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### The False Promise of Health Data Ownership

Jorge L. Contreras

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# THE FALSE PROMISE OF HEALTH DATA OWNERSHIP

JORGE L. CONTRERAS\*

*In recent years there have been increasing calls by patient advocates, health law scholars, and would-be data intermediaries to recognize personal property interests in individual health information (IHI). While the propertization of IHI appeals to notions of individual autonomy, privacy, and distributive justice, the implementation of a workable property system for IHI presents significant challenges. This Article addresses the issues surrounding the propertization of IHI from a property law perspective. It first observes that IHI does not fit recognized judicial criteria for recognition as personal property, as IHI defies convenient definition, is difficult to possess exclusively, and lacks justifications for exclusive control. Second, it argues that if IHI property were structured along the lines of traditional common law property, as suggested by some propertization advocates, prohibitive costs could be imposed on socially valuable research and public health activity and IHI itself could become mired in unanticipated administrative complexities. Third, it discusses potential limitations and exceptions on the scope, duration, and enforceability of IHI property, both borrowed from intellectual property law and created de novo for IHI.*

*Yet even with these limitations, inherent risks arise when a new form of property is created. When owners are given broad rights of control, subject only to enumerated exceptions that seek to mitigate the worst effects of that control, constitutional constraints on governmental takings make the subsequent refinement of those rights difficult if not impossible, especially when rights are distributed broadly across the entire population. Moreover, embedding a host of limitations and exceptions into a new property system simply to avoid the worst effects of propertization begs the question whether a property system is needed at all, particularly when existing contract, privacy, and anti-discrimination rules already exist to protect individual privacy and autonomy in this area. It may be that one of the principal results of propertizing IHI is enriching would-be data intermediaries with little net benefit to individuals or public health. This Article concludes by recommending that the propertization of IHI be rejected in favor of sensible governmental regulation of IHI research coupled with existing liability rules to compensate individuals for violations of their privacy and abusive conduct by data handlers.*

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INTRODUCTION

Concerns regarding the privacy and security of personal data have become particularly salient with respect to information about personal health (referred to here as individual health information or “IHI”).<sup>1</sup> One increasingly frequent proposal that has been made to

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<sup>1</sup> I use “IHI” as an overarching term to describe a range of individual health information including medical records, test results, clinical data, disease state, medications, genetic sequence, vital statistics, family history, and personal demographic information. This term should not be confused with “protected health information” or PHI, as used in the HIPAA Privacy Rule, 45 C.F.R. §§ 160, 164 (2012). Some authors have proposed special treatment for genetic information given its special information-carrying properties.

address perceived risks and inequities arising from the use and handling of IHI is treating it as the personal property of the individuals to whom it relates.

Debates regarding data ownership and privacy have been brewing in academic circles since the emergence of computers and digital records in the 1960s,<sup>2</sup> but it was the growth of the Internet in the late 1990s and early 2000s that sparked widespread debate among cyberlaw and intellectual property scholars.<sup>3</sup> In recent years, increasing wealth inequality and the rise of digital platforms have fueled a renewed conversation about the ownership of personal information.<sup>4</sup>

Joining this debate, some health law scholars have raised concerns regarding individual autonomy, privacy, and distributive justice in arguing for the propertization of genetic and other health information.<sup>5</sup> In his bestselling book *The Patient Will See You Now*, cardiolo-

*See, e.g.*, Ellen Wright Clayton et al., *The Law of Genetic Privacy: Applications, Implications, and Limitations*, 6 J.L. & BIOSCIENCES 1, 7–10 (2019) (describing the history of “genetic exceptionalism”); Patricia A. Roche & George J. Annas, *Protecting Genetic Privacy*, 2 NATURE REV. GENETICS 392, 393 (2001) (“[G]enetic information can radically change the way people view themselves . . . as well as the way that others view them.”). This Article, however, treats all health information in a uniform manner.

