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Sales, Acquisitions, and Mergers of Direct-to-Consumer Genetic Testing Companies: The Risks and a Solution

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COMMENTS

SALES, ACQUISITIONS, AND MERGERS OF DIRECT-TO-CONSUMER GENETIC TESTING COMPANIES: THE RISKS AND A SOLUTION

by: Alyssa McLeod*

ABSTRACT

Direct-to-consumer genetic tests have become increasingly popular in the United States within the last few years. However, these tests pose many risks to the consumer, most notably privacy risks. A subset of these privacy risks involves the issue of company mergers, acquisitions, and sales. Many companies in the direct-to-consumer genetic testing market have privacy policies that contain a variation of a “business transfer” clause. These clauses specify that in the event the company goes through a business transition such as a sale, merger, or acquisition, the consumer’s personal information—including the consumer’s DNA—will be among the assets transferred. This Article explores the risks associated with these business transfer clauses as they relate to the consumer, and presents a solution to mitigate said risks. The solution lies in FTC v. Toysmart, wherein a toy company that filed for bankruptcy was restricted in selling its assets—which included its customers’ personal data—only to entities with the same interests as the toy company. This Article urges that the default interpretation standard of business transfer clauses track similarly such that a direct-to-consumer genetic testing company may only be sold to, merged with, or acquired by a company with the same or like interests.

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I. INTRODUCTION

Direct-to-consumer (“DTC”) genetic tests have become increasingly popular over the last few years, and there seems to be no stopping point in sight. When the first DTC genetic test hit the market in 1996, the concept was not only novel, but also ambitious.¹ That consumers could simply send off a cheek swab and then receive a complete depiction of their human genome was a profound idea; nothing like it had ever been offered to consumers before.² However, consumers did not seem all too interested, as the industry for DTC genetic tests grew relatively slowly at first, and the purchase of these tests seemed reserved for a few wealthy individuals.³ Additionally, many medical experts warned consumers to view these tests with caution, as there was little evidence that results were “clinically useful” and many of the potential risks were unknown.⁴ But the world would change almost twenty-five years later.

Despite the slow start, the market for DTC genetic tests has grown dramatically in the last few years.⁵ The number of consumers who used a DTC genetic test “more than doubled during 2017” and exceeded twelve million in 2018.⁶ Genealogy has grown so much that as of 2018 it became America’s most popular hobby and one of the top trending topics for internet surfers.⁷

The sudden growth in the popularity of DTC genetic tests can be attributed to the changing landscape of the market. Today, not only are more DTC genetic tests readily available than ever before, but these tests are also cheaper.⁸ For example, 23andMe, a well-known and leading company in the market, now charges customers only \$99 for its services, compared to the original price of \$999 in 2007.⁹ Additionally, taking one of these DTC genetic tests is convenient and fairly straightforward. DTC genetic testing can be done from the comfort of the consumer’s home, without any involvement of a healthcare pro-

1. Scott Bowen & Muin J. Khoury, *Consumer Genetic Testing Is Booming: But What Are the Benefits and Harms to Individuals and Populations?*, CTRS. FOR DISEASE CONTROL & PREVENTION (June 12, 2018), <https://blogs.cdc.gov/genomics/2018/06/12/consumer-genetic-testing/> [<https://perma.cc/J37Q-EHWG>].

2. *See id.*

3. *Id.*

4. *Id.*

5. Antonio Regalado, *2017 Was the Year Consumer DNA Testing Blew Up*, MIT TECH. REV. (Feb. 12, 2018), <https://www.technologyreview.com/2018/02/12/145676/2017-was-the-year-consumer-dna-testing-blew-up/> [<https://perma.cc/6B8E-DX3R>].

6. *Id.*

7. Bowen & Khoury, *supra* note 1; *see also* Gregory Rodriguez, *How Genealogy Became Almost as Popular as Porn*, TIME (May 30, 2014, 12:01 AM), <https://time.com/133811/how-genealogy-became-almost-as-popular-as-porn/> [<https://perma.cc/UW3Q-3EGU>].

8. *See* J. Scott Roberts & Jenny Ostergren, *Direct-to-Consumer Genetic Testing and Personal Genomics Services: A Review of Recent Empirical Studies*, 1 CURRENT GENETIC MED. REPS. 182 (2013).

9. *Id.*

vider.¹⁰ A typical consumer purchases a test online from one of the many companies to choose from, is mailed an at-home collection kit by said company, and provides a DNA sample, usually in the form of saliva through a cheek swab.¹¹ Once the test results are in (usually several weeks later), the consumer can access them online through the company's website.¹²

DTC genetic testing provides consumers with various forms of data related to genealogy, ancestry, or health predictions.¹³ Most consumers use these at-home DNA tests to reveal ancestral and familial relationships, and while many seek to learn about their ancestral origins, others hope to find unknown blood relatives.¹⁴ A simple at-home genetic test may provide the consumer with several benefits, including individualized knowledge of a particular disease's likelihood (e.g., diabetes, heart disease, or cancer), disease screening, health-risk evaluation, and even suggestions for lifestyle changes, diets, dietary supplements, or medications.¹⁵ Further, some companies even claim that their tests can provide information about how a consumer's body will respond to a specific treatment or drug.¹⁶

While DTC genetic tests provide many benefits, they do not come without risks. When consumers take one of these tests and send in their DNA sample, they are providing the applicable company with important, sensitive information about themselves. Your DNA is a blueprint of your life;¹⁷ it discloses "what makes you *you*."¹⁸ Not only does your DNA reveal information about yourself, including your heritage and your health, but it also reveals information about your blood relatives.¹⁹ Because DNA can provide a nearly limitless amount of personal, sensitive information, allowing companies access to your DNA poses many risks, most notably privacy risks. Placing a con-

10. See Letter from Nathan Hopkins, Legis. Analyst, Minnesota House of Reps., to Members of the Legis. Comm'n on Data Practices and Personal Data Priv. (Nov. 15, 2018) (on file with author) [hereinafter Letter from Nathan Hopkins]; James W. Hazel & Christopher Slobogin, *Who Knows What, and When?: A Survey of the Privacy Policies Proffered by U.S. Direct-to-Consumer Genetic Testing Companies*, 28 CORNELL J.L. & PUB. POL'Y 35, 38 (2018).

