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ABSTRACT

Public genealogy websites, to which individuals upload family history, genealogy, and sometimes individual genetic data, have been used in an increasing number of public health, epidemiological, and genetic studies. Yet there is little awareness among researchers of the legal rules that govern the use of these online resources. We analyzed the online Terms of Use (TOU) applicable to 17 popular genealogy websites and found that none of them expressly permit scientific research, while at least 13 contain restrictions that may limit or prohibit scientific research using data obtained from those sites. In order to ensure that researchers who use genealogy and other data from these sites for public health and other scientific research purposes do not inadvertently breach applicable TOUs, we recommend that genealogy website operators consider revising their TOUs to permit this activity.

KEYWORDS: genealogy, genetic epidemiology, terms of use, family history, public health, contract

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I. INTRODUCTION

Interest in genealogy and family history is reportedly high and continuing to grow in the United States. A wide variety of online resources exist to support genealogical research by hobbyists and professionals alike.¹ Among these resources are instructions and tips for genealogical research, compilations of public records, and publicly accessible websites that permit individuals to access family history, genealogy, and sometimes individual genetic data ('Genealogy Websites'). Major Genealogy Website operators include AncestryDNA, FamilySearch, MyHeritage, and GEDMatch. Some of the major consumer-focused personal genomics firms such as 23andMe do not currently accept or display genealogy data and are thus not included in this category. The information contained on Genealogy Websites is generally accessible to the public, sometimes at no charge or at modest subscription fees.² Some Genealogy Websites have become extensive. MyHeritage, for example, reports that it hosts 48 million family trees.³

In recent years, the data found on Genealogy Websites have been accessed and used for a variety of purposes beyond genealogical research. Most notably, the use of Genealogy Websites and consumer uploaded genetic data for criminal investigation purposes has received significant attention in the wake of high-profile cases such as that of the 'Golden State Killer.'⁴ Likewise, a public dialog has begun regarding the appropriateness of using such technological resources in connection with crimes of a less serious nature—assault and battery as opposed to homicide.⁵ In response to privacy concerns raised by law enforcement use of data from Genealogy Websites, several prominent Genealogy Website operators, including GEDMatch and FamilyTreeDNA, amended their online terms of use (TOU) to prohibit the use of their data for law enforcement purposes without the consent of the data subject.⁶ Other leading Genealogy Website operators, including Ancestry, have publicly announced that they will not voluntarily make consumer-uploaded data available to law enforcement authorities or other third parties.⁷ All of these sites have genetic information linked to their pedigrees and the terms of use cover both genealogy and genetic data. In addition to law enforcement, there are other controversial uses of genealogy and linked genetic data including surveillance, insurance underwriting, direct marketing, and racial profiling.

Yet there is another, less controversial, use for Genealogy Website data: public health research. Since Genealogy Websites first went online, researchers have been using the

1 Cyndi's List, cyndislist.com (accessed Sept. 6, 2019).

2 The public nature of genealogy and other data contained on Genealogy Websites varies. In some cases, data is simply accessible to any web browser. In others, data are accessible only to other registered users or paying subscribers. In addition, the accessibility of genealogical and genetic data varies on some sites.

3 MyHeritage Ltd. (n.d.), <https://www.myheritage.com/> (accessed Oct. 28, 2019).

4 See Teneille R. Brown, *Why We Fear Genetic Informants: Using Genetic Genealogy to Catch Serial Killers*, 21 COLUM. SCI. TECH. L. REV. 1 (2020); Heather Murphy, *How an Unlikely Family History Website Transformed Cold Case Investigations*. N.Y. TIMES. Oct. 15, 2018.

5 Peter Aldhous, *The Arrest Of A Teen On An Assault Charge Has Sparked New Privacy Fears About DNA Sleuthing*. BuzzFeed News. May 14, 2019. <https://www.buzzfeednews.com/article/peteraldhous/genetic-genealogy-parabon-gedmatch-assault> (accessed Oct. 23, 2019).

6 Natalie Ram & Jessica L. Roberts, *Forensic genealogy and the power of defaults*. 37 NATURE BIOTECH. 707–08 (2019).

7 Ancestry, *Ancestry Guide for Law Enforcement* (n.d.), <https://www.ancestry.com/cs/legal/lawenforcement> (accessed Oct. 28, 2019).

data that they contain in large-scale epidemiological and population health studies.⁸ In many cases, data are collected from Genealogy Websites using automated tools and analyzed using sophisticated algorithms. These techniques have supported a growing number of discoveries and scientific papers. For example, Cannon-Albright et al. have shown evidence of excess familial clustering for Alzheimer's Disease in a veteran population using U.S. population genealogy resources,⁹ Kaplanis et al. have studied longevity and family dispersion using population-scale family trees representing 86 million individual Genealogy Website profiles,¹⁰ and Carbone et al. traced an inherited cancer syndrome found in four seemingly independent U.S. families back to a single German couple born in the 1700s using data from *Ancestry.com*.¹¹

Despite the increasing utility of Genealogy Website data in public health research, it is not always clear that the contractual TOUs associated with public genealogy databases permit the conduct of this research, and the increasing pressure on Genealogy Website operators to limit the use of these resources in the context of criminal investigation and other unwanted activity may result in further limitations on the ability of researchers to make use of these valuable resources. Moreover, we have informally observed that many researchers are unaware of either the existence, or legal effect, of Genealogy Website TOUs, thus making these researchers vulnerable to legal claims for which they are unprepared. Researchers may be lulled into a false sense of security due to the unrestricted access that members of the public are given to Genealogy Website data and the fact that even if such data are used in violation of applicable usage restrictions, the tracing of that data to a specific Genealogy Website may be difficult, if not impossible, given that there are often multiple publicly-accessible sources of the same genealogical data.¹²

To evaluate the impact of TOU restrictions on the conduct of biomedical research using data derived from Genealogy Websites, we analyzed the online TOUs of leading Genealogy Websites.¹³ The remainder of this article proceeds as follows: Section II provides a short overview of the legal landscape surrounding Genealogy Website data, including the enforceability of TOUs and the penalties for noncompliance. Section III presents the results of our study of the TOUs of major Genealogy Websites and their potential impact on biomedical research. In Section IV, we discuss our findings and make recommendations for both researchers and Genealogy Website operators who

8 Vigidis Stefansdottir, et al. *The use of genealogy databases for risk assessment in genetic health service: a systematic review*. 4 J. COMMUNITY GENET. 1 (2013).