<sup>2</sup> *See* ALAN F. WESTIN, *PRIVACY AND FREEDOM* 324 (1967) (“[P]ersonal information . . . should be defined as a property right . . .”); Arthur R. Miller, *Personal Privacy in the Computer Age: The Challenge of a New Technology in an Information-Oriented Society*, 67 MICH. L. REV. 1089, 1223–26 (1969) (challenging Westin and others and criticizing the use of property law to protect privacy as “facile”).

<sup>3</sup> *See, e.g.*, LAWRENCE LESSIG, *CODE AND OTHER LAWS OF CYBERSPACE* 156–63 (1999) (proposing a property-based framework to protect personal online privacy); Julie E. Cohen, *Examined Lives: Informational Privacy and the Subject as Object*, 52 STAN. L. REV. 1373, 1379 (2000) (recognizing some benefits of propertization of personal data); Jessica Litman, *Information Privacy/Information Property*, 52 STAN. L. REV. 1283, 1313 (2000) (“[P]ursuing a tort law strategy for privacy protection would be better than a property rights approach not because it would be especially effective, but rather because it would be comparatively benign.”); Patricia Mell, *Seeking Shade in a Land of Perpetual Sunlight: Privacy as Property in the Electronic Wilderness*, 11 BERKELEY TECH. L.J. 1, 81 (1996) (“Since the persona is identifiable to a specific individual, the electronic persona is ‘owned’ by that person . . . . It is this very identifiability which makes it property.”); Paul M. Schwartz, *Property, Privacy, and Personal Data*, 117 HARV. L. REV. 2056, 2056 (2004) (proposing a five-part framework defining rights in personal information).

<sup>4</sup> JOSHUA A.T. FAIRFIELD, *OWNED: PROPERTY, PRIVACY AND THE NEW DIGITAL SERFDOM* 3, 8 (2017) (“If we do not take back our ownership rights from software companies and overreaching governments, we will become digital peasants.”); ERIC A. POSNER & E. GLEN WEYL, *RADICAL MARKETS: UPROOTING CAPITALISM AND DEMOCRACY FOR A JUST SOCIETY* 241–49 (2018) (advocating labor-based payments to individuals for uploading and classifying online data without direct recourse to property arguments).

<sup>5</sup> *See, e.g.*, Jessica L. Roberts, *Progressive Genetic Ownership*, 93 NOTRE DAME L. REV. 1105, 1164–67 (2018) (promoting a “progressive” view of propertized health data that incorporates “plural values, communitarian interests, and distributive justice”).

gist and patient advocate Eric Topol asserts that “[t]he ownership of property is essential to emancipation. It’s unquestionably appropriate, a self-evident truth, that each individual is entitled to own all of his or her medical data.”<sup>6</sup> Popular awareness of these issues has been fueled, among other things, by the story of Henrietta Lacks, an indigent African-American cancer patient whose excised tumor cells formed the basis of a multi-billion dollar industry while her descendants continued to live in poverty.<sup>7</sup> At least six U.S. states have enacted legislation purporting to grant individuals ownership of their genetic information (though one has since repealed that legislation).<sup>8</sup> And even former President Barack Obama once opined that “if somebody does a test on me or my genes . . . that’s mine.”<sup>9</sup>

But the push toward individual data ownership has gained the most momentum thanks to a new crop of technology-focused startups. In a global health data market worth an estimated sixty-seven to one hundred billion dollars per year,<sup>10</sup> these aspiring data intermediaries

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<sup>6</sup> ERIC TOPOL, *THE PATIENT WILL SEE YOU NOW* 281 (2016). See *infra* notes 19–21, discussing Dr. Topol’s non-profit company formed to promote this position.

<sup>7</sup> REBECCA SKLOOT, *THE IMMORTAL LIFE OF HENRIETTA LACKS* 1–7 (2010). Skloot’s book was also adapted as an HBO movie starring Oprah Winfrey, further extending its reach into the popular awareness. *THE IMMORTAL LIFE OF HENRIETTA LACKS* (HBO Films, 2017).

