
Informed Consent, Body Property, and Self-Sovereignty

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Research using human biological materials is booming, yet many questions regarding such research remain unanswered. Is informed consent always necessary for the use of human biological materials in research, and if so, what counts as informed consent? Is a generalized blanket consent to all future research sufficient, or must the donors of biological specimens be provided with full information about the purposes of the research and affirmatively consent to each particular use? What about property rights — does the donor “own” his or her biological specimen and have a right to control its use? And if such research leads to patents and commercialization, does the donor have a right to share in any resulting profits? Even if donors do not possess property rights, what about the potential impact of such research upon the donor’s (and his or her family’s) right to privacy? Are there special concerns regarding research using vulnerable populations, such as newborn babies, indigenous tribes, and others groups who may lack knowledge and power?

In 2010, a book about an African-American woman whose cancer cells were taken without her knowledge or consent to create a valuable cell line became a best-seller.¹ Henrietta Lacks, a poor black woman from a family of tobacco farmers, supplied the cells which became the first immortal cell line — the HeLa line. HeLa cells ended up in labs across the country, were sent to the moon, led to development of the polio vaccine, improved our understanding of cancer, and helped pave the way for modern advances in in vitro fertilization, genetics, and cloning. Yet Henrietta Lacks’ contributions to science were seldom acknowledged,² except by the name given to the cell line, and many in her family remain too poor to afford health care. Rebecca Skloot, the author of *The Immortal Life of Henrietta Lacks*, captures the issue beautifully:

How you should feel about all this isn’t obvious. Scientists aren’t stealing your arm or some vital organ. They’re just using tissue scraps you parted with voluntarily. But still, someone is taking part of you. And people often have a strong sense of ownership when it comes to their bodies. Even tiny scraps of it. Especially when they hear that someone else might be making money off those scraps. Or using them to uncover potentially

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damaging information about their genes and medical histories.³

In 2013, researchers published the genome of the HeLa cell line on open-access databases without obtaining consent from the family of Henrietta Lacks, provoking yet another controversy because the gene sequence could reveal certain heritable aspects of Lacks' DNA, and thus be used to draw inferences about her descendants.⁴ Henrietta Lacks' history captivated the public imagination. Her story also encapsulates the controversy over informed consent, and hints at a possible resolution through the rubric of body property.

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Henrietta Lacks' cells were taken at a time when there were no rules requiring informed consent for research using human subjects or human biological materials. In 1981, the U.S. Department of Health and Human Services enacted regulations for the protection of human subjects, known as the "Common Rule," which establish the standard governing research that is supported by the federal government.⁵ The Common Rule applies to all research involving human subjects that is conducted, supported, or otherwise subject to regulation by any federal department or agency. Under the Common Rule, a researcher must provide the research subject with information about the potential risks and benefits of participating in research, and must obtain informed consent. But the Common Rule was developed for "research on living, breathing humans, not their disembodied tissues."⁶ Thus, it applies only to research obtained through direct interaction with a living, breathing human being, and to human biological specimens that involve identifiable private information. However, the Common Rule does not apply if the research is not federally funded, if the human subject is deceased, or if the biological specimens are de-identified, anonymous, or publicly available.⁷

In September 2015, the U.S. Department of Health and Human Services announced proposed revisions to the Common Rule, through a Notice of Proposed Rulemaking (NPRM). The proposed revisions seek to

expand the definition of "human subject" to encompass human biological materials, regardless of whether the biospecimens contain identifiable information. Yet this requirement would apply only prospectively, and would be delayed in its implementation until three years after publication of the final rule. And even if the proposed regulations succeed in expanding the scope of "human subject" under the Common Rule to incorporate biological specimens, it does not necessarily follow that the doctrine of informed consent would provide sufficient protection for the donors of biological materials. The proposed revisions would require only a one-time broad consent for the secondary use of human biological materials, meaning the use of biospecimens for a purpose different from the purpose for which the biospecimen was originally collected (for example, research use of tissue samples initially collected for clinical care). Such blanket consent is inadequate to fulfill the promise of informed consent.