9 Lisa A. Cannon-Albright, et al. *A Population Genealogy Resource shows evidence of familial clustering for Alzheimer's Disease*. 4 NEUROL. GENET. (2018).

10 Joanna Kaplanis, et al. *Quantitative analysis of population-scale family trees with millions of relatives*. 360(6385) SCIENCE 171 (2018).

11 Michele Carbone, et al. *Combined Genetic and Genealogic Studies Uncover a Large BAP1 Cancer Syndrome Kindred Tracing Back Nine Generations to a Common Ancestor from the 1700s*. 11 PLoS GENET. e1005633 (2015).

12 While this may be true, the difficulty of detection merely impacts the likelihood that a particular researcher will be identified as violating a relevant TOU, not whether or not the TOU is violated. We do not address the forensic and evidentiary questions raised by the unauthorized use of Genealogy Website data and assume that, in at least some cases, detection is possible, thus placing researchers at risk.

13 In addition to TOUs, most websites include a privacy policy, which describes the manner in which the site operator will treat user data. We did not analyze privacy policies because these largely restrict the actions of the site operator, as opposed to TOUs, which restrict the actions of the user (researcher).

wish to enable socially valuable biomedical research without fully relinquishing control over the use of their data in other, more controversial, applications.

II. THE LEGAL PROTECTION OF GENEALOGY WEBSITE DATA

Although the data found on many Genealogy Websites is accessible to the public, often without payment,¹⁴ ease of access does not mean that such data are available without restriction. Most websites today contain, or link to, TOUs that purport to govern the terms on which such websites, and the content available on them, may be accessed and used.¹⁵ Although many consumers are unaware of the precise terms of these TOUs, it is well-established under U.S. law that such TOUs, provided that users are notified of them, form binding contractual arrangements between website operators and users.¹⁶

The use of online content in a manner that violates applicable TOUs would constitute a breach of contract, subjecting the user (i.e., the researcher) to liability associated with contractual breaches including monetary damages and injunctions against further unauthorized use.¹⁷ Such a breach of contract claim would likely be brought by a site operator, as a researcher accessing a Genealogy Website would be deemed to have a contractual relationship with that operator through the TOU. It is also possible that an individual contributor of data to a Genealogy Website could bring a breach of contract action against a researcher using data in violation of a TOU under a third party beneficiary theory (i.e., the data contributor could claim that it was an intended beneficiary of the contractual TOU between the site operator and the researcher).¹⁸

The violation of online TOUs could also give data contributors other legal actions against researchers, including trespass to chattels, misappropriation, unjust enrichment and conversion.¹⁹ Some U.S. courts have also held that violating the terms of an online TOU can give rise to liability under the federal Computer Fraud and Abuse Act, a federal criminal statute.²⁰

14 See *supra* note 2.

15 Nancy S. Kim, Juliet M. Moringiello, & John E. Ottaviani, *Notice and Assent Through Technological Change: The Enduring Relevance of the Work of the ABA Joint Working Group on Electronic Contracting Practices*, 75 BUS. LAW. 1725 (2020).

16 See *Id.*

17 See Restatement (Second) of Contracts § 211 (1981); Jerome H. Reichman & Paul F. Uhlir, *A Contractually Reconstructed Research Commons for Scientific Data in a Highly Protectionist Intellectual Property Environment*, 66 L. & CONTEMP. PROBS. 315, 381 (2003) (“Electronic contracts become substitutes for intellectual property rights to the extent that they make it infeasible for third parties to obtain publicly disclosed but electronically fenced data without incurring contractual liability for damages”).

18 See, e.g., Restatement (Second) of Contracts § 302(1) (1981) (“Unless otherwise agreed between promisor and promisee, a beneficiary of a promise is an intended beneficiary if recognition of a right to performance in the beneficiary is appropriate to effectuate the intention of the parties and . . . the circumstances indicate that the promisee intends to give the beneficiary the benefit of the promised performance.”).

19 See, e.g., *HIQ Labs, Inc. v. LinkedIn Corp.*, 938 F.3d 985, 1004 (Ninth Cir. 2019); *Associated Press v. Meltwater U.S. Holdings, Inc.*, 931 F.Supp. 2d 537, 561 (S.D.N.Y. 2013).

20 18 U.S.C. § 1030. See *EF Cultural Travel BV v. Explorica, Inc.*, 274 F.3d 577, 583–84 (First Cir. 2001) (violations of contractual restraints supports a claim for unauthorized access under the CFAA); *United States v. Rodriguez*, 628 F.3d 1258, 1263 (11th Cir. 2010) (violating policies governing authorized use of a database can give rise to a claim under the CFAA). *But see* *HIQ Labs*, 938 F.3d at 1000 (“we reject[] the contract-based interpretation of the CFAA’s “without authorization” provision adopted by some of our sister circuits.”).

Of course, it is well-known that raw data and facts, including family relationships, vital statistics and medical histories, are not protected in the U.S. by copyright or other forms of intellectual property.²¹ As described by Justice Louis Brandeis more than a century ago, facts are as ‘free as the air to common use.’²² But the fact that Genealogy Website data are not protected by copyright or similar laws does not automatically free them from contractually-imposed restrictions on their use. Courts have long held that contractual restrictions can validly limit or prohibit the use of material that would otherwise be free to use under copyright law.²³

It is also important to note the distinction between the contractual restrictions imposed by TOUs and informed consent requirements under human subjects research regulations.²⁴ Under the Common Rule and other applicable U.S. research regulations, researchers are not permitted to use data collected from an individual without that individual’s informed consent. But Genealogy Website data are not collected by researchers from individuals. Rather, the individual sources of Genealogy Website data have, for the most part, voluntarily uploaded those data and thus made them publicly available.²⁵ Accordingly, issues of informed consent and data privacy are less salient here than in the typical medical research context.²⁶ Moreover, it is not clear that genealogical information—family relations, dates of birth, death and marriage, and the like—would be considered protected health information under other regulatory regimes, such as the HIPAA Privacy Rule.²⁷ As a result, the principal (though perhaps not the only)

