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# Comprehensive Protection of Genetic Information

## ONE SIZE PRIVACY OR PROPERTY MODELS MAY NOT FIT ALL

*Anya E.R. Prince*<sup>†</sup>

### INTRODUCTION

Genetic information is uniquely personal—it helps define what characteristics one will develop, what traits individuals could pass on to their offspring, and, given recent advances in science, it increasingly helps one to learn about medical predispositions and disease treatment options. The medical definition of genetic information is the heritable information coded in an individual's genes or DNA. Given both the personal nature of this information and the potential jackpot of valuable medical data, individuals have an important interest in maintaining control over their genetic information. Genetic information, however, is simultaneously uniquely individual and inexorably entwined with family members. Additionally, genetic information in the aggregate provides colossal potential to advance medical research and public health outcomes. Thus, laws that give individuals rights over their genetic information must balance the competing interests of the personal nature of the information against the informational power of genetic data. Current state laws in this arena generally grant individuals either a property interest or a privacy interest in genetic data. This article examines these state laws and argues that sweeping rights to genetic information under either a property or a privacy model are often overbroad and miss the mark, especially given the complexities of familial relationships and the societal implications arising out of genetic data.

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The number of genetic tests available has ballooned to over 2,000 tests in use in the clinical setting.<sup>1</sup> Additionally, in the future, more healthcare professionals will utilize wide-scale genetic testing in clinical practice as the cost of whole genome sequencing drops to below \$1,000 per test.<sup>2</sup> As the use of genetic testing increases in the clinical setting, powerful information about predispositions to disease and implications for offspring will emerge in patient files and medical records. While this information can greatly improve treatment options and public health, it also implicates privacy and discrimination concerns for the patients themselves.

Information gathered from genetic tests and family medical history can provide a patient with vital information about his or her propensity to develop a disease such as cancer, diabetes, or Alzheimer's. It can also provide information about whether a parent is a carrier of a gene that can lead to a genetic disorder in offspring, such as Tay-Sachs or cystic fibrosis. This knowledge gives power to the individual to plan for the future, establish treatment options, and practice preventive care. For these reasons, genetic information is personal and complexly intertwined with self-identity and family. Despite the individuality of genetic information, the information that is beneficial to the patient may also be desirable knowledge for other actors—precisely because of its identifying power.

Therefore, it is essential to examine how current laws address concerns over control of genetic information, what the best model is for protection of individuals' rights, and how protections need to be improved for the future. Currently, the premier law in the United States at the federal level regarding genetic privacy is the Genetic Information Nondiscrimination Act of 2008 (GINA).<sup>3</sup> GINA bans health insurance companies and employers from discriminating against individuals based on genetic information. Additionally, absent a few limited exceptions, GINA prohibits health insurance companies and employers from collecting the genetic information of individuals.<sup>4</sup>

While GINA has helped to alleviate some fears over misuse of genetic information, it is relatively narrower in scope

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<sup>1</sup> *Genomic Testing*, CNTRS. FOR DISEASE CONTROL & PREVENTION, [www.cdc.gov/genomics/gtesting/](http://www.cdc.gov/genomics/gtesting/) (last updated Apr. 23, 2013).

<sup>2</sup> See Erika C. Hayden & Nature News Blog, *The \$1,000 Human Genome: Are We There Yet?*, SCI. AM. (Jan. 10, 2012), [www.scientificamerican.com/article.cfm?id=1000-genome](http://www.scientificamerican.com/article.cfm?id=1000-genome).

<sup>3</sup> Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 2(5), 122 Stat. 881, 882-83 (2008) (codified as amended in scattered sections of 26, 29, and 42 U.S.C.).

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

than other civil rights acts because it only regulates health insurance companies and employers. With the burgeoning use of genetic testing and advances in understanding hereditary links for disease, laws need to address how the broader society—from government to educational institutions to researchers to nosy neighbors—can use an individual's genetic information in contexts outside of health insurance and employment.

There has been a recent increase in genetic rights legislation as states have begun to grapple with the question of what rights individuals have to their genetic information.<sup>5</sup> Most states have enacted legislation regulating third party use of genetic information; however, the majority of these statutes mirror GINA in that they only address health insurance companies and employers. Fifteen states have passed broader legislation that endows individuals with more comprehensive control over their genetic information.<sup>6</sup> Of these states, five provide individuals with a property interest<sup>7</sup> in their genetic data and 10 grant a privacy interest.<sup>8</sup> This article argues that the laws are so broadly written that they may become unworkable in practice and therefore will fail to adequately protect individuals and their genetic interests. State legislatures would benefit from a narrowly-tailored model law that addresses individuals' concerns. Additionally, states should create regulations for areas such as newborn screening, paternity testing, and law enforcement biobanks<sup>9</sup> to ensure full protection for individuals in all situations.

Part I of the article discusses the varying definitions of genetic information and how these variations affect individual rights over genetic information. Part II examines property rights and privacy rights in the context of genetic information. This part highlights the benefits and concerns of these two models, and evaluates how the differences in their underlying theories affect the protections and control individuals have.

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<sup>5</sup> Dan Vorhaus, *Is the Genetic Rights Movement Picking up Steam?*, GENOMICS L. REP., (Mar. 16, 2011), <http://www.genomicslawreport.com/index.php/2011/03/16/is-the-genetic-rights-movement-picking-up-steam/>.

<sup>6</sup> Given the wide range of types of protections available, this number could vary depending on how comprehensive legislation is viewed. This article counts those states whose laws apply broadly across society—not those whose legislation applies to more limited cases of insurance, employment, or family codes. *See infra* Parts III.B–C.

<sup>7</sup> These states include Alaska, Colorado, Florida, Georgia, and Louisiana. *See infra* Part III.B.

<sup>8</sup> Delaware, Illinois, Iowa, Minnesota, New Hampshire, New Jersey, New Mexico, New York, Oregon, and South Dakota. *See infra* Part III.C.

<sup>9</sup> Law enforcement biobanks are databases housing the biological and genetic information of arrestees and criminals. *See infra* Part III.D.3.

Part III analyzes state and federal laws that have expanded the rights individuals have over their genetic information and examines proposed state laws that seek to do the same. The section also comments on important exemptions that should be written into model legislation, such as newborn screening, paternity testing, and law enforcement biobanks. Finally, Part IV sets forth essential provisions that model state legislation must have in order to guarantee comprehensive genetic rights for individuals. Accordingly, model legislation for genetic information should include prohibitions on discrimination in major areas of the law, criminalize surreptitious genetic testing, create a private right of action for the unwanted disclosure of genetic information, and require that doctors and scientists provide subjects with an “advance research directive” to ensure that individuals will have greater control over the use of their genetic information in research.

I. PIN THE TAIL ON THE DEFINITION: GENETIC INFORMATION, GENETIC CHARACTERISTICS, AND GENETIC MATERIAL

Due to the patchwork nature of laws in this arena, there are varying definitions of genetic information at the state and federal level. This article focuses upon genetic information—intangible information that comes from DNA analysis, family medical history, test results, and other sources. It is beyond the scope of this article to discuss in detail the regulation of physical genetic material, such as tissue, blood samples, or other physical biological specimen, as this topic has been analyzed in other academic works.<sup>10</sup>

In 2008, Congress greatly expanded protection against genetic discrimination at the federal level by broadly defining genetic information in GINA. Under GINA, genetic information is

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<sup>10</sup> Other academic literature discusses individual rights in the realm of physical genetic material—especially given a California Supreme Court ruling in *Moore v. Univ. Cal. Regents*, 793 P.2d 479 (Cal. 1990) (holding that a patient has no right to monetary shares from a commercialized cell line developed from his cells). See, e.g., Michael M.J. Lin, Note, *Conferring a Federal Property Right in Genetic Material: Stepping Into the Future With the Genetic Privacy Act*, 22 AM. J. L. & MED. 109 (1996); Erik B. Seeney, Note, *Moore 10 Years Later—Still Trying to Fill the Gap: Creating A Personal Property Right in Genetic Material*, 32 NEW ENG. L. REV. 1131 (1998); Jeffery Lawrence Weeden, Note, *Genetic Liberty, Genetic Property: Protecting Genetic Information*, 4 AVE MARIA L. REV. 611 (2006).

information about [an] individual's genetic tests[,] the genetic tests of family members of such individual, and [] the manifestation of a disease or disorder in family members of such individual[;] . . . any request for, or receipt of, genetic services, or participation in clinical research which includes genetic services, by such individual or any family member of such individual.<sup>11</sup>

Prior to GINA, a patchwork of federal and state laws covered genetic discrimination. The Americans with Disabilities Act (ADA) prohibits discrimination on the basis of a disability in employment. The U.S. Equal Employment Opportunity Commission (EEOC) had indicated that the ADA could be used to bring an action for genetic discrimination, but this was never tested in court prior to the passage of GINA.<sup>12</sup> Additionally, in 2000, President Clinton signed Executive Order No. 13145 banning genetic discrimination against federal employees.<sup>13</sup>

The protections in the health insurance context were even sparser than in employment. The Health Information Portability and Accountability Act (HIPAA) prohibits group health insurers from using medical information in underwriting. HIPAA, however, does not prevent health insurers from charging a higher premium based on medical conditions. While some states had laws that regulated the use of genetic information in employment and health insurance, the bills were not consistent across the country. GINA filled many gaps in the law that existed prior to its passage.

Additionally, prior to GINA, many states had a narrow definition of genetic information, creating a confusing patchwork of coverage at the state level. The varying state definitions of genetic information were mostly limited to genetic test results or information directly gathered from deoxyribonucleic acid (DNA) analysis.

An examination of three states shows the breadth of definitions that exist at the state level. Nebraska's concise definition of genetic information is "information about a gene, gene product, or inherited characteristic derived from a genetic test."<sup>14</sup> New Mexico's slightly broader definition includes information gathered from "genetic testing, genetic analysis, DNA composition, participation in genetic research or use of genetic services."<sup>15</sup> And finally, under Tennessee law, genetic

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<sup>11</sup> 42 U.S.C. § 300gg-91 (2011).

<sup>12</sup> Mark A. Rothstein, *GINA, the ADA, and Genetic Discrimination in Employment*, 36 J. L. MED. & ETHICS 837, 838 (2008).

<sup>13</sup> Exec. Order No. 13145, 3 C.F.R. 235 (2000).

<sup>14</sup> NEB. REV. STAT. ANN. § 71-551(6)(a) (West 2007).

<sup>15</sup> N.M. STAT. ANN. § 24-21-2D (2005).

information must stem from genetic test results and also be linked to genes that are associated with a specific disease predisposition, a requirement that is not explicitly included in all state definitions of genetics.<sup>16</sup> The varying state definitions of genetic testing can be confusing for many, especially individuals who may move from one state to another and have varying levels of protection, or for genetic researchers who work with research subjects from multiple states. Model legislation for this area would help to minimize confusion and increase consistency of protection.

Increased legislation at the federal level can help to create a trickle-down use of definitions at the state level. By including family medical history and use of genetic services in its definition, GINA has begun to alter society's conception of genetic information. For individuals with family histories of hereditary diseases, actual legal protection is very limited if genetic information based on test results is protected, but information of family medical history is not. For example, an insurance company that asks extensive questions about an individual's family medical history of cancer can gain vital information about that person's predisposition to cancer without having a definitive genetic test result, such as a BRCA1 or BRCA2 mutation test for breast cancer, or an HNPCC (hereditary non-polyposis colorectal cancer) test for colon cancer.<sup>17</sup> Therefore, to ensure more complete protection of individual rights, the definition of genetic information should include not just genetic test results, but also family medical history.<sup>18</sup>

Since GINA's passage, states have begun to use this broader definition of genetic information. For example, California has moved from laws regulating "genetic characteristics" to laws regulating "genetic information." Prior to GINA, the California legislature had enacted a number of laws regulating the use of genetic characteristics. California defined genetic characteristics as

Any scientifically or medically identifiable gene or chromosome, or combination or alteration thereof, [or inherited characteristic that may derive from the individual or family member], that is known to be a cause of a disease or disorder in a person or his or her offspring, or that is determined to be associated with a statistically increased

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<sup>16</sup> TENN. CODE ANN. § 56-7-2702(2) (1997).

<sup>17</sup> Sagit Ziskind, *The Genetic Information Nondiscrimination Act: A New Look at an Old Problem*, 35 RUTGERS COMPUTER & TECH. L.J. 163, 182-83 (2009).

<sup>18</sup> *Id.* at 183.

risk of development of a disease or disorder, and that is presently not associated with any symptoms of any disease or disorder.<sup>19</sup>

The definition did not explicitly include family medical history or use of genetic services. After GINA's passage, California enacted a law, termed Cal-GINA, which incorporated GINA's more expansive definition of genetic information.<sup>20</sup> This example illustrates what is likely to be a growing trend among states to expand the definition of genetic information to incorporate family medical history.

The definition of genetic information is varied, especially at the state level. Sometimes there is variation even within a state depending on which section of the code is defining genetic information.<sup>21</sup> Unless otherwise noted in this article, genetic information will refer to the broad definition of genetic information found in GINA that includes family medical history and use of genetic services.

## II. LAYING THE FOUNDATION: UNDERLYING LEGAL THEORIES FOR CURRENT STATE LEGISLATION

### A. *Why Examine State and Not Federal Efforts*

A comprehensive federal bill governing individual genetic rights would be ideal in the United States—especially because family members who share genetic information often live across many different states. This article, however, focuses on the state level for a number of reasons. First, given the current political landscape, it is unlikely that Congress will pass broad-based genetic rights legislation in the near future. After passing healthcare reform—formally the Patient Protection and Affordable Care Act—in 2010, Congress has become increasingly polarized surrounding healthcare policy.<sup>22</sup> Beyond healthcare,

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<sup>19</sup> CAL. GOV'T CODE § 12926(i)(2) (West 2013).

<sup>20</sup> S.B. 559 (Padilla), 2011–2012 Reg. Sess. (Cal. 2011).

<sup>21</sup> See, e.g., ARIZ. REV. STAT. ANN. § 20-1379 (2009) (definition of genetic information in health insurance to include information about genes, test results, and family histories) and ARIZ. REV. STAT. ANN. § 20-448 (2009) (definition of genetic condition as a specific chromosomal or single-gene condition in life and disability insurances); N.Y. EXEC. LAW § 292 (McKinney 2012) (definition of genetics in employment that requires the gene alteration to be specifically linked to a disease or condition) and N.Y. CIV. RIGHTS LAW § 79-1 (McKinney 2012) (definition of genetics limited to genetic testing in insurance).

<sup>22</sup> For example, the House of Representatives has voted to repeal healthcare reform at least 30 times since its passage. See Tamara Keith, *GOP To Make 31st Attempt To Repeal Obamacare Act*, NPR (July 09, 2012), transcript available at <http://www.npr.org/2012/07/09/156474493/gop-to-make-31st-attempt-to-repeal-obamacare-act>.

