a different approach when it comes to gametic material, the genetic information found in eggs, sperm, and embryos.<sup>130</sup>

## II. DEFICIENCIES OF THE CURRENT LAWS GOVERNING 23ANDME

Currently, the law does not protect 23andMe users seeking to reclaim their genetic information. Although two federal statutes, the Genetic Information Nondiscrimination Act ("GINA") and the

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<sup>127</sup> *Fact Sheet: Genetic Information Nondiscrimination Act*, EEOC, <https://www.eeoc.gov/laws/guidance/fact-sheet-genetic-information-nondiscrimination-act> [<https://perma.cc/LBL4-MPYJ>]; 42 U.S.C. § 2000ff.

<sup>128</sup> *See, e.g.*, *Moore v. Regents of Univ. of Cal.*, 51 Cal. 3d 120, 136–37 (1990); *Greenberg v. Miami Child.'s Hosp. Rsch. Inst., Inc.*, 264 F. Supp. 2d 1064, 1074 (S.D. Fla. 2003); *Wash. Univ. v. Catalona*, 490 F.3d 667, 669 (8th Cir. 2007).

<sup>129</sup> *See, e.g.*, *Applebaum v. Lyft, Inc.*, 263 F. Supp. 3d 454, 469 (S.D.N.Y. 2017); *Nicosia v. Amazon.com, Inc.*, 834 F.3d 220, 232 (2d Cir. 2016)

<sup>130</sup> *See infra* Section II.E.; *Hecht v. Super. Ct.*, 20 Cal. Rptr. 2d 275, 283 (Cal. Ct. App. 1993); *Davis v. Davis*, 842 S.W.2d 588, 604 (Tenn. 1992), *reh 'g in part*, No. 34, 1992 WL 341632 (Tenn. Nov. 23, 1992). *See generally* William Boulier, *Sperm, Spleens, and Other Valuables: The Need to Recognize Property Rights in Human Body Parts*, 23 HOFSTRA L. REV. 693 (1995); Erin Colleran, *My Body, His Property?: Prescribing A Framework to Determine Ownership Interests in Directly Donated Human Organs*, 80 TEMP. L. REV. 1203 (2007); Mark Pawlowski, *Property in Body Parts and Products of the Human Body*, 30 LIVERPOOL L. REV. 35, 48–49 (2009); Abigail Hoglund-Shen, *Direct-to-Consumer Genetic Testing, Gamete Donation, and the Law*, 55 FAM. CT. REV. 472, 477 (2017).

Health Insurance Portability and Accountability Act (“HIPAA”), address the uses and misuses of information derived from DNA, these laws are inapplicable to 23andMe users’ situations. Moreover, courts have consistently held that people do not have property rights over their own body parts: once a person has relinquished a body part for research she no longer has any control over it.<sup>131</sup> Additionally, courts generally always hold people to the scrollwrap contracts they agreed to, even if they did not read or totally understand the contracts’ terms.<sup>132</sup>

To provide a broad overview, 23andMe users who want their DNA pulled from research are not protected by the United States’ current statutory scheme, traditional body part ownership jurisprudence, or contracts jurisprudence. The almost complete inability for 23andMe users to regain control over the disposition of their genetic material becomes extremely problematic once 23andMe begins to push the limits of the “consent” given to the company in its Research Consent Document.

In sum, courts have held that research participants have no property rights over their body parts once they have relinquished them to research.<sup>133</sup> Courts have adhered to this jurisprudence because precedent has established that byproducts of body parts are “factually and legally distinct from” the original body parts used to create them,<sup>134</sup> that the extension of property rights to body parts will have an adverse effect on research,<sup>135</sup> and that people who make an informed decision to give up their bodily materials for research do not retain an ownership interest in them.<sup>136</sup> This puts 23andMe users, such as Jane, in a difficult position to mount a conversion claim, because they have technically made an informed decision, based on the Research Consent Document they signed and were supposed to

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<sup>131</sup> *Moore v. Regents of Univ. of Cal.*, 51 Cal. 3d 120, 136–37 (1990); *Greenberg v. Miami Child. ’s Hosp. Rsch. Inst., Inc.*, 264 F. Supp. 2d 1064, 1074 (S.D. Fla. 2003); *Wash. Univ. v. Catalona*, 490 F.3d 667, 669 (8th Cir. 2007).

<sup>132</sup> *See Berkson v. Gogo LLC*, 97 F. Supp. 3d 359, 398–99 (E.D.N.Y. 2015); *Applebaum v. Lyft, Inc.*, 263 F. Supp. 3d 454, 465 (S.D.N.Y. 2017).

<sup>133</sup> *See Moore*, 51 Cal. 3d at 136–37; *Greenberg*, 264 F. Supp. 2d at 1074; *Catalona*, 490 F.3d at 669.

<sup>134</sup> *Moore*, 51 Cal. 3d at 141–42.

<sup>135</sup> *Id.* at 144; *Greenberg*, 264 F. Supp. 2d at 1070.

<sup>136</sup> *Catalona*, 490 F.3d at 674.

understand, to allow their genetic material to be used in research and have therefore relinquished any property rights they had to their genetic material under the law. Because the courts have expressly rejected the notion that people who have allowed their body parts to be used in research have sufficient property rights over those body parts to warrant conversion claims, 23andMe users who want to pursue this path are left with the difficult task of trying to convince the courts to overturn years of precedent to the contrary.

Moreover, despite consistent findings that people fail to fully read or comprehend contracts,<sup>137</sup> courts almost always find that when someone has the opportunity to read an internet contract, such as the case with scrollwrap agreements, that is sufficient to hold them to the terms of it, even if they did not read it or did not spend a sufficient amount of time reading it to understand it.<sup>138</sup> This poses a problem for those like the 23andMe users in 2018 who did not realize, for example, they were agreeing to potential drug research and creation when they agreed that their genetic information could be used in research until the GlaxoSmithKline deal.<sup>139</sup> This problem could become even greater if 23andMe begins pushing the boundaries of the provisions in the Research Consent Document to research something far more controversial, such as cloning.

This Part examines both and GINA and HIPAA, as well as the attendant case law, to demonstrate that people do not have control over the disposition of their body parts once relinquished, except under very limited circumstances. Moreover, if they agreed to 23andMe's Research Consent Document, they will most likely be held to it by the courts, leaving 23andMe users with little to no legal recourse to reclaim their genetic information once they have given it to 23andMe and agreed to participate in research.

#### A. *Hypothetical*

The lack of protection provided by current legislation and case law poses potentially large legal and ethical problems for 23andMe

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<sup>137</sup> See *infra* Section II.E.

<sup>138</sup> See *Berkson v. Gogo LLC*, 97 F. Supp. 3d 359 (E.D.N.Y. 2015); *Applebaum v. Lyft, Inc.*, 263 F. Supp. 3d 454 (S.D.N.Y. 2017); Nancy S. Kim, *The Wrap Contract Morass*, 44 SW. L. REV. 309, 312–13 (2014).

<sup>139</sup> Molteni, *supra* note 1.

users. Consider the following hypothetical. Jane Smith is a Catholic woman with a history of leukemia in her family. Leukemia may or may not be genetic and Jane wants to see if she is at risk. After hearing stories of people who used 23andMe to determine their predisposition to certain illnesses, Jane decides to buy a kit and sign up for the service. She sends in her cheek swab and creates an account on 23andMe's website so that she may receive her results. While on the website, she sees that she can consent to have her DNA used in research. Feeling compelled by her own family's history of illness, she decides to consent in the hopes that the research may help people like herself and her family. She looks at the Research Consent Document, reads the key points located at the top, skims the rest, and then clicks "I consent" at the bottom of the page. Jane occasionally provides more information about herself through surveys to 23andMe throughout the years. She is not notified of any particular research that has taken place using her DNA.

One day, years later, she sees on the news that 23andMe has performed research that has resulted in the beginning stages of cloning certain body parts, so that people who have lost body parts or are born without them may receive these cloned versions instead of prosthetics. Jane knows that cloning is against her religion, and fears that her DNA may have been involved in this cloning project even though Jane did not think her DNA would be used for that type of research or intend for it to be. She goes onto the 23andMe website to withdraw her consent but is informed by the terms that her genetic information will only be withdrawn from future research and cannot be withdrawn from past research or research that has already begun. Jane is upset and looks into her legal options to get back control of her genetic information from 23andMe. She does research and discovers that once a person has given up any type of body part for research, she cannot sue to get it back and that, in this context, her genetic information is not protected by either GINA or HIPAA. Remembering that she barely read the Research Consent Document, and therefore did not truly understand what she was signing up for, she researches whether she can say she did not really consent to the contract she signed and get her genetic information back that way. However, her research shows that most courts will hold her to the contract, even if she did not read the whole thing, because she was

technically given adequate notice of its terms. Jane has no legal recourse to reacquire her genetic information and may have contributed to something directly against her religion as a result.