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- 21 *Int’l News Serv. v. Associated Press*, 248 U.S. 215 (1918) The European Union has for years recognized a form of database protection under the EU Database Directive. Directive 96/9/EC of the European Parliament and of the Council of 11 March 1996 on the legal protection of databases. As such, yet a further layer of protection exists for the data contained on Genealogy Websites.
- 22 *Int’l News Serv. v. Associated Press*, 248 U.S. 215, 250 (1918) (Brandeis, J., dissenting). See, also, Jorge L. Contreras, *The False Promise of Health Data Ownership*, 94 N.Y.U. L. REV. 624 (2019) (refuting arguments regarding the existence of common law property rights in health information).
- 23 See, e.g., *Bowers v. Baystate Techs., Inc.*, 320 F.3d 1317 (Fed. Cir. 2003) (upholding provisions in a software license agreement that require the user to waive its copyright fair use rights to reverse engineer the software); Michael W. Carroll, *Copyright and the Progress of Science: Why Text and Data Mining Is Lawful*, 53 U.C. DAVIS L. REV. 893, 897 (2019) (“users’ rights can be waived by contract”); Reichman & Uhler, *supra* note 17, at 380 (“even if a given compilation of data lacked any copyrightable “fig leaf” whatsoever, . . . the electronic contract accepted at the gateway to the provider’s electronic fence may itself enable him to control all the uses of the noncopyrightable data, which would technically enter the public domain”).
- 24 Research on human subjects in the United States, when funded by the federal government or pursued in connection with drug or device approval, is regulated by the so-called “Common Rule”. General Requirements for Informed Consent, 45 C.F.R. § 46.116 (2019). See, generally, Christine Grady, *Enduring and Emerging Challenges of Informed Consent*, 372 N.ENG. J. MED. 855 (2015).
- 25 There are, of course, exceptions, such as a family member’s uploading of a relative’s data or a parent’s uploading of a minor child’s data.
- 26 See, e.g., *HIQ Labs*, 938 F.3d at 994 (“there is little evidence that LinkedIn users who choose to make their profiles public actually maintain an expectation of privacy with respect to the information that they post publicly, and it is doubtful that they do.”).
- 27 The HIPAA Privacy Rule protects “individually identifiable information”, including demographic data, that relates to: an individual’s past, present or future physical or mental health or condition, the provision of health care to the individual, or the past, present, or future payment for the provision of health care to the individual, and that identifies the individual or for which there is a reasonable basis to believe it can be used to identify the individual. See 45 C.F.R. § 160.103; Dept. Health Human Svcs., Summary of the HIPAA Privacy Rule, <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html> (accessed Apr. 21, 2020).

mechanism that limits the use of individual data uploaded to Genealogy Websites is the contractual TOU imposed by the site operator.

III. UNDERSTANDING TERMS OF USE OF PUBLIC GENEALOGY DATABASES

III.A. Methodology

In order to assess the restrictive nature of Genealogy Website TOUs, we first identified a set of leading Genealogy Websites from lists of ‘top’ Genealogy Websites contained in three popular genealogy resources visited in September 2019: *FamilyTree Magazine*, *GenealogyInTime Magazine* and *Cyndi’s List*. From these lists we selected those Genealogy Websites that allow users to download genealogy and family tree data, with or without genetic data. To avoid duplication, we eliminated websites powered or operated by the same corporate entity. This selection process resulted in a set of 17 relevant Genealogy Websites (Table 1).

From these 17 Genealogy Websites, we extracted and analyzed the relevant portions of their TOUs as of Sept. 26, 2019. The full text of these TOUs is contained in the Appendix. Within the TOUs we identified five common types of user restrictions, discussed below.

Four of the 17 Genealogy Websites focus on communities outside the United States (United Kingdom, Ukraine, France, and The Netherlands). The international sites showed a similar distribution of TOU restrictions as those found on U.S.-based sites.

III.B. Findings

Of the 17 Genealogy Websites that we analyzed, 11 charge for access and six appear to be freely accessible to the public. All 17 Genealogy Websites contained TOUs linked to usage of the sites. Of these, four contained TOUs that were rudimentary and open-ended, seemingly permitting all uses of their content. Thirteen Genealogy Websites, however, contained TOUs that restricted the use of content in some manner. We classified these restrictions in the following manner:

- **Genealogical Use Only:** limits usage to personal, private or professional genealogical use²⁸ [11 sites]
- **No Commercial Use:** prohibits any commercial use of content²⁹ [8 sites]
- **No Downloads:** prohibits downloading all or significant portions of other users’ content³⁰ [5 sites]

28 See, e.g., *Ancestry.com* TOU (Appendix): “You may use the Ancestry Content only as necessary for your personal use of the Services or your professional family history research, and download the Ancestry Content only as search results relevant to that research or where expressly permitted by Ancestry.”

29 See, e.g., *WikiTree* TOU (Appendix): “Non-Commercial Use Only. The Website is for noncommercial, personal use only. You may not use the Website for any commercial purpose without our prior, express authorization. Prohibited commercial uses include, but are not limited to the following: Posting content that advertises or provides a commercial service or product, including commercial advertisements, affiliate links, or other forms of solicitation, without our express written authorization. Selling access to the Website on another website or service or framing the Website on another website or service. Any use of the Website that we find, in our sole discretion, to use our resources, content, or Services in a manner that competes with or displaces the market for the Website or the content or Services provided here.”

30 See, e.g., *MyTrees* TOU (Appendix): “The download of all or a significant portion of any database in the archive is prohibited.”