Congress's bill-passage rate has been at an all-time low.<sup>23</sup> Given this climate, it is unlikely that Congress will act in the near future to pass the overarching comprehensive legislation that is needed to protect individuals in this arena.

In contrast, states have increasingly begun to pass broad genetic rights legislation.<sup>24</sup> In the future, there will likely be continued legislative efforts across other states to fill the gaps in genetic rights. Additionally, state legislatures will likely look to existing laws of other states as a model for their legislation. For this reason, it is essential to carefully examine state efforts to date and make suggestions for future state efforts.

Finally, if and when the federal government does address broad genetic rights, it may look to state legislation for inspiration. "[A] 'single courageous State' [can] serve as a laboratory for experiments that might lead to advances for society as a whole."<sup>25</sup> State action in this area can be a catalyst to prompt Congress to act. If enough states adopt comprehensive genetic legislation, it could be a tipping point that compels the federal government to adopt similarly comprehensive legislation. Therefore, providing guidance for current state legislatures acting in this field is beneficial for society and individual genetic rights overall.

### *B. Harms to be Avoided*

State legislatures must address four harms to create an appropriately tailored comprehensive genetic framework. First, individuals are often worried about negative consequences that stem from bad actors having access to genetic information—they are scared of genetic discrimination. As mentioned, GINA has vastly improved protections against discrimination in the employment and health insurance context, but has left gaps in the system for other areas such as life, long-term care, and disability insurance; housing; and education. Second, there is concern over possible surreptitious testing of genetic material. For example, in a political race, a candidate's genetic

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<sup>23</sup> Jonathan Strong & Humberto Sanchez, *Congress on Pace to Be Least Productive*, ROLL CALL (Sept. 13, 2012, 12:01 AM), [http://www.rollcall.com/features/Guide-to-Congress\\_2012/guide/Congress-On-Pace-to-Be-Least-Productive-217538-1.html](http://www.rollcall.com/features/Guide-to-Congress_2012/guide/Congress-On-Pace-to-Be-Least-Productive-217538-1.html).

<sup>24</sup> Jeeg, *Groundswell for Genetic Privacy Building in States*, COUNCIL FOR RESPONSIBLE GENETICS (Mar. 1, 2011, 9:07 PM), <http://www.councilforresponsiblegenetics.org/blog/post/groundswell-for-genetic-privacy-building-in-states.aspx>; Vorhaus, *supra* note 5.

<sup>25</sup> Sande L. Buhai, *In the Meantime: State Protection of Disability Civil Rights*, 37 LOY. L.A. L. REV. 1065 (2004) (quoting *New State Ice Co. v. Liebmann*, 285 U.S. 262, 310-11 (1932) (Brandeis, J., dissenting)).

information could be secretly tested and used against that person to show that he or she would not be fit for the office.<sup>26</sup> While some state laws prohibit this testing, many do not.<sup>27</sup> Third, individuals are concerned with the unwanted disclosure of their genetic information. This can stem from fear of discrimination and frustrations with lack of control over research, but there is also an inherent concern in wanting to keep genetic information private. Finally, due to the uniquely personal nature of genetic information, there is some desire to not have the information used for certain purposes, such as research that an individual does not agree with.

Current state models tend to focus on either a property or privacy model to address individual concerns about genetic information. The next sections will introduce the underlying legal theories of the property and privacy models as well as introduce implications of genetic information to the self, family, and society. Understanding these bases will help with analysis of whether these frameworks are addressing the harms to be avoided.

### C. Current Models of Genetic Rights

Property law grants positive ownership rights over an item, which are firmly “enshrined in the United States Constitution”<sup>28</sup> under the Fifth and Fourteenth Amendments.<sup>29</sup> Property rights are traditionally understood to encompass a bundle of rights, which, in this case, includes the ability for individuals to regulate the possession and transfer of their genetic information.<sup>30</sup> Additionally, property provides litigants with a definitive cause of action for the taking of the information. Therefore, states that grant a property right to

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<sup>26</sup> Robert C. Green & George J. Annas, *The Genetic Privacy of Presidential Candidates*, 359 NEW ENG. J. MED. 2192, 2192-93 (2008).

<sup>27</sup> See Genetics & Pub. Pol’y Ctr., *State Laws Pertaining to Surreptitious DNA Testing*, (2009), available at [www.dnapolicy.org/resources/State\\_law\\_summaries\\_final\\_all\\_states.pdf](http://www.dnapolicy.org/resources/State_law_summaries_final_all_states.pdf) (finding that 21 states and the District of Columbia do not have laws prohibiting surreptitious testing); see also, Elizabeth E. Joh, *DNA Theft: Recognizing the Crime of Nonconsensual Genetic Collection and Testing*, 91 B.U. L. REV. 665, 686 n.16, 687 (2011) (citing FLA. STAT. ANN. § 760.40 (West 2010) (prohibiting analysis or disclosure of results); GA. CODE ANN. § 33-54-3 (prohibiting testing without prior consent); MASS. GEN. LAWS ch. 111, § 70G(c) (2008) (prohibiting health related entities from analyzing or disclosing results); N.H. REV. STAT. ANN. § 141-H:2 (2012) (prohibiting analysis and disclosure); N.Y. CIV. RIGHTS LAW § 79-l(2)-(3) (McKinney 2012) (prohibiting testing and disclosure)).

<sup>28</sup> Weeden, *supra* note 10, at 650-51.

<sup>29</sup> Leigh M. Harlan, *When Privacy Fails: Invoking a Property Paradigm to Mandate the Destruction of DNA Samples*, 54 DUKE L.J. 179, 180-81 (2004).

<sup>30</sup> See Mary J. Hildebrand & Jacqueline Klosek, *Towards a Unified Approach on Protection of Genetic Information*, FINDLAW.COM (Mar. 26, 2008), <http://corporate.findlaw.com/law-library/towards-a-unified-approach-on-protection-of-genetic-information.html>.

genetic information enable their citizens to protect against the taking or misuse of genetic information.<sup>31</sup>

While theoretical underpinnings of property rights began in the physical realm, over time, the model has been expanded to include intangible concepts and ideas through advances in patent and copyright law. Its use in regulating nontangible data can be tricky in the area of medical records. Even without adding a layer of genetic information, there is not a clear ownership right over patient medical data.<sup>32</sup> For the most part, physical medical records are the property of the health care provider, but the data inside is not; this is similar to owning a book, but not owning the ideas contained inside.<sup>33</sup> Thus, if property rights attach to genetic information the model may look more like copyright law, rather than pure physical ownership law. As with copyright law in books and music, there are many more violations of property rights in these realms of easily transferable data, than when physical ownership is at issue.<sup>34</sup> Therefore, property law has many of the tools available to regulate ownership in genetic information, although enforcement may potentially be at issue.

While property theory encompasses positive rights, privacy theory imposes negative rights upon others. Privacy interests developed separately from property interests, and were intended to protect an individual's control over personal information and decision-making. Privacy theory emerged from both common and constitutional law, and the constitutional roots of privacy have been applied to medical data over time.<sup>35</sup> The Supreme Court, for example, has held that a privacy interest in medical information does implicate the constitutional right to privacy, to the extent that there is one.<sup>36</sup> Additionally, some states have recognized a constitutional right to privacy in their own state constitutions.<sup>37</sup>

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<sup>31</sup> Michael J. Markett, Note, *Genetic Diaries: An Analysis of Privacy Protection in DNA Data Banks*, 30 SUFFOLK U. L. REV. 185, 226 (1996); Weeden, *supra* note 10, at 617.

<sup>32</sup> Marc A. Rodwin, *Patient Data: Property, Privacy & the Public Interest*, 36 AM. J. L. & MED. 586, 587 (2010).

<sup>33</sup> *Id.* at 588.

<sup>34</sup> See, e.g., STEPHEN E. SIWEK, THE INST. FOR POLICY INNOVATION, THE TRUE COST OF SOUND RECORDING PIRACY TO THE U.S. ECONOMY (2007), available at [http://www.ipi.org/docLib/20120515\\_SoundRecordingPiracy.pdf](http://www.ipi.org/docLib/20120515_SoundRecordingPiracy.pdf).

<sup>35</sup> Sonia M. Suter, *Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy*, 72 GEO. WASH. L. REV. 737, 762-67 (2004).

<sup>36</sup> *Id.* at 766.

<sup>37</sup> E.g., CAL. CONST. art. 1, § 1.

Protecting an individual's control over personal information is an essential part of privacy theory.<sup>38</sup> Many argue that the privacy model best serves to protect this interest in control specifically with regard to genetic information.<sup>39</sup> "Our genetic information is unique to us and therefore can identify us. It has a familial component, revealing links with relatives and something about our reproductive risks. Genetic information is therefore deeply connected to us."<sup>40</sup> Thus, by protecting an individual's control of personal information and decisions, a privacy model helps to protect the sanctity of the self.

*D. Balancing Competing Interests: The Benefits and Detriments of Various Models on the Individual, Family, and Society*

Defining a personal interest in genetic information—whether as a property right or a privacy right—can have lasting effects on many groups. Genetic information is simultaneously individual, familial, and societal information. Therefore, it is important to consider how a privacy or property interest would affect each of these levels.

1. Implications for the Self

An individual's interest in the control over, and confidentiality of, genetic information is grounded in protecting the self-identity of a person. Control of genetic information goes beyond merely protecting the secrecy of the information. It extends to give an individual control over the manner in which others use this information, whether others can learn this information about them, and how others can interfere in personal decisions.<sup>41</sup> Personal control over genetic information can allow an individual to preserve his or her self-identity, while avoiding stigmatization and discrimination.

Because genetic information is inherently entwined with an individual's concept of self, many commentators have noted that recognizing a property interest in parts of the body

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<sup>38</sup> ALAN F. WESTIN, *PRIVACY AND FREEDOM* 324-25 (1967); Charles Fried, *Privacy*, 77 *YALE L.J.* 475, 482-83 (1968).

<sup>39</sup> See, e.g., Suter, *supra* note 35, at 739-40.

<sup>40</sup> *Id.* at 739.

<sup>41</sup> *Id.* at 739-40.

falls at odds with morality.<sup>42</sup> Therefore, they argue that privacy rights are preferred over property interests because such rights allow control over information without commodifying body parts and “disaggregat[ing] the parts from the self.”<sup>43</sup> Under a property model, genetic information is a commodity rather than something in which we have a personal interest. While property interests connote a certain control over genetic information, they also can have a negative effect. Privacy, on the other hand, does not treat the person as its “constituent parts,” but rather “understands it holistically,” which better protects our integrity.<sup>44</sup>

Courts that have addressed property rights in an individual’s body parts have expressed “distaste for the possibility of treating human body parts as a form of property.”<sup>45</sup> The legal system does not promote commodification of body parts. For example, it is illegal to buy or sell organs, which instead must be donated. Some argue that bestowing these property rights on individuals will turn bodies into commodities,<sup>46</sup> allowing exploitation of the needy, who will sell their cells even when it may harm their health.<sup>47</sup> However, criticisms against the commodification of body parts are mostly limited to physical tissue samples and organs, not personal data. Some have argued that the worry over commodification of the self is inapposite when only genetic information, not physical material, is at issue.<sup>48</sup> But the concerns of disaggregating the self into pieces, rather than the whole, can still come into play when information about the self is introduced. As Professor Jessica Roberts has written,

Allocating jobs, educations, or other social goods and privileges based on genetic traits fails to acknowledge that, while genetic information might reveal some aspects of a person’s identity—such as elements of her appearance, her health risks, or even her talents and

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<sup>42</sup> See, e.g., Donna M. Gitter, *Ownership of Human Tissue: A Proposal for Federal Recognition of Human Research Participants’ Property Rights in Their Biological Material*, 61 WASH. & LEE L. REV. 257, 277 (2004).

<sup>43</sup> Suter, *supra* note 35, at 737.

<sup>44</sup> *Id.* at 763.

<sup>45</sup> See Robin Feldman, *Whose Body is it Anyway? Human Cells and the Strange Effects of Property and Intellectual Property Law*, 63 STAN. L. REV. 1377, 1379 (2011).

<sup>46</sup> See, e.g., Suter, *supra* note 35, at 746-47.

<sup>47</sup> See Feldman, *supra* note 45, at 1384; Hildebrand & Klosek, *supra* note 30.

<sup>48</sup> See *Comparative Law—Genetic Privacy—Icelandic Supreme Court Holds that Inclusion of An Individual’s Genetic Information in a National Database Infringes on the Privacy Interests of His Child.*—Guðmundsdóttir v. Iceland, No. 151/2003 (Nov. 27, 2003), 118 HARV. L. REV. 810, 815-16 (2004) [hereinafter *Comparative Law*].

tendencies—it is incapable of capturing the essence of that person in her entirety.<sup>49</sup>

Proponents of maintaining privacy rights, therefore, argue that privacy law is more suitable because it recognizes the “integrity and continuity of the self,”<sup>50</sup> and is specifically made to protect individuals and their identities.<sup>51</sup>

Use of an individual’s genetic information also has moral implications where the use of the information can undermine the specific values and beliefs of the individual.<sup>52</sup> “For instance, individuals may oppose research on the genetics of certain behavioral or other traits, like intelligence or sexual orientation.”<sup>53</sup> In addition, some people may believe that genetic information should not be patented. Without personal rights over their genetic information, they lack any control over what their DNA is used for, which can conflict with their beliefs.<sup>54</sup> This right to decide what one’s body and its parts are used for is a fundamental right that therefore deserves the utmost protection—protection that goes beyond monetary compensation and requires informed consent from the individual. This informed consent plays a vital role in protecting individual interests in genetic information and respecting human dignity.<sup>55</sup>

Genetic information often implicates a person’s sense of personal identity. A privacy model, which stops others from accessing this information, may help an individual maintain his or her sense of self. Individuals may lose their sense of security or autonomy if others in society can access information that is so complexly entwined with personal identity.

## 2. Effect on the Family

Beyond self, genetic information is unique in its ability to provide enlightening information about an individual’s family.<sup>56</sup> There is an increasing movement to expand the definition of genetic information from individual genetic test

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<sup>49</sup> Jessica L. Roberts, *The Genetic Information Nondiscrimination Act as an Antidiscrimination Law*, 86 NOTRE DAME L. REV. 597, 612 (2011).

<sup>50</sup> See Suter, *supra* note 35, at 763.

<sup>51</sup> See *id.*

<sup>52</sup> Natalie Ram, *Assigning Rights and Protecting Interests: Constructing Ethical and Efficient Legal Rights in Human Tissue Research*, 23 HARV. J. L. & TECH. 119, 125 (2009).

<sup>53</sup> *Id.* at 125-26.

<sup>54</sup> *Id.* at 126.

<sup>55</sup> *Id.*

<sup>56</sup> Comparative Law, *supra* note 48, at 810.

results to include family medical history and the genetic test results of a family member.<sup>57</sup> Under the expanded definition, a mother's genetic information is also her children's genetic information. But assigning personal control of genetic information can create complications for family members who may want access to that information or to ban its dissemination.<sup>58</sup> As society embraces the inclusion of family medical history in genetic information, and states change their legal definitions of the term, regulation over control of genetic information must take family member rights into account.