<sup>8</sup> See Anya E.R. Prince, *Comprehensive Protection of Genetic Information: One Size Privacy or Property Models May Not Fit All*, 79 *BROOK. L. REV.* 175, 195–98 (2013) (discussing laws in Alaska, Colorado, Georgia, Louisiana, and Florida). Oregon, the first state to enact legislation recognizing a property interest in genetic information, repealed this law in 2001. *Compare* Genetic Privacy, 2001 *OR. LAWS* ch. 588, § 2 (codified as amended at *OR. REV. STAT. ANN.* § 192.537 (West 2019)) (repealing property provisions), *with* Genetic Privacy Act, *OR. REV. STAT. ANN.* § 659.715(1) (West 1997) (“[A]n individual’s genetic information and DNA sample are the property of the individual except when the information or sample is used in anonymous research.”). See also GENETIC RESEARCH ADVISORY COMM., *ASSURING GENETIC PRIVACY IN OREGON* 10–11 (2000) [hereinafter Oregon Report] (recommending repeal), <https://digital.osl.state.or.us/islandora/object/osl%3A1980>; *OR. PUB. HEALTH DIV., HISTORY OF OREGON’S GENETIC PRIVACY LAW* 3–4 (2007), [https://www.oregon.gov/oha/ph/DiseasesConditions/GeneticConditions/Documents/LAW\\_ORHxPrivacy.pdf](https://www.oregon.gov/oha/ph/DiseasesConditions/GeneticConditions/Documents/LAW_ORHxPrivacy.pdf).

<sup>9</sup> Julie Hirschfeld Davis, *President Weighs In on Data from Genes*, *N.Y. TIMES* (Feb. 25, 2016), <https://www.nytimes.com/2016/02/26/us/politics/president-obama-weighs-in-on-data-from-genes.html>. *But see* Jorge L. Contreras, *Letter to the Editor: The President Says Patients Should Own Their Genetic Data. He’s Wrong.*, 34 *NATURE BIOTECHNOLOGY* 585 (2016) (critiquing President’s statement).

<sup>10</sup> See Joyce E. Cutler, *How Can Patients Make Money Off Their Medical Data*, *BLOOMBERG L.* (Jan. 29, 2019, 5:46 AM), <https://news.bloomberglaw.com/pharma-and-life-sciences/how-can-patients-make-money-off-their-medical-data>; Sara Merken & Dana A. Elfin, *What’s Your Health Data Worth? Startups Want to Help You Sell It*, *BLOOMBERG L.* (Oct. 31, 2018) <https://biglawbusiness.com/whats-your-health-data-worth-startups-want-to-help-you-sell-it> (“The worldwide market for patient medical data is potentially huge, with estimates running as high as \$67 billion.”).

seek to use Blockchain<sup>11</sup> and mobile apps to enable consumers to control, and get paid for, the use of their IHI, and in the process retain a healthy portion of the proceeds.<sup>12</sup> These firms include Nebula Genomics (co-founded by Harvard Medical School professor and genomics pioneer George Church),<sup>13</sup> Genos (a spin-out from Chinese sequencing giant BGI-Shenzhen),<sup>14</sup> DNAsimple (a recent contestant on the ABC television show *Shark Tank*),<sup>15</sup> Invitae (seeking to sell “genome management” services),<sup>16</sup> and LunaDNA (backed by equipment manufacturer Illumina).<sup>17</sup> The motivations of these firms may be summed up by the Chairman of Genos, who has publicly stated that “our business is to make money enabling researchers and individuals to connect and transact with each other.”<sup>18</sup>

In a less commercial vein, Unpatient.org, a short-lived not-for-profit effort by Topol and Leonard Kish, sought to empower patients through data ownership.<sup>19</sup> Unpatient.org released its own “Data

