Legal Terms of Use and Public Genealogy Websites

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Legal terms of use and public genealogy websites

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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
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. 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. Some Genealogy Websites have become extensive. MyHeritage, for example, reports that it hosts 48 million family trees.

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’. 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. 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. 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. 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

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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.
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

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\(^12\) 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, 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. 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.

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. 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).

The violation of online TOUs could also give data contributors other legal actions against researchers, including trespass to chattels, misappropriation, unjust enrichment and conversion. 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.
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)


\(^{23}\) 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 & Uhlin, 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”).


\(^{25}\) 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., HQI 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: Family Tree Magazine, Genealogy In Time 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

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

- **No Automated Access**: prohibits automated scraping, crawling, and/or harvesting of content[^31] [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 content[^32] [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.”
Legal terms of use and public genealogy websites

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
IVA. 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
in the U.S. has been found in other contexts to be quite narrow. For example, in *Madey v. Duke University*, 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.’ 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.’

Under U.S. law, a second research exemption arises under the 1984 Drug Price Competition and Patent Term Restoration Act (the Hatch–Waxman Act), 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. Given the

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34 *Id.* at [1362].
35 *Id.*
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

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\(^{39}\) 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).

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.\footnote{Cf. Carroll, \textit{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].”).} 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.\footnote{See \textit{supra} note 41, and accompanying text.}

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.\footnote{Masha Shabani, Bartha M. Knoppers & Pascal Borry, \textit{Genomic Databases, Access Review, and Data Access Committees}. In \textit{MEDICAL AND HEALTH GENOMICS} 29–35 (Kumar D, Antonarakis S, eds, 2016).} 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,\footnote{\url{www.creativecommons.org}.} 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 \textit{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.\footnote{See, e.g., MyHeritage Ltd., MyHeritage—Terms and Conditions (n.d.) \url{https://www.myheritage.com/FP/Company/popup.php?p=terms_conditions} (accessed Oct. 28, 2019). See, generally, Jessica L. Roberts & Jim Hawkins, \textit{When health tech companies change their terms of service}, 367 \textit{SCIENCE} 745 (2020); Shmuel I. Becher & Uri Benoliel, \textit{Sneak In Contracts: An Empirical And Legal Analysis Of Unilateral Modification Clauses In Consumer Contracts}, 55 \textit{GEORGIA L. REV.} (2020, forthcoming); David Horton, \textit{The Shadow Terms: Contract Procedure and Unilateral Amendments}, 57 \textit{UCLA L. REV.} 605 (2010) (discussing the growth of unilateral contract amendments particularly in the context of consumer contracts).} 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.
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)

<table>
<thead>
<tr>
<th>Genealogy Website</th>
<th>TOU Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>Familytree.com</td>
<td>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.</td>
</tr>
<tr>
<td>FamilyTreeNow.com</td>
<td>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</td>
</tr>
</tbody>
</table>

(Continued)
<table>
<thead>
<tr>
<th>Genealogy Website</th>
<th>TOU Language</th>
</tr>
</thead>
</table>
| WikiTree          | General Use of the Website  
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:  
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.  
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. 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.  
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- never extract, download or copy data for non-genealogical purpose;
- never use the data for commercial purpose.

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