Assigning a property interest in genetic data may create a complicated realm of dual ownership of certain medical information. Property law envisages the possibility of joint ownership in goods, real estate, copyright, and other realms of possession. For example, easements or licenses provide certain individuals with the right to use another's private property.<sup>59</sup> Thus, some analysts argue that a property framework is an effective model for handling joint genetic information.<sup>60</sup> But joint ownership may create difficulties for family members. For example, if there is a dispute about what to do with a jointly owned piece of property, such as a house, the common legal recourse is to sell the property and then split the profits among all the joint owners. This, of course, is not a practical framework for genetic information. Ownership in genetic data can more appropriately be analogized to joint licensing under copyright law. However, this is not an ideal framework for genetic information among family members either. Under joint authorship, for example, an author can often give license to third parties to use the work.

This does not necessarily play out smoothly in a situation regarding genetic information. Imagine, for example, a politician with a family history of Alzheimer's running for office. A newspaper columnist wants to write an exposé about the politician, but the Alzheimer's information is only known within the family. Under joint ownership, a brother could sell his portion of the genetic information to the author for publication without permission from the politician. The politician would have no recourse, even though she is arguably the target for the information and deeply connected to the

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<sup>57</sup> See *supra* Part I.B.

<sup>58</sup> Weeden, *supra* note 10, at 653.

<sup>59</sup> Comparative Law, *supra* note 48 at 816.

<sup>60</sup> *Id.* at 815 (discussing the multiple stakeholders involved in privacy interests of genetic information and the complexities that the law must address).

genetic information of her brother. Therefore, while a property model envisions joint ownership possibilities, it does not necessarily address all concerns of individuals because it does not protect the privacy of the data or who the data is given to.

Other analysts have suggested that control of genetic information in the medical field should be seen as a “joint account model” rather than as an individualized notion.<sup>61</sup> Under this model, genetic information of one individual would be made available to all family members unless there are compelling reasons not to do so.<sup>62</sup> While this may seem at odds with the individualized privacy rights model entrenched in the system, this concept is enshrined in the mainstay of United States health privacy law: the Health Insurance Portability and Accountability Act. Although it is a widely unacknowledged provision, the Preamble to the privacy rule of HIPAA notes that medical information can be disclosed without violating HIPAA, even for the treatment of another individual—not the individual whose medical information is being disclosed.<sup>63</sup> The U.S. Department of Health and Human Services notes that this can be helpful when a family member is deceased and another family member could benefit from medical information for their own treatment.<sup>64</sup> This exception within HIPAA could have huge implications in the field of genetic privacy and shows that the federal government already predicts a framework where the health privacy of an individual is not absolute when it comes to the familial unit.

Courts have also grappled with joint privacy interests among family members. The cases have varied in addressing issues of privacy among individuals; however a joint right of privacy is not an absolutely foreign concept to United States courts. In *Vescovo v. New Way Enters*, a daughter sued for invasion of privacy because her mother had placed a lewd classified advertisement in the paper. The court held that this invaded the daughter’s right to privacy when men, in response to the ad, came to the house she and her mother shared.<sup>65</sup> In

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<sup>61</sup> See Weeden, *supra* note 10, at 653, (citing *Who Should Genetic Information Belong To?*, HEALTH & MED. WK. (Aug. 9, 2004)).

<sup>62</sup> See Weeden, *supra* note 10, at n.181.

<sup>63</sup> Standards for Privacy of Individually Identifiable Health Information, 45 C.F.R. § 164.500 (2000), available at <http://aspe.hhs.gov/admsimp/final/PvcPre02.htm>.

<sup>64</sup> U.S. Dep’t of Health and Human Servs., *Health Information Privacy: Frequently Asked Questions* (2006), [www.hhs.gov/ocr/privacy/hipaa/faq/right\\_to\\_access\\_medical\\_records/222.html](http://www.hhs.gov/ocr/privacy/hipaa/faq/right_to_access_medical_records/222.html).

<sup>65</sup> *Vescovo v. New Way Enters., Ltd.*, 130 Cal. Rptr. 86, 89 (Ct. App. 1976); see also *Comparative Law*, *supra* note 48, at 815-16.

other circumstances, however, United States courts have generally not “impose[d] a duty of confidentiality [in] interpersonal relationships.”<sup>66</sup>

In the context of genetics, there has been some movement by courts to require healthcare professionals to disclose medical information in the context of hereditary disease. For example, in *Safer v. The Estate of Pack*, a father was treated by a doctor for colon polyps and eventually passed away due to colon cancer when the patient’s daughter, the plaintiff, was ten.<sup>67</sup> Thirty-six years later, the daughter experienced abdominal pain and was eventually diagnosed with multiple polyposis. She sued her father’s doctor for failure to warn her of the hereditary nature of the illness.<sup>68</sup> The Superior Court of New Jersey held that a physician has a duty to warn a patient’s immediate family members who are at risk of avoidable harm from genetically transmissible conditions. This case shows that courts could move toward a model where certain third parties have a duty to warn and breach individual privacy rights where a disease has known hereditary causes.

If we return to the example of the politician above, under a privacy rights model we see that there are difficulties as well. The newspaper columnist would have a harder time arguing that the brother got informed consent to disclose the information because it violates the politician’s privacy rights and its value is tied to the politician. Thus, a privacy model may better protect the interests of an individual and allow him or her to avoid stigmatization and exploitation.

The line becomes more blurred in other circumstances. For example, imagine a situation where a doctor speaks to a local Boy Scout group, with permission and informed consent of a patient, about the patient’s family history of Alzheimer’s disease. The doctor’s talk is meant to teach the group about heredity diseases. But if the patient’s cousin is connected to the group, then the doctor has just shared the cousin’s information as well. This situation would also pose problems under a property rights model because the patient could give the doctor permission to use the data in the same manner as under a privacy model.

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<sup>66</sup> Trevor Woodage, *Relative Futility: Limits to Genetic Privacy Protection Because of the Inability to Prevent Disclosure of Genetic Information by Relatives*, 95 MINN. L. REV. 682, 707 (2010) (comparing a court decision allowing publication of private details about a relationship to publication of genetic information).

<sup>67</sup> 677 A.2d 1188 (N.J. Super. Ct. App. Div. 1996).

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

### 3. Consequences for Society

In the aggregate, genetic information also has implications for society as a whole. Researchers use the combined genetic information of many individuals to study the genetic mutations associated with certain diseases or traits. Without vital access to the genetic information of many individuals, researchers will not be able to properly compute trends and connections between proteins, DNA, and diseases. Due to this global benefit, some argue that genetic information should be owned by society as a whole.<sup>69</sup> Proponents of this theory note that the public should have access to genetic information because public money funded the Human Genome Project that created value in genetic information in the first place.<sup>70</sup> While it is very difficult to simultaneously balance privacy or property interests for both individuals and society as a whole,<sup>71</sup> it is important to consider how genetic research would be implicated by having a personal property interest, a personal privacy interest, or an altogether different interest in genetic information.

There is an overarching policy argument in genetic rights legislation regarding the need to encourage individual participation in genetic research. For example, Congress passed GINA to ease individual fear of genetic discrimination and therefore promote participation in genetic testing and research.<sup>72</sup> Similarly, property interests in genetic materials can incentivize patient participation because patients can bargain for pecuniary reimbursement.<sup>73</sup>

Conversely, the current property rights regime may discourage individual participation in research because researchers are not required to consider a donor's rights when using his or her cells.<sup>74</sup> A substantial amount of tissue used in biotechnology research has been obtained without paying compensation, and even without informing the cell donors that their cells can potentially generate economic returns.<sup>75</sup> Furthermore, if individuals are given property rights in their

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<sup>69</sup> See Ilise L. Feitshans, *Spider Silk Jeans or Spider Silk Genes? The Future of Genetic Testing in the Workplace*, 18 N.Y.L. SCH. J. HUM. RTS. 19 (2001).

<sup>70</sup> *Id.*

<sup>71</sup> *See id.*

<sup>72</sup> *See, e.g.,* David Resnick, *GINA—A Big Step Toward Personalized Medicine*, BOS. BUS. J. (Aug. 21, 2008, 6:04 PM), <http://www.bizjournals.com/boston/blog/mass-high-tech/2008/08/gina--a-big-step-toward-personalized-medicine.html?page=all>.

<sup>73</sup> Lin, *supra* note 10, at 229.

<sup>74</sup> *See* Gitter, *supra* note 42, at 280.

<sup>75</sup> *See id.* at 270-71 (citing Julia D. Mahoney, *The Market for Human Tissue*, 86 VA. L. REV. 163, 182 (2000)).

cells, researchers may be hampered if they are required to follow the chain of title in each piece of genetic material they obtain and if they are fearful of liability for mistakes.<sup>76</sup>

This potential negative effect on research may be overstated. Some authors argue that recognizing a property interest in an individual's genetic materials may, in fact, have a positive effect on research by providing individuals with an incentive to donate information.<sup>77</sup> Generally, when individuals are not compensated or are not given a small payment for a good that they provide, they will be less willing to provide that good, whether or not providing it places a high burden on them, or even any burden at all.

Despite the argument that the possibility for monetary compensation will encourage participation in genetic research, this may not hold true for both genetic material and genetic information. Some have argued that while a property interest in physical genetic material can promote research, a property interest in genetic information that stems from this material can actually hinder research because researchers would not be able to fully utilize the information in public datasets.<sup>78</sup>

Overall, both a privacy model and a property model could stymie essential public health research about the genetic links to disease. If research is hindered, this could slow the public health benefits of genomic advances.

#### *E. Effect on Enforcement and Front-End Protections*

Choosing either a property or a privacy model for protecting genetic information changes how an individual can enforce violations of those rights. Laws that merely establish a privacy right against the release of genetic information to employers and insurance companies arguably provide less protection than laws that give individuals a property right in their genetic information.<sup>79</sup> In states that grant a privacy interest, people "have some rights in relation to the cells of their body . . . . [T]hose rights, however, generally are grounded in notions of the fiduciary duty that a doctor owes to a patient and are frequently centered on the doctor's obligation to obtain

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<sup>76</sup> See *id.*, at 280.

<sup>77</sup> See Hildebrand & Klosek, *supra* note 30.

<sup>78</sup> Rodwin, *supra* note 32. Note, however, that Rodwin is not speaking of individual ownership of their genetic information, but of private database ownership.

<sup>79</sup> See Weeden, *supra* note 10, at 628.

informed consent.”<sup>80</sup> Additionally, because property rights are grounded in the Constitution and privacy rights are grounded in common law torts, some argue that this puts privacy rights on “weak ground.”<sup>81</sup> Unfortunately, an action against a physician for violation of his or her fiduciary duty may not be a sufficient deterrent for doctors to protect their patients’ cells and the genetic information contained within.

These proponents argue that a property right is stronger because of its Constitutional basis and that patients therefore may be able to better enforce any potential violations. Property interests may be beneficial in cases like *Moore v. U.C. Regents of the University of California*, where a patient brought suit against his doctor to recover money the doctor earned using the patient’s genetic material, but did not share any profits with the patient.<sup>82</sup> However, the privacy framework may be more adept at preventing some of the unwanted harms from the outset. In the case of genetic information, much of the concern stems from preventing the information from being released in the first place. Privacy is a stronger preventive framework, but is not as strong in enforcement. Once an individual’s genetic information has been leaked, compensation for a violation of privacy rights is likely insufficient, especially if the individual loses his or her job or is unable to obtain health insurance. Therefore, in order to best protect individual concerns, it is important to consider not only which framework is the strongest for enforcement, but also which framework is best for prevention. This is especially true because many individuals, unfortunately, do not have the resources to file a civil court case even if their rights were violated under either a property or privacy model.

### III. BUILDING THE FRAMEWORK: AN EXAMINATION OF STATE EFFORTS TO DATE

#### A. *Need for Broad Coverage*

While there has been some movement at the state level to legislate regarding rights to genetic information, most of these efforts have been narrowly focused. For the most part,

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<sup>80</sup> See Feldman, *supra* note 45, at 1380.

<sup>81</sup> Comparative Law, *supra* note 48, at 817.

<sup>82</sup> 793 P.2d 479 (Cal. 1990). In *Moore*, a doctor turned the cell line of a patient undergoing treatment for hairy cell leukemia into a commercialized line—without the patient receiving monetary benefit. *Id.*

states have genetic privacy legislation related to health insurance and employment—just as GINA only covers these realms at the federal level. These laws, therefore, leave a gap for entities outside of the health insurance and employment arena that might be interested in obtaining an individual's genetic information.<sup>83</sup> While health insurance and employment are certainly important areas, genetic progress implicates broader concerns such as education, banks, government entities, biobanks, restaurants, and more.<sup>84</sup> For example, in 2012 a student at Jordan Middle School in Palo Alto, California was required to transfer schools because he had the genetic mutation for cystic fibrosis.<sup>85</sup> The student was not diagnosed with the disease, but given his genetic make-up, the school felt that he may be a health risk to two other students who were diagnosed with cystic fibrosis.<sup>86</sup> Although he was allowed to return to school after an appeal by his parents, this example shows the potential for use of genetic information in realms outside of insurance and employment. To date, however, most states have limited genetic information legislation to only those two arenas. Forty-seven states and the District of Columbia have genetic information legislation that pertains to employment or insurances only, while three states—North Dakota, Mississippi, and Pennsylvania—have no regulations at all.<sup>87</sup>

Nineteen states have genetic information statutes that are broader than just health insurance and employment and extend to cover life, long-term care, or disability insurances.<sup>88</sup> Two states have limited scope statutes regulating areas beyond only employment and insurance. Arkansas, for example, has the Genetic Research Studies Nondisclosure Act, which prohibits disclosure of tissue samples in genetics research only if the samples have been made anonymous or if that patient has given informed consent.<sup>89</sup> This law does not explicitly address whether the data that stems from the tissue or blood samples are similarly

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<sup>83</sup> Ram, *supra* note 52, at 122; Natalie Anne Stepanuk, *Genetic Information and Third Party Access to Information: New Jersey's Pioneering Legislation As a Model for Federal Privacy Protection of Genetic Information*, 47 CATH. U. L. REV. 1105, 1115 (1998).

<sup>84</sup> Roberts, *supra* note 49, at 648.

<sup>85</sup> Colman Chadam, *California Boy Ordered to Transfer Schools for Carrying Cystic Fibrosis Gene, Goes Back to Class*, HUFFINGTON POST (Nov. 8, 2012, 10:58 AM), [http://www.huffingtonpost.com/2012/11/08/colman-chadam-california-\\_n\\_2092816.html](http://www.huffingtonpost.com/2012/11/08/colman-chadam-california-_n_2092816.html).

<sup>86</sup> *Id.*

<sup>87</sup> See *infra* Appendix, Table 1.

<sup>88</sup> See *infra* Appendix, Table 1.

