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Genetic Information, Privacy and Insolvency

Edward J. Janger

B iobanks hold out the prospect of significant public and private benefit, as genetic information contained in tissue samples is mined for information. However, the storing of human tissue samples and genetic information for research and/or therapeutic purposes raises a number of serious privacy and autonomy concerns.¹ These concerns are compounded when one considers the possibility that a biobank or its owner might go bankrupt.² Insolvency impairs the ability of enforcement regimes, and liability-based regimes in particular, to enforce legal norms.³ The goal of this essay is to develop guideposts for thinking about private and public enforcement of privacy imposed by donors on tissue samples and/or genetic information when a biobank becomes insolvent.

As with any form of nonpublic, personally identifiable information, the use of human tissues for purposes other than those for which they were donated (“secondary use”) raises important substantive policy issues. When I consent to medical treatment, do I consent to have my blood used in a research study? Is this consent limited to the doctors at the hospital where I am treated? What about private pharmaceutical companies, attempting to develop drug treatments? If I do consent to such secondary use, do I waive any rights to share in the financial benefits earned by any therapy developed using my tissue? If my consent was procured hastily on the eve of emergency surgery, and as a precondition to that surgery, should any such consent be viewed as binding?⁴ These concerns can be respectively categorized as (1) scope of consent (what did I agree to?), (2) permissible secondary use (what uses of my tissue are permissible even though I did not expressly consent to them?), and adhesion (was my consent meaningful and voluntary?). Unavoidably, these substantive concerns will inform this article, but they are not its focus: The focus of this essay is on remedies, and specifically how best to enforce limitations on secondary use when a biobank becomes insolvent. The key, I argue, is to tie the use restrictions directly to the information (or sample) *itself*, rather than focusing, as most regulation does, on the *act* of transferring information.

This article proceeds in three steps. Part I describes a typology of remedies for privacy violations that depends on whether rights are enforced through a property based regime, a liability based regime or a regime of public enforcement. Part II explains how the choice of enforcement regime affects the level of protection accorded a privacy entitlement when a biobank becomes

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insolvent. Liability based protection focuses on the act of transfer and gives the least protection in bankruptcy. Property based protection focuses on the item itself, and provides substantially more.⁵ Public enforcement regimes are unaffected by bankruptcy, but the level of protection is indeterminate, depending on how prosecutorial resources are allocated, and on whether restrictions on tissue or information use “run with the sample.” Part III explores the problems for biobanking that may be created by a purely property based regime. While property based protection provides the greatest protection for donor autonomy, the property right created should not be freely and completely alienable, nor should it be absolute. Adhesion, bounded rationality, and information asymmetry have the potential to render even property-based protection no protection at all.⁶ At the same time, absolute protection of genetic privacy has the potential to destroy the common benefits obtained through the aggregation of data.⁷ This article concludes by suggesting a collective mechanism for empowering bankruptcy courts to use a *cy pres* approach rooted in the bankruptcy concept of “adequate protection” to balance privacy protections with research and therapeutic imperatives.

The Question

To facilitate discussion, a concrete fact pattern might be helpful. Imagine that Paul Patient goes to the doctor for a cancer treatment. Dave Doctor asks Patient if he will agree to provide a blood sample for a biobank (“Biobank”) that his hospital is building to help study genetic link factors in cancer, and perhaps develop a new treatment. Patient agrees, authorizing Biobank to use his blood sample and related information for “research devoted to identifying the role of genetics in cancer and to develop new therapies.” For two years, the project runs along as expected, making some important advances.

Then Doctor’s hospital finds itself in financial difficulty. A private pharmaceutical company, called Genscreen, offers the hospital (and Doctor’s project) a significant amount of money for access to the blood samples collected by Doctor, and for access to the information (excluding names) about those samples in Doctor’s database. Instead of using the samples to iden-

tify cancer risks and develop treatment, Genscreen intends to develop a cheap screening device which will identify genetic risk of cancer and allow insurance companies to exclude people with high risk from coverage. This is not the purpose for which Donor donated his blood, nor is it a use for which he gave consent, nor would he give consent if asked. What

happens if the Biobank goes bankrupt? Can it sell samples to Genscreen in violation of its promises to Patient? Does Patient have a breach of contract claim? What happens to Patient’s breach of contract claim in bankruptcy? Should the answer to these questions change if the purchaser of the data is seeking to develop a cure for heart disease?