The true challenge of informed consent is that this venerable doctrine often functions as a charade, a collective fiction which thinly masks the uncomfortable fact that the subjects of human research are not actually afforded full information regarding the types of research that may be contemplated, nor do they provide meaningful consent. The elaborate bureaucratic formalities by means of which patients seeking medical treatment check off a series of boxes on a multitude of forms are not a substitute for genuine informed consent. Currently, there are various degrees of consent, which range from: (1) consent as merely the absence of coercion, such as when human biological materials are obtained through a voluntary transfer; (2) presumed consent based upon the failure to opt-out; and (3) actual affirmative consent. If affirmative consent is construed to encompass blanket consent, it gives the subjects of human research only the ability to say "yes" or "no," rather than providing them with a full array of options and granting them the power to authorize particularized consent to some uses, while withholding consent from other uses. Yet if informed consent actually required the provision of complete information, and mandated particularized consent to each type of research use, it would most probably be administratively unworkable.⁸ Indeed, underlying many of the judicial decisions in this area is the fear that the administrative burdens of obtaining consent would impede socially valuable research.⁹ Furthermore, particularized consent might also result in information overload, and ultimately diminish or even destroy

choice. Confronted with a mass of complicated information and a complete menu of options, individuals are likely to feel overwhelmed, unable to adequately process the information and choose the appropriate course of action.¹⁰ Thus, informed consent inevitably requires a choice between whether to provide too little or too much information.

The Havasupai Tribe's experience with Arizona State University vividly illustrates the limits of informed consent, as Deborah Zoe Laufer brilliantly reveals in her play on the subject.¹¹ Starting in 1990, members of the Havasupai Tribe voluntarily gave blood samples to researchers at Arizona State University in order to determine whether there was a genetic basis for the high rate of diabetes among tribe members. The researchers sought but ultimately did not find a genetic link to diabetes. However, they also used the stored blood samples to conduct other studies on schizophrenia, the degree of inbreeding, and the geographical origins of the tribe, even though these investigations threatened the Tribe's cultural and religious values. One of the published papers based upon research using the blood samples reported a high degree of inbreeding within the tribe, which tribe members found offensive. According to Carletta Tilousi, a member of the Havasupai tribal council, "We say if you do that, a close relative of yours will die."¹² And another article suggested that the tribe's ancestors had migrated from Asia across the frozen Bering Sea to arrive in North America, which contradicted the tribe's traditional religious belief that it had originated in the Grand Canyon. Members of the tribe even feared that they had unwittingly contributed to research that could undermine their right to tribal land: "Our coming from the canyon, that is the basis of our sovereign rights," stated Edmond Tilousi, the Tribe's vice-chairman.¹³

In 2005, Carletta Tilousi and the Havasupai Tribe filed a lawsuit against the researchers and Arizona State University in federal district court.¹⁴ The plaintiffs alleged eight counts of wrongdoing: (1) breach of fiduciary duty and lack of informed consent; (2) fraud, misrepresentation, and fraudulent concealment; (3) intentional and negligent infliction of emotional distress; (4) conversion; (5) violation of civil rights; (6) negligence, gross negligence, and negligence per se; (7) unreasonable disclosure of private facts; and (8) intentional intrusion upon seclusion. In their first claim for lack of informed consent, the plaintiffs contended that they donated biological materials solely for the purpose of diabetes research, so there was no consent to conduct other research. As Carletta Tilousi, a member of the Havasupai tribal council, explained, "I'm not against scientific research. I just want it to be

done right. They used our blood for all these studies, people got degrees and grants, and they never asked our permission."¹⁵ But the court ruled that there was informed consent because the tribe members had agreed to give their blood voluntarily, and had signed a form granting blanket consent for research "to study the causes of behavioral/medical disorders."¹⁶ The court concluded that their consent was not vitiated by fraud: "Plaintiffs consented to having blood drawn and were fully aware of the character of the contact. Thus their consent is not made ineffective even if defendants did make fraudulent representations to induce that consent."¹⁷ At best, the Havasupai case holds that blanket consent is sufficient to satisfy the standard of informed consent. At worst, the case suggests that consent exists so long as there was no coercion and the transfer of biological materials was voluntary, even if researchers made misrepresentations regarding the purpose of the research.