<sup>89</sup> ARK. CODE ANN. § 20-35-103 (2001); Note Arkansas is not included in the table as a state with regulation since only the physical specimen, not the DNA or information is regulated, see *infra* Appendix, Table 1.

protected. Similarly, Texas state law covers employment and insurance, but also forbids genetic discrimination in licensing.<sup>90</sup>

Several states, however, have broad reaching statutes regarding genetic rights. The next section will examine these statutes and examine which choose a property interest and which opt for a privacy interest.

### *B. Broad Coverage through a Property Interest*

Five states—Alaska, Colorado, Georgia, Louisiana, and Florida—have passed legislation that provides individuals with a property interest in their genetic information, although other states have proposed legislation in this area.<sup>91</sup> Overall, the legislation among these states follows similar patterns. First, these statutes tend to cover genetic materials or limited genetic information. If they cover genetic information at all, it is the information that derives specifically from a genetic test, not broad genetic information such as family history.<sup>92</sup> Therefore, most of these states do not raise questions of joint ownership of genetic information, assuming they are read narrowly to only pertain to the genetic test results of the individual being tested. Second, these statutes provide exemptions for specific areas of genetic information collection.

In Alaska, “a DNA sample and the results of a DNA analysis performed on the sample are the exclusive property of the person sampled or analyzed.”<sup>93</sup> The law requires written, informed consent for the collection, analysis, retention, or disclosure of information, with exceptions for law enforcement biobanks, paternity, newborn screenings, and emergency medical treatment.<sup>94</sup>

Colorado’s provisions are quite sweeping and declare that “genetic information is the unique property of the individual to whom the information pertains,” although there are exceptions to the confidentiality requirements of the information for use in law enforcement, research (if the information is anonymous), paternity suits, and public health.<sup>95</sup>

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<sup>90</sup> TEX. OCC. CODE ANN. § 58.051 (West 2003).

<sup>91</sup> See, e.g., Jennifer K. Wagner & Dan Vorhaus, *On Genetic Rights and States: A Look at South Dakota and Around the U.S.*, GENOMICS L. REP. (Mar. 20, 2012), [www.genomicslawreport.com/index.php/2012/03/20/on-genetic-rights-and-states-a-look-at-south-dakota-and-around-the-u-s/](http://www.genomicslawreport.com/index.php/2012/03/20/on-genetic-rights-and-states-a-look-at-south-dakota-and-around-the-u-s/); See *infra* Appendix, Table 1.

<sup>92</sup> See, e.g., COLO. REV. STAT. ANN. § 10-3-1104.7(1) (2010).

<sup>93</sup> ALASKA STAT. § 18.13.010(a) (2004).

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

<sup>95</sup> COLO. REV. STAT. ANN. § 10-3-1104.7(1)(a).

Georgia's law also uses Colorado's "unique property" language, with exceptions for law enforcement and anonymous research.<sup>96</sup> The law is housed in the insurance section of the Georgia code and certain insurances, such as life, disability, and Medicare supplemental plans, are exempt from the genetic testing chapter.<sup>97</sup> Therefore, it is unlikely that Georgia's law would apply outside the insurance context as a result of the law's location in the code.

Louisiana's legislation in this area is also housed under the insurance code and states that "[a]n insured's or enrollee's genetic information is the property of the insured or enrollee."<sup>98</sup> Under the law, authorization is required for anyone else to retain genetic information, unless it is for a criminal investigation or to determine paternity.<sup>99</sup> The statute defines genetic information broadly to include genetic test results of both the individual and family members, as well as manifested diseases of family members.<sup>100</sup> Due to the sweeping definition of genetic information under Louisiana law, this is one state where seemingly innocuous and routine events could violate the law. For example, the legislation states that "no person shall retain an insured's or enrollee's genetic information without first obtaining authorization from the insured, enrollee, or their representative" and person is defined to "include a family, corporation, partnership, association, joint venture, government, governmental subdivision or agency, and any other legal or commercial entity."<sup>101</sup> Under the broadest reading of this, a healthcare professional could not store information about a mother in her medical records without getting authorization from her children and other family members or without violating the family member's property interest. This expansive reading is unlikely given that the rules are contained in the insurance code and speak directly to the genetic information of the insured or enrollee. Thus, although "person" is defined very broadly, Louisiana's law most likely is much narrower and only covers the insurance context. As a result, the strong and important property rights regarding individuals' genetic information in Louisiana are not as powerful as needed because genetic rights implicate other areas beyond insurance.

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<sup>96</sup> GA. CODE ANN. § 33-54-1 (2009).

<sup>97</sup> *Id.* § 33-54-7.

<sup>98</sup> LA. REV. STAT. ANN. § 22:1023(E) (2011).

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

<sup>100</sup> *Id.* § 22:1023 (A)(8)

<sup>101</sup> *Id.* §§ 22:1023 (A)(13), (E).

The legislation passed in Florida states that “results of such DNA analysis . . . are the exclusive property of the person tested” and must remain confidential without the consent of the person tested except in the case of law enforcement biobanks and paternity testing.<sup>102</sup> Florida’s law is the only one of the five statutes that has been specifically tested in a court, although the ruling is limited as it was not in the highest court in the state. In *Doe v. Suntrust Bank*, a plaintiff brought suit to determine the identity of a deceased man’s children in order to properly distribute the man’s trust among his descendants.<sup>103</sup> Doe, the decedent, had two known children, and two alleged children. The trial court ordered the known children of Doe to submit to DNA testing to assist in the determination of the putative children’s parentage.<sup>104</sup> The legitimate children relied upon Florida’s code to argue that they could not be compelled to provide genetic data to the court without informed consent.<sup>105</sup> There is an exception in the Florida statute for paternity, but this exception only applies to the testing of “the child, mother, and alleged fathers,” not to alleged siblings.<sup>106</sup> In its opinion on the motion to quash decision, the Second District Court of Appeal of Florida held that

the primary purpose of the statute is to protect individuals who undergo DNA analysis by requiring informed consent before the analysis is performed, by providing confidentiality for the results, including exempting the results from disclosure as a public record, by providing control over how the results are disclosed, and by requiring notification that the analysis was performed and how it was used.<sup>107</sup>

Nevertheless, the court also noted that the exceptions listed in the statute are not the only times that a court can order an individual to submit to a genetic test.<sup>108</sup>

The dissent in *Suntrust* argues that the court’s opinion devalues the privacy interest in one’s DNA composition and undermines the legislative intent in § 760.40. “The majority, under the guise of discovery rules, would allow circuit courts to order DNA testing if the testing is arguably relevant to the pending matter, thereby ignoring the legislative determination

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<sup>102</sup> FLA. STAT. ANN. § 760.40(2)(a) (West 2009).

<sup>103</sup> *Doe v. Suntrust Bank*, 32 So. 3d 133, 135 (Fla. Dist. Ct. App. 2010), *appeal denied*, 46 So. 3d 47 (Fla. 2010).

<sup>104</sup> *Id.* at 135.

<sup>105</sup> *Id.* at 137.

<sup>106</sup> FLA. STAT. ANN. § 742.12(1) (West 2001).

<sup>107</sup> *Suntrust*, 32 So. 3d at 138.

<sup>108</sup> *Id.*

protecting an individual's privacy rights to his or her own DNA."<sup>109</sup> This difference between the majority and dissenting opinions illustrates not just the difficulty of writing comprehensive legislation surrounding genetic rights, but also the difficulties in court enforcement.

Although *Suntrust* raises questions about whether DNA testing falls within one of the exceptions to genetic testing, it did not specifically address the children's property right in the genetic information. Thus, across all states with a genetic property model, this right remains untested in the courts.

### C. *Broad Coverage through a Privacy Interest*

There is more variation among states that focus upon a privacy interest than those that focus on a property model.<sup>110</sup> As mentioned above, one reason for this is that some of the privacy laws tend to be narrow and focus only on employment and insurance,<sup>111</sup> but even among broader state laws, there is greater variation. Ten states have generally broad privacy-based laws regarding individual rights to genetic information: New Jersey, Delaware, Minnesota, Illinois, Iowa, New Hampshire, New Mexico, New York, Oregon, and South Dakota.<sup>112</sup> These state laws cover broader privacy rights of individuals and tend to establish rules for the collection, retention, and disclosure of genetic information. These laws generally include informed consent provisions, although the nature of the informed consent is altered depending on the state. As with the property states, these states also incorporate areas of exceptions into the law.

New Jersey's law—the Genetic Privacy Act—had one of the most interesting journeys through the legislative process. The bill, as originally passed by the state legislature, created a property right in genetic information; however Governor Whitman vetoed the bill because “the creation of a new statutory property right could lead to a proliferation of litigation in New Jersey—litigation that could have a chilling

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<sup>109</sup> *Id.* at 143.

<sup>110</sup> In the analysis of state laws, statutes that applied to limited circumstances, such as in the family code for paternity testing, or to employment or insurance only were not included. This section focuses on some of the states whose statutes may have broader implications.

<sup>111</sup> See *supra* Part III.A.

<sup>112</sup> See *infra* Appendix, Table 1; Nebraska is discussed below, but is not included in the total count because the provision is limited to physicians and therefore does not count as comprehensive.

effect on scientific research.”<sup>113</sup> The final bill signed into law was narrower, but is still considered one of the earliest broad genetic information laws to be passed.<sup>114</sup> Under the codified Genetic Privacy Act, genetic information cannot be collected, retained, or disclosed without authorization from the individual, although there are exceptions for anonymous research and other categories.<sup>115</sup> The law has been heralded as a model for other states, and most other state laws focusing on genetic privacy in broader categories have followed New Jersey’s example to regulate genetic information at multiple stages—collection, retention, and disclosure.

Delaware prohibits, with some exceptions, obtaining genetic information from an individual without obtaining informed consent.<sup>116</sup> Delaware’s definition of genetic information does not explicitly include family medical history, but it does not explicitly exclude that information either.<sup>117</sup> Therefore, a broad reading of the law would require informed consent to gather family history; however, a strict reading of the law only requires informed consent when performing a genetic test. Delaware’s statute is also notable because it requires genetic samples to be destroyed promptly after use unless retention is necessary for criminal proceedings, authorized by court order, authorized by the individual, or anonymized for use in research.<sup>118</sup>

Minnesota, Illinois, and Iowa are similar in that genetic information may only be collected, used, and stored in the manner for which an individual has given written informed consent.<sup>119</sup> Additionally, in Minnesota, written informed consent regarding dissemination of genetic information is only valid for a maximum of one year, but a lesser period can be specified in the consent agreement.<sup>120</sup> Therefore, after the period of informed consent had expired, healthcare professionals, researchers, and other actors would have to obtain informed consent again to disseminate genetic information to a third party.

New Hampshire also requires written informed consent to perform a genetic test, except for a few limited situations, including

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<sup>113</sup> Gov. Christine Todd Whitman, Senate Comm. Substitute for S.B. Nos. 695 and 854, 3 (Sept. 19, 1996), [http://www.njleg.state.nj.us/9697/Bills/s1000/695\\_v1.pdf](http://www.njleg.state.nj.us/9697/Bills/s1000/695_v1.pdf).

<sup>114</sup> See Stepanuk, *supra* note 83, at 1116.

<sup>115</sup> N.J. STAT. ANN. § 10:5-45 (West 2009).

<sup>116</sup> DEL. CODE ANN. 16 § 1202(a) (2012).

<sup>117</sup> *Id.* § 1201(b).

<sup>118</sup> *Id.* § 1203(b).

<sup>119</sup> MINN. STAT. ANN. § 13.386(3) (West 2012); 410 ILL. COMP. STAT. 513/15 (1998); IOWA CODE ANN. § 729.6 (West 2010).

<sup>120</sup> MINN. STAT. ANN. § 13.386(3)(4)(ii).

paternity, newborn testing, and criminal investigations.<sup>121</sup> The information cannot be distributed to anybody not approved of in writing, although there is an exception for disclosure by a physician within the medical practice or hospital.<sup>122</sup>

New Mexico, like New Hampshire, requires informed and written consent to obtain and retain genetic information, with exceptions for the original medical records of patients.<sup>123</sup> New Mexico's law also has a provision similar to Delaware's that genetic information must be destroyed upon request of the individual, with some exceptions.<sup>124</sup>

New York law is similar with regard to the requirement for informed consent for collection, retention, and disclosure; however, there are some unique provisions under New York law.<sup>125</sup> For example, one provision states that

no person who lawfully possesses information derived from a genetic test on a biological sample from an individual shall incorporate such information into the records of a non-consenting individual who may be genetically related to the tested individual; nor shall any inferences be drawn, used, or communicated regarding the possible genetic status of the non-consenting individual.<sup>126</sup>

However, this provision essentially terminates at death, because genetic testing may be performed on deceased individuals if informed consent is obtained from next-of-kin.<sup>127</sup> These provisions have immense implications for how family members can use their own genetic information—family medical history—in their personal healthcare.

Oregon has a provision similar to New York when the genetic information of a deceased person is in question. Oregon law requires informed consent to obtain, retain, and disclose genetic information.<sup>128</sup> There is, however, an exception to the rule for obtaining genetic information when it is “for the purpose of furnishing genetic information relating to a decedent for medical diagnosis of blood relatives of the decedent.”<sup>129</sup> Unlike New York's version of this provision, informed consent of the next-of-kin is not required in Oregon.

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<sup>121</sup> N.H. REV. STAT. ANN. § 141-H:2 (2012).

<sup>122</sup> N.H. REV. STAT. ANN. § 141-H:2(III) (2008).

<sup>123</sup> N.M. STAT. ANN. § 24-21-3(A) (West 1998).

<sup>124</sup> *Id.* § 24-21-5(B).

<sup>125</sup> N.Y. CIV. RIGHTS LAW § 79-1 (McKinney 2012).

<sup>126</sup> *Id.* § 79-1 (3)(b).

<sup>127</sup> *Id.* § 79-1 (11).

<sup>128</sup> OR. REV. STAT. ANN. § 192.531(1) (West 2009).

<sup>129</sup> *Id.* § 192.531(1)(f).

Finally, South Dakota and Nebraska have requirements to obtain informed consent prior to genetic testing.<sup>130</sup> Nebraska limits the requirement to physicians, but has an interesting provision whereby properly obtained informed consent is a bar on a civil suit against the physician for failure to inform.<sup>131</sup>

Overall, the states that follow a privacy model focus on individual control of genetic information, specifically regarding collection, storage, and dissemination of genetic information. Most of these state laws apply broadly across populations, but each includes exceptions for various reasons.

#### D. *Common Exceptions to the Rule*

Across the states, exceptions to genetics rights legislation continue to emerge—both in a privacy and a property model. It is important to examine these exceptions to see why these areas should potentially fall under different rules. Each of these exceptions are covered in full articles themselves.<sup>132</sup> This article argues that given the complexity of each of these areas, they should be exempted from this model state legislation. Given their unshakable implications for individual rights and privacy, states should address each of these in turn to truly establish comprehensive genetic rights for citizens. However, it is beyond the scope of this article to recommend model laws for these areas. Instead, this section gives a brief primer on the issues to highlight the complexities and illustrate why the exceptions exist.