11. Hazel & Slobogin, *supra* note 10, at 38.

12. *Id.*

13. Letter from Nathan Hopkins, *supra* note 10.

14. Ellen Wright Clayton et al., *The Law of Genetic Privacy: Applications, Implications, and Limitations*, 6 J.L. & BIOSCIENCES 1, 16 (2019), <https://doi.org/10.1093/jlb/lsz007>.

15. *Direct-to-Consumer Genetic Tests*, FED. TRADE COMM'N: CONSUMER INFO. (Feb. 2018), <https://www.consumer.ftc.gov/articles/0166-direct-consumer-genetic-tests> [<https://perma.cc/RT8E-PJYC>].

16. *Id.*

17. JUSTICE MING W. CHIN ET AL., FORENSIC DNA EVIDENCE: SCIENCE AND THE LAW § 13:13, Westlaw TRG-DNA (database updated June 2020).

18. Lesley Fair, *DNA Test Kits: Consider the Privacy Implications*, FED. TRADE COMM'N: CONSUMER INFO. (Dec. 12, 2017), <https://www.consumer.ftc.gov/blog/2017/12/dna-test-kits-consider-privacy-implications> [<https://perma.cc/T2TB-SWX4>].

19. CHIN ET AL., *supra* note 17.

sumer's DNA in the wrong hands could really damage that person's well-being.²⁰ In fact, consumers recognize privacy risks as one of their main concerns, with a 2016 study showing that 65% of DTC genetic test users worry about their personal data being shared with third-party companies.²¹ Further, many consumers are unaware of what, if any, privacy policies guide the use of their DNA by the applicable company. While many industry leaders provide policy statements, a 2017 survey analyzing the privacy policies proffered by U.S. DTC genetic testing companies ("2017 Survey") revealed that of the ninety companies surveyed, just under 40% failed to provide any information to consumers regarding their genetic data policies or what would become of consumer DNA samples.²²

These risks are only heightened by the fact that third parties may have access to a customer's DNA. Of the companies that do provide comprehensive policy statements, many fail to specify what information will be shared with third parties. In fact, out of the fifty-five companies in the 2017 Survey with policies addressing DNA, just under half of the companies' policies specified that data would or could be shared with third parties.²³ Additionally, eighteen companies specifically provided that the customer's deidentified data would be shared with third parties without the customer's consent.²⁴

Further, consumers might be even more shocked to know that their DNA could be sold to a third party. Many DTC genetic testing companies have what is called a "business transfer" clause in their privacy policies that allows them to transfer all of their assets—which includes the consumer's DNA—to another entity in the event of a sale, merger, or acquisition.²⁵ This means that if these companies, such as 23andMe or Ancestry.com, were to merge with, sell to, or be acquired by another company, 23andMe or Ancestry.com have the right to transfer all of their assets to the acquiring entity, including the customer's personal information and, critically, the customer's DNA sample.²⁶ For example, there is nothing stopping 23andMe from selling to a massive, well-known company like Facebook. In that case, Facebook would then not only have all of the user's personal and social information but would now also have the user's DNA. There is no telling what a company like Facebook would be able to do with all of that information.

20. June Mary Z. Makdisi, *Genetic Privacy: New Intrusion a New Tort?*, 34 CREIGHTON L. REV. 965, 965–66 (2001).

21. LAUREN FRIEND ET AL., KPMG INT'L, DIRECT-TO-CONSUMER GENETIC TESTING 6 (2018), <https://assets.kpmg/content/dam/kpmg/xx/pdf/2018/08/direct-to-consumer-genetic-testing.pdf> [<https://perma.cc/P454-34BD>].

22. Hazel & Slobogin, *supra* note 10, at 48.

23. *Id.* at 55.

24. *Id.*

25. See discussion *infra* Part II.

26. See Hazel & Slobogin, *supra* note 10, at 56.

Finally, as if these business transfer clauses do not pose enough risks on their own, the risks become heightened when one realizes that hardly any regulations, at either the state or federal level, exist that address the risks posed by these business transfer clauses.²⁷ While there are some regulations that address genetic privacy concerns in general or as they relate to healthcare and the workplace, none of them cover privacy concerns relating to DTC genetic testing.²⁸ Nor do any of the regulations address the business transfer clause specifically.²⁹

This Article offers a new solution to combat the risks posed by these business transfer clauses contained in the privacy policies of DTC genetic testing companies. Drawing from *FTC v. Toysmart.com*,³⁰ this Article urges that these business transfer clauses be interpreted as allowing the genetic testing company to sell to, merge with, or be acquired by only those companies that have like interests as those of the genetic testing company.

This Article proceeds in three parts. In Part II, I explore some of the privacy policies proffered by DTC genetic testing companies, paying special attention to the business transfer clauses contained in them. I break down the business transfer clause as it applies to DTC genetic testing companies. I then address and analyze the inherent risks that these clauses pose, particularly as they relate to the consumer.

In Part III, I provide an overview of the current legal landscape that makes up the genetic testing market. I discuss how the current regulations, at both the federal and state level, fail to address genetic privacy concerns relating to DTC genetic testing generally, as well as to business transfer clauses. While these regulations address genetic privacy concerns as they relate to discrimination in healthcare and in the workplace, they fail to address the privacy issues that consumers in the DTC genetic testing market experience, and more specifically, the risks that the business transfer clause poses to the consumer.