Property, Liability and Public Enforcement: Outside of Bankruptcy

Outside of bankruptcy, the status of Patient’s claim receives different levels of protection depending on how Patient’s rights are characterized. They may be protected, to use Calabresi and Melamed’s dichotomy, by a “property” rule, a “liability” rule, or to reach beyond the Calabresian terminology, by public enforcement (which may in turn be civil or criminal).⁸ Calabresi and Melamed draw the line between property and liability based on whether an obligor such as Biobank can choose to breach its obligation and pay damages – a liability rule, or the obligation will be enforced by an affirmative order, and enforced by contempt, punitive damages, or criminal sanction – a property rule.⁹ Others have focused on whether the right binds specific people, or whether the entitlement runs with an object, or bundle of entitlements.¹⁰ As Hansmann and Kraakman put it:

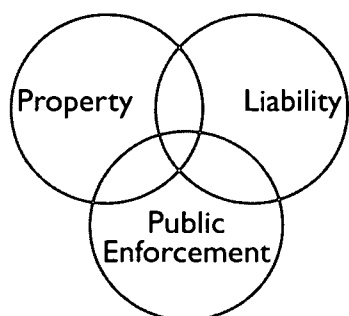
For our purposes, the attribute that distinguishes a property right from a contract right is that a property right is enforceable, not just against the original grantor of the right, but also against other persons to whom possession of the asset, or other rights in the asset, are subsequently transferred.¹¹

These two definitions are not necessarily inconsistent. However, the focus is different. Under the Calabresian approach to property, the focus is on the ability of the rights holder to unilaterally veto any transfer. Under the Hansmann and Kraakman approach, the focus is not on veto, but on whether any subsequent taker of the “property” takes subject to the rights of the initial transferor.

The question of public versus private enforcement, by contrast, goes to standing, rather than the nature of

the remedy *per se*. Entitlements may be enforceable through both public and private right of action, or they may be enforceable only privately, or only by public officials. Public enforcement may be property-like, in that violation is criminal, or enforced through high fines or statutory damages, or the relief can be liability-like, compensatory in nature, and tied to actual damage caused. The difference between public enforcement and private enforcement is that a party driven system is traded for, or supplemented by, a regime of prosecutorial discretion.

Figure 1



How does the law protect promises not to share information with companies like Genscreen? To the extent that they are based in contract, the focus is on Biobank's promise to Patient. The general rule is that Patient's rights are only against Biobank, and are protected only by a liability rule. Patient's rights can only be asserted against the contracting party. Patient's rights do not inhere in the information or the sample itself. The principal remedy for contractual violations is compensatory damages.¹² While specific performance of the promise through injunctive relief may be available, such relief is considered extraordinary,¹³ and, as discussed below, is of limited use in bankruptcy.¹⁴ While federal copyright and patent law give the status of property to certain forms of intellectual property, the same is not true for personal information, or for non-disclosure promises. The promise not to disclose, except for the purposes consented to, does not carry with it a veto right, or a right that runs with the Paul Patient's blood sample.¹⁵

Contract law is not the only source of protection, however. There are a number of federal statutes that might enhance privacy protection through public enforcement. For example, Section 5 of the Federal Trade Commission Act (FTC) protects against deceptive trade practices.¹⁶ The FTC has acted to enforce privacy promises under Section 5,¹⁷ and they would likely be troubled by sale of tissue in a biobank in violation of a promise not to do so. States also have their own deceptive trade

practices acts, some of which provide for private rights of action, which may give rise to a right to an injunction.¹⁸ The recently promulgated Health Insurance Portability and Accountability Act (HIPAA) regulations also place limit on disclosure of personal information without consent.¹⁹ Neither the FTC Act, nor the HIPAA regulations provide for a private right of action. Thus, enforcement is subject to prosecutorial discretion and is not party driven.

Finally, about 25 states have enacted statutes which give some form of protection to the privacy of genetic information. The various approaches reflect little consistency. Some give genetic information express status as property. Others give property-like protection, in that they prohibit use of genetic information without consent, regardless of how the information was obtained. Others give only liability based protection. Some provide only for public enforcement, some allow a private right of action. A table is set forth in the Appendix to this article. Many jurisdictions, however, say nothing, and offer no specific protection beyond state common law, and the federal overlays described above.

Property, Liability and Public Enforcement in Bankruptcy

The distinction between property, liability, and public enforcement is important outside of bankruptcy. The importance is even greater when a debtor becomes insolvent. Property rights are generally respected in bankruptcy, while liability based claims are generally discharged, and paid, if at all, in cents on the dollar.

Treatment of Contract (Liability-based) Claims in Bankruptcy

Both inside and outside of bankruptcy, the insolvency of a debtor undercuts the effectiveness of a liability-based regime. Outside of bankruptcy, this is manifested through the so-called "judgment proof" problem. A debtor who is going to be unable to pay a damage judgment may have less compunction about invading the rights of others.²⁰

Imagine, for example, that, in an effort to stave off bankruptcy, Biobank sells Patient's information to Genscreen. Assume that this is a breach of contract, and would give rise to liability. One problem common to privacy contexts is that the damages for such a disclosure are difficult to calculate. Even assuming, however, that Patient could prove damages of, say, \$1,000, his recovery will be significantly less than that.

If Biobank or its owner files for bankruptcy, a number of aspects of bankruptcy law undercut the enforcement of promises like that of Biobank to Patient. First, when a debtor files for bankruptcy, an automatic stay goes into effect which prohibits any action to collect on

or enforce a prepetition obligation.²¹ At the conclusion of the bankruptcy case, those obligations are discharged.²² Second, while Patient would be free to assert a claim for breach of contract in Biobank's bankruptcy case, damages would be treated as general unsecured claims, and paid *pro rata* with other such claims, likely in cents on the dollar.²³ For example, if Biobank has outstanding unsecured claims of \$100,000, and unencumbered assets of \$15,000, then Patient's recovery will only be fifteen cents on the dollar, or \$150. Biobank will not have fully internalized the harm caused by its acts.