The current legal landscape creates great problems for people like Jane Smith, who consented to research thinking that her DNA would be used one way while it was instead used for research which she finds objectionable. At present, there is no real legal recourse for Jane or those in similar situations. This is exacerbated by the fact that most people do not read contracts on the internet, yet courts do not recognize this reality.<sup>140</sup>

### B. 23andMe's Research Consent Document Concerns

23andMe's Research Consent Document presents a plethora of concerns for its users who agree to it. To start, the document provides broad language about what kind of research in which users' genetic information may be used, such as determining "the basic causes of disease, develop[ing] drugs or other treatments and/or preventive measures, or predict[ing] a 'person's risk of disease" which "may be sponsored by or conducted on behalf of third parties, such as non-profit foundations, academic institutions or pharmaceutical companies."<sup>141</sup>

This means that 23andMe can use a user's genetic information for a wide range of research topics, including diseases and migration patterns of certain peoples. However, it also provides that 23andMe can use this information to create drugs, medical treatments, and preventative measures. This provision is incredibly broad and

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<sup>140</sup> See *Berkson*, 97 F. Supp. 3d at 394; *Applebaum*, 263 F. Supp. 3d at 465–66; *Tompkins v. 23andMe, Inc.*, 840 F.3d 1016, 1020 (9th Cir. 2016); *Nicosia v. Amazon.com, Inc.*, 834 F.3d 220, 232 (2d Cir. 2016); Paul J. Morrow, *Cyberlaw: The Unconscionability / Unenforceability of Contracts (Shrink-Wrap, Clickwrap, and Browse-Wrap) on the Internet: A Multijurisdictional Analysis Showing the Need for Oversight*, 11 U. PITT. J. TECH. L. POL'Y 7 (2011); Jonathan A. Obar & Anne Oeldorf-Hirsch, *The Biggest Lie on the Internet: Ignoring the Privacy Policies and Terms of Service Policies of Social Networking Services*, 23 INFO. COMM'N & SOC'Y 1 (2018); Caroline Cakebread, *You're Not Alone, No One Reads Terms of Service Agreements*, BUS. INSIDER (Nov. 15, 2017, 7:30 AM), <https://www.businessinsider.com/deloitte-study-91-percent-agree-terms-of-service-without-reading-2017-11> [<https://perma.cc/6PJB-EB63>].

<sup>141</sup> *Research Consent Document*, *supra* note 12.

allows for 23andMe not only to create drugs, as it already has,<sup>142</sup> but also to push the boundaries of what “treatments and/or preventative measures” means all with users’ alleged “consent.” To put it another way, 23andMe can push the boundaries of ethical norms by stretching the meaning of treatments and preventative measures to include extreme measures such as cloning, all with people’s unwitting consent.

These provisions are on the fifth page of the ten-page Research Consent Document and after the initial “key points” portion that appears before the full agreement.<sup>143</sup> The key points portion of the document may discourage an average reader from reading beyond that point, figuring she can obtain all the information she needs from that section without having to read the entire document. But even if a user were to read beyond the key points, the information regarding use of genetic material for drug research is halfway through the document, making it less likely that someone who even attempts to read the entire contract will see or remember the provision.<sup>144</sup>

The document also explicitly provides information on the myriad of risks that can arise from allowing DNA to be used in research, but only starting on page seven.<sup>145</sup> The risks vary in severity.<sup>146</sup> For instance, one of the risks is that survey questions or data comparisons may make the user or her family members uncomfortable.<sup>147</sup> However, there are much more severe risks, such as the potential for the user’s genetic information, survey responses, or personally identifiable information to be stolen in a security breach, which could be made public or released to insurance companies. This may create a

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<sup>142</sup> Wetsman, *supra* note 1.

<sup>143</sup> *Research Consent Document*, *supra* note 12.

<sup>144</sup> See *infra* Section II.B; see generally Samuel A. Garner & Jiyeon Kim, *The Privacy Risks of Direct-to-Consumer Genetic Testing: A Case Study of 23andMe and Ancestry*, 96 WASH. U. L. REV. 1219, 1253 (2019).

<sup>145</sup> *Research Consent Document*, *supra* note 12.

<sup>146</sup> *Id.*; see also Drabiak, *supra* note 12 **Error! Bookmark not defined.**, at 156; Washburn, *supra* note 53, at 14; Park, *supra* note 53.

<sup>147</sup> *Research Consent Document*, *supra* note 12; see Kayte Spector-Bagdady, *Reconceptualizing Consent for Direct-to-Consumer Health Services*, 41 AM. J.L. & MED. 568, 596–99 (2015).

“negative effect on [the user’s] ability to obtain insurance coverage.”<sup>148</sup>

Likewise, if the user or her family member has genetic information linked to her own name or a family member’s name in a public database, it is possible that someone who has access to her 23andMe genetic information may be able to connect her genetic information to her or her family member’s name.<sup>149</sup> This means that it is possible for someone to connect a user’s genetic information to her or her family, which poses great privacy risks, especially if the genetic information exposes sensitive information about the user. 23andMe admits that it “cannot provide a 100% guarantee that your data will be safe” but claims to have “strong policies and procedures in place to minimize the possibility of a breach.”<sup>150</sup>

The consent document also provides that researchers may publish results which include the user’s genetic and self-reported information as part of a summary, lessening the chances of her personal information being exposed.<sup>151</sup> However, while identification from summaries would be difficult, it is still possible “that a third party that has obtained some of [her] genetic data could compare that partial data to the published results and infer some of [her] other personal information.”<sup>152</sup> This means that it is possible, albeit unlikely, for third parties to identify the individual user’s personal information even if it is published in a summary. The document further provides that “[t]here may be additional risks to participation that are currently unforeseeable.”<sup>153</sup> In other words, users blindly sign up for risks that neither they nor 23andMe even know about yet.<sup>154</sup>

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<sup>148</sup> *Research Consent Document*, *supra* note 12; *see also* Drabiak, *supra* note 12; Jennifer Cacchio, *What You Don’t Know Can Hurt You: The Legal Risk of Peering into the Gene Pool with Direct-to-Consumer Genetic Testing*, 87 UMKC L. REV. 219, 233 (2018); Nur Lalji, *Featurization and the Myth of Data Empowerment*, 15 WASH. J.L. TECH. & ARTS 1, 25–27 (2019).

<sup>149</sup> *Research Consent Document*, *supra* note 12.

<sup>150</sup> *Id.*

<sup>151</sup> *Id.*

<sup>152</sup> *Id.*; *see also* Drabiak, *supra* note 12.

<sup>153</sup> *Research Consent Document*, *supra* note 12; Cheung, *supra* note 12, at 17.

<sup>154</sup> *See* Hillary L. Kody, *Standing to Challenge Familial Searches of Commercial DNA Databases*, 61 WM. & MARY L. REV. 287, 308–10 (2019).

While the document thoroughly outlines the risks for users associated with providing their DNA for research, it is buried so deeply into the document that it is unlikely the average user would read to that point or read it carefully enough to truly understand what it means, like the other important provisions.<sup>155</sup> This is exacerbated by the fact that the document is online and not printed out, making it less likely that someone will reach page seven—let alone read it in its entirety.<sup>156</sup>

The document further states that even if the user did not consent to research, her information may still be used “for other purposes” described in the Privacy Statement but does not identify those other purposes.<sup>157</sup> The user’s information may be used in ways she did not intend or to which she did not explicitly consent as a result of signing up for the website, and thus agreeing to the Terms of Service and Privacy Statement.

Additionally, the document states that if the user does consent to participate in research, she can choose not to take certain surveys.<sup>158</sup> This gives a user the choice to participate passively in research by just providing her genetic information or to participate more actively where she can answer questions that might provide more insight to researchers. However, the user may not understand that she has a choice to take a more passive role. As a result, she may provide more information than she has to, thinking it is necessary or without understanding the true purpose. Significantly, users are unable to opt out of specific research initiatives; rather, they must agree broadly or not agree at all.<sup>159</sup>

The document also provides that users who have consented to participate in research may withdraw all or some of her genetic and self-reported information from 23andMe research at any time.

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<sup>155</sup> See *infra* Section II.B; Garner & Kim, *supra* note 144, at 1253.