In Part IV, I propose a solution to combat the risks associated with the business transfer clause. I argue that these genetic testing companies should adopt a default interpretation standard, whereby these companies will interpret the business transfer clause as allowing them to sell to, merge with, or be acquired by only companies that have like interests as those of the genetic testing company. A similar conclusion was reached in *FTC v. Toysmart.com*, in which the parties stipulated in federal bankruptcy court that the defendant, Toysmart, could only sell or assign its assets, including its customers' personal information,

27. See discussion *infra* Part III.

28. See discussion *infra* Part III.

29. See discussion *infra* Part III.

30. *FTC v. Toysmart.com, LLC*, No. 00-11341-RGS, 2000 WL 34016434 (D. Mass. July 21, 2000).

to a company with like interests as those of Toysmart.³¹ I discuss how the *Toysmart.com* litigation provides a framework for mitigating the risks associated with business transfer clauses that are contained in the privacy policies of DTC genetic testing companies. I then explore different types of companies that could be considered as having “like interests” as those of DTC genetic testing companies. Finally, I explain how the solution proposed here is in line with industry best practices.

II. PRIVACY POLICIES AND THE “BUSINESS TRANSFER” CLAUSE

There are numerous companies that provide DTC genetic testing services, and many of them provide consumers with easily accessible policy documents, such as privacy policies and terms of service documents. Most companies publish privacy documents, including privacy policies and service terms, on their websites.³² In fact, of the ninety companies in the 2017 Survey, 90% had readily accessible privacy documents.³³ These documents usually discuss the type of information that the company collects, how it stores and uses the information, and how it attempts to keep the information safe.³⁴ In addition, these privacy documents are generally easy to find. A consumer can do a quick Google search and have access to a company’s full privacy document and terms of service document.³⁵

A. *A Breakdown of the Business Transfer Clause*

One of the common provisions included in these privacy policy documents can be referred to as a “business transfer” clause. A business transfer clause specifies what will happen to a company’s assets, including company data, when the company decides to merge with another company or sell all of its assets.³⁶ The business transfer clause establishes whether the new company will have rights to consumer data and sets forth any transfer terms and notice requirements for the data.³⁷ In regard to the business transfer clauses provided in DTC genetic testing companies’ policy statements, these clauses spell out what will happen to a company’s assets when the company goes through a

31. *In re Toysmart LLC*, No. 00-13995-CJK (Bankr. E.D. Mass. filed July 21, 2000), <https://www.ftc.gov/sites/default/files/documents/cases/toysmarttbankruptcy.1.htm> [<https://perma.cc/YVG5-B2Q6>] (“Stipulation and Order Establishing Conditions On Sale Of Customer Information”).

32. Hazel & Slobogin, *supra* note 10, at 48.

33. *Id.*

34. *See id.* at 45.

35. *See id.* at 45 n.59, 48.

36. *Business Transfer Clause in Privacy Policy*, TERMSFEED (Dec. 21, 2020), <https://www.termsfeed.com/blog/business-transfer-privacy-policy/> [<https://perma.cc/7XF7-K2QJ>].

37. *Id.*

sale, merger, or acquisition.³⁸ Notably, a company's assets include all of its customers' DNA.³⁹ Therefore, part of the assets that will be transferred to the purchasing or acquiring entity includes customers' DNA. Many companies' privacy statements explicitly provide for this.⁴⁰ While not every company in the market has some form or variation of a business transfer clause—despite the constant evolution of the market with mergers and acquisitions being commonplace—the companies that do specify that the consumer's data would be transferred to the other entity.⁴¹ Of the companies in the 2017 Study with business transfer clauses, all provided that the consumer's data would or could be transferred in a merger or sale just like other company assets.⁴²

While not every DTC genetic testing company has some form of a business transfer clause, many of the larger companies in the at-home DNA testing market do. Two of the largest companies in the market, Ancestry.com and 23andMe,⁴³ both contain a variation of a business transfer clause in their policy statements. Ancestry.com has a section in its privacy statement titled, “If Ancestry is Acquired,” which states:

If Ancestry or its businesses are acquired or transferred (including in connection with bankruptcy or similar proceedings), we will share your Personal Information with the acquiring or receiving entity. The promises in this Privacy Statement will continue to apply to your Personal Information that is transferred to the new entity.⁴⁴

Similarly, 23andMe's full privacy statement contains a “Business Transactions” section, which states:

In the event that 23andMe goes through a business transition such as a merger, acquisition by another company, or sale of all or a portion of its assets your Personal Information will likely be among the assets transferred. In such a case, your information would remain subject to the promises made in any pre-existing Privacy Statement.⁴⁵

38. See, e.g., *Your Privacy*, ANC., <https://www.ancestry.com/cs/legal/privacystatement> [<https://perma.cc/N3V7-F7MB>] [hereinafter *Ancestry Privacy Policy*]; *Privacy Highlights*, 23ANDME (Oct. 30, 2020), <https://www.23andme.com/about/privacy/> [<https://perma.cc/A5TA-GTUX>] [hereinafter *23andMe Privacy Policy*].

39. See *23andMe Privacy Policy*, *supra* note 38 (defining “Personal Information” as including “Genetic Information” which includes the customer's DNA sample); see also *Ancestry Privacy Policy*, *supra* note 38 (stating “[y]our DNA Data and any information derived from it . . . are Personal Information and referred to as ‘Genetic Information’”).

40. See *Ancestry Privacy Policy*, *supra* note 38; see also *23andMe Privacy Policy*, *supra* note 38.

41. Hazel & Slobogin, *supra* note 10, at 56.

42. *Id.*

43. Regalado, *supra* note 5.

44. *Ancestry Privacy Policy*, *supra* note 38.

45. *23andMe Privacy Policy*, *supra* note 38.