<sup>11</sup> Blockchain refers to a distributed ledger technology that enables trusted and authenticated electronic transactions without the need for centralized administration. See Tsung-Ting Kuo, Hyeon-Eui Kim & Lucila Ohno-Machado, *Blockchain Distributed Ledger Technologies for Biomedical and Health Care Applications*, 24 J. AM. MED. INFORMATICS ASS'N 1211, 1214 (2017) (summarizing key benefits of adopting blockchain technology in biomedical and health care applications as “(1) decentralized management, (2) immutable audit trail, (3) data provenance, (4) robustness/availability, and (5) security/privacy”).

<sup>12</sup> See Merken & Elfin, *supra* note 10; Megan Molteni, *These DNA Startups Want to Put All of You on the Blockchain*, WIRED (Nov. 16, 2018) <https://www.wired.com/story/these-dna-startups-want-to-put-all-of-you-on-the-blockchain> (“In the last three years, nearly 150 companies building biomedical blockchain applications have raised more than \$660 million in the private and cryptocurrency markets. About a quarter of those projects aim to be decentralized clearinghouses for various kinds of health data.”).

<sup>13</sup> See John Lauerman, *This Startup Is Building a Market to Help You Sell Your DNA Data*, BLOOMBERG (Aug. 29, 2018, 9:34 AM), <https://www.bloomberg.com/news/articles/2018-08-29/put-a-price-on-your-dna-data-with-this-harvard-professor-s-firm>; Megan Scudellari, *Get Paid for Your Genetic Data*, IEEE SPECTRUM (Apr. 2018), <https://ieeexplore.ieee.org/stamp/stamp.jsp?arnumber=8322030>.

<sup>14</sup> Misha Angrist, *Do You Belong to You?*, GENOME MAG. (Jan. 2, 2018), <http://genomemag.com/do-you-belong-to-you>.

<sup>15</sup> See Ali Montag, *This Company Will Pay You \$50 for Your Spit—And Mark Cuban Just Invested \$200,000 on ‘Shark Tank,’* CNBC (Nov. 13, 2017, 12:56 PM), <https://www.cnbc.com/2017/11/13/mark-cuban-invested-200000-in-dna-simple-on-shark-tank-heres-why.html>; see also Roberts, *supra* note 5, at n.217.

<sup>16</sup> See Jessica L. Roberts, Stacey Pereira & Amy L. McGuire, *Letter to the Editor: Should You Profit from Your Genome?*, 35 NATURE BIOTECHNOLOGY 18, 18 (2017).

<sup>17</sup> Kristen V. Brown, *Share Your DNA, Get Shares: Startup Files an Unusual Offering*, BLOOMBERG (Oct. 5, 2018, 8:46 AM), <https://www.bloomberg.com/news/articles/2018-10-05/illumina-backed-startup-asks-sec-to-let-it-pay-people-for-dna>.

<sup>18</sup> Roberts, Pereira & McGuire, *supra* note 16, at 18 (quoting Chairman Cliff Reid).

<sup>19</sup> See Leonard J. Kish & Eric J. Topol, *Unpatients – Why Patients Should Own Their Medical Data*, 33 NATURE BIOTECHNOLOGY 921, 923 (2015). By December 2018, the Unpatient.org website was no longer active. According to one of the co-founders, Unpatient.org has suspended operations, but hopes to continue to advance patient privacy

Ownership Manifesto”<sup>20</sup> which proclaimed that “[d]ata that reflects you should belong to you,” rather than to healthcare providers and pharmaceutical companies.<sup>21</sup>

But perhaps the most intriguing addition to the propertization camp is Hu-munity.org, which approaches the issue of data propertization from the perspective of international human rights, arguing that a “31st human right” in personal data ownership should be recognized under the Universal Declaration of Human Rights,<sup>22</sup> following from which individuals should be able to sell, and profit from, access to their data.<sup>23</sup>

In each of these business models, the aspiring data intermediary acts as the consumer’s authorized agent in selling or licensing her IHI to healthcare providers, pharmaceutical manufacturers, and anyone else interested in it, remitting a share of the revenue back to the consumer and, of course, retaining a portion for itself. While the idea that consumers, as a matter of equity and distributive fairness, should share in the profits earned from the use of their data is not a new one,<sup>24</sup> it is only today, with the advent of technologies such as Blockchain and pervasive mobile connectivity, that markets in IHI have become feasible.