The Havasupai case exposes the emptiness of informed consent, for a form that permits research in order to study "the causes of behavioral/medical disorders" is so vague and broad as to be virtually meaningless. The tribe members' consent to diabetes research clearly did not encompass other types of research, especially research offensive to their religious and cultural values. The researcher who performed this research, Therese Markow, now a professor at the University of California, San Diego, declared, "I was doing good science."¹⁸ She defended her actions as ethical, suggesting that the very notion of particularized consent stems from a failure to understand the fundamental nature of genetic research, where progress often occurs from studies that do not appear to bear directly on a particular disease.¹⁹ She explained that the consent form was purposefully simple because English was a second language for many Havasupai, and few of the tribe's 650 members had graduated from high school.²⁰ Under such conditions, a more comprehensive consent form, providing complete information and requiring particularized consent for each type of research use would not necessarily be better. Indeed, as the Havasupai experience reveals, the entire enterprise of informed consent is fraught with the potential for miscommunication and cultural misunderstanding, and undermined by its inability to protect those who lack knowledge and power.

Although the Havasupai Tribe lost the legal battle because the court dismissed all of its claims, it was morally vindicated in April 2010, when Arizona State University (ASU) agreed to a settlement to "remedy the wrong that was done."²¹ ASU agreed to pay \$700,000 to 41 members of the Tribe, return the remaining blood samples, and provide other forms of assistance

to the Tribe, such as scholarships and help in setting up a clinic.²² In spite of this moral victory, the legal opinions in the case demonstrate the inadequacy of informed consent to articulate and render actionable claims of cultural and dignitary harms.²³

If the doctrine of informed consent fails to provide adequate protection to the subjects of human research who donate biological materials, why not turn to the language of property law? Property is power, as the legal realist Morris Cohen recognized long ago. In his classic article on the connection between property and sovereignty, Cohen warned, “We must not overlook the actual fact that dominion over things is also *imperium* over our fellow human beings.”²⁴ Yet current law permits everyone *except* for those who donate human biological materials to possess property rights. The reluctance to invoke property law probably stems from fears of resurrecting slavery and the commodification of human beings.²⁵ But ironically, the avoidance of property transforms the subjects of human research into objects of property that can be owned only by others, resulting in new forms of oppression and exploitation. Human research subjects are autonomous individuals who should not only possess the power to contribute their biological materials, but also the right to help control the course of research, and to share in the resulting benefits or profits. Conferring body property might enable research subjects to regain power and a measure of self-sovereignty.

Newborn blood screening programs also illustrate the ambiguity of informed consent, and exemplify inconsistent attitudes towards body property. In every state, blood spots are routinely collected from newborn babies in order to detect and treat a variety of genetic diseases, often without the parents’ knowledge or consent. However, Texas and some other states started to store these blood samples indefinitely and made them available to others for research use. A group of Texas parents sued the state health agency for violating their rights to privacy and liberty under the Due Process Clause of the 14th Amendment, arguing that the blood spots contained deeply private medical and genetic information that was expropriated without their knowledge or consent, and a federal district court refused to dismiss their complaint.²⁶ This resulted in a new law in Texas requiring parents to be given the opportunity to opt-out of such research, as well as a settlement agreement which gave the state 70 days to destroy approximately 5 million blood samples collected from newborn babies over the past 7 years. Thus, the Texas case resulted in a law that presumes parental consent unless parents exercise their opportunity to opt-out of newborn screening. In a similar lawsuit in Minnesota, the state Supreme Court ruled

that the state’s dissemination and use of newborn dried blood samples for research without obtaining written informed consent violated its Genetic Privacy Act.²⁷ Despite these “Baby DNA lawsuits,” informed consent for newborn screening varies widely from state to state.²⁸ Many states do not even notify parents about potential research use of newborn dried blood samples or give them the opportunity to opt-out, let alone require actual affirmative consent. In 4 states, dried blood samples are conceptualized as the property of the state, and in 10 states, the Department of Health is granted authority over the use of dried blood samples, although it is unclear who retains ownership.²⁹

In all of these contexts, the legal status of the human body remains hotly contested. Sometimes human bodies and body parts are classified as objects of property, while at other times they are characterized as the subject of privacy rights to be protected under informed consent doctrine, and some are even endowed with dignity and afforded the status of persons.³⁰ This is true not only for different types of human tissue; disparate treatment may be accorded the same body part in different contexts. Thus, the body may be deemed property for some people but not others, and it may be treated as property in some contexts but not others. For example, under California law, human eggs may be purchased and sold for fertility treatments but not for purposes of research.³¹