Both of these companies' privacy policies explicitly state that "Personal Information" includes the customer's "Genetic Information."⁴⁶ Further, many other large, well-known DTC genetic testing companies also contain a variation of a business transfer clause in their privacy policies.⁴⁷

B. *Risks Associated with the Business Transfer Clause*

The business transfer clause and variations of it pose many risks to the consumer, specifically when it comes to the sharing of the consumer's private and personal information. These business transfer clauses allow DTC genetic testing companies to transfer all of a customer's personal information—including the customer's DNA—to the acquiring entity.⁴⁸ For example, if 23andMe or Ancestry.com were to merge with, sell to, or be acquired by another company, 23andMe and Ancestry.com would have the right to transfer all of their assets to the acquiring company, which includes not only the customer's personal information such as name, address, date of birth, sexual orientation, ethnicity, etc., but also the customer's DNA and the subsequent findings and results from the provided DNA sample.⁴⁹

Further, these business transfer clauses fail to place any limitations on the type of company the DTC genetic testing company may sell to, merge with, or be acquired by. If a company like 23andMe or Ancestry.com wanted to sell to a company like Apple or Facebook, there is nothing in their policy statements to stop them from doing so. Moreover, there is also nothing stopping them from sharing all of their customers' personal information—including the customers' DNA—with these companies. In fact, 23andMe and Ancestry.com even state in their versions of the business transfer clause that they have the right

46. See *Ancestry Privacy Policy*, *supra* note 38; see also *23andMe Privacy Policy*, *supra* note 38.

47. See, e.g., *MyHeritage Privacy Policy*, MYHERITAGE, <https://www.myheritage.com/privacy-policy> (Dec. 31, 2019) [<https://perma.cc/9ZRJ-XPM3>] ("[I]n the event that MyHeritage, or substantially all of its assets or stock are acquired, personal information will as a matter of course be one of the transferred assets. In such event, your information would remain subject to the promises made in the pre-existing Privacy Policy prior to the event."); *FamilyTreeDNA Privacy Statement*, FAMILYTREEDNA, <https://www.familytreedna.com/legal/privacy-statement> (May 7, 2019) [<https://perma.cc/H9FJ-J7CS>] ("If FamilyTreeDNA or its businesses are acquired or transferred to another entity (in part or in whole and including in connection with any bankruptcy or similar proceedings), we will share your Personal Information with that entity. The promises in this Privacy Statement will apply to your Personal Information as transferred to the new entity.").

48. See *Ancestry Privacy Policy*, *supra* note 38; see also *23andMe Privacy Policy*, *supra* note 38.

49. See *Ancestry Privacy Policy*, *supra* note 38; see also *23andMe Privacy Policy*, *supra* note 38.

to, and will in fact, transfer all of their customers' personal information to the third-party company.⁵⁰

Additionally, the risks posed to the consumer are heightened by the volatility of the DTC genetic testing market. Because businesses in this industry regularly enter and exit the market, mergers and acquisitions are commonplace.⁵¹ Therefore, the risks posed by the business transfer clause seem even greater due to the increased likelihood that a company will in fact go through a sale, merger, or acquisition and thus transfer the customer's data, including the customer's DNA.

Some companies in the market are already linked to very large, well-known businesses. In fact, Ancestry.com partners with the Google subsidiary, Calico, for research.⁵² Calico researches medical interventions that will help humans live longer and healthier.⁵³ While Calico's purpose seems cutting edge, the company "discloses little about its DNA work, and many view it as a vanity project for . . . billionaires seeking breakthroughs to extend their own lives."⁵⁴ No matter your stance on the type of research that Calico engages in, it is easy to see the risks that this type of relationship poses to the customer. By sharing the customer's DNA with a third party such as Calico, Ancestry.com is increasing the likelihood that the customer's DNA will be compromised, with many experts concerned about stealing and exploitation.⁵⁵

Ancestry.com is not the only company in the market that is linked to a larger company. 23andMe partnered with the pharmaceutical company, GlaxoSmithKline, providing the company with access to 23andMe's large collection of genetic data to create new drugs.⁵⁶ By partnering with and sharing the customer's DNA with these third-party companies, Ancestry.com and 23andMe are essentially magnifying the risk of the customer's genetic information being misused.⁵⁷ Simply, information transfer is always susceptible to unintended third-party interception.⁵⁸

50. See *Ancestry Privacy Policy*, *supra* note 38; see also *23andMe Privacy Policy*, *supra* note 38.

51. Anelka M. Phillips, 'Only a Click Away—DTC Genetics for Ancestry, Health, Love . . . and More: A View of the Business and Regulatory Landscape', 8 *APPLIED & TRANSLATIONAL GENOMICS* 16, 16, 22 (2016).

52. Stuart Leavenworth, *Who Is the Secretive Google Subsidiary with Access to Ancestry's DNA Database?*, *CONSUMER WATCHDOG* (June 1, 2018), <https://consumerwatchdog.org/news-story/who-secretive-google-subsidiary-has-access-ancestrys-dna-database> [<https://perma.cc/A73Q-CG6F>].

53. *Understanding the Biology of Aging and Longevity*, CALICO, <https://www.calicolabs.com/research-technology> [<https://perma.cc/86UM-GG34>].

54. Leavenworth, *supra* note 52.

55. *Id.*

56. Jamie Ducharme, *A Major Drug Company Now Has Access to 23andMe's Genetic Data. Should You Be Concerned?*, *TIME* (July 26, 2018, 3:47 PM), <https://time.com/5349896/23andme-glaxo-smith-kline/> [<https://perma.cc/FHP2-YXEZ>].

57. See *id.*

58. *Id.*

The risks increase even further by the fact that not all of these business transfer clauses address whether the acquiring or purchasing company will be bound by the same privacy policies contained in the original privacy statements that the consumer agreed to. While many large DTC genetic testing companies contain language in their privacy statements that address this concern, it is certainly not widespread.⁵⁹ 23andMe's privacy statement specifies that in the event of a merger, acquisition, or sale, the consumer's information "would remain subject to the promises made in any pre-existing Privacy Statement."⁶⁰ Ancestry.com contains a similar provision in its privacy statement that says "[t]he promises in this Privacy Statement will continue to apply to your Personal Information that is transferred to the new entity."⁶¹ Other large, well-known DTC genetic testing companies also contain similar language in their privacy policies.⁶² While it is reassuring to see that some of the larger companies in the market do contain language addressing whether the new entity will be bound by the same privacy policies, it is not commonplace.⁶³ The 2017 Survey revealed that of the companies that had a policy regarding the fate of the consumer's data in the event of sale, merger, or acquisition, just over half of these called for the acquiring company to adhere to the current privacy policies in effect at the time of transaction.⁶⁴ Therefore, a little less than half of the companies surveyed failed to address whether the acquiring or purchasing company would be bound by the same privacy policies.