Though there are differences among these proposed offerings, an individual who signed up with one of these data intermediaries would be given the ability to opt-in to one or more research studies and con-

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as the technology matures. E-mail from Leonard J. Kish, Co-Founder, Unpatient.org, to author (Mar. 21, 2019) (on file with author).

<sup>20</sup> See Roberts, *supra* note 5, at 1151 (describing Unpatient Health Data Ownership Manifesto).

<sup>21</sup> *Id.*

<sup>22</sup> The Universal Declaration of Human Rights currently recognizes thirty fundamental human rights, several of which (such as the rights to privacy, liberty, and property) may already, though imperfectly, address concerns regarding control over one’s own electronic data. See G.A. Res. 217 (III) A, Universal Declaration of Human Rights, arts. 3, 12, 17 (Dec. 10, 1948).

<sup>23</sup> See Ron Miller, *Hu-munity Wants to Create a Health Data Marketplace with Help from Blockchain*, TECHCRUNCH (July 18, 2018), <https://techcrunch.com/2018/07/18/hu-munity-wants-to-create-a-health-data-marketplace-with-help-from-blockchain> (explaining that consumers will be able to provide their data to researchers in exchange for a fee).

<sup>24</sup> See, e.g., ANNE WELLS BRANSCOMB, WHO OWNS INFORMATION? FROM PRIVACY TO PUBLIC ACCESS 29 (1994) (“If such information has economic value, we should receive something of value in return for its use by others.”); Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 31, 50 (Mark A. Rothstein ed., 1997); Mark A. Hall & Kevin A. Schulman, *Ownership of Medical Information*, 301 J. AM. MED. ASS’N 1282, 1284 (2009) (proposing a trading market in IHI); Mark A. Hall, *Property, Privacy, and the Pursuit of Interconnected Electronic Medical Records*, 95 IOWA L. REV. 631, 659–63 (2010) (discussing ownership of medical records).

tribute all or a portion of her stored data to the study.<sup>25</sup> In some cases, an individual may not wish to share certain types of information, such as a family history of schizophrenia or an HIV-positive diagnosis. In that case, the intermediary could screen the studies offered to the individual or exclude IHI relating to the sensitive subject area. DNAsimple advertises that it will pay donors for saliva samples to help genetic disease research.<sup>26</sup> Genos estimates that IHI payments to consumers would be in the range of \$50 to \$250,<sup>27</sup> while LunaDNA offers participants a mere \$3.50 for the use of their genetic marker data and \$21 for a full genomic sequence.<sup>28</sup>

The linchpin of this new business model is the recognition of an individual's ownership of IHI. Without it, companies, hospitals, insurers, and data intermediaries can (and today do) aggregate and sell individual health information without consulting, or paying, the individual.<sup>29</sup> But if consumers *owned* their data, anyone who tried to use or sell it without permission would be stealing (or at least converting) that data. Ownership of IHI would potentially invest individuals with powerful and legally enforceable mechanisms to prevent intrusion, appropriation, and exploitation of information that they do not wish to share—authority that seems particularly desirable in today's world of untrammelled data exploitation.

Recognizing a property right in IHI, of course, would represent a significant departure from current U.S. law,<sup>30</sup> which has held for more than a century that data—objective information and facts—cannot be

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<sup>25</sup> See, e.g., DNAsimple, FACEBOOK, <https://www.facebook.com/pg/dnasimple/about> (last visited July 21, 2019) (describing one company's options for study participation); Molteni, *supra* note 12 (same).