##### 1. Newborn Screenings

Most babies in hospitals are required to go through this common routine: “a small prick to the heel and a few drops of

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<sup>130</sup> S.D. CODIFIED LAWS § 34-14-22 (2013); NEB. REV. STAT. ANN. § 71-551 (West 2007).

<sup>131</sup> NEB. REV. STAT. ANN. § 71-551(4).

<sup>132</sup> See generally Michelle Hibbert, *DNA Databanks: Law Enforcement's Greatest Surveillance Tool?*, 34 WAKE FOREST L. REV. 767 (1999) (examining state practices for law enforcement DNA databanks and suggesting policy changes to protect genetic information); Paul Ohm, *Broken Promises of Privacy: Responding to the Surprising Failure of Anonymization*, 57 UCLA L. REV. 1701 (2010) (discussing the inability for information in databases to be completely anonymous and suggesting possible responses); Jaclyn S. D'Arminio, Note, *“The Life of the Flesh Is in the Blood”*: *State Storage and Usage of Baby's Blood Sample*, 18 CARDOZO J. L. & GENDER 753 (2012) (discussing the ethical, legal, and social implications of storing newborn screening samples); Dee O'Neil Andrews, Comment, *DNA and Dads: Considerations for Louisiana in Using DNA Blood Tests to Determine Paternity*, 38 LOY. L. REV. 425 (Summer 1992) (examining the use of DNA testing in paternity suits).

blood collected on a piece of paper.”<sup>133</sup> The tests done on this blood sample are part of one of the nationwide Newborn Screening (NBS) programs. Each state tests newborns for a number of genetic conditions and disorders.<sup>134</sup> The number and type of tests vary among the states. One example of a common newborn screening measure is the test for phenylketonuria (PKU). This test checks whether a baby can process phenylalanine, an amino acid found naturally in many foods containing protein. If it cannot, the phenylalanine will build up in the body and can cause brain damage. If caught early, PKU can be treated through simple dietary changes.<sup>135</sup> In this way, NBS programs help detect otherwise undiagnosed genetic disorders, but they also do much more. In many cases, there is a likelihood that a baby’s blood sample, called a bloodspot, will sit in a biobank where scientific researchers may be granted access to these samples.<sup>136</sup>

One of the salient problems with NBS programs is their lack of regulations. Most NBS programs do not have a formalized consent process; only Maryland, Wyoming, and the District of Columbia require informed consent from the parents.<sup>137</sup> Most of the other states use an opt-out form of consent, which “assumes that unless the parents specifically ask for the bloodspot to be destroyed, they have consented to the continued storage and presumed use of those bloodspots in research studies approved by the state.”<sup>138</sup> This can be problematic because parents, who would not have consented to storage of their child’s bloodspot, may not be aware that they need opt out. “The mandatory data collection under opt-out programs and potential use of newborn samples in later research implicate a myriad of legal and ethical issues, particularly for programs with no requirements for any parental education regarding the screening program.”<sup>139</sup>

Some argue that states should have the burden of ensuring that parents have given the state consent to have

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<sup>133</sup> D’Arminio, *supra* note 132, at 753.

<sup>134</sup> NAT’L NEWBORN SCREENING & GENETICS RES. CENT., NAT’L NEWBORN SCREENING STATUS REPORT (Jan. 6, 2013), *available at* <http://genes-r-us.uthscsa.edu/sites/genes-r-us/files/nbsdisorders.pdf>.

<sup>135</sup> *Newborn Screening*, CNTRS. FOR DISEASE CONTROL & PREVENTION (May 13, 2013) [www.cdc.gov/ncbddd/pediatricgenetics/newborn\\_screening.html](http://www.cdc.gov/ncbddd/pediatricgenetics/newborn_screening.html).

<sup>136</sup> D’Arminio, *supra* note 132, at 753-54.

<sup>137</sup> *Id.* at 754 n.7.

<sup>138</sup> *Id.* at 759.

<sup>139</sup> Rachel L. Schweers, Note, *Newborn Screening Programs: How Do We Best Protect Privacy Rights While Ensuring Optimal Newborn Health?*, 61 DEPAUL L. REV. 869, 870 (2012) (footnote omitted).

their child's information.<sup>140</sup> States argue that consent is not required because NBS involves a public health issue, but when the state's interest in identifying the disease no longer exists—either because the child does not have a disease or because the child has been treated—the state's only interest with the DNA is for research purposes.<sup>141</sup> Opt-in programs can be beneficial because they respect parents' and patients' right to privacy and their choice in medical treatment and care, require physicians to educate their patients about the available options, and may result in greater research use of the samples currently available.<sup>142</sup>

Statutory guidelines are necessary to safeguard the privacy rights of newborns. One possible consequence of not protecting newborns' privacy and not requiring informed consent is that parents may opt out of screening their children. "This prevents their children from [receiving] the diagnosis and lifesaving treatment they may need, and the state's public health interest is no longer being met."<sup>143</sup> Given the complications of balancing the privacy interests of newborns and families with the public interest in decreasing the number of children suffering or dying from genetic conditions such as PKU, this area should be addressed with specific legislation.

## 2. Law Enforcement Biobanks

Another common exception in genetics rights legislation relates to the question: to what extent should DNA sampling be used by law enforcement? Genetic analysis can be a powerful tool for law enforcement and criminal courts because DNA profiling serves as a more reliable form of identification than fingerprinting and matches individuals to hair, skin cells, or other cells containing DNA at the scene of a crime. As such, many law enforcement agencies at the state and federal levels have begun to collect DNA samples in biobanks. This allows investigators to cross check evidence from a wide variety of crimes with DNA samples within the biobank. Due to the ability for these biobanks to be such powerful tools for law enforcement, the laws governing DNA sampling in the criminal context has been rapidly expanding. For example, Virginia initially required only certain sex offenders and certain violent

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<sup>140</sup> D'Arminio, *supra* note 132, at 759.

<sup>141</sup> *Id.* at 760.

<sup>142</sup> Schweers, *supra* note 139, at 872-73 & n.23.

<sup>143</sup> D'Arminio, *supra* note 132, at 760.

felons to provide DNA samples for the state's DNA biobank.<sup>144</sup> But within a year, the law was expanded so that all newly-convicted felons must provide DNA samples for the state DNA biobank and that all felons in Virginia prisons must provide DNA samples upon their release.<sup>145</sup> Other states that require DNA samples from all convicted felons, violent or non-violent, include Alabama, New Mexico, Virginia, and Wyoming.<sup>146</sup>

Felons are not the only ones at risk of having their DNA samples collected. By simply being arrested, an individual may be required to provide his or her DNA sample. In California, individuals arrested on felony charges are required to provide a DNA sample for analysis and inclusion in a biobank.<sup>147</sup> DNA databases not only reveal genetic information about the individual who has DNA on file, but also information about his or her close relatives.<sup>148</sup> One of the most prominent examples of this is the case of the "Grim Sleeper" in California. In 2010, the police were able to arrest a man linked to 10 murders in the Los Angeles area—dating as far back as 1985—through a familial DNA search.<sup>149</sup> This was possible because law enforcement officers had arrested the Grim Sleeper's son and collected his DNA sample. Standard tests revealed that his DNA partially matched DNA evidence from the unsolved murders. The partial match indicated that a family member would be the culprit.<sup>150</sup> This example highlights one of the most controversial aspects of California's—and other jurisdictions'—biobanking DNA collected from arrestees, not just convicted individuals. In this case, the young man may not have even committed the crime he was arrested for, but simply by being arrested he unwittingly gave the police evidence of his father's crime. Some may argue that this also shows the benefit of the law enforcement biobanks because 10 unsolved murders were resolved and future murders were potentially thwarted. Nevertheless, policymakers should take the privacy concerns of arrestees and their family members into consideration because of these situations.

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<sup>144</sup> Hibbert, *supra* note 132, at 774.

<sup>145</sup> *Id.*

<sup>146</sup> ALA. CODE § 36-18-24 (1994); N.M. STAT. ANN. § 29-16-6 (West 2006); VA. CODE ANN. § 19.2-310.2 (2011); WYO. STAT. ANN. § 7-19-403 (2010).

<sup>147</sup> CAL. PENAL CODE § 296(a)(2)(C) (West 2008).

<sup>148</sup> Hibbert, *supra* note 132, at 782.

<sup>149</sup> Joel Rubin, *Grim Sleeper: How LAPD Followed the DNA to an Arrest*, L.A. TIMES (July 8, 2010, 11:11 AM), <http://latimesblogs.latimes.com/lanow/2010/07/how-dna-led-to-the-arrest-of-the-grim-sleeper.html>.

<sup>150</sup> *See id.*

At the federal level, law enforcement is allowed to collect DNA from arrestees without a warrant and place this information in the Combined DNA Index System (CODIS).<sup>151</sup> If cleared of the crime, arrestees can seek expungement; however, the federal government is not required to grant such a request.<sup>152</sup> This begs the question: why should individuals who were wrongly arrested have their DNA profile in the federal database, and why is it their responsibility to have the information removed?

Some argue that DNA sampling is the next natural step to fingerprinting, but DNA sampling is very different from fingerprinting. Making DNA sampling a part of the same routine as fingerprinting is problematic. Courts have upheld arrestee DNA sampling because they reason that law enforcement has the right to be certain of the identity of the arrestee.<sup>153</sup> But this reasoning “is undermined by the fact that there has [been no evidence] that an individual’s fingerprints can be altered,” whereas “DNA evidence can be successfully fabricated.”<sup>154</sup> More importantly, fingerprinting is an ideal way to determine who a person is because fingerprints do not offer any other personal information.<sup>155</sup> On the other hand, DNA samples contain all sorts of revealing information beyond that of the individual’s identity. Although some argue that the DNA that is collected for this purpose is only “junk” DNA and does not reveal medical information of individuals, this idea has been challenged.<sup>156</sup>

Given the complexities of rules surrounding collection of genetic information for law enforcement purposes, it is important to address these concerns separately from a general genetics model. States must consider from whom DNA can be collected, how and for how long it should be stored, and what purposes the information in the biobanks can be used for.

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<sup>151</sup> Ashley Eiler, *Arrested Development: Reforming the Federal All-Arrestee DNA Collection Statute to Comply with the Fourth Amendment*, 79 GEO. WASH. L. REV. 1201, 1202 (2011).

<sup>152</sup> *Id.*

<sup>153</sup> Corey Preston, Note, *Faulty Foundations: How the False Analogy to Routine Fingerprinting Undermines the Argument for Arrestee DNA Sampling*, 19 WM. & MARY BILL RTS. J. 475, 484 (2010).

<sup>154</sup> *Id.* at 484-85.

<sup>155</sup> *Id.* at 490-91.

<sup>156</sup> Cory Doctorow, *Court to Hear Argument on the Privacy Implications of ‘junk’ DNA Databases*, BOING BOING (Sept. 19, 2012, 7:00 AM), <http://boingboing.net/2012/09/19/court-to-hear-argument-on-the.html>.

### 3. Paternity

Many states have excluded paternity testing from statutes regarding genetic testing.<sup>157</sup> In fact, many of the family law statutes in states have specific rules over the usage of genetic testing in the context of paternity testing.<sup>158</sup> The use of genetic testing to determine paternity is generally less controversial than its use in law enforcement biobanks and newborn screening—likely for two main reasons. First, scientific testing to determine paternity has been occurring since the 1930s, beginning with ABO blood type testing.<sup>159</sup> Second, given the wide availability of direct-to-consumer paternity testing,<sup>160</sup> a person can get tested for paternity without concerns about inappropriate storage and use of genetic material attached to his or her name. There are other public policy concerns with wide availability of direct-to-consumer genetic testing;<sup>161</sup> however, the ability to send anonymous samples often eases concerns about privacy, thus making paternity testing less controversial. Despite the minimal controversy in this area, full comprehensive legislation of genetics rights needs to ensure that there is proper regulation of genetic information use in paternity testing that meets societal goals while maintaining privacy.

### 4. Anonymous Data

The final common exception in state statutes for individual genetic rights is for anonymous data. In an effort to protect individuals' privacy, researchers have tried to "anonymize" data. Anonymization is a technique researchers use to protect the privacy of individuals in large databases by deleting or changing personal, identifying information.<sup>162</sup> "Data may be anonymized by not collecting or completely removing identifiers, by aggregating data into groups and ranges and not reporting individuals' identities, or by micro-aggregating the

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<sup>157</sup> See, e.g., ALASKA STAT. § 18.13.010 (2012); LA. REV. STAT. ANN. § 22:1023(D)(2) (2009); N.J. STAT. ANN. § 10:5-45(a)(2) (West 2009).

<sup>158</sup> See, e.g., FLA. STAT. ANN. § 742.12 (West 2010).

<sup>159</sup> See O'Neil Andrews, *supra* note 132, at 428.

<sup>160</sup> See, e.g., Jennifer A. Gniady, Note, *Regulating Direct-to-Consumer Genetic Testing: Protecting the Consumer Without Quashing a Medical Revolution*, 76 FORDHAM L. REV. 2429, 2444 (2008).

<sup>161</sup> Stuart Hogarth et al., *The Current Landscape for Direct-to-Consumer Genetic Testing: Legal, Ethical, and Policy Issues*, 9 ANN. REV. GENOMICS & HUM. GENETICS 161, 165, 168 (2008).

<sup>162</sup> Ohm, *supra* note 132, at 1701.

data into pseudocases representative of the real population.”<sup>163</sup> However, some policy analysts argue that this is not a sufficient protection because it is not difficult to “reidentify” or “deanonymize” individuals. The copious amount of information contained within DNA makes identification possible.<sup>164</sup> A second strategy is to keep research participant information confidential by keeping identifying information separate from other research data and assigning a meaningless code to the research data. There would remain a “key” that could link information back to the identity of the participant, but only certain researchers would have access to the key.<sup>165</sup>

Neither method—anonimization nor confidentiality—can completely guarantee privacy.<sup>166</sup> Two of the most striking examples of this come from a recent study where researchers identified men in an anonymous gene registry based on publically available information,<sup>167</sup> and a computer science professor identifying the “anonymous” medical records of the governor of Massachusetts through publically available information.<sup>168</sup> Additionally, even if individual anonymity is somewhat protected, biobank data can identify members of discrete populations.<sup>169</sup> This can be extremely problematic when the collection of data deals with highly sensitive information, such as HIV infection, mental illness, or alcoholism.<sup>170</sup>

Many states that have laws granting a privacy or property interest in genetic information specifically exempt anonymous data from the protections. But given the inability to make genetic information completely anonymous in research, states should not include anonymous data as an exception.<sup>171</sup>

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<sup>163</sup> ERIN D. WILLIAMS, CONFIDENTIALITY AND SECURITY, AHLA-PAPERS P05049804 (1998).

<sup>164</sup> Gabrielle Kohlmeier, *The Risky Business of Lifestyle Genetic Testing: Protecting Against Harmful Disclosure of Genetic Information*, 11 UCLA J. L. & TECH. 1, 44 (2007).