Despite the overwhelming concerns these business transfer clauses present, one might argue that they actually pose no risk to the consumer, as the consumer consents to the business transfer clause by agreeing to the privacy policy and terms of conditions offered by the applicable company. After all, the consumer must agree to such provisions before sending in his or her sample or purchasing one of the DNA testing kits. However, it is often the case that consumers do not actually read or understand these policies, and therefore they do not necessarily realize what they are in fact consenting to.

These agreements normally present themselves as "click-wrap," which requires the consumer to indicate consent to the policy upon purchase, or similarly "browser-wrap," which means the consumer's consent is implied from using the company's website.⁶⁵ The United States currently operates under a self-regulatory "Notice and Choice" framework, meaning that when the consumer clicks "I agree," or sim-

59. Hazel & Slobogin, *supra* note 10, at 56.

60. 23andMe Privacy Policy, *supra* note 38.

61. Ancestry Privacy Policy, *supra* note 38.

62. See MyHeritage Privacy Policy, *supra* note 47; see also FamilyTreeDNA Privacy Statement, *supra* note 47.

63. Hazel & Slobogin, *supra* note 10, at 56.

64. *Id.*

65. *Id.* at 38.

ply proceeds to use the company's services, the consumer has sufficiently provided consent.⁶⁶ However, consumers are largely unaware of the contents of these agreements, and therefore lack *informed* consent.⁶⁷ Many scholars have criticized this method of consent for "leaving users uninformed—or misinformed, as people rarely see, read, or understand privacy policies."⁶⁸ Additionally, even if consumers actually read the policies, they tend to misunderstand them because the policies are usually lengthy and contain legalese.⁶⁹ Therefore, consumers reading these policies are prone to incorrectly assuming that the company will protect their privacy.⁷⁰ Thus, while the consumer may "consent" to the terms and conditions contained in the privacy statements offered by DTC genetic testing companies, consumers may not actually understand or realize what they are in fact consenting to.

The business transfer clause clearly poses many risks to the consumer, risks that are heightened by the rapidly growing genetic testing market. Even more concerning is that these risks are relatively unaddressed in the legal context. As will be explained in the following Part, there are little to zero regulations or laws in place, at either the federal or state level, that specifically address the business transfer clauses contained in DTC genetic testing companies' privacy policies.

III. OVERVIEW OF THE CURRENT LEGAL LANDSCAPE

Despite the immense amount of risks associated with DTC genetic testing, and specifically business transfer clauses, there are few regulations that address privacy concerns for genetic testing in general, let alone privacy concerns related to DTC genetic testing. The need for privacy protection related to genetic information has long been recognized, with federal legislators proposing genetic privacy legislation beginning in 1991.⁷¹ Despite this necessity, scholars are concerned that existing laws inadequately protect consumer privacy.⁷² The current legal landscape of genetic privacy can be broken down by federal and state level.

There are some federal laws that address genetic privacy concerns; however, they either address privacy in general or genetic privacy as it relates to discriminatory use.⁷³ One would think that the Privacy Act of 1974 would cover genetics, but that is not the case.⁷⁴ This Act aims

66. *Id.*

67. *Id.*

68. Joel R. Reidenberg et al., *Privacy Harms and the Effectiveness of the Notice and Choice Framework*, 11 I/S: J.L. & POL'Y FOR INFO. SOC'Y 485, 491 (2015).

69. *Id.*

70. *Id.*

71. Makdisi, *supra* note 20, at 975.

72. *Id.*

73. *Id.*

74. *Id.* at 975–76; *see generally* Privacy Act of 1974, Pub. L. No. 93-579, 88 Stat. 1896 (1974) (codified as amended at 5 U.S.C. § 552a).

generally to protect privacy but does not specifically address genetic privacy concerns.⁷⁵ Further, one could also look to the Health Insurance Portability and Accountability Act (“HIPAA”)⁷⁶ and the Genetic Information Nondiscrimination Act of 2008 (“GINA”)⁷⁷ for genetic privacy protection, but both HIPAA and GINA cover only genetic privacy issues related to employment discrimination and improper use of genetic information by insurance companies.⁷⁸ HIPAA was enacted in 1996 and is largely concerned with protections for patient privacy and health insurance coverage.⁷⁹ HIPAA prohibits employers who provide health insurance coverage under a group plan from using an individual’s genetic information as a criterion for coverage eligibility.⁸⁰ In 2008, Congress enacted GINA to expand HIPAA and prevent health-insurance providers from altering coverage terms because of an individual’s genetic information.⁸¹ While GINA prohibited insurers from using genetic tests as a basis to deny coverage, it still permitted insurers to deny coverage based on a pre-existing genetic disease.⁸² However, in 2010 Congress passed the Patient Protection and Affordable Care Act, more commonly known as “Obamacare,” which closed that loophole.⁸³ GINA even went a step further by extending these anti-discrimination protections to cover employment, doing so by inserting “genetic information” to the list of impermissible forms of discrimination.⁸⁴ Employers may not base their employment decisions on genetic data, nor may they ask for or receive an employee’s genetic information unless an exception, such as DNA testing for law enforcement purposes, applies.⁸⁵ While these federal provisions do address genetic privacy, they do not cover the privacy risks relating to DTC genetic testing.

State legislative efforts also fail to address genetic privacy concerns relating to DTC genetic testing and business transfer clauses. How-

75. Makdisi, *supra* note 20, at 975.

76. *See generally* Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (1996).

77. *See generally* Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (2008).

78. Makdisi, *supra* note 20, at 977 (discussing HIPAA); *see* Kerry Abrams & Brandon L. Garrett, *DNA and Distrust*, 91 NOTRE DAME L. REV. 757, 760–61 (2015) (discussing GINA).

79. Abrams & Garrett, *supra* note 78, at 769; CHIN ET AL., *supra* note 17.

80. *See* 29 U.S.C. § 1182(a)(1)(F).

81. Abrams & Garrett, *supra* note 78, at 769; *see* Genetic Information Nondiscrimination Act of 2008 § 105 (codified at 42 U.S.C. § 1320d-9).