Table 1. Summary of Restrictions Found in Genealogy Website TOUs

<i>Website</i>	<i>Free/Pay</i>	<i>Restrictions</i>
Ancestry	Pay	Genealogical Use Only, No Downloads, No Transfer
FamilySearch.org	Free	None Applicable
Familytree.com	Free	No Automated Access, No Transfer
FamilyTreeNow.com	Free	No Commercial Use, Genealogical Use Only
findmypast.co.uk	Pay	No Commercial Use, Genealogical Use Only, No Downloads, No Automated Access
GEDmatch.com	Free	None Applicable
Genealogie Online (Dutch)	Pay	No Transfer
Genealogie.com (Filae.com) (French)	Pay	Genealogical Use Only, No Automated Access
GeneaNet	Pay	No Commercial Use, Genealogical Use Only, No Automated Access
geni.com	Pay	No Commercial Use, Genealogical Use Only
MyHeritage.com	Pay	No Commercial Use, Genealogical Use Only, No Downloads, No Automated Access, No Transfer
Myrelatives.com	Pay	No Commercial Use, Genealogical Use Only, No Automated Access
MyTrees	Pay	Genealogical Use Only, No Downloads, No Transfer
One Great Family	Pay	None Applicable
Rodovid	Free	None Applicable
Tribal Pages	Pay	No Commercial Use, Genealogical Use Only, No Automated Access
WikiTree	Free	No Commercial Use, Genealogical Use Only, No Downloads, No Automated Access

- **No Automated Access:** prohibits automated scraping, crawling, and/or harvesting of content³¹ [8 sites]
- **No Transfer:** prohibits unauthorized distribution, reproduction, retransmission, publication, sale, exploitation (commercial or otherwise), or any other form of transfer of any portion of the content³² [5 sites]

31 See, e.g., [MyRelatives.com](#) TOU (Appendix): “You also agree that you will not use any type of automated device, including but not limited to robots, spiders or any data mining technique, for the purpose of downloading, copying, storing or distributing MyRelatives content, or to copy or manipulate MyRelatives Applications or services.”

32 See, e.g., [FamilyTree.com](#) TOU (Appendix): “It is further prohibited to cut and paste, sell, license, rent, lease, modify, distribute, copy, reproduce, transmit, publicly or display derivative works from materials, code or content on or from [FamilyTree.com](#).”

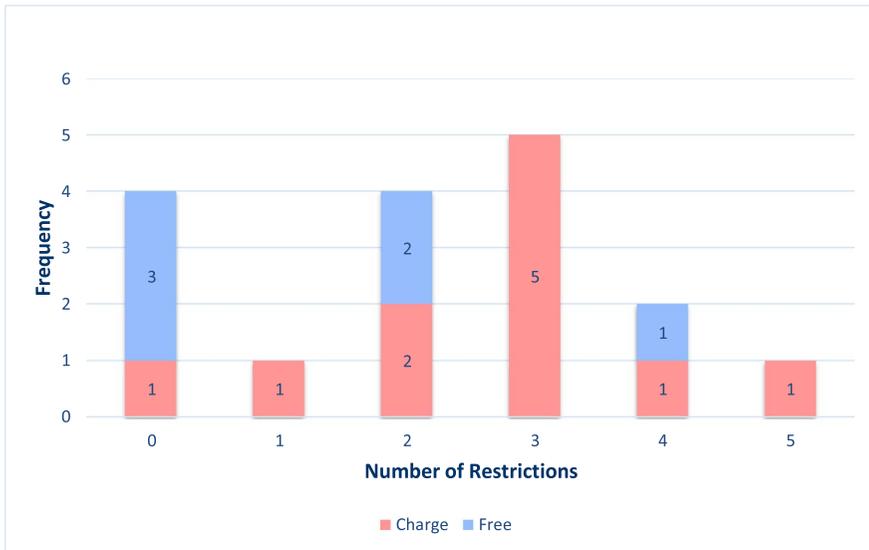


Figure 1. Frequency of Genealogy Websites by Number of TOU Restrictions

Table 1 summarizes the TOU restrictions for each Genealogy Website studied.

Restrictions on use were found in both paid and free Genealogy Website TOUs. However, of the six free Genealogy Websites, half had permissive TOUs with no stated restrictions on data use, whereas 10 of 11 paid Genealogy Websites (91%) had restrictive TOUs. This finding is not surprising, given that paid sites are more likely to have funding for legal advice and those TOUs that are more legalistic and restrictive in nature.

Of TOUs with usage restrictions, most contained multiple types of restrictions (Figure 1). This suggests that Genealogy Website operators, and the attorneys who draft their TOUs, often view these restrictions as a package, without much differentiation among them.

IV. DISCUSSION

IV.A. Implications

Our findings indicate that it is possible that the use of data obtained from a majority of popular Genealogy Websites for scientific research, including most paid sites and at least half of free sites, could be inconsistent with one or more restrictions imposed by the TOUs associated with those sites.

Figure 2 shows the prevalence of different types of restrictions within the TOUs studied.

Each of the identified restrictions has the potential to prohibit or limit biomedical research using data obtained from Genealogy Websites in the following ways:

Genealogical Use Only—Restrictions permitting genealogical use only prohibit all other uses, which include, by definition, epidemiological and population health research.

No Commercial Use—While ‘no commercial use’ could, under some circumstances, be interpreted to permit academic research, the legal scope of ‘noncommercial’ usage

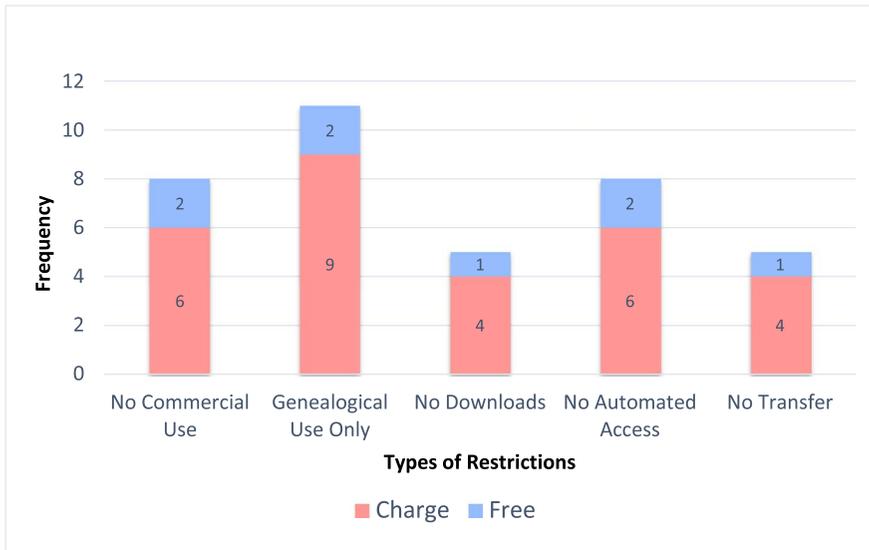


Figure 2. Frequency of TOU Restriction Types

in the U.S. has been found in other contexts to be quite narrow. For example, in *Madey v. Duke University*,³³ the leading U.S. case on the so-called ‘research exemption’ from patent infringement, the U.S. Court of Appeals for the Federal Circuit held that, in order to avoid infringement of a patent held by one of its former faculty members, a university had to show that its activities were conducted ‘solely for amusement, to satisfy idle curiosity, or for strictly philosophical inquiry.’³⁴ Under this standard, most research projects at universities, would fail to escape liability under the research exemption, as they ‘unmistakably further the institution’s legitimate business objectives, including educating and enlightening students and faculty participating in these projects[,] increase the status of the institution and lure lucrative research grants, students and faculty.’³⁵