There are three important cases in which individuals have claimed ownership of their own bodies in the context of biomedical research. In all three cases, the courts refused to accord property rights to those who supply body parts for medical research, although the same courts were willing to recognize the property rights of *other persons* in the body parts themselves and the resulting products. Almost every student of property law is familiar with the first case, *Moore v. Regents of the University of California*,³² in which the California Supreme Court ruled that Moore’s spleen was not his property. At the same time, the court found that the Mo cell line — which had been created from Moore’s spleen cells and, ironically, named after him — was the property of the researchers who had been granted a patent upon it. But *Greenberg v. Miami Children’s Hospital* goes one step further than *Moore* by holding not only that the blood, tissue, and other body parts that the Greenbergs had supplied to researchers were not their property, but also that the gene responsible for their disease was the property of the scientists who isolated it and the hospital that patented it, rather than the persons in whose bodies it remained.³³ And *Washington University v. Catalona*³⁴ goes far beyond both *Moore* and *Greenberg* by making explicit what was only implicit in those cases.

In *Catalona*, the court concluded that not just intellectual property in the body but also tangible physical parts of the body (such as blood and tissue samples) were owned by the university that stored them in its Genito-Urinary Biorepository; thus, they were not owned by the patients from whose bodies these biological materials had been derived.³⁵

Why is the law willing to confer property rights upon some while denying the same rights to others? At first glance, the lopsided treatment of the human body seems to stem from the distinction between physical body parts and intellectual property in the body. Specifically, body parts are seen as a form of raw material to be harvested, whereas cell lines and certain categories of human genes are conceptual-

ply eggs be prevented from treating them as property, subject to market pricing?

Rejection of property is generally justified by a paternalistic desire to protect the sources of biological materials, stemming from fears that commodification of the human body could lead to coercion or exploitation of vulnerable persons, such as women who donate their eggs. But ironically, failure to treat the body as property may actually result in a lack of protection against the misuse of body parts and enable wrongdoing. This is evident in the egg-stealing scandal that erupted at UC Irvine in 1995. At the time, prosecutors were unable to press charges against the physicians who misappropriated eggs without the knowledge or consent of women seeking fertility treatments, and

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ized as a kind of man-made technology.³⁶ Hence, the “inventor” of intellectual property in the body is granted broad protection that extends across space and time, whereas bodily property is conceived as a tangible thing that is protected only insofar as it remains in the possession of its “owner,” or that may be deemed un-ownable and thus not protected at all. But even physical body parts may receive property protection when they are in the possession of a university or scientist rather than an ordinary person, which suggests that the divergence lies deeper than a distinction between tangible body parts and intellectual property in the body.

Despite the disavowal of property terminology, property concepts are so pervasive and powerful that they continue to creep back into the doctrine and the discourse. In January 2015, for example, a tax court for the first time addressed the question whether payments received by women for the “donation” of their eggs constitute taxable income. The court ruled that women must pay tax on the proceeds from egg sales.³⁷ More recently, several women have filed a lawsuit challenging limits on the amount of compensation for egg donors implemented by fertility clinics; the plaintiffs contend that these limits constitute price-fixing in violation of the antitrust laws.³⁸ But if the IRS may tax payments to egg sources, and if fertility clinics and physicians may reap huge profits from the reproductive enterprise, why should only the women who sup-

gave them to other patients. Prosecutors were unable to prosecute for grand theft, which is defined as the taking of personal property valued at more than \$400, because it was unclear whether human eggs constitute “property” under the California precedent of *Moore v. Regents of the University of California*. Yet the prosecutors could not prosecute for kidnapping, either, because human eggs and embryos clearly do not constitute persons under California law. In response to this scandal, lawmakers were forced to enact new legislation which made the theft of human eggs a crime and authorized fines of up to \$50,000 or penalties of up to 5 years in prison for the intentional transfer of human sperm, eggs, or embryos without the written consent of donors and recipients.³⁹