<sup>165</sup> Henry T. Greely, *The Uneasy Ethical and Legal Underpinnings of Large-Scale Genomic Biobanks*, 8 ANNU. REV. GENOMICS HUM. GENET. 343, 349 (2007).

<sup>166</sup> *Id.*; see also Woodage, *supra* note 66, at 703-04.

<sup>167</sup> See Dan Vergano, *Gene Detectives ID ‘Anonymous’ Men in Registry*, USA TODAY (Jan. 17, 2013, 4:44 PM), <http://www.usatoday.com/story/home/2013/01/17/personal-genome-male-identified/1842175/>.

<sup>168</sup> Greely, *supra* note 165, at 352.

<sup>169</sup> Lawrence O. Gostin, *Health Information Privacy*, 80 CORNELL L. REV. 451, 520 (1995).

<sup>170</sup> *Id.* at 521.

<sup>171</sup> While many states specifically exempt anonymous data from genetic rights statutes, some states have taken steps to try to ensure the privacy rights of individuals of anonymized data. For example, in Oregon, the Oregon Privacy Act requires someone to notify patients that their tissue may be used for anonymous genetic research. See Ken M. Gatter, *Genetic Information and the Importance of Context: Implications for the*

Thus, genetic rights protections for genetic information should include both general genetic information and anonymized genetic information. The next section outlines the ideal model for this legislation.

#### IV. DETERMINING THE IDEAL: ESSENTIAL COMPONENTS OF THE STATE MODEL

##### A. *Dangers of Statutes that are Overbroad*

Although a broad individual interest in genetic information is an important right—especially given the personal and familial nature of genetic information—many of the current laws end up being so broad as to be unworkable in some circumstances. There are two main concerns with overbroad laws in this area which may inhibit free speech and chill potential research. First, if not carefully written, legislation can unintentionally result in making certain common activities illegal. For example, states that have made disclosure of genetic test results illegal without written informed consent from the individual potentially make some journalism unlawful. In 2008, several news outlets published stories about actress Christina Applegate's cancer diagnosis and her decision to get a double mastectomy given that she carries the BRCA-1 mutation and had a higher-risk of developing cancer again in the future.<sup>172</sup> These news outlets would have violated multiple state laws assuming that they did not get informed consent from Ms. Applegate that met the legal requirements in each state—even though Ms. Applegate is open about her BRCA status and has started the Right Action for Women foundation, an organization that provides high-risk women with access to breast screenings.<sup>173</sup>

As states begin to incorporate a broader definition of genetic information into their laws, the concern over disclosure of information, leading to the breadth of laws in this area, will be somewhat exacerbated. For example, in California, the Genetic Information Privacy Act has been introduced in the

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*Social Meaning of Genetic Information and Individual Identity*, 47 ST. LOUIS U. L.J. 423, 444 (2003).

<sup>172</sup> See, e.g., Liz Szabo, *Applegate and Other High-risk Women Act Fast Against Cancer*, USA TODAY (Aug. 19, 2008, 10:43 PM), [http://www.usatoday.com/news/health/2008-08-19-applegate-mastectomies\\_N.htm](http://www.usatoday.com/news/health/2008-08-19-applegate-mastectomies_N.htm).

<sup>173</sup> In fact, this article may violate a number of state laws by disclosing her genetic status, helping to show how truly broad these restrictions can be.

state senate.<sup>174</sup> This proposed legislation includes an expanded definition of genetic information and requires written informed consent to obtain, analyze, or disclose genetic information.<sup>175</sup> Thus, under this law, for example, writing about how President Obama's mother had ovarian cancer could be a violation. At the broadest level, telling a coworker that a friend's father has high blood pressure would be a violation of the law unless written informed consent was first obtained from the friend and his father. Therefore, under both examples of broad interpretations of the law, there may be violations that were not meant to be legislated by the states. Yet these laws still provide important and essential protections for individuals in a growing area of privacy: The solution would not be simply to not pass these laws, but to carefully word and tailor protections necessary to avoid these expansive violations.

Second, there is a concern that overbroad laws will hinder scientific innovation and research. In both the property and privacy models, there is potential to obstruct important public health research if scientists have to follow a chain of title for genetic information or have to get informed consent for each new research protocol. Therefore, because genetic information in the aggregate can have immense societal and public health implications, it is important to strongly consider the implications on research when establishing the laws.

### *B. Addressing the Concerns*

Current state law genetic information privacy and property models tend to be overbroad in their protections. Nevertheless, these frameworks often fail to address some issues related to family disclosure of genetic information, implicate additional concerns about commodification of the self, and hinder research participation.<sup>176</sup> Therefore, a different model designed to address these additional concerns is necessary.

As mentioned above, there are four main concerns for individuals in the realm of genetic rights: fear of discrimination, surreptitious genetic testing, unwanted disclosure of genetic information, and control over how personal information is used in research.

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<sup>174</sup> S.B. 1267 (Padilla), 2011–2012 Reg. Session (Cal. 2012).

<sup>175</sup> *Id.*

<sup>176</sup> *See supra* Parts II.B–C.

### 1. Fear of Discrimination: Need for Comprehensive Ban on Discrimination

Fear of discrimination is a major concern for individuals seeking genetic testing. For many, the interest in genetic privacy stems from concerns that genetic test results will be misused.<sup>177</sup> While GINA has expanded protections against genetic discrimination at the federal level, it only extends that protection in the context of employment and health insurance. Thus, individuals are not protected from discrimination at the federal level in other areas—most notably in the context of life, long-term care, and disability insurances.<sup>178</sup> While the majority of literature has focused on gaps in federal law regarding life, long-term care, and disability insurances,<sup>179</sup> there is also the potential for misuse of genetic information in other realms, such as education, licensing, mortgage lending, and public accommodations. Due to the broad range of areas in which genetic information can be inappropriately used, a comprehensive law protecting genetic information must include broad anti-discrimination protections.

Additionally, these laws must completely ban the use of genetic information in these realms, rather than simply regulate the use of genetic testing. Currently, some states have laws that protect against the use of genetic information in life, long-term care, and disability insurance, but these laws generally regulate how genetic information is collected and used. For example, in Maryland, a long-term care insurer can only use genetic information in coverage or premium decisions if it is based on actuarial justification.<sup>180</sup> This is a common state trend to ban only “unfair” discrimination that is not based on actuarial principles. This does not, however, provide sufficient protection for individuals who have genetic predispositions to certain conditions or chronic diseases because it can effectively bar them from getting access to these insurances—having a predisposition to a disease will likely have strong actuarial justification for increased premium rates or denials. Therefore, anti-discrimination laws must be expanded to ban the use of genetic information in a variety of areas at the state level.

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<sup>177</sup> Roberts, *supra* note 49, 603.

<sup>178</sup> Susannah Baruch, *Your Genes Aren't Covered for That: One Year Later, Gaps in Genetic Discrimination Legislation Reveal the Challenges Ahead*, SCI. PROGRESS BLOG, (June 29, 2009), <http://www.scienceprogress.org/2009/06/gina-challenges/>.

<sup>179</sup> *See id.*

<sup>180</sup> MD CODE ANN., INS., § 18-120 (LexisNexis 2008); MD CODE ANN., INS., § 27-208 (LexisNexis 2005).

California is one of the first states to provide strong, comprehensive protections against genetic discrimination in a broad range of arenas. In 2011, California passed “Cal-GINA,” which protects individuals against genetic discrimination in many of these areas.<sup>181</sup> As Senator Padilla, the author of the bill noted, “SB 559 [(Cal-GINA)] will include genetic information as a prohibited basis for discrimination in the areas of housing, employment, education, public accommodations, health insurance coverage, life insurance coverage, mortgage lending, and elections.”<sup>182</sup> Cal-GINA amends California’s civil rights statute, the Unruh Civil Rights Act, to make genetic information a protected class. Unruh is very broad and applies to “all business establishments of every kind whatsoever.”<sup>183</sup> Comprehensive legislation at the federal level or in other states must also be this broad in order to truly protect individuals from having their genetic information misused.

## 2. Control of Genetic Material: Banning Surreptitious Testing

Another concern for individuals seeking genetic testing revolves around unauthorized access to their genetic information. Due to the personal nature and potential misuse of genetic information, individuals often have a strong interest in keeping their genetic information private. Two major concerns stemming from this are fears that somebody may gather genetic information without an individual’s knowledge and concern about inappropriate disclosure of that information. These fears can be addressed with properly tailored legislation regarding surreptitious genetic testing and disclosure. As mentioned above, many of the current laws attempting to protect genetic privacy in this area are too broad.<sup>184</sup> Therefore, the laws must be more narrowly tailored to avoid unintended consequences. This does not mean that the laws should lose their comprehensive protections—a properly tailored law can give broad protections without making innocuous behavior illegal.

The first step toward narrowly tailoring genetic privacy legislation is to explicitly make surreptitious genetic testing

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<sup>181</sup> S.B. 559 (Padilla), 2011–2012 Reg. Session (Cal. 2011).

<sup>182</sup> Press Release, Senator Alex Padilla, Governor Signs Padilla Bill to Prevent Genetic Discrimination, (Sept. 7, 2011), *available at* <http://sd20.senate.ca.gov/news/2011-09-07-governor-signs-padilla-bill-prevent-genetic-discrimination>.

<sup>183</sup> Unruh Civil Rights Act, CAL. CIV. CODE § 51(b) (West 2013).

<sup>184</sup> *See supra* Part IV.A.

illegal. With the ever-increasing number of direct-to-consumer testing sites available, it is becoming much easier for somebody to collect another individual's genetic material and send it to a lab for analysis.<sup>185</sup> Testable genetic material can be pulled from strands of hair, discarded cups, or used cigarettes.<sup>186</sup> This practice of surreptitiously testing another person's DNA without their knowledge is not illegal in many states. In a recent survey, the Genetics and Public Policy Center found that only 10 states restrict surreptitious collection for both health and non-health related purposes.<sup>187</sup> Other states regulate specific areas, such as health-related testing, paternity testing, and employment, but 21 states have no laws relating to surreptitious testing.<sup>188</sup> Even among those states with laws regarding genetic testing without an individual's knowledge, the laws may not provide strong enough protections to cover all circumstances.<sup>189</sup>

Accordingly, a comprehensive model of genetic rights must prohibit intentionally taking or collecting an individual's genetic material, without written informed consent, for the purpose of analyzing, disseminating, or disclosing genetic information. This portion of the model state law should explicitly deal with the collection of genetic material—not the collection of genetic information overall. As the definition of genetic information expands to include family medical history and use of genetic services, it is essential to clarify that this broad definition does not apply to the surreptitious testing portion of a model law. It is not practical to require written, informed consent each time somebody asks about a family member's condition or about a test result.

Commentators have suggested criminalizing surreptitious genetic testing.<sup>190</sup> A prospective criminal law should have three elements. First, the law must be broad enough to encompass collection from discarded items, such as cigarette butts, as well as direct collection of DNA samples

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<sup>185</sup> Sara Katsanis & Gail Javitt, *Surreptitious DNA Testing*, GENETICS & PUBLIC POL'Y CENTER (Jan. 21, 2009), [http://www.dnapolicy.org/images/issuebriefpdfs/Surreptitious\\_testing\\_issue\\_brief.pdf](http://www.dnapolicy.org/images/issuebriefpdfs/Surreptitious_testing_issue_brief.pdf).

<sup>186</sup> *Id.*

<sup>187</sup> *State Laws Pertaining to Surreptitious DNA Testing*, GENETICS & PUB. POL'Y CENTER (Jan. 21, 2009), [http://www.dnapolicy.org/resources/State\\_law\\_summaries\\_final\\_all\\_states.pdf](http://www.dnapolicy.org/resources/State_law_summaries_final_all_states.pdf).

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

<sup>189</sup> See Mark A. Rothstein, *Genetic Stalking and Voyeurism: A New Challenge to Privacy*, 57 U. KAN. L. REV. 539, 560-61 (2009).

<sup>190</sup> See, e.g., Elizabeth E. Joh, *DNA Theft: Recognizing the Crime of Nonconsensual Genetic Collection and Testing*, 91 B.U. L. REV. 665, 689 (2011).

through saliva, blood, or tissue. Therefore, the language of the law must be broad enough to include a ban on collecting discarded genetic material, as well as taking genetic material directly from a person. For example, New York state law bans genetic testing on a sample “taken” from an individual without informed consent.<sup>191</sup> But this prohibition may not encompass all surreptitious testing because it may not apply to “abandoned” items.<sup>192</sup> Second, if genetic material is collected from an individual, written, informed consent should be required. While some have argued that there should be exceptions for law enforcement and healthcare professionals, this article argues that there should only be an exception for law enforcement.<sup>193</sup> Especially given the concerns about research, discussed below, there are compelling reasons why patients should have to give written, informed consent when undergoing genetic testing in the healthcare setting.<sup>194</sup> Finally, the law must only ban collection of genetic information if the collectors intend to analyze or disseminate the information. This helps to tailor the law so as not to make it overly broad.<sup>195</sup>

In some circumstances, intent can be difficult to prove. While protective laws are important, not every person has equal access to the judicial system and not every violation of the law is easy or possible to prove. Therefore, state laws can add additional protections that will help to thwart surreptitious testing from occurring in the first place. For example, genetic testing facilities should be prohibited from extracting genetic information from anything other than a blood sample, buccal swab, saliva test, or other generally accepted laboratory practice.<sup>196</sup> This regulation would prohibit testing to be done off of discarded samples, such as drinking glasses or cigarette butts—thus making surreptitious testing more difficult to complete. As in the case of a criminal law against surreptitious testing, there should be an exception for law enforcement purposes. However, this is one area where paternity testing should not be exempt from the state comprehensive law. Surreptitious testing for parentage determinations is one of the main areas of concern for policy

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<sup>191</sup> N.Y. CIV. RIGHTS § 79-1(2)(a) (McKinney 2009).

<sup>192</sup> See, e.g., Rothstein, *supra* note 189, at 560-61.

<sup>193</sup> See, e.g., Joh, *supra* note 190, at 691-92.

<sup>194</sup> See *infra* Part IV.B.4.

<sup>195</sup> See, e.g., Joh, *supra* note 190, at 690 (noting that intent is essential to avoid criminalizing the purchase of celebrity mementos that may have DNA on them when the individual has no intent to analyze the DNA).

<sup>196</sup> See, e.g., Rothstein, *supra* note 189, at 575.

analysts in this arena.<sup>197</sup> There is concern that women will test unknowing men to determine if they are the fathers of children, or men will take genetic material from children to determine whether they are their fathers. The rights of men and children to not be surreptitiously tested should remain intact. This is an area, however, where it may be appropriate to create an exception for court-ordered testing.