82. Abrams & Garrett, *supra* note 78, at 770.

83. *Id.* at 769–70; *see* Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 2705(a)(6), 124 Stat. 119, 156 (2010) (codified at 42 U.S.C. § 300gg-4(a)(6)).

84. Genetic Information Nondiscrimination Act of 2008 §§ 201–210 (codified at 42 U.S.C. §§ 2000ff to 2000ff-11).

85. *Id.* § 202 (codified at 42 U.S.C. § 2000ff-1); *see also* Abrams & Garrett, *supra* note 78, at 770.

ever, many states have taken steps to protect genetic privacy “beyond the protections provided for other types of health information.”⁸⁶ State laws generally require an entity to obtain consent before it may act on your genetic data.⁸⁷ Sixteen states require a consumer to consent before a third party can conduct or demand a genetic test or even acquire genetic information, and twenty-four states condition genetic information disclosure on informed consent.⁸⁸ Further, eighteen states have provided for specific penalties (civil, criminal, or both) for genetic privacy violations.⁸⁹ However, as is also the case at the federal level, these state legislative efforts hardly address DTC genetic testing.

In addition to the legislation at the federal and state level, the Future of Privacy Forum released a Privacy Best Practices for Consumer Genetic Testing Services (“Best Practices Guide”).⁹⁰ The Future of Privacy Forum, along with leading DTC genetic testing companies including 23andMe and Ancestry.com, created the Best Practices Guide.⁹¹ However, the Best Practices Guide is merely a guide, and in no way are DTC genetic testing companies required to follow the guidelines contained in it.⁹² It merely encourages companies in the market to adopt certain privacy policies that can build consumer trust.⁹³ The Best Practices Guide establishes company privacy-policy standards for handling consumer-created genetic data.⁹⁴ The recommendations included in the guide address: “(1) Transparency; (2) Consent; (3) Use and Onward Transfer; (4) Access, Integrity, Retention, and Deletion; (5) Accountability; (6) Security; (7) Privacy By Design; and (8) Consumer Education.”⁹⁵ The Future of Privacy Forum developed the Best Practices Guide “to ensure continued innovation and consumer trust within the consumer genetic and personal genomic testing industry.”⁹⁶ While the Best Practices Guide serves as a good

86. *State Genetic Privacy Laws*, NAT’L CONF. OF ST. LEGISLATURES, <http://pierce.wesleyancollege.edu/faculty/hboettger-tong/docs/hbt%20public%20folder/FYS/State%20Genetic%20Summary%20Table%20on%20Privacy%20Laws.htm> [<https://perma.cc/4UWT-3F88>].

87. *Id.*

88. *Id.*

89. *Id.*

90. Carson Martinez, *Privacy Best Practices for Consumer Genetic Testing Services*, FUTURE OF PRIV. F. (July 31, 2018), <https://fpf.org/2018/07/31/privacy-best-practices-for-consumer-genetic-testing-services> [<https://perma.cc/DQ8R-Q5H2>].

91. *Id.*

92. *See id.* (indicating that the Best Practices Guide provides “recommendations”).

93. *Id.*

94. *Id.*

95. FUTURE OF PRIV. F., *PRIVACY BEST PRACTICES FOR CONSUMER GENETIC TESTING SERVICES 2* (2018), <https://fpf.org/wp-content/uploads/2018/07/Privacy-Best-Practices-for-Consumer-Genetic-Testing-Services-FINAL.pdf> [<https://perma.cc/2KFM-WGXX>].

96. *Id.*

starting point for the industry, it is not mandatory and therefore there is nothing to ensure that DTC genetic testing companies will follow the recommendations contained in it.

While some provisions at the federal and state level address genetic privacy concerns, none cover privacy concerns relating to DTC genetic testing, aside from requiring consent. Nor do any of the provisions relate to the business transfer clauses contained in these companies' privacy statements. Despite the easily recognizable risk associated with these business transfer clauses, there is nothing stopping a company from handing over a consumer's DNA in the event of a merger, sale, or acquisition. Therefore, safeguards should be put into place to combat the risks associated with these business transfer clauses.

IV. A SOLUTION TO THE BUSINESS TRANSFER CLAUSE

It is not hard to see the magnitude of privacy risks that business transfer clauses pose to the consumer, and with the constant growth of the DTC genetic testing market, it is important that the risks are addressed and mitigated.

A. *Default Interpretation Standard*

One possible solution that would mitigate the risks posed by the business transfer clause is for companies to adopt a default interpretation standard, whereby companies read the business transfer clause as requiring them to merge with, sell to, or be acquired by an entity with like interests. This would mean that in the event a DTC genetic testing company, such as 23andMe or Ancestry.com, goes through a sale, acquisition, or merger, they will only sell to, be acquired by, or merge with companies that have like interests as those of the genetic testing company.

Toysmart.com, LLC agreed to a similar requirement in its litigation with the Federal Trade Commission ("FTC") and related bankruptcy proceeding.⁹⁷ After Toysmart's creditors filed a petition for involuntary bankruptcy, Toysmart allegedly solicited bids for the purchase of its assets, including its "Customer Lists."⁹⁸ Toysmart's Customer Lists included "consumers' names, addresses, billing information, shopping preferences, and family profile information."⁹⁹ However, Toysmart's privacy policy on its website stated that "Personal Information voluntarily submitted by visitors to our site, such as name, address, billing information and shopping preferences, is never shared with a third

97. See generally *FTC v. Toysmart.com, LLC*, No. 00-11341-RGS, 2000 WL 34016434 (D. Mass. July 21, 2000).

98. See First Amended Complaint for Permanent Injunction and Other Equitable Relief, *FTC v. Toysmart.com, LLC*, No. 00-11341-RGS, 2000 WL 34016434 (D. Mass. July 21, 2000), 2000 WL 34016406.