Moreover, rejection of property in human biological materials does not actually prevent commodification and commercialization of the body. The researchers who invest intellectual capital and the companies and universities that invest financial capital are permitted to reap profits from human research, so why not those who provide the human capital in the form of their own bodies? If the concern is commodification and commercialization, why should everyone but the donor possess property rights and be permitted to share in the profits from human research? Such a lopsided system appears to demand altruism from the subjects of human research, while enabling everyone but the person who donated the raw materials to

commodify, commercialize, and ultimately profit from human biological materials. Henrietta Lacks' daughter, Deborah, criticizes the asymmetric altruism which underlies the lack of bodily property, saying, "But I always have thought it was strange, if our mother cells done so much for medicine, how come her family can't afford to see no doctors? Don't make no sense. People got rich off my mother without us even knowin' about them takin her cells, now we don't get a dime."⁴⁰

Such expectations of asymmetric altruism appear even more troubling when imposed in ways that reflect and reinforce underlying racial, gender, and other hierarchies. For example, inconsistent attitudes towards the compensation of sperm and egg donors may embody an assumption that egg donations should result from pure altruism, rather than self-interest.⁴¹ To the extent that such assumptions are invoked when women are providing material that is intertwined with reproduction, they may stem from deep-seated stereotypes regarding the natural role of women as altruistic and the natural sphere of woman as the family, which should be kept separate from the market. The use of African-Americans and other minority groups, Native American tribes, such as the Havasupai, and newborn babies in human research also raises such concerns.

If the rejection of property is problematic, why not embrace property? In his influential Commentaries, William Blackstone portrayed property as the "sole and despotic dominion which one man claims and exercises over the external things of the world, in total exclusion of the right of any other individual in the universe."⁴² Despite this pervasive image, property does not necessitate Blackstone's vision of an absolute and individual right.⁴³ Instead, according to Hohfeldian theory, property is conceptualized as a bundle of rights, so property need not be all or nothing. Individuals need not possess every stick in the bundle of rights: they may have the right to possess and the right to exclude others, but not the right to buy, sell, or destroy. Moreover, the concept of property as a bundle of rights means that it is possible to disaggregate the various sticks in the bundle and apportion them to different parties. Hence, different sticks in the bundle of rights with respect to biological materials could be allocated to different individuals, or even shared by a family, a group, or the public collectively.

Property provides a powerful framework that is capable of addressing the manifold attributes of human biological materials. First, human biological materials are not just physical objects; they also incorporate genetic information. Property encompasses the dual character of biological materials as tangible things as well as intellectual property.⁴⁴ Moreover, biological materials may undergo multiple transfers and end up

in the hands of those who possess no connection to the donor. Property rights provide ongoing protection because they are *in rem*, meaning that they run with the object or thing and are enforceable against the whole world, unlike contractual rights, which are *in personam*, meaning that they bind only the parties to the agreement or contract. In addition, property provides a mechanism that is able to mediate conflicts not just against the government and outsiders (who are non-owners), but also among multiple owners of a valuable resource. The framework of property is perfectly designed to accommodate shared interests among multiple owners of a resource because property can be distributed between many owners simultaneously, and it can also be divided over time, with current interests belonging to some individuals and future interests to others. Indeed, property is conceptualized as a bundle of rights, so that different sticks in the bundle may be disentangled and allocated to different persons. Thus, some persons may possess the right to exclude, while others may possess the right to use or to transfer to others. Finally, property offers a variety of flexible forms to accommodate different types of shared ownership interests, including the trust, which divides legal and equitable title; joint tenancy, tenancy in common, and tenancy by the entirety; the partnership and the corporation; as well as a variety of intellectual property regimes. Indeed, some scholars explicitly analogize overlapping familial interests in genetic information to various forms of shared property.⁴⁵

Property is a flexible concept that may afford power to research participants, transforming them from mere research subjects into partners or shareholders who possess a measure of autonomy and control over the research enterprise, whereas a lack of property in their own bodies may leave persons vulnerable to abuse and exploitation. The controversy over the publication of the HeLa genome led to one type of creative approach to these problems. Following discussions, Henrietta Lacks' family and the National Institutes of Health reached an innovative agreement to form the HeLa Genome Data Access Working Group, which is composed of researchers and two members of Lacks' family. This group controls access to the HeLa genome; thus it could be viewed as investing limited property rights to shared genetic information in Henrietta Lacks' family. The NIH has requested all researchers who generate or use genomic data from HeLa cells to include an acknowledgment of the contribution of Henrietta Lacks and the continued generosity of her family. According to the NIH, "the relationship between researchers and participants is evolving: seeking permission emphasizes that participants are partners, not just 'subjects'"; thus this plan