Indeed, if the only safeguard against disclosure of information is a contract claim, this same principle of discharge and pro rata distribution may allow Biobank to sell Patient's information post-bankruptcy, in the interest of maximizing the value of its assets for the benefit of its creditors. Similarly, if Biobank's promise of confidentiality is treated as an executory contract, Biobank will likely have the power to "reject" or breach the promise post-petition and have Patient's claim treated as "prepetition," and dischargeable.²⁴ Even if the contract is entitled to specific enforcement outside of bankruptcy, the trustee's strong-arm power may render that property-like protection "avoidable" and unenforceable against creditors.²⁵ If the contract is viewed as non-executory, then rejection may not even be necessary.²⁶

Property

By contrast, if Patient is viewed as "owning" his genetic information, then Patient will receive better treatment in bankruptcy. If an obligation of the debtor is secured by an interest in specific property of the debtor, the creditor will be treated as having a "secured claim."²⁷ Secured status confers on the creditor a number of benefits. First, in any distribution, the secured creditor is entitled to receive payment of the value of his or her collateral.²⁸ More generally, if property of the debtor is encumbered by an interest that would be enforceable against third parties outside of bankruptcy, subject to certain specific avoiding powers, discussed below, that encumbrance will be respected. Finally, and most importantly, there are restrictions on the debtor's ability to sell the property free of the non-debtor's property interest.²⁹

Unlike patent, copyright, or other forms of intellectual property, there is no federal statute giving personal information the status of property. In the absence of a special statute conferring such a right, Patient will not have the status of an owner, entitled to adequate protection. Four states have enacted statutes that purport

to grant Patient a "property interest" in personal information. Those states are: Colorado, Florida, Georgia and Louisiana. The nature of the property right in each

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state is different. In none of them, however, is the "property" right one that would entitle Patient to preferred treatment in bankruptcy.

For example, in Georgia, while legislative findings characterize genetic information as "property" they only provide a remedy in the event that an insurer misuses the information. The statute does not provide a right of action in the event that Biobank itself misuses the information. Louisiana, by contrast, gives some meaning to the concept of "property," by saying that storing genetic information without authorization will give rise to liability and in some cases treble damages. However, even these statutes which purport to create a property right don't necessarily give Patient rights beyond damages.

Even if Patient is given a property interest in tissue samples and/or genetic information, the power of the debtor to sell assets free and clear of liens and interests under 363(f) may pose some risk. Section 363(f) provides:

(f) The trustee may sell property under subsection (b) or (c) of this section free and clear of any interest in such property of an entity other than the estate, only if:

- (1) applicable nonbankruptcy law permits sale of such property free and clear of such interest;
- (2) such entity consents;
- (3) such interest is a lien and the price at which such property is to be sold is greater than the aggregate value of all liens on such property;
- (4) such interest is in bona fide dispute; or
- (5) such entity could be compelled, in a legal or equitable proceeding, to accept a money satisfaction of such interest.³⁰

Thus, in bankruptcy, a debtor has the ability to sell free and clear of liens *and* interests, so long as any one of the five criteria listed in 363(f) is satisfied, and the interest holder is provided with adequate protection of its interest under section 363(e). Thus, whether section

363(f) will permit sale of tissue samples or genetic information free and clear of a promise not to do so will depend on the nature of the protection given to that right outside of bankruptcy. If a liability rule is used (f)(1) will apply. Even if the protection is in the nature of a lien, or a statutory fine, then (f)(3) or (f)(5) might apply. If the lien or interest can be stripped off, the interest holder is still entitled to adequate protection of that interest.³¹ However, the nature of that protection will again turn on the nature of the underlying interest. Under current law, the status is uncertain at best.

The general rule is that debtors cannot sell property out from under restrictive covenants or other property interests that are not in the nature of a lien. For example, in *Gouveia v. Tazbir*,³² a debtor was unable to sell real property free and clear of restrictive covenants contained in the debtor's deed. However, bankruptcy courts, when considering whether to allow an asset to be sold free of an encumbrance must weigh the impact of prohibiting the sale on the bankruptcy case as a whole. Recent cases manifest this tension. In a recent ninth Circuit case, *In re Rodeo Canyon Development Corporation*,³³ the Ninth Circuit held that a bankruptcy court could not sell property free and clear of interests until it had first adjudicated the status of the asserted ownership interest. By contrast, in *In re Trans World Airlines*, the Third Circuit held that where TWA was selling all of its assets to American Airlines, that sale could be accomplished free and clear of certain successor liability claims, on the theory that those claims could be reduced to a money judgment.³⁴ And, in *Precision Industries v. Qualitech Steel*,³⁵ the Seventh Circuit held that property encumbered by a lease could be sold free and clear of that lease, even where other provisions of the Bankruptcy Code would have prevented such sale (if the lessee had objected at the time). Where the assets of an entire business are being sold, and the package has value which exceeds those of its individual parts, courts have shown a willingness to stretch the limits of section 363(f) to get the job done.³⁶ While adequate protection is still available under section 363(e), it is difficult to figure out how to give meaning to that term where genetic privacy is concerned.