<sup>156</sup> See *infra* Section II.B; Garner & Kim, *supra* note 144, at 1253.

<sup>157</sup> *Research Consent Document*, *supra* note 12; see also Drabiak, *supra* note 12.

<sup>158</sup> *Research Consent Document*, *supra* note 12; see also Drabiak, *supra* note 12.

<sup>159</sup> *Research Consent Document*, *supra* note 12; see also Drabiak, *supra* note 12; Natalie Ram, *Review: Body Banking from the Bench to the Bedside*, 129 HARV. L. REV. 491, 494 (2015); Koch, *supra* note 12, at 62–66; Valerie Gutmann Koch & Kelly Todd, *Research Revolution or Status Quo?: The New Common Rule and Research Arising from Direct-to-Consumer Genetic Testing*, 56 HOUS. L. REV. 81, 97–100 (2018).



However, if the user does withdraw, the user's genetic information will only be removed from 23andMe's research thirty days after it receives receipt of the withdrawal. Moreover, the user's information will not be pulled from any research that has been "performed or published" before this date.<sup>160</sup> This clause, combined with the indemnity clause in the Terms of Service, denies legal recourse to a user who wants her DNA pulled out of research.<sup>161</sup> Many of these provisions raise a plethora of concerns for users who agree to it.

First, the way the document is presented to users—with the key points before the rest of the contract—may discourage users from reading the whole thing. The key points section, in fact, does not list all the key points, as it fails to mention that users' genetic information could be used for pharmaceutical research. This could trap users into agreeing to terms they were discouraged from reading in the first place. Second, the definition of research is broad enough to cover topics which may not be widely accepted or considered ethical by the scientific community now, such as cloning, but may be in the future. This once again places users in positions where they may not have known what they were signing up for, even if they did read the whole contract, since these topics of research were not foreseeable at the time of consent. Third, while the document outlines the numerous risks of taking part in research, these risks are not mentioned in detail until the last few pages. The broad language and the deeply buried provisions put users at great risk that their genetic information will be used in a way in which they did not intend.

### C. 23andMe Research Concerns

23andMe's almost unfettered access to and control over its users' genetic information is concerning for a myriad of reasons that implicate criminal, insurance, employment, information misuse, and cloning and broader research concerns. In the criminal context, 23andMe says it will not give a user's DNA to law enforcement without a subpoena or court order.<sup>162</sup> However, the company does not say whether it can or will refuse to stop law enforcement from

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<sup>160</sup> *Research Consent Document*, *supra* note 12.

<sup>161</sup> *Terms of Service*, *supra* note 11.

<sup>162</sup> *Privacy Policy*, *supra* note 44.

using the site as does GEDmatch, a DNA and genealogy website that allows users to compare their DNA test results against other's results.<sup>163</sup> Law enforcement used GEDmatch to catch the Golden State Killer by creating an account and uploading the Golden State Killer's DNA to deduce his identity from potential relatives already on the website.<sup>164</sup> In fact, studies have shown that people generally do not understand the risk that the use of their DNA by law enforcement poses to them.<sup>165</sup>

23andMe's practices also raise insurance and employment concerns. 23andMe says it does not give users' information to employers.<sup>166</sup> However, given that 23andMe has joined forces with GlaxoSmithKline to create drugs, it is quite possible that it will team up with an insurance company and sell users' genetic information leading to people being insured based on their genetic information.<sup>167</sup> 23andMe itself warns of the potential ways health insurance companies or employers can access users' genetic information, which are outside the scope of GINA.<sup>168</sup>

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<sup>163</sup> GEDMATCH.COM, <https://www.gedmatch.com/login1.php> [<https://perma.cc/58KC-T36J>].

<sup>164</sup> See generally Claire Abrahamson, *Guilt by Genetic Association: The Fourth Amendment and the Search of Private Genetic Databases by Law Enforcement*, 87 *FORDHAM L. REV.* 2539 (2019); Natalie Ram, *Genetic Privacy After Carpenter*, 105 *VA. L. REV.* 1357 (2019); Jacqueline Moran, *Privacy Perspectives on Direct-to-Consumer Genetic Testing in the Era of Big Data: Role of Blockchain Technology in Genomics*, 22 *TUL. J. TECH. & INTELL. PROP.* 185, 197–99 (2020); Entrikin, *supra* note 12, at 868–78; Michael R. Dohn, *Personal Genomics and Genetic Discrimination: Is Increased Access A Good Thing?*, 45 *W. ST. L. REV.* 107, 113 (2018); Sonia M. Suter, *All in the Family: Privacy and DNA Familial Searching*, 23 *HARV. J.L. & TECH.* 309, 310 (2010); Teneille R. Brown, *Why We Fear Genetic Informants: Using Genetic Genealogy to Catch Serial Killers*, 21 *COLUM. SCI. & TECH. L. REV.* 1 (2019); Drew M. Baldwin, *Redefining the Third-Party Doctrine: Carpenter's Effect on DNA Privacy*, 108 *KY. L.J.* 153, 167 (2020); Jesse Kitnick, *Killer's Code—Familial DNA Searches Through Third-Party Databases Under Carpenter*, 41 *CARDOZO L. REV.* (2020); Jason Tashea, *Genealogy Sites Give Law Enforcement A New DNA Sleuthing Tool, but the Battle over Privacy Looms*, *ABA* (Nov. 1, 2019, 4:20 AM), <https://www.abajournal.com/magazine/article/family-tree-genealogy-sites-arm-law-enforcement-with-a-new-branch-of-dna-sleuthing-but-the-battle-over-privacy-looms> [<https://perma.cc/AKC6-C54W>].

<sup>165</sup> Baldwin, *supra* note 164, at 175–76.

<sup>166</sup> *Privacy Policy*, *supra* note 44.

<sup>167</sup> See Cacchio, *supra* note 148, at 233; see also Drabiak, *supra* note 12.

<sup>168</sup> *Terms of Service*, *supra* note 11.

As with any information on the internet, there are always hacking and blackmail concerns. 23andMe explains that there is a risk of users' genetic information being compromised in the event of a data breach.<sup>169</sup> Although the company claims to have put systems in place to make a breach unlikely, the possibility remains that hackers could access and use embarrassing or damaging information from a user's DNA to blackmail or publicly humiliate her or her family members.<sup>170</sup> Additionally, any de-identified information can be re-identified, making this an even more likely possibility.<sup>171</sup>

23andMe's contracts also raise cloning concerns. It has become clear that 23andMe uses people's DNA for research and drug development without their full understanding.<sup>172</sup> 23andMe admits in its Research Consent Document that there are risks and benefits that are currently unforeseeable.<sup>173</sup> Once the user has consented to research, 23andMe may research:

[T]herapeutics development, conduct or support the development of drugs, diagnostics or devices to diagnose, predict or treat medical or other health conditions, work with public, private and/or non-profit entities on genetic research initiatives, or otherwise create, commercialize, and apply this new knowledge to improve health care.<sup>174</sup>

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<sup>169</sup> *Research Consent Document*, *supra* note 12.

<sup>170</sup> Angela Chen, *Why A DNA Data Breach Is Much Worse Than a Credit Card Leak*, THE VERGE (June 6, 2018, 3:54 PM), <https://www.theverge.com/2018/6/6/17435166/myheritage-dna-breach-genetic-privacy-bioethics> [<https://perma.cc/HC6J-GETT>]; *see also* Dohn, *supra* note 164, at 118–19; Ifeoma Ajunwa, *Genetic Testing Meets Big Data: Tort and Contract Law Issues*, 75 OHIO ST. L.J. 1225, 1229–31 (2014). *See generally* Charles Matranga, Note, *Family Ties: The Familial Privacy Implications of Direct to Consumer Genetic Testing*, 75 FOOD & DRUG L. J. 456 (2020).

<sup>171</sup> Cacchio, *supra* note 148, at 231; Drabiak, *supra* note 12, at 166–67; Moran, *supra* note 164, at 195–97; Alda Yuan, *Blurred Lines: The Collapse of the Research/Clinical Care Divide and the Need for Context-Based Research Categories in the Revised Common Rule*, 74 FOOD & DRUG L. J. 46, 65–67 (2019).

<sup>172</sup> *See* Molteni, *supra* note 1; Johnson T. Laney, *The Shifting Landscape of Medicine: Patents of Personalized Biologic Treatments and Their Potential Conflicts with Right-to-Try Laws*, 26 J. INTELL. PROP. L. 159, 170 (2019).

<sup>173</sup> *Research Consent Document*, *supra* note 12.