<sup>26</sup> DNAsimple, *supra* note 25.

<sup>27</sup> Angrist, *supra* note 14, at 45.

<sup>28</sup> Julian Segert, *Understanding Ownership and Privacy of Genetic Data*, HARV. UNIV. SCI. IN THE NEWS (Nov. 28, 2018), <http://sitn.hms.harvard.edu/flash/2018/understanding-ownership-privacy-genetic-data>. One reporter who investigated a number of personal health data sites came to the conclusion that the amounts paid were so small as to make them not worth the effort. Kristen V. Brown, *How I Got Cash, Gift Cards and Cryptocurrency for My DNA Data*, Bloomberg Prognosis Podcast, Episode 13 (May 23, 2019).

<sup>29</sup> Kish & Topol, *supra* note 19, at 921.

<sup>30</sup> In the United States, property law is traditionally a matter of state common law, while certain intellectual property rights (e.g., copyright and patent) are governed by federal statutory law. Proposals for the propertization of health data are generally not specific as to whether the new property right would be created under state or federal law, though, as discussed in note 8, *supra*, some state laws have already been enacted in this regard. Finally, while the focus of this Article is on U.S. law, similar discussions regarding data propertization have been occurring in Europe, Canada, and elsewhere. See Teresa Scassa, *Data Ownership* 14–16 (CIGI, Paper No. 187, 2018) (discussing EU consideration of *sui generis* data protection regulations and Canadian positions).



owned as property.<sup>31</sup> As Justice Louis Brandeis wrote, facts are “free as the air to common use.”<sup>32</sup> This longstanding rule has been applied consistently to information ranging from the news of the day,<sup>33</sup> stock recommendations,<sup>34</sup> and sports scores<sup>35</sup> to the sequence of naturally occurring human DNA.<sup>36</sup> The federal court in *Greenberg v. Miami Children’s Hospital Research Institute, Inc.* expressly rejected property-based claims under which the plaintiffs sought a share of the profits made using discoveries based on their children’s genetic data.<sup>37</sup> Thus, under current law, facts—raw information about the world—once generally known, cannot be owned.

Some who advocate for individual ownership of IHI argue that data ownership is nothing new: institutions already “own” data in the form of trade secrets, copyrighted material, and medical records.<sup>38</sup> They argue that if there is no legal impediment to institutions owning personal data, why, then, should there be any objection to *individuals* owning the same data?<sup>39</sup> Yet, contrary to these assertions, the laws of copyright, trade secret, databases, and patents do *not*, in fact, create a property interest in IHI.<sup>40</sup> Thus, the invocation of these related bodies of law resists, rather than supports, the application of intellectual

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<sup>31</sup> *Int’l News Serv. v. Associated Press*, 248 U.S. 215, 234 (1918) (holding that information about current events cannot be copyrighted); *Feist Publ’ns, Inc. v. Rural Tel. Serv. Co.*, 499 U.S. 340, 344–45 (1991) (explaining that it is a basic axiom of copyright law that authors cannot copyright facts). The refusal to recognize a property interest in data is not unique to the United States. *See, e.g.*, John Rumbold & Barbara Pierscionek, *Why Patients Shouldn’t ‘Own’ Their Medical Records*, 34 NATURE BIOTECHNOLOGY 586 (2016) (discussing applicability to the UK and EU); Scassa, *supra* note 30, at 14–16 (discussing EU and Canadian perspectives).

<sup>32</sup> *Int’l News Serv.*, 248 U.S. at 250 (Brandeis, J., dissenting).

<sup>33</sup> *See id.* at 234 (majority opinion).