Under U.S. law, a second research exemption arises under the 1984 Drug Price Competition and Patent Term Restoration Act (the Hatch–Waxman Act),³⁶ which enables generic drug competition once the patents on an FDA-approved drug have expired. In particular, § 271(e)(1) of the Act creates a safe harbor for research and experimentation with drugs (including medical devices) conducted in anticipation of an application for FDA approval. The provision was created in order to allow generic drug manufacturers to begin testing their products during the last years of a drug patent’s life without infringing that patent, but it has been expanded through judicial interpretation to encompass a wide variety of drug-related R&D activity.³⁷ Given the

33 *Madey v. Duke Univ.*, 307 F.3d 1351, 1352 (Fed. Cir. 2002).

34 *Id.* at [1362].

35 *Id.*

36 Public Law 98–417, codified at 21 U.S.C. § 301 et seq.

37 See *Merck KGAA v. Integra Lifesciences I, Ltd.*, 545 U.S. 193 (2005) (the statute gives “wide berth for the use of patented drugs in activities related to the federal regulatory process”); Alicia A. Russo & Jason Johnson, *Research Use Exemptions to Patent Infringement for Drug Discovery and Development in the United States*, 2015 COLD SPRING HARBOR PERSPECTIVES IN MED. 5:a020933 (2015).

prevailing state of the law, TOU restrictions on commercial use could be interpreted to prohibit biomedical research, particularly if that research is not in pursuit of regulatory approval of a drug or device.³⁸

No Downloads, No Automated Access—Restrictions on downloading and automated access impact not the purposes for which Genealogy Website data may be used, but the means by which they are accessed. Because the analysis of Genealogy Website data would, in all likelihood, require downloading to the researcher's computer, this restriction would practically prevent research usage of Genealogy Website data. Likewise, given the need to access and analyze large data sets (e.g., the 86 million individual Genealogy Website profiles studied by Kaplanis et al.), prohibitions on the automated scraping or ingestion of Genealogy Website data would, for all practical purposes, limit research use to small data sets that could be entered and manipulated by hand.³⁹

No Transfer—Finally, restrictions on transfer, reproduction, and distribution of Genealogy Website data would severely limit the ability of researchers to combine Genealogy Website data with other data sets and to make it available to collaborators.⁴⁰ In addition, such restrictions could seriously limit the ability of researchers to make the data upon which their findings are based available for validation and experimental reproducibility, an obligation that is increasingly imposed by funding agencies and scientific journals.⁴¹

It is notable that *no* Genealogy Website TOUs that we examined, even those lacking specific restrictions on data usage, expressly *permit* the use of publicly available data for public health or other scientific research. While express permission is not necessarily required to use data for research purposes, it is possible that applicable background laws and regulations concerning data privacy, individual consent and the like could tilt the balance against the use of such data without the permission of the individual data contributor. Thus, even without express prohibitions on use, any use of Genealogy Website data without the permission of the data contributor could give rise to liability on the part of the data user/researcher.

In all of these cases, the use of Genealogy Website data for nonpermitted purposes could expose researchers to legal liability under applicable contract, privacy and other laws and regulations. And while we are not aware that any legal action has yet been initiated against a researcher for violation of a TOU or other law in connection with research using Genealogy Website data, the growing public awareness of these issues (e.g., in connection with criminal investigations) increases the likelihood that such liability could arise in the future.

IV.B. Recommendations

TOU restrictions should not be ignored, and both researchers and Genealogy Website operators should approach the use of Genealogy Website data with care. In order to

38 See, generally, Jorge L. Contreras, *Research and Repair: Expanding Exceptions to Patent Infringement in Response to A Pandemic*, J.L. BIOSCI. (forthcoming, 2020) (critiquing narrow scope of the research exemption under U.S. law).

39 Cf. Carroll, *supra* note 23 (arguing for the importance of text and data mining to scientific research).

40 See *Id.* at [897] (discussing online contractual limitations on reproduction and manipulation of data).

41 See Heather Piwower & Wendy Chapman, *A review of journal policies for sharing research data*. NATURE PRECEDINGS (2008). <https://doi.org/10.1038/npre.2008.1700.1>.

ensure that researchers who use online Genealogy Website content for legitimate public health and other scientific research purposes do not inadvertently breach applicable TOUs, research institutions should make an effort to caution their researchers about the indiscriminate use of Genealogy Website data (and other online materials).

To the extent that Genealogy Website operators and their users wish to enable biomedical research using Genealogy Website data, operators should amend their TOUs to expressly allow such research to be conducted.⁴² Any such amendment should clearly define the types of research activities that are allowed, and grant researchers express permission to access, download, combine, and analyze the data. In addition, site operators should consider whether to allow researchers to reproduce and/or republish such data, particularly if they may be operating under data sharing mandates imposed by research funders or scientific journals.⁴³

The Genealogy Website operator may also wish to emphasize, and expressly state, that allowing data to be used for scientific research purposes does not include law enforcement, surveillance, racial profiling, insurance underwriting, direct marketing, or other commercial purposes. Site operators that are particularly concerned about data being used for nefarious purposes may also wish to implement a data access committee (DAC) like those used by many nonpublic databases containing individual-level information.⁴⁴ Such a DAC could screen proposed data uses to ensure that they align with the goals and standards of the site operator and its users.

Finally, TOUs may be amended to require that the data user acknowledge the Genealogy Website data source in any publications or public presentations making substantial use of the data obtained from the site. Such ‘attribution’ requirements are common in online content agreements such as those published by Creative Commons,⁴⁵ and it is notable that one of the Genealogy Websites that we studied (Rodovid) makes its contents available under such a licensing scheme.