In Personam v. In Rem

Figuring out how and when to permit transfer of tissue samples and genetic information free of Patient's consent is the key question posed by bankruptcy. The key incident of "property" that can mitigate the effect of bankruptcy on privacy is to focus on the "in rem" nature of property rights. Calabresi and Melamed focus on the

distinction between rights enforceable through damages and rights enforceable by affirmative order. As noted above, Hansmann and Kraakman focus instead on rights that run with the property. Here, the Louisiana statute is illustrative. It contains a restriction on "onward transfer." It is not just Biobank's transfer of Patient's genetic information to Genscreen that vio-

A regime which subjects users to liability unless they can demonstrate consent of the donor mitigates the harm caused to donors by the bankruptcy of a biobank.

lates the statute. Any storage or use of the information without Patient's consent would subject Genscreen to liability. In short, a regime which subjects users to liability unless they can demonstrate consent of the donor mitigates the harm caused to donors by the bankruptcy of a biobank.

Under current law, however, the focus of state law regulating transfer and use of genetic information seems calculated to maximize the effect of bankruptcy rather than to minimize it. As noted above, only four states characterize the privacy entitlement as property. To the extent that other states have passed statutes safeguarding genetic privacy, 25 states prohibit unauthorized transfer of information. Only 11 prohibit genetic testing without consent, 5 prohibit accessing genetic information without consent, and 6 prohibit retaining genetic information without consent. Thus, the most common form of regulation focuses on unauthorized transfer of genetic information. This is an important protection, but because it focuses on the transferor, rather than the user of the information, the effect is *in personam* rather than *in rem*, and the insolvency of the transferor is likely to limit the effect of such regulation. Regulations that prohibit access, use or storage of information without consent reach beyond the single insolvent transferor, and deprive the information (unaccompanied by consent) of its value.

Public Enforcement

Bankruptcy has somewhat less serious impact on rights that are protected by public enforcement. The automatic stay in bankruptcy contains an exception for both criminal prosecutions, and litigation aimed at protecting "public safety."³⁷ To give one example, a company known as Toysmart sought to sell customer lists in bankruptcy after promising prior to bankruptcy not to do so. The FTC sought to enjoin the sale under Section 5 of the FTC Act, and obtained an injunction. The action by the FTC was not stayed, and the sale was blocked. State and federal statutory schemes that pro-

vide for public enforcement and injunctive relief as part of the remedial scheme are not affected by the bankruptcy of a biobank.

Public enforcement is not a panacea, however. Where the disclosure happens before the enforcement action can be brought, insolvency will still limit the impact of enforcement where the remedies are limited to monetary damages or fines. Such fines while assertable in the bankruptcy, may be subject to subordination, to the extent that they are non-compensatory, and even if not subordinated will be payable in cents on the dollar.³⁸ Perhaps more important, however, than the right to public enforcement *per se* is the ability to enforce Biobank's privacy obligations on subsequent holders of Patient's information.

II.

As discussed above, the principal effect of bankruptcy on a regime seeking to protect the privacy of personal information in biobanks is to limit the effectiveness of monetary remedies as a disincentive to disclosure. This presents a problem under current law. While a number of federal statutes provide for public enforcement of genetic privacy and a number of states have statutes that create private rights of action, the default is that the protection of genetic privacy lies in contract, and contract rights are enforced through liability rules.

There are two remedies for this problem. Both remedies involve giving genetic information the attributes of property. The first might be to give the donor of genetic information a right in the nature of a lien, which would be entitled to adequate protection. This would provide some protection to the information insofar as it was being used by the debtor in bankruptcy, and it would require compensation if the information was sold. But liens are generally satisfied by selling the property subject to the lien, and by paying the proceeds to the lienholder. Where the harm caused by disclosure of genetic information is principally dignitary, and where the value of a particular tissue sample is relatively small, this protection may be little better than a liability rule. Second, we might follow the lead of Louisiana and prohibit any use of the information without authorization. In other words, genetic information would be treated as another form of intellectual property, where any use must be pursuant to a license from the creator/donor. If protection of Patient's privacy is the goal of the statute, then an essential attribute of any property regime is that Patient's conditions on the use of his information run with the information itself.

However, while minimizing the effect of bankruptcy on privacy protections is a laudable goal where genetic information is involved, there are problems with a pure property regime that need to be addressed. These prob-

lems fall into two broad categories: (1) market imperfections and (2) coordination problems. The first leads to the underprotection of privacy in a simple property regime, and the second focuses on inefficiencies and welfare loss caused by overprotection of property rights in a simple property regime. I will discuss these in order.