<sup>174</sup> *Privacy Policy*, *supra* note 44,

23andMe can also use its research “to understand the basic causes of disease, develop drugs or other treatments and/or preventive measures, or predict a person’s risk of disease.”<sup>175</sup>

This allows 23andMe to utilize users’ DNA in a wide range of initiatives that could one day include cloning, given the language that includes treatment of medical conditions and improvement of health care.<sup>176</sup> While cloning may seem like a far-off dream, it is “[n]o longer the wackadoodle scheme it once was.”<sup>177</sup> Technology is certainly evolving in such a way where it may be possible to clone human beings, if ethically sanctioned.<sup>178</sup> For instance, various types of animals have already been cloned successfully.<sup>179</sup> The first successful cloning occurred in 1997 with the cloning of the sheep Dolly.<sup>180</sup> In 2018, scientists in China successfully cloned monkeys for the first time.<sup>181</sup> Recently, people have even been cloning their deceased dogs.<sup>182</sup> Moreover, recent research has led to a 9% increase in the cloning of animal embryos that lead to successful live births.<sup>183</sup> Not only will this increase the success rate of therapeutic cloning, where scientists or doctors inject skin cells from other people into certain women’s removed eggs in order to clone small embryos and create stem cells,<sup>184</sup> but it will also increase the success rate of reproductive cloning, where a cloned version of an embryo is placed in a woman’s uterus to result in a pregnancy.<sup>185</sup>

While there have been debates about whether cloning is ethical, some argue that there are various justifications for human cloning

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<sup>175</sup> *Research Consent Document*, *supra* note 12 (emphasis added).

<sup>176</sup> *See generally* Kody, *supra* note 154, at 308–10.

<sup>177</sup> Antonio Regalado, *Is It Time to Worry About Human Cloning Again?*, *GUARDIAN* (Apr. 20, 2018), <https://www.theguardian.com/lifeandstyle/2018/apr/20/pet-cloning-is-already-here-is-human-cloning-next> [<https://perma.cc/X5AE-BCVB>].

<sup>178</sup> *Id.*

<sup>179</sup> *Id.*

<sup>180</sup> KERRY LYNN MACINTOSH, *HUMAN CLONING: FOUR FALLACIES AND THEIR LEGAL CONSEQUENCES* 1–3 (2013).

<sup>181</sup> Regalado, *supra* note 177.

<sup>182</sup> *Id.*

<sup>183</sup> *Id.*

<sup>184</sup> *Id.*

<sup>185</sup> MING W. CHIN ET AL., *FORENSIC DNA EVIDENCE: SCIENCE AND THE LAW* § 13:15 (2020).

including medical benefits,<sup>186</sup> “such as growing new tissue and using genes to prevent or improve the treatment of diseases”<sup>187</sup> as well as other the possible developments of “life-saving and life-enhancing technologies.”<sup>188</sup> Likewise, human cloning may provide a way for couples facing infertility to have children.<sup>189</sup> Scientists have also argued that “there are several potentially useful plant and animal technologies yet to be created which could also have vast human advantages.”<sup>190</sup> All of these justifications fall under the language in 23andMe’s research guidelines.<sup>191</sup>

Given that there are ever-growing justifications for human cloning, once the technology becomes available, 23andMe may very well begin using its users’ DNA to do it. The language in the Research Consent Document certainly allows as much, as there are many medicinal and health-related justifications for cloning. While 23andMe outlines some of these risks in its various contracts, it is safe to assume that most users do not know about them because people generally do not read or understand online contracts.<sup>192</sup>

The biggest concern, however, is 23andMe’s employment of its users’ genetic information in researching and creating drugs without their full understanding, knowledge, or consent.<sup>193</sup> When users agree to have their genetic information used for research, they agree that “[d]iscoveries made as a result of this research could be used to understand the basic causes of disease, develop drugs or other treatments and/or preventive measures, or predict a person’s risk of disease” which may be sponsored by non-profit foundations, academic institutions, or pharmaceutical companies.<sup>194</sup> The language in this provision is incredibly broad and opens the door for

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<sup>186</sup> Russell Korobkin, *Stem Cell Research and the Cloning Wars*, 18 STAN. L. & POL’Y REV. 161, 161–66 (2007).

<sup>187</sup> Heidi Forster & Emily Ramsey, *Legal Responses to the Potential Cloning of Human Beings*, 32 VAL. U. L. REV. 433, 436 (1998).

<sup>188</sup> *Id.* at 465.

<sup>189</sup> MACINTOSH, *supra* note 180, at 224.

<sup>190</sup> Forster & Ramsey, *supra* note 187, at 465.

<sup>191</sup> See *Privacy Policy*, *supra* note 44; *Research Consent Document*, *supra* note 12.

<sup>192</sup> See *infra* Section II. **Error! Reference source not found.**; see generally Garner & Kim, *supra* note 144, at 1253; Entrikin, *supra* note 12, at 867.

<sup>193</sup> See Lalji, *supra* note 148, at 3–4.

<sup>194</sup> *Research Consent Document*, *supra* note 12.

23andMe to take its research to possibly extreme lengths, such as cloning, to create drugs, treatments, or preventative measures all with the “consent” of 80% of its users.<sup>195</sup> While 23andMe also provides that users can withdraw their consent from research, it states that it will only prevent information from being used in new research initiated after thirty days from receipt of the user’s request but that any research on the user’s data “*that has been performed or published prior to this date will not be reversed, undone, or withdrawn.*”<sup>196</sup> This means that anyone who discovers that their genetic information is being used in a way they did not intend will not have their information withdrawn from any previous studies, it will only not be used in future studies. This presents grave risks for users whose genetic information may be used in objectionable ways, such as cloning, that they did not understand they were signing up for and from which they cannot fully withdraw.<sup>197</sup>

#### D. *People Do Not Read Internet Contracts*

While the benefits and risks of DNA research may be great, 23andMe users may not totally understand what they are signing up for because people simply do not read online contracts.<sup>198</sup> Since users generally do not know what they’re signing up for, the marked absence of laws that prospectively regulate the use of DNA is problematic. Studies have shown that most people do not read “exculpatory provisions, forum selection clauses, or other provisions in clickwrap/shrink-wrap or browser-wrap agreements.”<sup>199</sup>

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<sup>195</sup> *About Us*, *supra* note 1.

<sup>196</sup> *Research Consent Document*, *supra* note 12 (emphasis added).

<sup>197</sup> See generally Josef A. Mejido, *Personalized Genomics: A Need for a Fiduciary Duty Remains*, 37 RUTGERS COMPUT. & TECH. L.J. 281, 299 (2011); Drabiak, *supra* note 12, at 159; Harbord, *supra* note 63, at 279; Enrikin, *supra* note 12, at 867; Alessandra Suuberg, *Buck v. Bell, American Eugenics, and the Bad Man Test: Putting Limits on Newgenics in the 21st Century*, 38 L. & INEQ. 115 (2020); Gardner, *supra* note 71.

<sup>198</sup> See generally Heather Daiza, *Wrap Contracts: How They Can Work Better for Businesses and Consumers*, 54 CAL. W. L. REV. 201 (2017); Uri Benoliel & Shmuel I. Becher, *The Duty to Read the Unreadable*, 60 B.C. L. REV. 2255, 2258 (2019); Anelka M. Phillips, *Think Before You Click: Ordering a Genetic Test Online*, ABA (July 1, 2015), [https://www.americanbar.org/groups/gpsolo/publications/gp\\_solo/2015/julyaugust/science\\_and\\_technology\\_law\\_think\\_you\\_click\\_ordering\\_genetic\\_test\\_online/](https://www.americanbar.org/groups/gpsolo/publications/gp_solo/2015/julyaugust/science_and_technology_law_think_you_click_ordering_genetic_test_online/) [https://perma.cc/KHZ9-KUH3].

<sup>199</sup> Morrow, *supra* note 140, at 1, 28.