One particularly thorny issue with respect to amending TOU terms is the effect of an amendment on data that was uploaded to the Genealogy Website prior to the amendment. In other words, will the amendment have *retroactive* effect? The answer to this question will vary based on factors including the jurisdiction and the other terms of the site’s TOU. Some TOUs permit a website operator to amend the TOU unilaterally, upon notice to users or posting of the revised TOU to the site.⁴⁶ If a particular Genealogy Website had followed this approach, then an amendment could have an immediate effect on all data available on the site (with the understanding that a data contributor that does not agree should then be free to withdraw his or her data

42 Cf. Carroll, *supra* note 23, at 897 (urging librarians to “negotiate with vigor to eliminate or to reduce [publishers’] contractual restrictions on researchers’ rights to engage in [text and data mining]”).

43 See *supra* note 41, and accompanying text.

44 Masha Shabani, Bartha M. Knoppers & Pascal Borry, *Genomic Databases, Access Review, and Data Access Committees*. In MEDICAL AND HEALTH GENOMICS 29–35 (Kumar D, Antonarakis S, eds, 2016).

45 www.creativecommons.org.

46 See, e.g., MyHeritage Ltd., MyHeritage—Terms and Conditions (n.d.) https://www.myheritage.com/FP/Company/popup.php?p=terms_conditions (accessed Oct. 28, 2019). See, generally, Jessica L. Roberts & Jim Hawkins, *When health tech companies change their terms of service*, 367 SCIENCE 745 (2020); Shmuel I. Becher & Uri Benoliel, *Sneak In Contracts: An Empirical And Legal Analysis Of Unilateral Modification Clauses In Consumer Contracts*, 55 GEORGIA L. REV. (2020, forthcoming); David Horton, *The Shadow Terms: Contract Procedure and Unilateral Amendments*, 57 UCLA L. REV. 605 (2010) (discussing the growth of unilateral contract amendments particularly in the context of consumer contracts).

from the site). For sites that have not adopted unilateral amendment provisions, the effect on existing data is less clear, and the site operator may need to obtain asset to the amendment by individual data contributors, or make the amendment applicable only to data uploaded after the change.

V. CONCLUSION

The data contained in public Genealogy Websites are increasingly valuable resources for genetic and epidemiological research. Yet our analysis of the online Terms of Use (TOUs) applicable to 17 popular Genealogy Websites found that none of them expressly permit scientific research, while at least 13 of them contain restrictions that may limit scientific research in some manner. In order to ensure that valuable research can be pursued and that researchers who use online Genealogy Website data for legitimate research purposes do not inadvertently breach applicable TOUs, we suggest that Genealogy Website operators consider amending their TOUs in a manner that expressly allows such research to be conducted. This express authorization need not permit more controversial uses such as law enforcement, surveillance, racial profiling, insurance underwriting, direct marketing, or other commercial purposes.

APPENDIX

Terms of Use Restrictions from Genealogy Websites (accessed Sept. 2019)

Genealogy Website	TOU Language
Familytree.com	Unauthorized access, distribution, reproduction, copying, retransmission, publication, sale, exploitation (commercial or otherwise), or any other form of transfer of any portion of FamilyTree.com , including but not limited to all content, reviews, user data, forum posts, blog entries, or blog commentary, databases, services, digital products, listings, courses, events, tools or products is hereby expressly prohibited. It is further prohibited to cut and paste, sell, license, rent, lease, modify, distribute, copy, reproduce, transmit, publicly or display derivative works from materials, code or content on or from FamilyTree.com .
FamilyTreeNow.com	Personal Use Only. The FamilyTreeNow.com Applications, the Content and the Services are intended for your personal, noncommercial use in accordance with these Terms. You agree that you will not, unless specifically permitted by us (i) copy, display or distribute any part of the Content or FamilyTreeNow.com Applications, in any medium, without FamilyTreeNow.com 's prior written consent

(Continued)

Genealogy Website	TOU Language
WikiTree	<p>General Use of the Website</p> <p>Non-Commercial Use Only. The Website is for non-commercial, personal use only. You may not use the Website for any commercial purpose without our prior, express authorization. Prohibited commercial uses include, but are not limited to the following:</p> <p>Posting content that advertises or provides a commercial service or product, including commercial advertisements, affiliate links, or other forms of solicitation, without our express written authorization.</p> <p>Selling access to the Website on another website or service or framing the Website on another website or service.</p> <p>Any use of the Website that we find, in our sole discretion, to use our resources, content, or Services in a manner that competes with or displaces the market for the Website or the content or Services provided here.</p> <p>No Automated Copying. You agree not to use or launch any automated system, including without limitation, “robots,” “spiders,” or “offline readers,” that accesses the Website in a manner that sends more request messages to our servers in a given period of time than a human can reasonably produce in the same period by using a conventional on-line web browser.</p> <p>Notwithstanding the foregoing, we grant the operators of public search engines permission to use spiders to copy materials from the site for the sole purpose of and solely to the extent necessary for creating publicly available searchable indices of the materials, but not caches or archives of such materials. We reserve the right to revoke these exceptions either generally or in specific cases</p> <p>No Personal Information Harvesting. You agree not to collect any personally identifiable information, including WikiTree IDs, from the Website, nor to use the communication systems provided by the Website for the purpose of sending unsolicited solicitations or “spam.”</p> <p>Acceptable Use Policy. You acknowledge that further obligations governing your use of the Website are set forth in our Acceptable Use Policy, which is found at https://www.wikitree.com/about/acceptable-use.html, and which we may update from time to time.</p>

(Continued)

Genealogy Website	TOU Language
	<p>6. License to User.</p> <p>We grant you a license to use information and other content provided by the Website (“Content”) for purposes of personal or professional research. You may download and copy only as much Content as is customary and necessary for your personal use and research regarding a specific research inquiry, but you may not in any case copy all or any substantial portion of the information contained on the Website (during any one visit or cumulatively over time) without the express consent of Interesting.com. Your licenses granted in this Section do not apply to any Content accessed by circumventing any technological or password protections or otherwise in violation of these Terms of Service. Please note that since the Website is a wiki, we cannot and do not warrant or represent that the User Content is non-infringing.</p>
Rodovid	<p>Except where otherwise specified, all text added to Rodovid is available for reuse under the terms of the Creative Commons Attribution License.</p>
GeneaNet	<p>5.2. Reasonable use</p> <p>The Geneanet Premium subscription gives access to all public data provided on the Site (except private data in the Members’ family trees).</p> <p>These data are provided to Premium members for their personal or professional genealogy research, within the limits defined below.</p> <p>The Member undertakes to:</p> <ul style="list-style-type: none"> ● access the Site using a common web browser and for personal or professional research only; ● never share its login information, strictly personal, and never share its Geneanet access with other people; ● never use a temporary email address; ● never use a web robot, for any reason. A web robot, or simply -bot-, is a software application that runs automated tasks (scripts) over the Internet to fetch, analyze and file information from web servers. The use of web robots is specifically prohibited; ● never threaten the security and never restrain the use of the Geneanet Sites; ● never extract, download or copy data for non-genealogical purpose; ● never use the data for commercial purpose. <p>Geneanet reserves the right to block access to its services in case of abnormal use of the Site and data.</p>