First, one concern about a simple property regime goes to the quality of the consent. How was it obtained? Was it fully voluntary? This issue looms large in the medical literature on informed consent.³⁹ Concerns about adhesion, information asymmetry, and bounded rationality also play a role in the privacy debate.⁴⁰ One can imagine Patient in the above scenario granting blanket consent to use of his DNA in a number of ways that would raise concerns. First, cognition and information asymmetry can cast doubt on the validity of consent. The consent to use of the genetic material for research purposes may have been obtained as part of consent to treatment. The two may have been contained on the same form, and Patient may not have even realized that he/she was giving the doctors a right to make secondary use of genetic information. Further, adhesion plays a role here too. Sometimes agreement to participate in a study is the only way that a Patient can obtain access to a particular treatment. Where treatment and information sharing are linked as a take it or leave it proposition, Patient has no choice but to consent.

Where this is the case, the best property protection will not help.⁴¹ Property based protection is worthless without some legal efforts to police bargains, and/or create spheres of inalienability, where even blanket consents are interpreted as having certain limits.

Second, property can be overprotective of privacy.⁴² Banking of genetic information for public purposes can produce important social benefits. There are perfectly good public health reasons for invading a person's privacy in the interest of identifying and/or curing diseases. The identity of Patient need not necessarily be revealed to the researcher, but certain medical information might be important. A strict property regime, limiting any use of information without consent, might deprive society of these important benefits. This problem has been described as an anticommons.⁴³ Where property rights are fragmented, and any stakeholder has the ability to veto the use of common property, coordination problem may result in the destruction of, or underuse of the common asset. Biobanks are such common assets. The value of genetic data lies not in the information about the individual alone, but in the ability to aggregate data about many people and to note trends and patterns. If an individual, or a significant group, withholds consent, important research can be stifled.

III.

Thus propertization may be necessary in order to protect genetic privacy in the event of bankruptcy, but two additional components may also be necessary to strike the appropriate balance. To deal with problems like adhesion, bounded rationality, and information asymmetry, it may be necessary to police the privacy bargains struck by patients and information donors. This policing may take a number of forms. For example, it might take the form of a sticky default rule, where express consent or specific consideration are required to give effect to consent. It could also take the form of an inalienability rule, prohibiting blanket consents, and/or even prohibiting consent to certain uses of genetic information. Finally, it could take the form of a standard form license, where the terms and scope of consent are specified by law instead of private negotiation. Which of these forms should be used is beyond the scope of this article, and will probably vary significantly depending on context.⁴⁴

In addition to policing the bargain to protect individuals from overreaching or overbroad consents, it may also be necessary to limit the ability of individuals to tie up their information, and prohibit its use. The public interest in gathering information necessary to protect public health, or to develop effective therapies may trump the individual's desire to sequester genetic data. Any such limits on privacy should, of course, be narrowly tailored to a necessary public purpose, and the compulsory use of the information should carry with it privacy safeguards, such as removal of names and other identifying information.

These comments go, however, to the substance of genetic privacy rather than the remedy for violation, and this, to a certain extent, is the point. While propertization of genetic information may be a solution to the bankruptcy problem, the scope of the property right, the extent to which it is alienable, and the extent to which it is inviolate are all up for grabs. While propertization may be necessary to ensure enforcement of privacy protections, propertization is neither sufficient, nor is it possible for it to be absolute. Norm and remedy are inextricably linked in the context of genetic privacy. The answers to most of these questions are likely to be context specific. Hard bargains may need to be softened, and narrow restrictions on information use may need to be broadened. These questions will inevitably need to be answered *ex post*.

In an earlier article, I suggested that any mechanism for making such *ex post* determinations would need to comprise a pair of key attributes: (1) mandatory muddied standardization; and (2) a collective procedure for quieting title.⁴⁵ Mandatory muddied standardization deals with the fact that informed consent is not, and cannot

be, about bargaining. The various ways in which tissue samples and genetic information are, and can be used, are too complex, too hard to predict, and too hard to describe, for a short conversation between Patient and Doctor to produce anything but unfortunate and random results. As such, a regime that allowed patients to specify broad types of use, but which allowed deviations from those specifications when justified by important research or therapeutic justifications makes some sense. The key point is that the source of this rule is unlikely to be bargained consent. It may take the form of a rule about deviations from, or limitations on the requirement from consent, but the rule itself is not likely to be bargained for. Moreover, while such rules may, in the first instance be legislative, or regulated, in order to work, they will need some play in the joints in order to allow decisionmakers to handle the variety of circumstances that may arise. The collective procedure for quieting title focuses on the decisionmaker. Since biobanks will, by definition contain samples from and information about many individuals, there needs to be a forum and procedure where multiple issues of consent and multiple parties can be dealt with simultaneously. That procedure must allow for representation of patient's interests, and authoritative decisions about secondary use.

In my earlier article, I suggested that a flawed, but promising model is proposed in amendments to the Bankruptcy Code. That provision, the Leahy Amendment,⁴⁶ grants the holders of privacy promises a right to have their privacy expectations "adequately protected," and provides for the appointment of a "privacy ombudsmen" charged with negotiating on behalf of, and representing the interests of the people whose information is contained in the database.⁴⁷

The Leahy Amendment has two principal weaknesses. First, it defers absolutely to bargained-for privacy policies where they exist. As such, it is likely to fall victim to the problems of adhesion, information asymmetry, bounded rationality and coordination described above. It also fails to define "adequate protection."⁴⁸ These concerns go to substance, rather than remedy. A procedure like the Leahy Amendment, if properly constructed, has the potential both to protect Patient's privacy and wishes with regard to the use of his genetic information, and to allow for flexibility over time and in changed circumstances.