<sup>34</sup> *Barclays Capital Inc. v. Theflyonthewall.com*, 700 F. Supp. 2d 310, 344–45 (S.D.N.Y. 2010), *rev’d in part*, 650 F.3d 876 (2d Cir. 2011).

<sup>35</sup> *Nat’l Basketball Ass’n v. Motorola, Inc.*, 105 F.3d 841, 846–47 (2d Cir. 1997).

<sup>36</sup> *Ass’n for Molecular Pathology v. Myriad Genetics, Inc.*, 133 S. Ct. 2107, 2111 (2013).

<sup>37</sup> 264 F. Supp. 2d 1064, 1074 (S.D. Fla. 2003).

<sup>38</sup> *See, e.g.*, Leonard J. Kish & Eric J. Topol, *Reply to Why Patients Shouldn’t ‘Own’ Their Medical Records*, 34 NATURE BIOTECH. 586, 586 (2016) (“[R]esearch data are often considered IP and are covered as a trade secret, or copyrighted. . . . The bottom line is that personal data are already viewed as property in a variety of contexts.”).

<sup>39</sup> *See id.* at 587 (“There rarely seems to be debate on whether or not institutions can ‘own’ data, but questions arise when it comes to individuals and their personal data.”).

<sup>40</sup> *See* Jane B. Baron, *Property as Control: The Case of Information*, 18 MICH. TELECOMM. & TECH. L. REV. 367, 381 n.66 (2012) (arguing that personal information does not fit existing IP categories “as it involves no invention or innovation that would make it patentable, it lacks the originality and creativity that would make it eligible for copyright protection, and it is not the sort of secret business information that would make it a trade secret”); Cohen, *supra* note 3, at 1387 (arguing that intellectual property law does not provide a basis for assigning a property interest in personal data, because, unlike intellectual property law, incentives are not relevant to discussions of personal data).

property law frameworks to human health data. Because no existing legal regime provides a suitable framework for the ownership of IHI, IHI would have to fall under a *de novo* form of personal intangible property.

Numerous scholars have argued against the creation of a new form of personal property covering individual data. Their objections range from moral and dignitary concerns over commodification of the individual,<sup>41</sup> to utilitarian concerns about barriers that individual ownership of health information could impose on biomedical research<sup>42</sup> and its potential impact on patient safety and public health,<sup>43</sup> to a sense that the propertization of IHI is unnecessary in view of existing common law and regulatory protections of individual privacy and safety.<sup>44</sup>

But, as noted above, the current movement toward ownership of IHI is driven, to an increasing degree, by concerns over privacy, autonomy, and distributive justice.<sup>45</sup> These core ethical considerations are difficult to balance against a “communitarian” instrumental analysis.<sup>46</sup> Thus, even if granting individuals ownership over IHI is likely to impede scientific research and public health monitoring, this cost

<sup>41</sup> See, e.g., Baron, *supra* note 40, at 397–99 (“If personal information connects in important ways to our selves, then trading it has the potential to undermine our identity. . . .”); Sonia M. Suter, *Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy*, 72 GEO. WASH. L. REV. 737, 798–811 (2004) (explaining that certain things, such as human tissue, should never be alienable on dignitary grounds). These arguments draw upon Radin’s seminal work on property and personhood. Margaret Jane Radin, *Market-Inalienability*, 100 HARV. L. REV. 1849, 1885 (1987).

<sup>42</sup> See, e.g., Jorge L. Contreras, *Genetic Property*, 105 GEO. L.J. 1, 7 (2016); Richard A. Spinello, *Property Rights in Genetic Information*, 6 ETHICS & INFO. TECH. 29, 35–36 (2004); Cohen, *supra* note 3, at 1388 n.50.