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reflects a “true partnership between the Lacks family and the biomedical research community.”⁴⁶

Similarly, controversy over the use of newborn blood samples in Michigan prompted the establishment of the Michigan BioTrust for Health, pursuant to which the state’s citizens are granted a communal right to benefit from research using a valuable public resource.⁴⁷ Dried blood spots are collected from newborns under a mandatory public health program, but the state retains the blood samples indefinitely for research use. In 2008, the Michigan Department of Community Health created the Michigan BioTrust after convening a roundtable of experts to discuss the issues and determine policy. The roundtable determined that parental consent would be required, not for newborn screening itself, but for subsequent research use of the blood samples after October 1, 2010 (the Michigan Department of Community Health IRB granted a waiver of consent for blood samples that were already stored prior to May 1, 2010, based on the impracticability of obtaining consent for some 4 million specimens dating back to 1984). The roundtable concluded that under Michigan law, the Michigan Department of Community Health has “qualified ownership” of dried blood samples collected for newborn screening; thus it is required to act as a fiduciary and exercise control over the biological specimens for the benefit of the child and the public. Accordingly, the Michigan BioTrust makes the blood samples available for research to benefit the public health, but not for research on non-medically useful cosmetic products. Moreover, the governing structure of the Michigan BioTrust includes a Community Values Advisory Board to represent the citizens of Michigan regarding the types of research that would be deemed appropriate by laypeople in the state. Thus, the state of Michigan has actually built a biobank that is modeled upon the charitable trust, implementing the seminal scholarship of David Winickoff.⁴⁸ The Michigan BioTrust imaginatively incorporates and reframes an ancient property mechanism — the trust — to provide a paradigm for a biobank that treats the donors of biological materials not just as objects of property or even subjects of human research, but rather as full-fledged partners and shareholders in the research enterprise.

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2. There were a few notable exceptions. Lacks’ contributions were acknowledged in Michael Gold’s book, *A Conspiracy of Cells*, Victor McKusick’s textbook on *Medical Genetics*, and the works of Harriet Washington. See M. Gold, *A Conspiracy of Cells: One Woman’s Immortal Legacy and the Scandal It Caused* (New York: State University of New York Press, 1985); *Medical Genetics* (Victor McKusick and Robert Claiborne, editors) (H.P. Publishing, 1974); H. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (New York: Doubleday, 2006); H. Washington, *Deadly Monopolies* (New York: Anchor Publishing, 2012).
3. R. Skloot, “Taking the Least of You,” *New York Times Magazine*, April 16, 2006, at 40.
4. R. Skloot, *The Immortal Life of Henrietta Lacks, the Sequel*, *New York Times*, March 23, 2013.
5. 45 C.F.R. Section 46 (2009). See also J. Belisle, “Recognizing a Quasi-Property Right in Biomaterials,” *UC Irvine Law Review* 3, no. 3 (August 2013): 767-799, at 778; G. Javitt, “Why Not Take All of Me? Reflections on the Immortal Life of Henrietta Lacks and the Status of Participants in Research Using Human Specimens,” *Minnesota Journal of Law, Science & Technology* 11, no. 2 (Spring 2010): 713-754, at 731-34.
6. See Skloot, *supra* note 3, at 45.
7. J. Belisle, *supra* note 5, at 778.
8. In contrast to blanket consent, Natalie Ram describes a form of particularized consent known as project-specific consent “under which tissue providers are contacted before each use of their tissues for research in order to provide the opportunity for consent.” According to Ram, project-specific consent “best approaches the paradigm of informed consent, as it makes available to tissue providers the most precise information for a given consent interaction. Because tissue providers consent to one research project at a time, they are necessarily more informed about the specific research projects in which their tissues are used.” Nevertheless, Ram declares, “Although theoretically possible, project-specific consent has not been commonly used in the context of human tissue research because of its administrative burdens to researchers...[such as] maintaining accurate phone or mail records and tracking tissue providers and their consent decisions.” N. Ram, “Tiered Consent and the Tyranny of Choice,” *Jurimetrics Journal* 48, no. 2 (Spring 2008): 253-284, at 265-266.
9. See, e.g., *Moore v. Regents of the University of California*, 793 P.2d 479, 483 (Cal. 1990) (“The second important policy consideration is that we not threaten with disabling civil liability innocent parties who are engaged in socially useful activities, such as researchers who have no reason to believe that their use of a particular cell sample is, or may be, against a donor’s wishes.”). Similar concerns regarding administrative burdens, as well as the possibility for discrimination, motivated the district court’s rejection of a patient’s right to choose whom and for what purposes to donate tissue in *Washington University v. Catalona*, 437 F. Supp. 2d 985, 1002 (E.D. Missouri 2006) (stating that the “integrity and utility of all biorepositories would be seriously threatened if [research participants]