And even if they do read the provisions, “most people do not understand the language.”<sup>200</sup> As a result, recourse is difficult because contract law is fairly confusing and inconsistent from state to state.<sup>201</sup>

A survey conducted by Deloitte of 2,000 US consumers found that “91% of people consent to legal terms and services conditions without reading them”<sup>202</sup> and, even more stark, 97% of people ages eighteen to thirty-four agree to terms and conditions before reading them.<sup>203</sup> Moreover, the language used in the terms and conditions are usually “too complex and long-winded for most.”<sup>204</sup>

In another study conducted by professors Jonathan A. Obar and Anne Oeldorf-Hirsch, two researchers created a fake social media site, NameDrop, to demonstrate that people do not really read contracts online.<sup>205</sup> The researchers put absurd “gotcha” clauses in NameDrop’s terms which stated that the company would share people’s data with the National Security Agency and employers as well as take their first born children as payment for access to its social networking service.<sup>206</sup> About 98% of people missed these clauses.<sup>207</sup> The researchers added the child clause, which approximately 93% of participants missed, specifically to show that it is difficult to predict the future uses and concerns by big data.<sup>208</sup>

The researchers also collected data on how much time people spent reading the terms, if they ever reached them.<sup>209</sup> The majority of people took a quick look and then scrolled to the bottom and clicked “accept.”<sup>210</sup> Of those who did not automatically select the clickwrap and looked at the contracts to which they were agreeing, “96% spent less than 5 minutes on the [Privacy Policy] and 98% spent less than 5 minutes on the” Terms of Service.<sup>211</sup> In fact,

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<sup>200</sup> *Id.*

<sup>201</sup> *Id.*

<sup>202</sup> Cakebread, *supra* note 140.

<sup>203</sup> *Id.*

<sup>204</sup> *Id.*

<sup>205</sup> Obar & Oeldorf-Hirsch, *supra* note **Error! Bookmark not defined..**

<sup>206</sup> *Id.* at 2.

<sup>207</sup> *Id.*

<sup>208</sup> *Id.* at 25.

<sup>209</sup> *Id.* at 21.

<sup>210</sup> *Id.*

<sup>211</sup> *Id.* at 16.

81% of those who read the Privacy Policy at all spent less than a minute reading it and 96% spent less than five minutes reading it.<sup>212</sup> Likewise, 86% of the people who read the Terms of Service spent less than a minute reading it while 98% spent less than five minutes reading it.<sup>213</sup>

According to the researchers, the NameDrop Privacy Policy should have taken thirty minutes to read and the Terms of Service should have taken more than fifteen minutes.<sup>214</sup> However, they found that some people who looked at the Privacy Policy and Terms of Service only spent less than five seconds on each.<sup>215</sup> On average, though, participants spent seventy-four seconds reading the Privacy Policy and fifty-one seconds reading the Terms of Service.<sup>216</sup> While the average reading times were still too short for what the Privacy Policy and Terms of Service required, the median reading times were a “more accurate representation of the general trend, at approximately 14 seconds for both.”<sup>217</sup> As the researchers state, “[f]ourteen seconds is hardly enough time to read, understand and provide informed consent to policies between 4,000 and 8,000 words in length. Spending 14 seconds (or 60 seconds for that matter) is akin to not reading the policies at all.”<sup>218</sup>

While the NameDrop study looked specifically at a fake social media site, it shows, along with the other studies, that people simply do not read online contracts. This begs the question: how can we expect people to really understand what they are accepting when they agree to participate in 23andMe’s research program? It has already been documented that people who signed up for the program did not understand what they were signing up for until they found out 23andMe teamed up with a pharmaceutical company.<sup>219</sup> Even those who want to participate in research for the greater good feel

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<sup>212</sup> *Id.* at 21.

<sup>213</sup> *Id.* at 16.

<sup>214</sup> *Id.* at 21.

<sup>215</sup> *Id.*

<sup>216</sup> *Id.*

<sup>217</sup> *Id.*

<sup>218</sup> *Id.*

<sup>219</sup> Molteni, *supra* note 1; *see generally* Garner & Kim, *supra* note 144, at 1253.



differently once educated on privacy concerns.<sup>220</sup> It is thus likely that the vast majority of 23andMe users did not read or understand the consent documents before they “consented” to 23andMe’s research program.<sup>221</sup>

23andMe users have no legal recourse if their DNA is used in a way they did not intend.<sup>222</sup> There is very little statutory legal protection over genetic information in the United States.<sup>223</sup> People do not have property rights over their own body parts, particularly after they have “relinquished” their body parts for research purposes, even if they did not totally understand what kind of research would be performed.<sup>224</sup> Additionally, courts have continuously found that clickwrap and scrollwrap agreements, like the contracts found on 23andMe’s website, are valid even if the users did not read the contracts before agreeing to them.<sup>225</sup> This is in direct contrast to social research which shows that the vast majority of people do not read online contracts or, if they do, spend very little time reading them.<sup>226</sup> This leaves 23andMe users who have allowed the company to use their genetic information for research purposes that they did not understand or in a way they did not intend without an avenue to remove their genetic information from research that is complete or already underway.

#### E. *Rights to Disposition of Gametic Material*

While courts usually refuse to recognize people’s ownership in their body parts once relinquished, courts have acknowledged that, because of their potential to create human life, parties have a special interest in their genetic material found in sperm and pre-embryos,

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<sup>220</sup> Russo, *supra* note 14, at 467; *see generally* Garner & Kim, *supra* note **Error! Bookmark not defined.**

<sup>221</sup> Garner & Kim, *supra* note **Error! Bookmark not defined.**; Daiza, *supra* note 198; Rachel A.H. Horton, *Knowledge Is Power: Physician Abandonment as a Model for the Duty to Disclose Research Findings*, 5 DREXEL L. REV. 265, 267 (2013).

<sup>222</sup> *See Terms of Service*, *supra* note 11.

<sup>223</sup> *Genetic Information Privacy*, *supra* note 76.

<sup>224</sup> *See Terms of Service*, *supra* note 11.

<sup>225</sup> *See infra* Section I.D; *see also* Nicosia v. Amazon.com, Inc., 834 F.3d 220, 232 (2d Cir. 2016); Applebaum v. Lyft, Inc., 263 F. Supp. 3d 454, 465–66 (S.D.N.Y. 2017); Berkson v. Gogo LLC, 97 F. Supp. 3d 359, 394–98 (E.D.N.Y. 2015).

<sup>226</sup> Obar & Oeldorf-Hirsch, *supra* note 140**Error! Bookmark not defined.**; Cakebread, *supra* note 140.

fertilized eggs created during invitro fertilization (“IVF”) that have not yet been gestated.<sup>227</sup> When disputes about the use of such gametic material arise, courts have taken one, or a combination, of the following three approaches: “(1) interpreting the parties’ contract or agreement regarding disposition of the pre-embryos” generally by looking to the parties’ intent; “(2) balancing the parties’ respective interests in receiving the pre-embryos; or (3) requiring the parties’ mutual contemporaneous consent regarding disposition of the pre-embryos.”<sup>228</sup>

In two seminal cases, *Kass v. Kass* and *McQueen v. Gadberry*, courts looked to the intent of the donors to determine the correct disposition of their gametic material.<sup>229</sup> In *Kass*, the donors, a couple that had previously tried becoming pregnant through IVF, had gotten divorced.<sup>230</sup> The wife wanted the pre-embryos created through the IVF process implanted in her and the husband wanted them donated for research purposes.<sup>231</sup> The *Kass* court stressed the need for written agreements when embarking on IVF procedures to avoid litigation later on.<sup>232</sup> However, the court also recognized that this venture is difficult because “[a]ll agreements looking to the future to some extent deal with the unknown.”<sup>233</sup> These agreements are exacerbated by the uncertainties that flow naturally from IVF technology and process itself, including “cryopreservation, which extends the viability of pre-zygotes indefinitely and allows time for minds, and circumstances, to change” as well as divorce, aging,

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<sup>227</sup> *Hecht v. Super. Court*, 20 Cal. Rptr. 2d 275, 283 (Cal. Ct. App. 1993); *Davis v. Davis*, 842 S.W.2d 588, 597 (Tenn. 1992), *reh’g in part*, No. 34, 1992 WL 341632 (Tenn. Nov. 23, 1992). See generally Boulier, *supra* note 130; Collieran, *supra* note 130; Pawlowski, *supra* note 130, at 48–49.

<sup>228</sup> *In re Marriage of Rooks*, 429 P.3d 579, 587 (Sup. Ct. Colo. 2018), *cert. denied sub nom*, *Rooks v. Rooks*, 139 S. Ct. 1447 (2019); Mary Joy Dinger, *Family Law’s Coldest War: The Battle for Frozen Embryos and the Need for A Statutory White Flag*, 43 SEATTLE U. L. REV. 293, 293 (2019); Sarah B. Kirschbaum, *Who Gets the Frozen Embryos During A Divorce? A Case for the Contemporaneous Consent Approach*, 21 N.C. J. L. & TECH. 113, 116–17 (2019).

<sup>229</sup> *Kass v. Kass*, 91 N.Y.2d 544 (1998); *McQueen v. Gadberry*, 507 S.W.3d 127 (Mo. Ct. App. 2016).

<sup>230</sup> *Kass*, 91 N.Y.2d at 557 (internal citations omitted).