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Genealogy Website

TOU Language

Failure to comply with one of these obligations will result in the immediate cancellation of the account of the Member. Geneanet reserves the right to undertake legal action against any User which may be the source of any abnormal use.

Genealogie.com
(Filae.com)
(French)

Fair-use

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The user agrees to:

access content only through an individual browser for personal research.

to never use, for any reason, a robot. A "Robot" is any software tool designed to automatically emulate the actions of a human user used to enter data, data migration, bulk data upload, load testing, performance testing, performance monitoring, performance measurement and/or "stress tests". Bots, crawlers, spiders, dataminers, scraping software and other automatic access tools are expressly prohibited.

do not circumvent, disable, or interfere with Filae's website security features or that prevent or restrict the use or copying of content or services.

do not communicate personal access codes to share access to services reserved for subscribers.

do not create multiple accounts or use temporary email addresses to accumulate the benefits reserved for new registrants.

make reasonable and strictly personal use of free trial offers.

Any breach by the user of any of these commitments may result in the immediate termination of his membership and the suspension of his account. Filae reserves the right to bring actions against users who have been the origin of unfair practices.

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Genealogy Website	TOU Language
Genealogie Online (Dutch)	Unauthorized use or abuse of Genealogy Online or its contents can result into infringement of intellectual rights, privacy laws, publication and/or communication in the broadest meaning of the word. You are responsible for everything you send from this webpage.
geni.com	Except for your Content, the Geni Services and all materials therein or transferred thereby, including, without limitation, software, images, text, graphics, illustrations, logos, patents, trademarks, service marks, copyrights, photographs, audio, videos, music, and user Content belonging to other users or Members (“Geni Content”) and all intellectual property rights related thereto, are the exclusive property of Geni and its licensors (including other users or Members who post their Content to the Geni Services). Geni Content is protected by copyright, trademark, patent, trade secret and other laws, and Geni owns or licenses and retains all rights in the Geni Content and the Geni Services. Geni hereby grants you a limited, revocable, nonsublicensable, non-transferable license to reproduce and display the Geni Content (excluding any software code) solely for your personal non-commercial use in connection with viewing the Website and using the Geni Services in accordance with this Agreement. Use of Data and Attribution Users of the Website or Members may collect and use other user Content only to the extent allowed by such Member’s privacy settings subject to our Privacy Policy and solely limited to that Content that is designated as public by the Member. If you collect and/or use any such Content you agree to the following: (a) provide proper attribution to Geni, (b) provide a link to the Geni Website, and (c) include a statement that your use/product/website is not endorsed by or affiliated with Geni.
MyHeritage.com	<p>You must not:</p> <ul style="list-style-type: none"> Impersonate anyone else or otherwise misrepresent your identity or status. Hold yourself out as an employee or representative of MyHeritage Ltd. or any of its affiliates. Stalk or harass or make persistent or regular contact with other users without their consent or encouragement or after any consent or encouragement has, expressly or impliedly, been withdrawn. Send commercial emails, spam emails, unsolicited bulk mail or any other email which may harass its recipient(s).

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**Genealogy
Website**

TOU Language

Use our Website or Service in a way that might damage our name or reputation.

Restrict or inhibit any other person from using the Website or Service.

Exploit for any commercial purposes any portion of, use of or access to the Website.

Perform any activity that requires any form of payment from Members and/or users of the family sites or any other area of MyHeritage.

Advertise or offer to sell products or services, except where this is expressly permitted by us and by law (in which case you must comply with any terms relating to such activities that we specify).

Include links on our Website or Service to third party websites outside the MyHeritage Website Group.

Except with our express prior written consent, you must not copy or store electronically all or part of our Website or its contents, or make available, distribute, sell or offer to sell all or any part of the Website or its contents, or systematically download content and data from or through the Website to make or populate another database for any purpose. Scraping, crawling and/or harvesting of any data and any pages from the Website without our explicit prior written consent is strictly prohibited.

Except with our express prior written consent, reselling any MyHeritage products (including, without limitation MyHeritage DNA kits) is strictly prohibited. Buying a MyHeritage DNA kit and then selling it to someone else is strictly prohibited.

Non-commercial Use by Members

The DNA Services are for the personal, private and informational use of members only and may not be used in connection with any commercial or research endeavors except those that are specifically endorsed or approved in writing by us. Illegal and/or unauthorized use of the DNA Services, including collecting DNA Results and/or DNA Reports, is prohibited. We reserve the right to protect and enforce all rights associated with the DNA Services offered. **Use of Data**

Members or those who otherwise use the Website and/or the DNA Genealogy Services may use another member's DNA Genealogy Reports only to the extent allowed by such member's privacy settings and solely limited to the DNA Genealogy Reports designated as available to other members. If you collect and/or publicize any DNA Results and/or DNA Reports in a different website or application or otherwise use it outside the

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Genealogy Website

TOU Language

DNA Services, please note that the DNA Results and/or DNA Reports will be used in accordance with the terms and policies of these other websites and/or applications and this use is solely at your own risk. Limited Use License
 You are hereby granted a license to use the Service and its content solely for personal use, and subject to the terms and conditions of this Agreement (the "License"). The Service is not intended nor licensed for any commercial use. We reserve the right to cancel any or all of the Service at any time. Downloading any or all portions of any functionality of the Service, or any part of the public areas of the Service, is prohibited. Online or other republication of content in the public areas is prohibited. Violation of this License may result in the immediate termination of your membership and may result in legal action for injunction, damages and/or any other equitable relief. You may use the Service and any software provided by the Service only while online and may not download, copy, reuse or distribute that software, except where it is clearly stated in connection with such software that it is made available for offline use and a license for that use is provided in connection with that software.