Conclusion

In sum, insolvency has the potential to undercut the enforcement of privacy promises made by Biobanks, but Bankruptcy law may hold promise as a locus for developing procedures which will provide both appropriate protection and needed flexibility.

Appendix

State Genetic Privacy Laws

| State and Statute | Informed Consent Required to | | | | | Define as Personal Property | | Specific Penalties for Genetic Privacy Violations |
|---------------------------------------------------------------------------------|-------------------------------------------------|------------------------------|-----------------------------------|----------------------------|------------------------------|-----------------------------|-------------|---------------------------------------------------|
| | Personal Access to Genetic Information Required | Perform/Require Genetic Test | Obtain/Access Genetic Information | Retain Genetic Information | Disclose Genetic Information | Genetic Information | DNA Samples | |
| Alabama | | | | | | | | |
| Alaska | | | | | | | | |
| Arizona §20-448.02 | | ✓ | | | ✓ | | | |
| Arkansas SB764 | | | | | ✓ | | | |
| California Insurance §10149.1 | | | | | ✓ | | | ✓ |
| Colorado §10-3-1104-7 | | | | | ✓ | ✓ | | ✓ |
| Connecticut | | | | | | | | |
| Delaware §16.2.1220 to §16.2.1227 | ✓ | | ✓ | ✓ | ✓ | | | ✓ |
| Florida §760.40 | | ✓ | | | ✓ | ✓ | | ✓ |
| Georgia §§33-54-1 to 8 | | ✓ | | | ✓ | ✓ | | ✓ |
| Hawaii §431-10A-118 | | | | | ✓ | | | |
| Idaho | | | | | | | | |
| Illinois §410-513 | | | | | ✓ | | | ✓ |
| Indiana | | | | | | | | |
| Iowa | | | | | | | | |
| Kansas | | | | | | | | |
| Kentucky | | | | | | | | |
| Louisiana §22:213.7; §40:1299.6 | | | | | ✓ | ✓ | | ✓ |
| Maine | | | | | | | | |
| Maryland Ins §27-909 Labor & Emp §49B-15 and 16 | | | | | ✓ | | | |
| Massachusetts §111.70G | | ✓ | | | ✓ | | | ✓ |
| Michigan §333.17020 §333.17520 | | ✓ | | | | | | |
| Minnesota | | | | | | | | |
| Mississippi | | | | | | | | |
| Missouri §375.1309 | | | | | ✓ | | | ✓ |
| Montana | | | | | | | | |
| Nebraska §71-1, 104.1 | | ✓ | | | | | | |
| Nevada §629.101 to §629.201 | ✓ | | ✓ | ✓ | ✓ | | | ✓ |
| New Hampshire §141-H:2 | | | | | ✓ | | | |
| New Jersey §10:5-43 to §10:5-49 | | | ✓ | ✓ | ✓ | | | ✓ |
| New Mexico §24-21-1 to 24-21-7 | ✓ | ✓ | ✓ | ✓ | ✓ | | | ✓ |
| New York CVR §79-L | | ✓ | | ✓ | ✓ | | | ✓ |
| North Carolina | | | | | | | | |
| North Dakota | | | | | | | | |
| Ohio | | | | | | | | |
| Oklahoma | | | | | | | | |
| Oregon §192.531 to 192.549; SB 618 | ✓ | | ✓ | ✓ | ✓ | | | ✓ |
| Pennsylvania | | | | | | | | |
| Rhode Island §27-18-52, 52.3, §27-19-44, 44.1, §27-20-39, 39.1, §27-41-53, 53.1 | | | | | ✓ | | | |
| South Carolina §38-93-10 to §38-93-60 | | ✓ | | | ✓ | | | ✓ |
| South Dakota SBI | | ✓ | | | | | | |
| Tennessee | | | | | | | | |
| Texas Vernon's Civil §9031 | | | | | ✓ | | | |
| Utah ¹ HB 56 | | | | | | | | ✓ |
| Vermont §18:9331 to §18:9335 | | ✓ | | | ✓ | | | ✓ |
| Virginia §38.2-508.4 | | | | | ✓ | | | |
| Washington ² SB 5207 | | | | | ✓ | | | |
| West Virginia | | | | | | | | |
| Wisconsin | | | | | | | | |
| Wyoming | | | | | | | | |
| Total | 4 | 11 | 5 | 6 | 25 | 4 | 0 | 17 |

1. Limits disclosures of and access to genetic information by employers and insurers. 2. Requires written authorization only. Source: NCSL