<sup>231</sup> *Id.*

<sup>232</sup> *Id.*

<sup>233</sup> *Id.* at 565.

death, or the incapacity of one or both donors that may inevitably change their outlook.<sup>234</sup> The court most importantly recognized that “[t]he central issue is whether the consents *clearly express the parties’ intent* regarding disposition of the pre-zygotes in the present circumstances.”<sup>235</sup>

The court determined that the donors manifested an intent to donate the pre-embryos for research upon review of the contracts that they signed at the beginning of the IVF process.<sup>236</sup> The court looked at the consent agreements, which were provided by the IVF program, that the couple signed and found that they had “signed consents indicating their dispositional intent...[and] neither party dispute[d] that they [were] an expression of their own intent regarding disposition of their pre-zygotes” or that they were illegal.<sup>237</sup> When the couple signed these agreements and were provided with options on what the IVF program should do in case the couple no longer wished to proceed, they specifically initialed next to the option giving the pre-embryos to the program for research, clearly manifesting their intent.<sup>238</sup>

The court emphasized that when determining if there is ambiguity in an agreement, courts should look at the whole contract, the circumstances surrounding the contract, and the relationship between the parties.<sup>239</sup> Importantly, courts should consider particular words, “not as if isolated from the context, but in the light of the obligation as a whole and the intention of the parties as manifested thereby. Form should not prevail over substance and a sensible meaning of words should be sought.”<sup>240</sup> The court thus instructed other courts to take the entire contract and its surrounding circumstances into account when deciding if there is ambiguity or not.<sup>241</sup> The court also recognized that particular words can be important but

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<sup>234</sup> *Id.*

<sup>235</sup> *Id.* (emphasis added).

<sup>236</sup> *Id.* at 567.

<sup>237</sup> *Id.* at 566–67.

<sup>238</sup> *Id.*

<sup>239</sup> *Id.* at 566 (quoting *Atwater & Co. v. Panama R.R. Co.*, 246 N.Y. 519, 524 (1927)).

<sup>240</sup> *Id.*

<sup>241</sup> *Id.*

should be considered within the context of the whole contract and how the words may manifest the intention of the parties.<sup>242</sup>

In *McQueen v. Gadberry*, the wife wanted to keep the pre-embryos and the husband wanted to give them away for research purposes, to an infertile couple, or have them destroyed.<sup>243</sup> The trial court originally awarded the pre-embryos to the two jointly and the wife appealed.<sup>244</sup> The appellate court focused on the parties' intent upon entering the contract that governed the disposition of the pre-embryos.<sup>245</sup> It identified some serious issues; the trial court found that the wife may have adjusted the disposition of the pre-embryos after her husband had initialed the page and that the two did not have any discussions about the pre-embryos before the divorce began.<sup>246</sup> Additionally, and most importantly, the appellate court agreed with the trial court's finding that the husband did not sign the contract "*with the intent that [his wife] be awarded the frozen pre-embryos in the event of a divorce.*"<sup>247</sup>

Taking the evidence into account, including the husband's lack of intent, the appellate court concluded that "there was not sufficient disclosure allowing Gadberry to make a meaningful decision whether to waive any or all of his rights to the frozen pre-embryos."<sup>248</sup> Therefore, the appellate court found that "the trial court's findings of fact and credibility determinations regarding the circumstances surrounding the signing and initialing of the Directive indicate it was not entered into *freely, fairly, knowingly, understandingly, and in good faith with full disclosure*" but they affirmed the trial court's order that the two could not do anything with the pre-embryos unless they both consented.<sup>249</sup>

Even when there is no pre-existing agreement over gametic material, courts have looked to outside factors to determine the intent of the person as to whom his genetic material should be

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<sup>242</sup> *Id.*

<sup>243</sup> *McQueen v. Gadberry*, 507 S.W.3d 127, 135–36 (Mo. Ct. App. 2016).

<sup>244</sup> *Id.* at 127.

<sup>245</sup> *Id.* at 151–52.

<sup>246</sup> *Id.* at 155.

<sup>247</sup> *Id.*

<sup>248</sup> *Id.*

<sup>249</sup> *Id.* at 155, 157.

awarded.<sup>250</sup> In *In re Zhu*, a West Point cadet, Zhu, suffered a ski accident.<sup>251</sup> He was declared brain dead and taken off life support, after which his organs were donated pursuant to his wishes.<sup>252</sup> His parents then sued Westchester County Medical Center, where their son died, for retrieval of their son's sperm.<sup>253</sup> The court stated that to determine where the sperm should go, "the talisman must be the decedent's intent."<sup>254</sup> While Zhu had not left any express instructions about what to do with his gametic material in the event of his death, the court gleaned his "presumed intent" from some of Zhu's particular actions and statements made before his death.<sup>255</sup> The court decided that there was presumed intent based on several factors including Zhu's organ donation card, his "devotion" to his family, and his conversations with various people where he expressed that he wanted children.<sup>256</sup> The court held that, in light of these factors, Zhu's parents were the correct parties to make decisions about his gametic material.<sup>257</sup>

It is clear that courts take the intent of the donors of gametic material very seriously when determining its disposition due to its special potential to create life. This holds true not only where there have been disputes about whether signed agreements between parties accurately reflected their intent as to the gametic material's disposition, but also when there have been no agreements or directives at all. Courts clearly recognize that people have a special interest in their gametic material because of its great potential and take great care in determining its disposition and possession thereof.

#### F. *Havasupai Indian Case*

Institutions outside the legal sphere have also begun to recognize people's rights to their own genetic material.<sup>258</sup> In 1990, members

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<sup>250</sup> *Matter of Zhu*, 64 Misc. 3d 280, 281 (N.Y. Sup. Ct. 2019).

<sup>251</sup> *Id.* at 283.

<sup>252</sup> *Id.* at 284.

<sup>253</sup> *Id.* at 284–85.

<sup>254</sup> *Id.* at 288.

<sup>255</sup> *Id.* at 284.

<sup>256</sup> *Id.*

<sup>257</sup> *Id.* at 289.

<sup>258</sup> See generally Katherine Drabiak-Syed, *Lessons from Havasupai Tribe v. Arizona State University Board of Regents: Recognizing Group, Cultural, and Dignitary Harms as*

of the Havasupai Indian Tribe gave their genetic information in the form of blood samples to Arizona State University for the specific purpose of looking into the tribe's predisposition to diabetes.<sup>259</sup> Instead, the University took the tribe members' blood samples and researched their predispositions to mental illness and the geographic origins of the tribe,<sup>260</sup> betraying the tribe's trust.<sup>261</sup> While some of the concern over the University's research stemmed from tribe tradition,<sup>262</sup> the tribe made clear they had not consented to the kind of research the University performed on their blood.<sup>263</sup> This lack of consent stemmed from the tribe members' lack of understanding, which was exacerbated by the fact that most of the tribe spoke English as a second language and did not have a high school education.<sup>264</sup> Therefore, the tribe members likely could not understand the consent agreement as well as a native speaker could.<sup>265</sup>

In 2005, the tribe sued Arizona State University claiming a lack of informed consent and "that they donated biological materials solely for the purpose of diabetes research, so there was no consent to conduct other research."<sup>266</sup> However, the court held that there was "informed consent because the tribe members had agreed to give their blood voluntarily, and had signed a form granting blanket consent for research 'to study the causes of behavioral/medical disorders.'"<sup>267</sup> Additionally, it held that the tribe's consent was not "made ineffective even if defendants did make fraudulent representations to induce that consent."<sup>268</sup>

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*Legitimate Risks Warranting Integration into Research Practice*, 6 J. HEALTH & BIOMED. L. 175 (2010).

<sup>259</sup> Amy Harmon, *Indian Tribe Wins Fight to Limit Research of Its DNA*, N.Y. TIMES (Apr. 21, 2010), <https://www.nytimes.com/2010/04/22/us/22dna.html> [<https://perma.cc/H9K6-V3T8>]; Radhika Rao, *Informed Consent, Body Property, and Self-Sovereignty*, 44 J.L., MED. & ETHICS 437, 439 (2016).

<sup>260</sup> Harmon, *supra* note 259; Rao, *supra* note 259, at 439.

<sup>261</sup> Harmon, *supra* note 259; Rao, *supra* note 259, at 439.

<sup>262</sup> The concerns stemmed from tribe tradition because the geographic origins directly contradicted the tribe's traditional stories. Harmon, *supra* note 259; Rao, *supra* note 259, at 439.

<sup>263</sup> Harmon, *supra* note 259; Rao, *supra* note 259, at 439.