Tribal Pages

Non-commercial Use by Members. The TribalPages Services are for the personal use of Members only and may not be used in connection with any commercial endeavors except those that are specifically endorsed or approved in writing by TribalPages. Illegal and/or unauthorized use of the TribalPages Services, including collecting usernames and/or email addresses of Members by electronic or other means for the purpose of sending spam, unsolicited email or unauthorized framing of or linking to the Website is prohibited. Commercial advertisements, affiliate links, and other forms of solicitation may be removed from Member profiles without notice and may result in termination of Membership privileges. Appropriate legal action will be taken for any illegal or unauthorized use of the TribalPages Services. Content/Activity Prohibited. The following is a partial list of the kind of Content that is illegal or prohibited to post on or through the TribalPages Services. TribalPages.com reserves the right to investigate and take appropriate legal action against anyone who, in TribalPages's sole discretion, violates this provision, including without limitation, removing the offending communication from the TribalPages Services and

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Genealogy Website	TOU Language
	<p>terminating the Membership of such violators. Prohibited Content includes, but is not limited to Content that, in the sole discretion of TribalPages: use or launch any automated system, including without limitation, “robots,” “spiders,” “offline readers,” etc., that access the TribalPages Services in a manner that sends more request messages to the TribalPages Services servers than a human can reasonably produce in the same period by using a conventional on-line web browser; collect or harvest any personally identifiable information, including names or email addresses, from the TribalPages Services, nor use the TribalPages Services for any commercial solicitation purposes without prior written consent from TribalPages.com; or rent, lease, transfer, sell, resell, or otherwise exploit for any commercial purpose, any portion of or access to the TribalPages Services.</p>
MyTrees	<p>You are licensed to use the Content only for personal or professional family history research, and may download Content that is specific to your relevant research. The download of all or a significant portion of any database in the archive is prohibited. Resale of a work or database or portion thereof, except as specific results relevant to a specific research for an individual, is prohibited. Online or other re-publication of Content is prohibited except as specific data elements that are part of a specific family history or genealogy. Violation of this License may result in immediate termination of your membership and may result in legal action to obtain an injunction, damages or both.</p>
One Great Family	<p>CONFIDENTIALITY All information that you provide to OneGreatFamily.com is subject to the OneGreatFamily.com Privacy Policy and Data Usage Policy. Unless the Privacy Policy or Data Usage Policy specifically protects the submitted information, you should not have any expectation of privacy for any information that you provide to OneGreatFamily.com.</p>
GEDmatch.com	<p>users participating in this Site agree that their information will be shared with other users. . . . Genealogy research requires the exchange of information. For that reason, all Genealogy Data provided to GEDmatch can be viewed, searched, and compared by any GEDmatch user. Use of Results The nature of genealogy research requires the exchange of information. That use must also be tempered by respect for the rights and privacy of other individuals. Anybody found to be using this Site in ways not consistent with this principle of human</p>

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**Genealogy
Website**
TOU Language

decency will be subject to an immediate ban with all their data removed. Examples include, but are not specifically limited to, spam mailing lists or publishing other people's results or personal information without their permission. This principle also applies to the related or non-related persons included in Genealogy Data or other data uploaded to this Site. Determination of any violation of this principle will be at the sole discretion of GEDmatch administrators.

While the results presented on this Site are intended solely for genealogical research, we are unable to guarantee that users will not find other uses, including both current and new genealogical and non-genealogical uses. For example, some of these possible uses of Raw Data, personal information, and/or Genealogy Data by any registered user of GEDmatch include but are not limited to:

- Discovery of identity, even if there is an alias, unidentifiable email address, and other obscuring information;
- Finding genetic matches (individuals that share DNA);
- Paternity and maternity testing;
- Discovery of unknown or unidentified children, parents, or siblings;
- Discovery of other genetic and genealogical relatives, including both known and unknown or unexpected genetic and genealogical relatives;
- Discovery of ethnic background;
- Discovery of a genetic relationship between parents;
- Discovery of biological sex;
- Discovery of medical information or physical traits;
- Obtaining an email address; and/or
- Familial searching by third parties such as law enforcement agencies to identify the perpetrator of a crime, or to identify remains.

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Genealogy Website

TOU Language

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**Genealogy
Website**
TOU Language

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**Genealogy
Website**

TOU Language

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Restrictions on your use of MyRelatives Applications

The MyRelatives Applications come with a limited guarantee.

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Copy, distribute or display any content or part of the MyRelatives Applications in any medium.

You also agree that you will not use any type of automated device, including but not limited to robots, spiders or any data mining technique, for the purpose of downloading, copying, storing or distributing MyRelatives content, or to copy or manipulate MyRelatives Applications or services. The MyRelatives Applications and/or services may not be used in any way that might disable, damage, impair or burden our servers or any

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**Genealogy
Website**
TOU Language

networks that are connected to any MyRelatives servers. You agree that you will not attempt to interfere with any other party's use of and/or enjoyment of any and all MyRelatives Applications or services. You may not attempt to gain unauthorized access to MyRelatives Applications or services, any systems or networks connected to MyRelatives servers, any accounts connected to MyRelatives or any other proprietary systems via counterfeit software, hacking, password mining or any other means. You may not obtain or attempt to obtain any type of information or materials that belong to MyRelatives and any third party service providers that were not intentionally made available via our applications or servers. You may not reverse engineer, disassemble or decompile software that was accessed via MyRelatives Applications or services, including but not limited to any and all proprietary communications protocol that is used by the company. You may not use data that you obtain via MyRelatives Applications in order to transmit advertisements or any type of promotional materials. You may not use this site to harass, threaten, embarrass or invade the privacy of any individual or entity. You may not use MyRelatives Applications to violate any currently existing or future laws, regulations or rules. In addition to the above, you further agree that you will abide by the following rules that govern your use of MyRelatives Applications:

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You will not attempt to use our services to harass, threaten, harm or otherwise interfere with any individual

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You will not reuse, sell or distribute any information that you obtain from the company unless you are expressly permitted to do so in writing

You will take all reasonable steps to ensure that any and all information you receive from the company is stored securely