99. See *id.*

party” and “[w]hen you register with toysmart.com, you can rest assured that your information will never be shared with a third party.”¹⁰⁰ Despite this explicit language, Toysmart allegedly attempted to share this information by soliciting bids to sell all of its assets, including customer information.¹⁰¹ The FTC and Toysmart ultimately stipulated that Toysmart could only sell or assign its assets to a company with like interests.¹⁰² The stipulated order stated that Toysmart “shall only assign or sell its Customer Information as part of its Goodwill and only to a Qualified Buyer approved by the Bankruptcy Court.”¹⁰³ “Qualified Buyer” was defined as “an entity that (1) concentrates its business in the family commerce market, involving the areas of education, toys, learning, home and/or instruction, including commerce, content, product and services, and (2) expressly agrees to be Toysmart’s successor-in-interest as to the Customer Information”¹⁰⁴ Therefore, Toysmart had to go back to the drawing board and solicit bids to companies only with like interests.

The stipulation between the FTC and Toysmart can be applied to the business transfer clauses contained in DTC genetic testing companies’ privacy statements. The default interpretation standard should be that these companies, such as 23andMe and Ancestry.com, are only allowed to transfer their assets—including their customers’ DNA—to entities with like interests. After all, considering the personal and sensitive nature of DNA, it is highly unlikely that consumers would expect their DNA to be transferred or sold to *any* company out there. This solution would solve that problem. Instead of the company putting its own interests first, the company would now have to balance both its own interests and the consumer’s interests before transferring any assets.

While ultimately Toysmart was unable to find a company to sell to, thus resulting in all of its “Customer Information” being destroyed,¹⁰⁵ this is an unlikely result for companies in the DTC genetic testing market. This market is booming, with new companies entering and existing companies leaving rapidly.¹⁰⁶ Roughly 100 million people will

100. *See id.*

101. *See id.*

102. *In re* Toysmart LLC, No. 00-13995-CJK (Bankr. E.D. Mass. filed July 21, 2000), <https://www.ftc.gov/sites/default/files/documents/cases/toysmarttbankruptcy.1.htm> [<https://perma.cc/YVG5-B2Q6>] (“Stipulation and Order Establishing Conditions On Sale Of Customer Information”).

103. *Id.*

104. *Id.*

105. Ultimately, the bankruptcy court never approved the order because there were no offers to buy Toysmart’s database. Instead, the bankruptcy judge agreed to allow Toysmart to sell its database to Disney, with the agreement that Disney would destroy the customer list. DANIEL J. SOLOVE & PAUL M SCHWARTZ, *INFORMATION PRIVACY LAW* 861–62 (5th ed. 2015).

106. Phillips, *supra* note 51, at 16, 22.

use a DTC genetic test by 2021.¹⁰⁷ With this increase in users comes an increase in the monetary value of the market itself, thereby attracting more companies. The DTC genetic testing market growth rate may reach 22% annually during the next decade, and the overall monetary value may exceed \$6 billion by 2028.¹⁰⁸ At this rate, the DTC genetic testing market would be ten times as large as it was in 2017.¹⁰⁹

Also worth noting, the growth in the market is not coming solely from inside actors; some growth can be attributed to outsiders entering the market. Recently, the Mayo Clinic, a nonprofit focused on educating, researching, and clinical practice,¹¹⁰ partnered with the DNA sequencing business, Helix, to market Gene Guide, a testing kit that “provides healthy customers with insights related to health and disease.”¹¹¹ Based on the expected market growth, along with the rapid increase of new entrants, it will be much easier for DTC genetic testing companies to find other companies with like interests, the result being the opposite of that in the *Toysmart* case.

Additionally, DTC genetic testing companies can go even further in establishing consumer trust by providing customers with notice and choice in the event of a sale, merger, or acquisition. Before the company transfers all of its data to the third-party entity, the company should: (1) provide its customers with notice; and (2) allow them a choice to opt-out. Opting-out would mean that consumers would instead prefer their data to be deleted, rather than transferred to the new entity. As FTC Commissioner Mozelle Thompson stated in the *Toysmart* case, “[C]onsumers would benefit from notice and choice before a company transfers their information to a corporate successor.”¹¹² It is highly unlikely that when providing these companies with their DNA, consumers expected or even thought about the potential of their DNA, and the rest of their personal information for that matter, being transferred to another company. As Commissioner Thompson put it, “[M]any of the consumers who disclosed their families’ personal information to Toysmart might not have been willing to turn over the same information to the particular corporate entity that ultimately succeeds Toysmart.”¹¹³ Commissioner Thompson goes on to state this is true even where the company’s assets are transferred to a

107. *Consumers Buy into Genetic Testing Kits*, AM. HOSP. ASS’N, <https://www.aha.org/aha-center-health-innovation-market-scan/2019-09-16-consumers-buy-genetic-testing-kits> [<https://perma.cc/9KC5-FW2B>].

108. *Id.*

109. *Id.*

110. *About Mayo Clinic*, MAYO CLINIC, <https://www.mayoclinic.org/about-mayo-clinic> [<https://perma.cc/SR6Q-MPRJ>].

111. *Consumers Buy into Genetic Testing Kits*, *supra* note 107.

112. Statement of Comm’r Thompson, *Toysmart.com, LLC*, FTC File No. X000075 (July 21, 2020), <https://www.ftc.gov/sites/default/files/documents/cases/toysamrt-thompsonstatement.htm> [<https://perma.cc/82ZJ-U8MT>].

113. *Id.*

company with like interests.¹¹⁴ Further, he “urge[s] any successor to provide Toysmart customers with notice and an opportunity to ‘opt-out’ as a matter of good will and good business practice.”¹¹⁵

B. *Types of Companies with “Like Interests”*

With the above solution in mind, it is worth discussing what types of companies have “like interests” as those of DTC genetic testing companies. But before doing that, one must determine what the “interests” of these DTC genetic testing companies actually are. One common goal of these companies is to provide consumers with information on and access to their human genome, which allows consumers insight into their origin, family tree, health history, and more.¹¹⁶ 23andMe’s mission is to “help people access, understand and benefit from the human genome.”¹¹⁷ Similarly, Ancestry.com wants to help consumers understand their genealogy and historical background, while also providing them with information relating to their families’ health.¹¹⁸ DTC genetic testing companies further advance the developments in the health industry through research.¹¹⁹ For example, 23andMe aims to change the scope of healthcare and disease prevention by accelerating the pace and quality of research and by providing people with power over their health data.¹²⁰