<sup>264</sup> Harmon, *supra* note 259; Rao, *supra* note 259, at 439.

<sup>265</sup> Rao, *supra* note 259, at 439.

<sup>266</sup> *Id.*

<sup>267</sup> *Id.*

<sup>268</sup> *Id.* (internal quotations omitted).

Although the case did not succeed in court, Arizona State University settled and paid \$700,000 to forty-one Havasupai tribe members, returned their blood samples, and provided “other forms of assistance” in order to “remedy the wrong that was done.”<sup>269</sup> Legal experts found this settlement to be significant because “it implied that the rights of research subjects can be violated when they are not fully informed about how their DNA might be used.”<sup>270</sup>

It is clear here that the court, like many other courts, did not take into account the tribe’s unique circumstances when deciding whether the members actually gave informed consent or intended for their DNA to be tested for purposes beyond diabetes research.<sup>271</sup> The court simply decided that because the tribe members had signed the documents, they must have consented.<sup>272</sup> However, the University’s settlement reflects how popular understanding of genetic information privacy and intent is changing by recognizing that the tribe did not intend for its DNA to be used beyond diabetes research and independently remedying that wrong.<sup>273</sup>

There are certain similarities between the issues in the Havasupai case and the current problems faced by 23andMe users. While 23andMe users have wide educational and literacy ranges, all of the users share one thing in common: they are people agreeing to contracts on the internet. Although this is not the same as lack of education or ability to completely understand a certain language, studies have shown that most people do not read contracts online and, if they do, they spend too little time reading them or simply do not understand what they are agreeing to.<sup>274</sup> Courts can look at the Havasupai Tribe settlement as a rare example of rectification in an all too common scenario—that is, when a sophisticated party uses contract law to take advantage of an unsophisticated party. Here, like some 23andMe users might reasonably assert, the sophisticated

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<sup>269</sup> Harmon, *supra* note 259; Rao, *supra* note 259, at 439–40 (internal quotations omitted).

<sup>270</sup> Harmon, *supra* note 259.

<sup>271</sup> See generally Harmon, *supra* note 259; Rao, *supra* note 259, at 439.

<sup>272</sup> See generally Harmon, *supra* note 259; Rao, *supra* note 259, at 439.

<sup>273</sup> See generally Drabiak-Syed, *supra* note 258.

<sup>274</sup> Obar & Oeldorf-Hirsch, *supra* note 140; Cakebread, *supra* note 140.

party used the genetic information in ways to which the unsophisticated party did not knowingly agree.<sup>275</sup>

### III. EVALUATING SOLUTIONS: PROPERTY LAW AND GAMETIC MATERIAL

Users do not have any legal recourse if they decide they want their genetic information pulled from research studies that have already begun or begin less than thirty days after they have withdrawn consent.<sup>276</sup> Thus, given the complete lack of avenues provided by the current statutory scheme, case law, and the studies that show most people do not read or understand internet contracts, it is probable that 23andMe will use users' genetic information in ways the users did not fully comprehend when they signed the Research Consent Document and there will be no way to prevent it.<sup>277</sup>

There are two viable avenues to legal recourse a user might pursue to have their DNA pulled out of ongoing research at 23andMe. One option is for users to petition courts to recognize their genetic information as property and thus allow conversion claims under these limited circumstances. A more promising option—given the current jurisprudence—would be for users to petition courts to treat their genetic material like gametic material so they could have greater influence over its disposition. Additionally, 23andMe users could petition the courts to eschew current internet contracts jurisprudence based on studies which show that most people do not read internet contracts.<sup>278</sup> Litigants can also emphasize that 23andMe's Research Consent Document presents far greater risks to 23andMe users than most other internet contracts that have been held valid by courts in the past.

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<sup>275</sup> See David M. Parker et al., *Privacy and Informed Consent for Research in the Age of Big Data*, 123 PENN ST. L. REV. 703, 711 (2019).

<sup>276</sup> *Research Consent Document*, *supra* note 12. See generally Garner & Kim, *supra* note 144, at 1253.

<sup>277</sup> See generally Morrow, *supra* note 140; Garner & Kim, *supra* note 144, at 1253; Daiza, *supra* note 198; Obar & Oeldorf-Hirsch, *supra* note 140; Cakebread, *supra* note 140.

<sup>278</sup> See Kim, *supra* note 138, at 313.



### A. *Treat Body Parts as Traditional Property*

One possible form of legal recourse for 23andMe users is to petition courts to reject *Moore* jurisprudence and treat genetic information as property that can be repossessed under property law. This could be a feasible form of legal recourse, especially if litigants can demonstrate to the courts that genetic information should be treated as property—specifically because of the extremely sensitive information that genetic material reveals about people from whom it originates—instead of just focusing on the idea that ownership rights should extend to those from whom the material originated.<sup>279</sup> This option would give plaintiffs a stronger claim to the genetic material than 23andMe. Property rights may also give rise to “some due process claims to genetic material taken or used without her consent or knowledge of its removal,” mainly that people’s property cannot be taken from them without due process of law, which would further protect litigants from research misuse.<sup>280</sup>

However, there are also numerous drawbacks to this solution. For one, having property rights over one’s body parts “does not ensure that one’s property will be protected under property rules.”<sup>281</sup> For example, under certain circumstances, the “owner can be forced to give up her property in return for compensation . . . set, often by a court, legislature, or administrative agency.”<sup>282</sup> This, in turn, might lead to people having their property taken from them without any compensation at all because a court or agency may set the compensation at zero.<sup>283</sup> This problem has already sprung up in the context of newborn screening procedures, where states mandate blood samples to be taken from a newborn and screened without the parents’ knowledge or consent.<sup>284</sup> The eschewal of consent without

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<sup>279</sup> See Russo, *supra* note 14, at 459; see generally Jessica L. Roberts, *Progressive Genetic Ownership*, 93 NOTRE DAME L. REV. 1105 (2018) (arguing that genetic material should be considered property under the progressive property theory); W. Peter Guarnieri, *Prince Harry and the Honey Trap: An Argument for Criminalizing the Nonconsensual Use of Genetic Information*, 48 AM. CRIM. L. REV. 1789, 1813–15 (2011); Mejido, *supra* note 63, at 304.

<sup>280</sup> Russo, *supra* note 14, at 459.

<sup>281</sup> *Id.* at 464.

<sup>282</sup> *Id.* (internal citations omitted).

<sup>283</sup> *Id.*

<sup>284</sup> *Id.*

compensation is considered to be justified by the public health benefit and demonstrates that existing institutions do not respect the relationship between property rights and genetic material.<sup>285</sup> So while property rights continue to apply to people's commonplace possessions, like books, they do not apply to people's genetic material.

Additionally, in order to sue under property law, there must be an actual injury, so “the current judicial regime does little to protect individuals from harm before, or when, their genetic data is actually being used.”<sup>286</sup> While there has been some success for litigants using property law, usually it does not succeed.<sup>287</sup> In the case of 23andMe, if users' genetic information has been used in research but no harm has occurred (such as theft), users could not sue under property law even if courts recognized their body parts as property.

The awarding of property rights over body parts may also create problems for researchers. As courts have noted, allowing people to have property rights over their body parts might stifle innovation and scientific developments because it could restrict “access to the necessary raw materials” needed for research that could be potentially helpful or lifesaving for others.<sup>288</sup> Additionally, researchers—and the companies that sponsor them—may be less inclined to “invest heavily in developing, manufacturing, or marketing a product when uncertainty about clear title exists.”<sup>289</sup> These, of course, would lead to “an obvious harm to the public good” by limiting potential research and advancements that could help others in dire medical circumstances.<sup>290</sup>

While property rights over one's body may be a good form of legal recourse for those who have already been harmed in some way by the use of their bodily or genetic material, it will not help those who may feel harmed but have not been legally harmed.

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<sup>285</sup> *Id.*

<sup>286</sup> *Id.* at 462; *see also* Ajunwa, *supra* note 170, at 1254–55.

<sup>287</sup> Russo, *supra* note 14, at 462; Newman v. Sathyavaglswaran, 287 F.3d 786 (9th Cir. 2002); United States v. Kriesel, 720 F.3d 1137 (9th Cir. 2013).

<sup>288</sup> Moore v. Regents of Univ. of Cal., 51 Cal. 3d 120, 144 (1990).

<sup>289</sup> *Id.* at 143 (internal quotations omitted); *see also* Peter J. Gardner, *U.S. Intellectual Property Law and the Biotech Challenge: Searching for an Elusive Balance*, 44 N.H. B. J. 24, 25 (2003).