### 3. Maintenance of Privacy: Avoiding Disclosure of Genetic Information

A ban on surreptitious genetic testing alone will not provide adequate protection for the privacy rights of individuals. In addition to banning secret testing, states also need to legislate regarding disclosure of genetic information. The statute should prohibit disclosure of genetic information with the intent to harm the individual whose information was disclosed, or with the intent to give personal gain to the discloser. This requirement is especially important when genetic information includes not only test results, but an individual's family history. A ban on surreptitious testing may help to avoid covert analysis of genetic material, but this does not preclude an individual from collecting and disclosing sensitive family history. Because family medical history has the potential to reveal information about an individual's propensity to a disease, this information must be regulated in order to fully protect an individual.

Legislating against disclosure of genetic information has a strong basis in common law and some state tort doctrines. For example, in many states, the common law right to privacy includes both the rights to be free from intrusion upon an individual's seclusion or solitude, and from public disclosure of embarrassing private facts.<sup>198</sup> But common law itself does not provide sufficient enough protection in this area because it is not clear that courts will apply these principles to disclosure of genetic information.<sup>199</sup> For purposes of comprehensive genetic rights legislation, the public disclosure of private facts should be banned. Further, the elements of this violation should be altered from the general common law definition in order to be effectively protective.

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<sup>197</sup> See, e.g., Katsanis & Javitt, *supra* note 185.

<sup>198</sup> RESTATEMENT (SECOND) OF TORTS §§ 652A-652E (1977); see also Rothstein, *supra* note 189 (discussing how states have adopted pieces of the restatement).

<sup>199</sup> Rothstein, *supra* note 189, at 548-53.

First, at common law in many states, the disclosure of private facts must be embarrassing in nature.<sup>200</sup> There are pieces of genetic information, however, that may be positive or neutral, but that an individual still maintains a desire to keep private.<sup>201</sup> Additionally, due to the familial nature of genetic information, a neutral disclosure about one person may implicate family members. For example, if an individual tests negative for Huntington's Disease, this is not "embarrassing" for the individual, but indicates that other family members did have the disease—hence the need to be tested. Therefore, legislation in this area should make clear that disclosure also means any private genetic information that the individual does not want disclosed—not only those that a reasonable person would find embarrassing.

Second, under the tort of disclosure of private facts, the revelation must be given to the public. Therefore, a line must be drawn that clarifies what constitutes public disclosure. If an individual gossips to two other coworkers about the genetic information of their boss, does this rise to the level of public disclosure? If a public blog that only has 10 followers publishes the family history of a local political candidate, is this sufficient to count as public disclosure? Courts have varied in interpretations of how many people it takes to constitute public disclosure.<sup>202</sup> In order to create the most comprehensive protections at the state level, legislatures should define public disclosure broadly to include giving information to a small number of individuals.

Third, states must decide whether and how they will define the "newsworthy" or "noteworthy" exception to the public disclosure tort. Often, an individual is allowed to disclose private facts if it is of legitimate concern to the public.<sup>203</sup> This means that it will be more difficult for a public figure to win under the disclosure law than a private individual. This exception is enshrined in First Amendment jurisprudence, and may therefore be difficult to alter. It is important to note in the law—to the extent possible—where this line may be drawn. An exception for newsworthy or noteworthy disclosure may leave a gap in protection for public individuals whose genetic information is disclosed—such as a

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<sup>200</sup> *Id.* at 548.

<sup>201</sup> *Id.* at 551-52.

<sup>202</sup> *See id.* (discussing the court split between whether disclosure to a small number of coworkers rises to the level of public disclosure).

<sup>203</sup> Teneille R. Brown, *Double Helix, Double Standards: Private Matters and Public People*, 11 J. HEALTH CARE L. & POL'Y 295, 311 (2008).

candidate's genetic information.<sup>204</sup> Nonetheless, this model framework fixes two current problems in the realm of public figures. First, because it bans surreptitious testing, it makes it more difficult to legally gather information from the outset. Second, this law corrects the concerns about criminalizing some journalism about individuals such as Christina Applegate by tailoring the anti-disclosure laws more narrowly.

These broad changes in the tort elements should be coupled with an additional intent element. While intent can be difficult to prove in some circumstances, this addition creates an appropriate balance between allowing the free-flow of information in journalism, research, healthcare, and daily life, while protecting privacy interests of individuals. Therefore, the statutory ban on disclosure in a state comprehensive genetics bill should ban the disclosure of genetic information with the intent to harm the individual or family member or with the intent to obtain personal gain for the discloser. Including an intent requirement would avoid banning most daily conversations, but would make illegal the disclosure of genetic information to harm an individual, create sensational news, or give one individual's private information simply to harm a family member. This ban on disclosure of all genetic information—including family history—coupled with the ban on surreptitious testing can offer comprehensive privacy of genetic information without creating overbroad privacy or property rights.

The addition of the intent requirement will make some public disclosure of private facts not actionable—even some disclosures that may be offensive or upsetting to the individual. For example, the Boy Scout example<sup>205</sup> would most likely not be actionable under this model. Still, this solution creates a more desirable balance than the current state laws in this area that are overbroad and make illegal many innocuous conversations. Laws that protect every possible unwanted disclosure of genetic information will be overbroad and significantly hinder important daily activities, journalism, and research. The balance drawn between individual protection and efficiency is best when state laws ban surreptitious testing and simultaneously prohibit certain intentional disclosure of genetic information

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<sup>204</sup> Green & Annas, *supra* note 26.

<sup>205</sup> See *supra* Part II.D.2.

#### 4. Control over Research: Providing Meaningful Informed Consent through an “Advance Research Directive”

The final area of concern for many individuals in genetics rights is research data. Many individuals have their genetic material and genetic information stored in biobanks where researchers can collect data for research projects. These individuals may not even be aware that their genetic information is stored. In other situations, individuals may have given permission for their tissue sample or information to be used for one type of research, but are unaware that their data has been stored for other research in the future. Many biobanks store data in a deidentified or anonymous manner; but, as discussed above, there is no such thing as truly “anonymous” data in this arena.<sup>206</sup> Due to the uniquely personal nature of genetic information, individuals may not want their information used for research that they find offensive.<sup>207</sup> There are a variety of harms that can come from unwanted participation in genetic research, such as possible reidentification of “anonymous” data, objectionable uses, and harms to discrete groups.<sup>208</sup>

Once an individual’s data is housed in a biobank, it is rare that a person will be contacted again to give informed consent for subsequent research. However, “information or material collected for one purpose may have tremendous value for additional purposes, particularly if analyzed by techniques not previously available.”<sup>209</sup> Indeed, restricting the use of genetic material to single tests would be impractical and greatly hinder the benefits and ease of use of biobanks.<sup>210</sup> In some cases, an individual has signed loose informed consent documents for the initial research that they enrolled in, but these documents do not adequately give information regarding subsequent research or the possibility of reidentification of anonymous data.<sup>211</sup> In order to give individuals comprehensive rights to their genetic information, a state law must provide some amount of individual

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<sup>206</sup> See *supra* Part III.D.4.

<sup>207</sup> See *supra* Part II.B.

<sup>208</sup> Mark Rothstein, *Is Deidentification Sufficient to Protect Health Privacy in Research?* 10 AM. J. BIOETHICS 3, 5-7 (2010).

<sup>209</sup> Henry T. Greely, *Breaking the Stalemate: A Prospective Regulatory Framework for Unforeseen Research Uses of Human Tissue Samples and Health Information*, 34 WAKE FOREST L. REV. 737, 740 (1999).

<sup>210</sup> Greely, *supra* note 165, at 357.

<sup>211</sup> E.W. Clayton et al., *Informed Consent for Genetic Research on Stored Tissue Samples*, 274 JAMA 1786, 1786-92 (1995).

control over research without hindering the research and public health benefits of population databases and biobanks.

Giving an individual a meaningful informed consent opportunity when genetic information is first gathered for research is an essential step toward individual control. Note, however, that this will not solve the dilemma of how to regulate the large amount of genetic information already housed in biobanks across the country. In the past, scholars in this field have suggested mechanisms such as a newsletter or specialized review board to keep individuals informed of research, especially in cases of controversial research.<sup>212</sup> These systems can help to ensure continued individual involvement in research, but this article will focus on informed consent at the initial collection point.

Informed consent documents are difficult to create in a manner that will truly inform patients of future research and future uses,<sup>213</sup> but, when properly conducted, informed consent ensures that individuals understand their rights regarding their genetic information. Studies have found that individuals generally view societal benefits as a positive reason to enroll in research and discrimination or abuse of information as deterrents.<sup>214</sup> Thus, effective informed consent may encourage further participation in research. However, meaningful informed consent is difficult to give in this arena.

If the creation of these database resources is to be practicable, the materials and information will need to be available to investigate many diseases and many target genes. But that kind of broad availability will make it impossible for researchers to give the kind of full information about the potential risks and benefits of *specific* research that existing law seems to require for informed consent.<sup>215</sup>

Therefore, states may need to alter the way in which informed consent is provided for research to ensure a balance between individual protection and research benefits.

Most importantly, informed consent needs to include information, not just about risks and benefits of current research, but also about potential future research. Laws regarding informed consent should apply to both research and clinical settings—both arenas may lead to future research

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<sup>212</sup> Greely, *supra* note 165, at 358.

<sup>213</sup> Erika Check Hayden, *A Broken Contract*, 486 NAT. 312, 312 (2012).

<sup>214</sup> See, e.g., Henderson et al., *Great Expectations: Views of Genetic Research Participants Regarding Current and Future Genetic Studies*, 10 GENETICS MED. 193 (2008).

<sup>215</sup> Greely, *supra* note 209, at 741.

using initial sample collection.<sup>216</sup> In a 1999 report, the National Bioethics Advisory Commission (NBAC) recommended that informed consent for research should be obtained separately from informed consent for clinical procedures.<sup>217</sup> This article does not contradict that recommendation, as the recommendation speaks to when informed consent should be gathered, not the fact that informed consent should be collected. Comprehensive state laws should require informed consent for all initial contexts in which an individual's genetic material and information will be used for research—whether stemming from clinical care or from direct enrollment in research.

It is impractical, for both individuals and researchers, to require new informed consent for every subsequent research protocol performed with an individual's genetic information.<sup>218</sup> But current informed consent forms do not adequately inform individuals of future research and potential risks and benefits of that research.<sup>219</sup> Therefore, a balance in the middle of these extremes must be created. One option would be to allow individuals to complete an informed consent document that acts as an "advance healthcare directive" for the use of genetic material—an "advance research directive."

In most states, advance healthcare directives have multiple sections for an individual to fill out and make decisions about their health decisions in case of incapacity. For example, the California advance healthcare directive includes parts that relate to: (1) naming a "power of attorney for healthcare," (2) establishing individual wishes for treatment, (3) delineating guidelines for organ donation, (4) designating a primary care physician, and (5) signing the form.<sup>220</sup> Informed consent documentation should be established to follow a similar model.

In particular, there should be five main sections of informed consent in an advance research directive: (1) delineating options for future research, (2) clarifying views on "anonymous" research, (3) listing family members, (4) designating a primary care physician, and (5) signing the form.

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<sup>216</sup> While newborn screening is often an exception to state laws in this area, informed consent in newborn screening has been increasingly in the spotlight in recent years. States considering legislation in this area may need to specifically address newborn screening informed consent. *See, e.g.*, Hayden, *supra* note 213, at 312.

<sup>217</sup> NAT'L BIOETHICS ADVISORY COMM'N, 1 RESEARCH INVOLVING HUMAN BIOLOGICAL MATERIALS: ETHICAL ISSUES AND POLICY GUIDANCE 64 (1999).

<sup>218</sup> Greely, *supra* note 165, at 357.

<sup>219</sup> Hayden, *supra* note 213, at 312.

<sup>220</sup> CAL. PROB. CODE § 4701 (2000).

*a. Options for Future Research*

The first section of informed consent should give individuals the space to delineate what type of research they consent to for future use of their genetic information. The NBAC suggested this concept in its 1999 report.<sup>221</sup> For samples collected in the future, the NBAC recommended that “consent forms be developed to provide potential subjects with a sufficient number of options to help them understand clearly the nature of the decision they are about to make.”<sup>222</sup> The report lists six sample options:

- [1] refusing use of their biological materials in research,
- [2] permitting only unidentified or unlinked use of their biological materials in research,
- [3] permitting coded or identified use of their biological materials for one particular study only, with no further contact permitted to ask for permission to do further studies,
- [4] permitting coded or identified use of their biological materials for one particular study only, with further contact permitted to ask for permission to do further studies,
- [5] permitting coded or identified use of their biological materials for any study relating to the condition for which the sample was originally collected, with further contact allowed to seek permission for other types of studies, or
- [6] permitting coded use of their biological materials for any kind of future study.<sup>223</sup>

Another option would be to allow individuals to opt-in, or out, of research for a particular type of disease or condition. For example, an individual could state that his or her genetic information could be used for any research, except for research regarding Alzheimer’s disease. In that case, there would be the potential that an individual’s instructions do not clearly line up with research resulting in confusion for researchers as to whether consent was truly given. However, this potential lack of clarity also exists in the context of advance healthcare directives. No advanced method is truly perfect, but allowing for patient choice is important. Under this system researchers would at least have some guidance and individuals would have more control.

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<sup>221</sup> NAT’L BIOETHICS ADVISORY COMM’N, *supra* note 217, at 65.

<sup>222</sup> *Id.*

<sup>223</sup> *Id.* Two commissioners argued that the last two options should not be made available to the public. *Id.*

Additionally, this potential lack of clarity can be mitigated by providing some guidance to individuals. For example, some advance healthcare directives specifically give options for feeding tubes or palliative care, but also provide a free-form section for individuals to write more specific instructions. Similarly, informed consent for research could list common diseases, conditions, or behaviors that may be studied—especially controversial potential research areas such as behavioral genetics or the genetics of homosexuality—and also leave space for individuals to write in more specific instructions.

Allowing individuals this control over their genetic information will make use of biobanks more difficult for researchers. The researchers must create a system to code for individual's desires and only use the genetic information in each project of individuals who have consented to that type of research. This creates work to create such a system, and the possibility that fewer genetic samples will be available for studies. This is still preferable to those current state laws that have the potential to make research nearly impossible by requiring new informed consent documentation for each use of genetic information. Given the uniquely personal aspect of genetic information, this system creates a fair balance between individual control and research functionality. Additionally, researchers have begun to use models like these for returning research results to participants and therefore, may be able to be modified for use at the front end research participation.

*b. Anonymity*

As mentioned above, there is almost no way to make genetic data both useful and truly anonymous.<sup>224</sup> Therefore, informed consent documents must explain this to individuals. The procedures for how patient information will be made as anonymous as possible should be delineated. In this section, individuals will sign that they understand the limitations of the anonymity of data. If they do not want research done where anonymity cannot be guaranteed, they should be able to note this in the first section above.

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<sup>224</sup> See *supra* Part III.D.4.

*c. Family Members*

Due to the familial nature of genetic information, individuals should have the option of designating a family member or family members to contact in the event that there are research results that could be returned, but the individual is no longer accessible.<sup>225</sup> This would be similar to appointing a power of attorney for healthcare decisions, but would appoint a family designee to obtain relevant research findings.