Thus, companies with “like interests” would be dedicated to using research to develop insights and breakthroughs in the healthcare industry, while also enabling consumers to learn more about their health background and history. But what types of companies fall under that umbrella? The first type that comes to mind is pharmaceutical companies. Like DTC genetic testing companies, pharmaceutical companies want to prevent disease through the advancement of drugs.¹²¹ The pharmaceutical industry prioritizes creating drugs that curb infections, sustain wellness, and remedy diseases.¹²² As discussed above, 23andMe similarly operates to prevent disease and facilitate quality

114. *Id.*

115. *Id.*

116. *See, e.g., Our Mission, 23ANDME*, <https://mediacenter.23andme.com/> [<https://perma.cc/EVX2-SCAX>]; *ANC.*, https://www.ancestry.com/?ancid=WKacajo4j8US&pgrid=33867221429&ptaid=kwd-42681891025&s_kwid=%2bancestrycom&gclid=EAIAIqObChMI2cn366ez5wIVzsDACH1qBwhsEAAAYASAAEgK72_D_BwE&gclidsrc=aw.ds&o_xid=57465&o_lid=57465&o_sch=paid+Search+Brand [<https://perma.cc/4ZJN-G3V9>].

117. *Our Mission, supra* note 116.

118. *ANC.*, *supra* note 116.

119. *Our Mission, supra* note 116.

120. *Id.*

121. Sybil Prowse, *An Easier Way to Understand the Pharma Industry*, *MKT. REALIST*, <https://articles2.marketrealist.com/2019/12/easier-way-understand-pharma-industry/#> (Dec. 9, 2019) [<https://perma.cc/VK4C-W2CR>].

122. *Id.*

drug manufacturing.¹²³ Additionally, pharmaceutical companies want to use research to develop better solutions in the healthcare field.¹²⁴ Over the last decade, the pharmaceutical industry has enhanced technology and infrastructure in the bioscience field using a research-oriented philosophy.¹²⁵ This research has helped with the development of various formulations that target and mitigate infections, such as HIV and cancer.¹²⁶ Both pharmaceutical companies and DTC genetic testing companies are devoted to using research to help prevent certain diseases. Ultimately, it seems as if pharmaceutical companies have “like interests” as those of DTC genetic testing companies, as their end goals are the same.

Any company dedicated to research in the medical field could be considered as having “like interests” as those of DTC genetic testing companies. Take, for example, medical marketing research companies. These companies gather, study, and categorize patient health information with attention to demographics and outcomes.¹²⁷ Likewise, DTC genetic testing companies also collect DNA data from consumers and break it down in a way that allows consumers to understand it and how it corresponds to certain illnesses and diseases. Therefore, medical marketing research companies would also have “like interests” as those of DTC genetic testing companies.

There are many other companies out there that could be considered as having “like interests” as those of DTC genetic testing companies. This Article does not attempt to define every single one, but instead explores what types of companies could qualify. When considering what types of companies have “like interests,” it is important to remember those interests of the DTC genetic testing companies themselves: to use research to develop insights and breakthroughs in the healthcare industry, while also providing more information to enable consumers and others to learn more about their health background and history.

C. *Conformity to Industry Best Practices*

Finally, the solution proposed here is in line with the recommendations contained in the Best Practices Guide.¹²⁸ As discussed earlier, leading companies in the market, including Ancestry.com and 23andMe, assembled the guide.¹²⁹ This Best Practices Guide encourages companies in the market to adopt certain privacy policies that

123. *Our Mission*, *supra* note 116.

124. *See Prowse*, *supra* note 121.

125. *Id.*

126. *Id.*

127. *26 Top Medical Marketing Research Companies for 2018*, QUIRK'S MEDIA (Oct. 2018), <https://www.quirks.com/articles/26-top-medical-marketing-research-companies> [<https://perma.cc/WPH4-DG57>].

128. FUTURE OF PRIV. F., *supra* note 95, at 7.

129. Martinez, *supra* note 90.

can build trust with consumers.¹³⁰ Focusing on the Use and Onward Transfer section, the guide addresses the ability of companies to transfer consumer data to other entities.¹³¹ The Best Practices Guide states that the industry best practice is to only collect, use, and share genetic data “in ways that are compatible with reasonable Consumer expectations for the context in which the data was collected.”¹³² The Best Practices Guide recommends that in the event the company goes through a sale, acquisition, or merger, the company “should either dispose of Consumers’ Genetic Data and Biological Samples securely, or ensure recipient third party commitments consistent with the original notices provided to the Consumer.”¹³³ Therefore, following the solution proposed here would also ensure that the DTC genetic testing company conforms with industry best practices. By only selling to, merging with, or being acquired by companies with like interests, DTC genetic testing companies are ensuring that the consumer’s expectations are met and that the third-party company will only use the consumer’s information in a way that adheres to the original privacy policies that the consumer agreed to.

V. CONCLUSION

With the ever-growing popularity of DTC genetic tests, it is important that the risks posed by these tests are mitigated, especially privacy risks. And within this group of privacy risks comes the risk that is posed by the business transfer clauses contained in DTC genetic testing companies’ privacy policies. The business transfer clause allows these companies to transfer all of their data—including the consumer’s DNA—to any entity that they sell to, merge with, or are acquired by, notwithstanding the third-party entity potentially having completely different interests and goals. This poses a privacy risk to the consumer who probably did not expect, or even know, that the business transfer clause existed. With the lack of regulations addressing the privacy implications of DTC genetic tests, any solution must be consumer-oriented. This Article urges DTC genetic testing companies to interpret the business transfer clause as only allowing them to sell to, merge with, or be acquired by entities with “like interests.” This solution not only protects the consumer, but also conforms with industry best practices. With the growing market and increase of new entrants, there will be many options for DTC genetic testing companies to choose from, thereby making the solution an easy one to conform with.

130. *Id.*

131. FUTURE OF PRIV. F., *supra* note 95, at 7.

132. *Id.*

133. *Id.*