<sup>290</sup> Russo, *supra* note 14, at 461; *see also* Gardner, *supra* note 289, at 24, 26.

Additionally, even if 23andMe users successfully petition the courts to recognize property rights in their genetic material, courts may take the newborn screening approach that compensation is not necessary for the taking of certain genetic material because of the public health benefits that result from 23andMe's research on its users' genetic information. Finally, courts may be more inclined to find that genetic material is not really different from other body parts, like *Moore*, and be unwilling to take a position which may hinder scientific research. While this may be a course of action worth exploring, it is unlikely courts would overturn years of jurisprudence and therefore is probably not the best solution.

B. *Proposed Solution: Treat DNA like Gametic Material and Eschew Current Online Contracts Jurisprudence*

The best legal recourse for users who want their DNA taken out of already commenced 23andMe research is to petition the courts to treat genetic material like gametic material. Users should ask the courts to take the gametic material approach of looking to the intent of the donor in deciding its disposition. Moreover, courts should eschew traditional online contracts jurisprudence for a more nuanced approach that takes into account the overwhelming evidence that people do not read or necessarily understand internet contracts and the significant risks 23andMe's Research Consent Document poses for users.

First, courts should treat DNA like gametic material because it has the "potential for human life."<sup>291</sup> Cloning is becoming less of a whacky idea and more of a plausible route for scientific research.<sup>292</sup> Even if DNA is not currently used to entirely clone a human being, cloning and creating human embryos—however small—could be considered creating "human life" depending on one's ethical views.<sup>293</sup> With this consideration, courts should look to the intent of

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<sup>291</sup> *Hecht v. Super. Court*, 20 Cal. Rptr. 2d 275, 283 (Cal. Ct. App. 1993); *Davis v. Davis*, 842 S.W.2d 588, 597 (Tenn. 1992), *reh'g in part*, No. 34, 1992 WL 341632 (Tenn. Nov. 23, 1992). See generally Boulier, *supra* note 130; Colleran, *supra* note 130; Pawlowski, *supra* note 130, at 48–49.

<sup>292</sup> Regalado, *supra* note 177.

<sup>293</sup> *Id.* See generally Dianne N. Irving, *When Do Human Beings Begin?*, 19 INT'L J. SOCIO. & SOC. POL'Y 22 (1999).

23andMe users who pursue legal recourse to determine their intent in using the 23andMe website.<sup>294</sup> While the Research Consent Document itself may and should be considered a factor, courts can also look to what kind of kit the user bought, which may point to the user's intent. For example, the buying of just an ancestry kit may point to use for entertainment or educational purposes and away from the intent to help others by providing one's genetic information for research. The courts could also look outside the website to statements the user made to other people, her participation in other research studies or lack thereof, and whether she elected to be an organ donor to determine her intent.<sup>295</sup>

When looking at the Research Consent Document itself, the court—like the courts in *Kass* and *McQueen*—should look to the intent of the users when executing the contracts and should look at the entire contract, considering the relationship of the parties, “*and the circumstances under which it was executed.*” Particular words should be considered, not as if isolated from the context, but in the light of the obligation as a whole and the *intention* of the parties as manifested thereby.”<sup>296</sup> Here, the Research Consent Document is executed in an online format, where the user simply scrolls down and clicks “I agree” to consent. While this is technically an affirmative sign of agreement, the fact that this takes place online probably means the users did not read all the terms before clicking “I agree.”<sup>297</sup> Moreover, simply clicking “I agree” at the end of the web page is a lot different than initialing next to a specific option to indicate how the user would like her genetic material used or disposed of. The latter would certainly indicate a stronger form of intent due to the time it would take to look through the options and choose one.<sup>298</sup>

Courts should also eschew traditional scrollwrap jurisprudence for the more refined understanding that most people do not read or

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<sup>294</sup> See generally Mariusz Goniewicz et al., *Legal Concept of Consent as a Declaration of Intent to Use Genetic Material*, 12 REVISTA ROMÂNĂ DE BIOETICĂ 15 (2014).

<sup>295</sup> *Matter of Zhu*, 64 Misc. 3d 280, 281 (N.Y. Sup. Ct. 2019).

<sup>296</sup> *Kass v. Kass*, 91 N.Y.2d 554, 566 (1998) (quoting *Atwater & Co. v. Panama R.R. Co.*, 246 N.Y. 519, 524 (1927)) (emphasis added).

<sup>297</sup> *Obar & Oeldorf-Hirsch*, *supra* note 140; *Cakebread*, *supra* note 140.

<sup>298</sup> *Kass*, 91 N.Y.2d at 566; *Ram*, *supra* note 159, at 494.

understand online contracts.<sup>299</sup> Courts have traditionally held that a user does not need to read a contract in order to be bound by it, as long as she is on notice of its terms.<sup>300</sup> As a result, courts consider scrollwrap agreements—where the user has to scroll all the way to the bottom of the page before they click “I accept”—to put people on notice and therefore bind them by their terms.<sup>301</sup> However, these rulings put almost everyone who has agreed to a scrollwrap agreement at a disadvantage because, as many studies have shown, people do not read the contracts they are agreeing to and even if they attempt to read it, they either do not spend enough time to entirely read it or simply do not understand what they are agreeing to.<sup>302</sup>

The court should also take into account that a user allowing her genetic information to remain in the hands of a company that is using it for research has risks which are vastly different than the risk of a user blindly agreeing to mandatory arbitration. While one contract may result in an unpleasant proceeding at a venue one did not choose, the other may result in research that is eventually used for cloning, which may go against the user’s moral beliefs and raise a plethora of other concerns.<sup>303</sup>

Given the risks users are exposing themselves to by agreeing that 23andMe can use their DNA in research and the fact that most people probably did not read or understand the terms, courts should not simply hold users to 23andMe’s Research Consent Document. Instead, they should look to each individual user’s intent when she signed up for 23andMe and agreed to research before determining whether the user should be bound by its terms.

There are multiple benefits to this approach. First, 23andMe users will have legal recourse if their genetic information is used in a

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<sup>299</sup> Obar & Oeldorf-Hirsch, *supra* note 140; Cakebread, *supra* note 140.

<sup>300</sup> *Nicosia v. Amazon.com, Inc.*, 834 F.3d 220, 232 (2d Cir. 2016).

<sup>301</sup> *Applebaum v. Lyft, Inc.*, 263 F. Supp. 3d 454, 465 (S.D.N.Y. 2017) (quoting *Berkson v. Gogo LLC*, 97 F. Supp. 3d 359, 394–95 (E.D.N.Y. 2015)).

<sup>302</sup> Obar & Oeldorf-Hirsch, *supra* note 140; Cakebread, *supra* note 140.

<sup>303</sup> Other concerns include trust and estate issues. For example, if a decedent’s genetic material is used in a cloning experiment, they may have more heirs than they knew about. This could affect their intended (or known) heirs’ rights to the estate or trust of the cloned decedent. It should be noted that this Note will not be discussing how cloning could affect trust and estates issues.

way they did not intend for it to be used and will be able enforce its removal from 23andMe research that has already begun. Moreover, people will be in better control of their genetic material and companies will no longer be able to take advantage of people through scrollwrap agreements. It will also protect people from current unknown risks that may present themselves in the future, such as the possibility of cloning.<sup>304</sup>

There are also multiple drawbacks to this approach. First, there will be more judicial intervention and litigation over 23andMe contracts. Likewise, finding the intent of the users will be on a case-by-case basis, which would probably prevent a class action lawsuit and result in many individual lawsuits. This path may not be the most efficient, since only a select group of people have used 23andMe and will revoke consent for their DNA to be used in research. It is tailored enough, however, that it will not create a total upheaval in contracts law.

#### CONCLUSION

We live in a society that tells us that, at the end of the day, scientific research and contracts law are more important than the ability to enjoy decision-making authority over one's own genetic information. That is, in a word, crazy. Courts need to get with the times and acknowledge that many people in modern society share the most intimate details about themselves online, including their genetic information. This greatly increases the stakes under current bodily autonomy and internet contracts jurisprudence, according to which individuals have virtually no say over what happens to their DNA once they have signed an internet contract that they likely did not read or understand. The time is now for courts to recognize that we live in a different world than we did 100—or even just twenty—years ago; there are new legal problems created by the advancement of technology that require new legal solutions. By following genetic material jurisprudence and eschewing traditional contracts jurisprudence, courts can recognize the brave new world that we now inhabit and protect 23andMe users from having their genetic material used in ways they did not intend.

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<sup>304</sup> See generally Kody, *supra* note 154, at 308–10.