*d. Primary Care Physician*

Individuals should also have the opportunity to provide the name of a primary care physician from whom to receive research results. As more biobanks are determining how to best return research results to their subjects, some individuals may decide that they do not wish to hear this information directly from the researcher. In some circumstances, individuals may prefer to have their doctor share this information with them so that they have the opportunity to ask questions and to determine next steps for clinical care. Therefore, the advance research directive should include a space to provide contact information for a primary care physician.

Other laws in the genetic arena have acknowledged the advantages of having a doctor, rather than another party, disseminate the information to the originator of genetic information. For example, in Minnesota, a life insurance company can notify an individual of genetic test results by releasing information to either the individual or their designated physician.<sup>226</sup> “If the individual tested has not given written consent authorizing a physician to receive the test results, the individual must be urged, at the time that the individual is informed of the genetic test result described in this subdivision, to contact a genetic counselor or other health care professional.”<sup>227</sup> New Jersey, New York, Maine, and Texas all have similar provisions in their codes.<sup>228</sup>

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<sup>225</sup> It is beyond the scope of this paper to discuss returning research results and implications of duty to warn family members, but the creation of a comprehensive informed consent document provides an opportunity to address some of these concerns at the front end.

<sup>226</sup> MINN. STAT. ANN. § 72A.139(6) (2012).

<sup>227</sup> *Id.*

<sup>228</sup> N.J. STAT. ANN. § 10:5-43 (West 2009); N.Y. INS. LAW § 2615(e) (McKinney 2005); ME. REV. STAT. ANN. 24-A § 2159-C(3)(B) (2009); TEX. REV. CIV. STAT. ANN. art. 2, § 21.404 (West 2003).

Allowing individuals to include a physician on their advance research directive may increase participation in research because it may help to alleviate individual fears regarding knowledge of predispositions. Speaking to a trusted physician about a test result, rather than receiving information through a researcher or computer print-out, may be more palatable to some individuals.

## CONCLUSION

As the use of genetic testing rises, many states are beginning to pass legislation aimed at filling the gaps in GINA and providing comprehensive genetic rights to individuals. Comprehensive genetic rights are essential to encourage the use of testing, ensure participation in research, and strengthen individual rights in a deeply personal and familial realm. However, many state efforts to date provide overbroad property or privacy rights in genetic information and are not sufficiently tailored to create truly comprehensive rights. An article in the *Genomics Law Report* summarizes the trend in its review of a proposed South Dakota bill.

In under 200 words, the South Dakota bill, if passed, would (1) grant property rights to individuals in their DNA samples and genetic information, (2) prohibit surreptitious testing, (3) call into question many forensic and law enforcement uses of DNA, (4) eliminate newborn blood spot screening without explicit consent and (5) impose broadly worded informed consent requirements on all collections and uses of individual genetic data.<sup>229</sup>

Genetic rights are too complicated to fully protect with a law containing fewer than 200 words. The growing trend among states to make overbroad laws in this arena jeopardizes individual rights because it waters down the law, makes innocuous behavior illegal, and makes it harder to pass corrective legislation the second time around.

In order to provide comprehensive genetic rights for individuals, states should make broad laws that are specifically tailored to address the four major concerns of individuals in the genetic arena—fear of discrimination, surreptitious genetic testing, unwanted disclosure of genetic information, and control over how personal information is used in research. To do this, states should expand anti-discrimination laws to ban the use of genetic information in all businesses and

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<sup>229</sup> Wagner & Vorhaus, *supra* note 91.

government practices, prohibit surreptitious genetic testing, forbid intentional disclosure of genetic test results for personal gain or to harm an individual or family member, and create meaningful informed consent in research by creating an advance research directive for individuals whose genetic information will be used in research. Only with tailored components of a broad genetic rights bill will individuals truly be given comprehensive rights over their genetic information.

## APPENDIX

OVERVIEW OF STATE LEGISLATION REGARDING  
GENETIC INFORMATION

	Provisions Covering Employment or Health Insurance	Provisions Regulating Other Insurances	Provisions Providing for a Property Right	Provisions Providing for a Privacy Right
Alabama <sup>i</sup>	X			
Alaska <sup>ii</sup>	X		X	
Arizona <sup>iii</sup>	X	X		
Arkansas <sup>iv</sup>	X			
California <sup>v</sup>	X	X		
Colorado <sup>vi</sup>	X	X	X	
Connecticut <sup>vii</sup>	X			
Delaware <sup>viii</sup>	X			X
District of Columbia <sup>ix</sup>	X			
Florida <sup>x</sup>	X		X	
Georgia <sup>xi</sup>	X		X	
Hawaii <sup>xii</sup>	X			
Idaho <sup>xiii</sup>	X	X		
Illinois <sup>xiv</sup>	X			X
Indiana <sup>xv</sup>	X			
Iowa <sup>xvi</sup>	X			X
Kansas <sup>xvii</sup>	X	X		
Kentucky <sup>xviii</sup>	X	X		
Louisiana <sup>xix</sup>	X		X	
Maine <sup>xx</sup>	X	X		
Maryland <sup>xxi</sup>	X	X		
Massachusetts <sup>xxii</sup>	X	X		
Michigan <sup>xxiii</sup>	X			
Minnesota <sup>xxiv</sup>	X	X		X
Mississippi				
Missouri <sup>xxv</sup>	X	X		
Montana <sup>xxvi</sup>	X			
Nebraska <sup>xxvii</sup>	X			
Nevada <sup>xxviii</sup>	X			
New Hampshire <sup>xxix</sup>	X	X		X
New Jersey <sup>xxx</sup>	X	X		X
New Mexico <sup>xxxii</sup>	X	X		X
New York <sup>xxxiii</sup>	X	X		X
North Carolina <sup>xxxiii</sup>	X			
North Dakota				
Ohio <sup>xxxiv</sup>	X			
Oklahoma <sup>xxxv</sup>	X			
Oregon <sup>xxxvi</sup>	X	X		X
Pennsylvania				
Rhode Island <sup>xxxvii</sup>	X			
South Carolina <sup>xxxviii</sup>	X			

	Provisions Covering Employment or Health Insurance	Provisions Regulating Other Insurances	Provisions Providing for a Property Right	Provisions Providing for a Privacy Right
South Dakota <sup>xxxix</sup>	X			X
Tennessee <sup>xl</sup>	X			
Texas <sup>xli</sup>	X	X		
Utah <sup>xlii</sup>	X			
Vermont <sup>xliii</sup>	X	X		
Virginia <sup>xliv</sup>	X			
Washington <sup>xlv</sup>	X			
West Virginia <sup>xlvi</sup>	X			
Wisconsin <sup>xlvii</sup>	X	X		
Wyoming <sup>xlviii</sup>	X			

<sup>i</sup> ALA. CODE § 27-53-2 (1997) (regulating only genetic tests for a predisposition to cancer in health insurance).

<sup>ii</sup> ALASKA STAT. § 21.36.480 (2009) (requiring health insurance companies to comply with GINA); ALASKA STAT. § 18.13.010(a) (2004) (creating a property interest).

<sup>iii</sup> ARIZ. REV. STAT. ANN. § 20-448 (2009) (regulating health, life, long-term care, and disability insurance); ARIZ. REV. STAT. § 41-1463 (2010) (regulating employment).

<sup>iv</sup> ARK. CODE ANN. § 11-5-403 (West 2001) (regulating employment); Genetic Nondiscrimination in Insurance Act, ARK. CODE ANN. § 23-66-320 (West 2001).

<sup>v</sup> CAL. CIV. CODE § 51(b) (West 2012); CAL. GOV'T CODE § 12926(i)(2) (West 2013).

<sup>vi</sup> COLO. REV. STAT. ANN. § 10-3-1104.7(1) (West 2010).

<sup>vii</sup> CONN. GEN. STAT. ANN. § 38a-816 (West 2012) (regulating insurance); CONN. GEN. STAT. ANN. § 46a-60 (West 2009) (regulating employment).

<sup>viii</sup> DEL. CODE ANN. 16 § 1202(a) (West 2012) (establishing a privacy interest); DEL. CODE ANN. 18 § 2317 (1998) (regulating insurance); DEL. CODE ANN. 19 § 711 (West 2013) (regulating employment).

<sup>ix</sup> D.C. CODE § 2-1401.01 (3)(e) (West 2012) (regulating employment).

<sup>x</sup> FLA. STAT. ANN. § 760.40(2)(a) (West 2010); FLA. STAT. ANN. § 627.6561 (West 2011).

<sup>xi</sup> GA. CODE ANN. § 33-54-1 (2013) (creating a property interest); GA. CODE ANN. § 33-54-3 (2013) (regulating insurance).

<sup>xii</sup> HAW. REV. STAT. § 431:10A-118 (LexisNexis 2003) (one of multiple statutes regulating genetic information in health insurances); HAW. REV. STAT. § 378-1 (LexisNexis 2012) (regulating employment).

<sup>xiii</sup> IDAHO CODE ANN. §§ 39-8301 – 8304 (2006) (regulating employment); *Id.* § 41-1313 (2006) (regulating health and disability insurances).

<sup>xiv</sup> 410 ILL. COMP. STAT. 513/1 – /35 (1998).

<sup>xv</sup> IND. CODE ANN. § 27-8-26-5 (West 2013).

<sup>xvi</sup> IOWA CODE ANN. § 729.6 (West 2010).

<sup>xvii</sup> KAN. STAT. ANN. § 40-2259 (West 2010) (regulating health, disability, and long-term care insurances); KAN. STAT. ANN. § 44-1009(a)(9) (West 2012) (regulating employment).

<sup>xviii</sup> KY. REV. STAT. ANN. § 304.12-085(2) and (3) (West 2013) (regulating health and disability insurances).

<sup>xix</sup> LA. REV. STAT. ANN. § 22:1023(E) (2011) (regulating health insurance and establishing a property interest); LA. REV. STAT. ANN. § 23:368 (2010) (regulating employment).

<sup>xx</sup> ME. REV. STAT. ANN. tit. 24-A, § 2159-C (2013) (regulating health, life, long-term care, disability, and dental insurances); *Id.* § 19302 (2013) (regulating employment).

<sup>xxi</sup> MD. CODE ANN., INS. § 18-120 (LexisNexis 2008) (regulating long-term care insurance); MD. CODE ANN., INS. § 27-909 (2001) (regulating health insurance); MD. CODE ANN., STATE GOV. § 20-606 (LexisNexis 2009).

- xxii MASS. GEN. LAWS ANN. ch. 151B, § 4 (West 2013) (regulating employment); MASS. GEN. LAWS ANN. ch. 175, § 108H (West 2011) (regulating health insurance); *id.* § 108I (West 2011) (regulating disability and long-term care insurances); *id.* § 120E (West 2011) (regulating life insurance).
- xxiii MICH. COMP. LAWS ANN. § 37.1202 (West 2013) (regulating employment); *Id.* § 500.3407b (regulating health insurance).
- xxiv MINN. STAT. § 13.386(3)(4)(ii) (2012) (establishing a privacy interest); *id.* § 72A.139 (2012) (regulating health and life insurance); *id.* § 181.974 (2012) (regulating employment).
- xxv MO. ANN. STAT. § 375.1303 (2012) (regulating health insurance); *Id.* § 375.1306 (regulating employment).
- xxvi MONT. CODE ANN. § 33-18-903 (2013) (regulating health insurance); *id.* § 33-18-206 (regulating life, long-term care, and disability insurance under the more narrow definition of genetic condition).
- xxvii NEB. REV. STAT. ANN. § 44-7,100 (2012) (regulating health insurance); *id.* § 48-236 (regulating employment); *id.* § 71-551(6)(a) (granting a limited privacy right only in the context of physicians).
- xxviii NEV. REV. STAT. ANN. § 695C.207 (LexisNexis 2012) (regulating health insurance); *id.* § 613.345 (regulating employment); *id.* § 629.151 (requiring informed consent in the healing arts).
- xxix N.H. REV. STAT. ANN. §§ 141-H:1 to :4 (2013).
- xxx N.J. STAT. ANN. § 10:5-43 to -48 (West 2009) (establishing a privacy interest); *id.* § 17B:26-3.2 (one of several provisions regulating genetic information in health insurance); *id.* § 17B:30-12 (regulating life and disability insurance).
- xxxi N.M. STAT. ANN. § 24-21-1 to -7 (1998).
- xxxii N.Y. EXEC. LAW § 296 (McKinney 2010) (regulating employment); N.Y. CIV. RIGHTS LAW § 79-1 (McKinney 2002) (establishing a privacy right); N.Y. INS. LAW § 2615 (McKinney 2006) (regulating health, life, long-term care, and disability insurances).
- xxxiii N.C. GEN. STAT. § 58-3-215 (2013) (regulating health insurance); *id.* § 95-28.1A (regulating employment).
- xxxiv OHIO REV. CODE ANN. § 1751.65 (LexisNexis 2013) (regulating health insurance).
- xxxv OKLA. STAT. ANN. tit. 36 § 3614.1 (West 2013) (regulating health insurance); *id.* § 3614.2 (regulating employment).
- xxxvi OR. REV. STAT. ANN. § 192.531 (West 2009) (establishing a privacy right); OR. REV. STAT. ANN. § 659A.303 (West 2011) (regulating employment); *id.* (regulating health, life, long-term care, and disability insurances).
- xxxvii R.I. GEN. LAWS § 27-18-52 (2002) (one of several provisions regulating health insurance); *id.* § 28-6.7-1 (regulating employment).
- xxxviii S.C. CODE ANN. §§ 38-93-10-80 (2010) (regulating health insurance).
- xxxix S.D. CODIFIED LAWS § 34-14-22 (2013) (establishing a privacy right); S.D. CODIFIED LAWS § 58-1-25 (2001) (regulating health insurance); *id.* § 60-2-20 (regulating employment).
- xl TENN. CODE ANN. §§ 56-7-2701-2704 (1998) (regulating health insurance).
- xli TEX. INS. CODE ANN. §§ 546.001-.051 (West 2005) (regulating health insurance); TEX. LAB. CODE ANN. § 21.401-.402 (West 2003) (regulating employment).
- xlii UTAH CODE ANN. §§ 26-45-101-104 (West 2003) (regulating employment and health insurance).
- xliii VT. STAT. ANN. tit. 18 §§ 9331-34 (2012) (regulating employment and health, long-term care, disability, and life insurance).
- xliv VA. CODE ANN. § 38.2-3450 (2013) (regulating health insurance); VA. CODE ANN. § 40.1-28.7;1 (2002) (regulating employment).
- xlv WASH. REV. CODE ANN. § 49.44.180 (2004) (regulating employment).
- xlvi W. VA. CODE § 33-16-3k (1997) (regulating health insurance).
- xlvii WIS. STAT. §§ 111.32-.335 (2010) (regulating employment); *id.* § 631.89 (regulating health, life, long-term care, and disability insurance).
- xlviii WYO. STAT. ANN. § 26-19-107 (2013) (regulating health insurance).