References

1. M. A. Rothstein, "Genetic Privacy and Confidentiality: Why They Are So Hard to Protect," *Journal of Law, Medicine, & Ethics* 26, no. 3 (1998): 198-204 ("If a third party has enough leverage and economic power, it can go to an individual and require him/her to execute a release that authorizes a physician to release the medical records to a third party."); M. R. Anderlick and M. A. Rothstein, "Privacy and Confidentiality of Genetic Information: What rules for the New Science?" *Annual Review of Genomics and Genetics* (2001-2): 401-33.
2. For a discussion of the effects of bankruptcy on privacy, see E. J. Janger, "Muddy Property: Generating and Protecting Information Privacy Norms in Bankruptcy," *William & Mary Law Review* 44 (2003): 1801-1881; see also E. J. Janger, "Privacy Property, Information Costs and the Anticommons," *Hastings Law Review* 54 (2003): 899-929.
3. L. M. LoPucki, "The Death of Liability," *Yale Law Journal* 106 (1996): 1-91, at 3. LoPucki analogizes the liability-based enforcement of rights to a card game:
Think of the liability system as a poker game...Players risk their chips, that is, their wealth, by tossing them into the pot, that is, investing them in liability-generating economic activity. Chips contributed to the pot are at risk of loss; the system can take them to satisfy liability. Chips withheld are not at risk.
4. The focus of regulation in healthcare is often phrased in terms of "informed consent." P. H. Schuck, "Rethinking Informed Consent," *Yale Law Journal* 103 (1994): 899-959; Rothstein, "Genetic Privacy," *supra* note 1: ("I believe less emphasis should be placed on regulating procedures for disclosure of information by physicians and other holders of medical records and more detailed focus placed on the circumstances surrounding the acquisition of the information by third parties. Who are these third parties? What need do they have for the information?")
5. As I will discuss below, "property" regimes can operate either as a "veto" on transfer, or as an encumbrance that runs with the item.
6. Janger, "Muddy Property," *supra* note 2, at 1852: ("Property rule or liability rule, the result is the same. Customers give their information away for free.")
7. Janger, "Anticommons," *supra* note 2: at 921-22.
8. G. Calabresi and A. D. Melamed, "Property Rules, Liability Rules, and Inalienability: One View of the Cathedral," *Harvard Law Review* 85 (1972): 1089-1128, at 1089.
9. *Id.*
10. H. Hansmann and R. Kraakman, "Property, Contract, and Verification: The Numerous Clauses Problem and the Divisibility of Rights," *Journal of Legal Studies* 31 (2002): 373-420, at 378.
11. *Id.*
12. Restatement (Second) of Contracts § 344 (1979) ("Judicial remedies [for breach of contract] serve to protect...his 'expectation interest,' which is his interest in having the benefit of his bargain by being put in as good a position as he would have been in had the contract been performed...."). In the absence of a statute allowing for statutory or punitive damages, or a separate tort cause of action, the financial incentives associated with a liability regime are likely to understate the actual harm caused by a sale of data. See *Stern v. Delphi Internet Services Corp.*, 626 N.Y.S.2d 694 (N.Y. Sup. Ct. 1995) (detailing an unsuccessful attempt to use misappropriation theory to sue electronic bulletin board); D. B. Dobbs, *The Law of Torts* (West: Saint Paul, 2000): 1198-1200.
13. Restatement (Second) of Contracts § 359 ("Specific performance ...will not be ordered if damages would be adequate to protect the expectation interest of the injured party.")
14. Janger, "Muddy Property," *supra* note 2, at 1832-35.
15. Janger, "Anticommons," *supra* note 2, at 1823. See also W. W. Miller, Jr. and M. A. O'Rourke, "Bankruptcy Law v. Privacy Rights: Which Holds the Trump Card?" *Houston Law Review* 38 (2001): 777-854, at 799-807 (noting that while privacy policies may be enforceable as contracts, the damages are likely to be difficult to calculate).
16. 15 U.S.C. § 45(a)(1) (2000).
17. *In re Toysmart.com, LLC*, No. 00-13995-CJK (Bankr. D. Mass. filed June 9, 2000). Stipulation and [Proposed] Order Establishing Conditions on Sale of Customer Information, presented by Toysmart.com, LLC and the Federal Trade Commission, reprinted *Workouts & Bankruptcies in the E-commerce Economy* 247, J. Samet and J. Walshe Murray eds. (New York: Practising Law Institute, 2001) (reproducing a stipulation and proposed order placing conditions on the sale of customer information by Toysmart.com).
18. Texas Business and Commerce code § 17.50(b) (2004).
19. 45 C.F.R. Parts 160, 164.
20. S. Shavell, "The Judgment Proof Problem," *International Review of Law & Economics* 6 (1986): 45-58, at 45 ("An injurer will treat liability that exceeds his assets as imposing an effective financial penalty only equal to his assets....").
21. 11 U.S.C. § 362.
22. 11 U.S.C. § 524.
23. 11 U.S.C. § 502 (allowed unsecured claims), 726 (distribution of estate property).
24. 11 U.S.C. § 365.
25. V. Countryman, "Executory Contracts in Bankruptcy: Part I," *Minnesota Law Review* 57 (1973): 439-491, at 465, 471 n. 121; J.L. Westbrook, "A Functional Analysis of Executory Contracts," *Minnesota Law Review* 74 (1989): 227-337, at 255. Michael Andrew reaches a similar result by a slightly different route. Under his approach, executory contracts are not binding upon the estate until assumed. According to Professor Andrew:
[T]he supposed "rule" that there is no specific performance in bankruptcy is actually just a consequence of the fact that the estate itself is not, absent assumption, bound by the debtor's contracts. Not only is there no right of specific performance of an unassumed contract against the estate, there is likewise no right to recover damages against the estate itself—i.e., administratively. The estate is simply not a party to the contract.
M. T. Andrew, "Executory Contracts in Bankruptcy: Understanding 'Rejection,'" *University of Colorado Law Review* 59 (1988): 845-932, 920-21.
26. J. L. Westbrook, "A Functional Analysis of Executory Contracts," *Minnesota Law Review* 74 (1989): 227-337, at 246 ("The first concrete consequence of the equality principle is that the trustee can breach (reject) a contract profitably far more often than can other contract parties because the trustee pays only a fraction of contract damages rather than the full amount of the Other Party's breach loss. From that simple proposition flows most of the economic "magic" associated with bankruptcy contract doctrine.") See also, M. T. Andrew, "Executory Contracts Revisited: A Reply to Professor Westbrook," *University of Colorado Law Review* 62 (1991): 1-35 ("But while unnecessary, rejection is also harmless: It does not make the contract obligation somehow vanish, and its 'breach' consequence does nothing more than create a claim. Thus, whether the contract is 'executory' or not, the result is the same: The non-debtor party has a claim.")
27. 11 U.S.C. § 506.
28. 11 U.S.C. § 724.
29. 11 U.S.C. § 363(f).
30. *Id.*
31. 11 U.S.C. § 363(e).
32. See *Gouveia v. Tazbir*, 37 F.3d 295, 299 (7th Cir. 1994) (holding that debtor is unable to sell land free and clear of restrictive covenants).
33. 362 F.3d 603 (9th Cir. 2003).
34. 322 F.3d 283 (3rd Cir. 2003).
35. 327 F.3d 537 (7th Cir. 2003).
36. For an extreme example, see *Precision Industries, Inc. v. Qualitech SBQ, LLC*, 327 F.3d 537 (7th Cir., 2003), reh'g denied, 2003 U.S. App. LEXIS 10626 (7th Cir., May 7, 2003), where a debtor was allowed to sell leases under section 363(f) without formally assuming or assignning them under section 365.
37. 11 U.S.C. § 362(b)(4).
38. 1 U.S.C. § 510(c).
39. *Canterbury v. Spence*, 464 F.2d 772 (1972). For a discussion of in-