- could move their samples from institution to institution any time they wanted,” and that allowing a research participant “to choose who can have the sample, where the sample will be stored, and/or how the sample can be used is tantamount to a blood donor being able to dictate that his/her blood can only be transfused into a person of a certain ethnic background, or a donated kidney being transplanted only into a woman or man. This kind of ‘selectiveness’ is repugnant to any ethical code which promotes medical research to help all of mankind.”)
10. See Ram, *supra* note 8, at 253 (contending that new evidence emerging from the fields of behavioral economics and consumer psychology suggests that too much choice can actually provoke anxiety among decision makers, causing them to experience information overload, make arbitrary choices, or refrain from choosing altogether, resulting in systematically lower quality decision making).
 11. D. Zoe Laufer, *Informed Consent*. (Playscript; copy in author’s files, available upon request.)
 12. A. Harmon, “Indian Tribe Wins Fight to Limit Research of Its DNA,” *New York Times*, April 21, 2010.
 13. *Id.*
 14. *Tilousi v. Arizona State Univ. Bd. of Regents*, No. 04-CV-1290, 2005 WL 6199562, at *1 (D. Ariz., March 3, 2005).
 15. See Harmon, *supra* note 12.
 16. *Id.*
 17. *Tilousi v. Arizona State Univ. Bd. of Regents*, No. 04-CV-1290, 2005 WL 6199562, at *1, *3 (D. Ariz., March 3, 2005).
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 19. *Id.*
 20. *Id.*
 21. *Id.*
 22. *Id.*
 23. See K. Drabiak-Syed, “Lessons from Havasupai Tribe v. Arizona State Board of Regents: Recognizing Group, Cultural, and Dignitary Harms as Legitimate Risks Warranting Integration into Research Practice,” *Journal of Health & Biomedical Law* 6, no. 2 (2010): 175-225..
 24. M. Cohen, “Property and Sovereignty,” *Cornell Law Review* 13, no. 1 (1927-28): 8-30.
 25. See M. Goodwin, “Altruism’s Limits: Law, Capacity, and Organ Commodification,” *Rutgers Law Review* 56, no. 2 (Winter 2004): 305-407, at 361 (“Critics suggest it would be a mistake...to apply the language of property to the human body. They caution that applying the concept of property to the human body would be as morally reprehensible as slavery...”).
 26. *Beleno v. Texas Dept. of State Health Services*, U.S. District Court for W. Dist. Texas (March 2009).
 27. *Bearder v. Minnesota*, 806 N.W. 2d 766 (Minn. 2011).
 28. See S. Suter, “Did You Give the Government Your Baby’s DNA? Rethinking Consent in Newborn Screening,” *Minnesota Journal of Health Law, Science & Technology* 15, no. 2 (Spring 2014): 729-790.
 29. See M. H. Lewis et al., “State Laws Regarding the Retention and Use of Residual Newborn Screening Blood Samples,” *Pediatrics* 127, no. 4 (April 2011): 703-712.
 30. See R. Rao, “Property, Privacy and the Human Body,” *Boston University Law Review* 80, no. 2 (2000): 359-460.
 31. See R. Rao, “Coercion, Commercialization, and Commodification: The Ethics of Compensation for Egg Donors in Stem Cell Research,” *Berkeley Technology Law Journal* 21, no. 3 (2006): 1055-1066.
 32. *Moore v. Regents of the University of California*, 793 P.2d 479 (Cal. 1990).
 33. *Greenberg v. Miami Children’s Hospital*, 264 F. Supp. 2d 1064 (S.D. Fla. 2003).
 34. *Washington University v. Catalona*, 490 F.3d 667 (8th Circuit 2007).
 35. See R. Rao, “Genes and Spleens: Property, Contract or Privacy Rights in the Human Body,” *Journal of Law, Medicine & Ethics* 35, no. 3 (2007): 371-382.
 36. In *Myriad Genetics*, the Supreme Court prohibited the patenting of human genes that are merely isolated and purified forms of the DNA discovered and sequenced from the human body, on the grounds that they are products of nature, rather than man-made inventions. But the Court suggested that certain forms of human DNA that do not exist in nature or have been modified or transformed by the hand of man may continue to be patentable. *Association for Molecular Pathology v. Myriad Genetics*, 133 S.Ct. 2107 (U.S. 2013).
 37. *Perez v. Commissioner*, 144 T.C. 4 (2015).
 38. A. Jones, “Putting a Price on a Human Egg,” *Wall Street Journal*, July 26, 2015. In 2016, the American Society for Reproductive Medicine (ASRM) settled the price-fixing lawsuit, agreeing to delete language in the egg donor compensation guidelines alleged to violate antitrust laws. J. Gershman, “Fertility Industry Group Settles Lawsuit Over Egg Donor Price Caps,” *Wall Street Journal*, Feb. 3, 2016.
 39. E. Bailey, “Wilson Signs Bill Making Theft of Human Eggs a Crime,” *LA Times*, September 26, 1996.
 40. R. Skloot, *The Immortal Life of Henrietta Lacks* (New York: Crown Publishers, 2010): at 9.
 41. See R. Almeling, *Sex Cells: The Medical Market for Eggs and Sperm* (Berkeley: University of California Press, 2011) (depicting gendered ways in which payments to sperm donors are framed as remuneration for an easy “job”, as opposed to egg donors, who are encouraged to view egg donation as the ultimate “gift”).
 42. W. Blackstone, *Commentaries on the Laws of England*, volume 2, at 2.
 43. J. Williams, “The Rhetoric of Property,” *Iowa Law Review* 83, no. 2 (1998): 277-361, at 280 (describing “the gap between the political rhetoric of absolute property rights and the practice of limited property rights.”).
 44. See *United States v. Kriesel*, 720 F.3d 1137 (9th Circuit 2013) (holding that convicted offender who had completed his period of supervised release had standing to seek return of the blood sample taken from him for forensic analysis and acknowledging that Kriesel was “seeking the return of ‘property’...[T]he blood sample itself is a tangible object, and the genetic code contained within the blood sample is information.”)
 45. See, e.g., N. Ram, “DNA by the Entirety,” *Columbia Law Review* 115, no. 4 (May 2015): 873-939 (comparing shared familial interests in DNA to tenancy by the entirety, and drawing upon this ancient property framework to grapple with overlapping interests in modern genetic identification and analysis); L. Maria Franciosi and A. Guarneri, “The Protection of Genetic Identity,” *Journal Civil Law Studies* 1, no. 1 (2008): 139-188, at 186 (suggesting that “regulations pertaining to the theme of joint ownership (joint tenancy, co-ownership) could be applied. These norms in fact would allow disciplining potential conflicts among individuals that hold the same right.”); E. Murphy, “Relative Doubt: Familial Searches of DNA Databases,” *Michigan Law Review* 109, no. 3 (2010): 291-348, at 336 (drawing an analogy “to the joint interest held by property owners who share common space”).
 46. K. Hudson and F. Collins, “Biospecimen Policy: Family Matters,” *Nature* 500, no. 7461 (August 2013): 141-142.
 47. D. Chrysler, H. McGee, J. Bach, E. Goldman, P. Jacobson, “The Michigan Biotrust for Health: Using Dried Bloodspots for Research to Benefit the Community While Respecting the Individual,” *Journal of Law, Medicine & Ethics* 39, No. S1 (2011) 98-101.
 48. D. Winickoff and R. Winickoff, “The Charitable Trust as a Model for Genomic Biobanks,” *New England Journal of Medicine* 349, no. 12 (2003): 1180-1184.

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