formed consent in healthcare settings, see C. E. Schneider, *The Practice of Autonomy: Patients, Doctors, and Medical Decisions*, (New York: Oxford University Press, 1998), 87-92; J. Goldstein, "For Harold Lasswell: Some Reflections on Human Dignity, Entrapment, Informed Consent and the Plea Bargain," *Yale Law Journal* 84 (1975): 683-703, at 690-94; P.H. Schuck, "Rethinking Informed Consent," *Yale Law Journal* 103 (1994): 899-959, at 902-04; A. D. Twerski and N. B. Cohen, "The Second Revolution in Informed Consent," *Northwestern University Law Review* 94 (1999):1-49, 2-5.

40. See M. J. Radin, "Humans, Computers and Binding Commitment," *Indiana Law Journal* 75 (2000): 1125-1162, at 1148-49. Professor Radin explains:

Market-emergent schemes of uniform contracts, on the other hand, have to some courts and commentators looked like a property scheme imposed by private companies for their own interests instead of by the government for the interest of all. In other words, in public choice rhetoric, the traditional view has been that legislative enactment is presumptively efficiency-enhancing, and market emergence is presumptively rent-seeking. Because market-emergent sets of terms are dictated by one party rather than arrived at by negotiation between the parties, they have been dubbed contracts of adhesion, or take-it-or-leave-it contracts.

See generally T. D. Rakoff, "Contracts of Adhesion: An Essay in Reconstruction," *Harvard Law Review* 96 (1983): 1173-1284 (arguing that contracts of adhesion should be presumed to be unenforceable).

41. Janger, "Muddy Property," *supra* note 2 ("Property rule or liability rule, the result is the same. Customers give their information away for free.").
42. Janger "Anticommons," *supra* note 2.
43. M. A. Heller, "The Boundaries of Private Property," *Yale Law Journal* 108 (1999): 1163-1223, at 1173-74; M. A. Heller, "The Tragedy of the Anticommons: Property in the Transition from Marx to Markets," *Harvard Law Review* 111 (1998): 621-688, at 665-67.
44. P. M. Schwartz, "Property, Privacy, and Personal Data," *Harvard Law Review* 117 (2004): 2055-2128.
45. Janger, "Anticommons," *supra* note 2 at 922-26.
46. The Leahy Amendment can be found in sections 231 and 232 of the conference report to the Bankruptcy Abuse Prevention and Consumer Protection Act of 2002. See H.R. CONF. REP. NO. 107-617, at 51-52 (2002).
47. Janger, "Anticommons," *supra* note 2 at 928-29. Janger, "Muddy Property," *supra* note 2 at 1873-75.
48. As a remedy, I have recommended the use of mandatory set of defaults tailored to particular contexts and based on Fair Information Practices, or "FIPS."