<sup>43</sup> See, e.g., I. Glenn Cohen, *Is There a Duty to Share Healthcare Data?*, in BIG DATA, HEALTH LAW, AND BIOETHICS 209, 216–17 (I. Glenn Cohen et al., eds., 2018); Jorge L. Contreras & Francisca Nordfalk, *Liability (and) Rules for Health Information*, 29 HEALTH MATRIX J.L. MED. 179 (2019); Marc A. Rodwin, *Patient Data: Property, Privacy & the Public Interest*, 36 AM. J.L. MED. & ETHICS 586, 589 (2010).

<sup>44</sup> See Barbara J. Evans, *Barbarians at the Gate: Consumer-Driven Health Data Commons and the Transformation of Citizen Science*, 42 AM. J.L. & MED. 651 (2016) (protections sought through property law already exist in the regulatory frameworks that govern medical records and research); Barbara J. Evans, *Would Patient Ownership of Health Data Improve Confidentiality?*, 14 AM. MED. ASS’N J. ETHICS 724, 728 (2012) (“There are few discernible differences between the level of confidentiality patients would enjoy if they owned their data . . . and what they presently have under the HIPAA Privacy Rule and the Common Rule.”).

<sup>45</sup> See Roberts, *supra* note 5, at 1164–67.

<sup>46</sup> See, e.g., *id.* at 1145–48 (“Informed consent is . . . decidedly anti-utilitarian and can lead to outcomes that favor individual rights over wealth creation and net social welfare.”); see also Cohen, *supra* note 3, at 1428–49 (making reference to the “communitarian” strain of argument in debates over data ownership).

may be acceptable to those who value personal privacy and autonomy above aggregate net benefits to society.

This Article thus asks whether IHI should be recognized as property not from a purely instrumental standpoint, but from an internal property law perspective: Is propertized IHI workable under property law? Part I first considers whether IHI possesses the characteristics of property that courts have recognized when considering whether other types of intangibles should be recognized as property. Part II considers what propertized IHI might look like, situating IHI within the traditional common law rules of personal property and assessing how different attributes of existing property frameworks—exclusivity, infinite duration, divisibility, alienability and the like—might be applied to IHI. Concluding that traditional common law property rules would result in numerous problems if applied to IHI, Part III considers whether certain limitations and exceptions on the scope and enforceability of propertized IHI, derived both from adjacent areas such as patent and copyright law and from the unique nature of IHI itself, could beneficially be applied to an IHI property framework. This Article concludes by recognizing that while a set of limitations and exceptions applied to an otherwise traditional common law IHI property framework might address some of the issues raised by IHI propertization, the need for such a constrained property system is less than clear.

## I

### DOES IHI POSSESS THE ATTRIBUTES OF PERSONAL PROPERTY?

In assessing the applicability of common law property rules to IHI, it is first useful to understand the characteristics of IHI through a property law lens. As explained in one property law casebook, “To create a system of property rights, a legal system needs to be able to identify the things that are the subject of those rights, to decide who owns those things, and to be able to say when an owner’s rights have been violated.”<sup>47</sup> And as the Ninth Circuit has noted, a property interest “need not be one that was considered property at common law and, of course, need not be tangible.”<sup>48</sup> Thus, in considering whether and to what degree a property interest can be recognized in

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<sup>47</sup> JEREMY SHEFF, *OPEN SOURCE PROPERTY: A FREE CASEBOOK* 68 (2019) (ebook).

<sup>48</sup> *G.S. Rasmussen & Assocs., Inc. v. Kalitta Flying Serv., Inc.*, 958 F.2d 896, 902 (9th Cir. 1992) (citation omitted).

IHI, some attention must be paid to what “thing” will be considered the *res* subject to that interest.<sup>49</sup>

Over the years, courts have considered whether or not to recognize property interests in a variety of intangible assets when analyzing the applicability of different legal doctrines. For example, courts have evaluated whether a particular intangible is “property” to determine whether a regulatory curtailment of that intangible constitutes a governmental taking requiring the payment of compensation under the Fifth Amendment and the observation of due process under the Fourteenth Amendment.<sup>50</sup> Other courts have been required to consider whether an intangible is property in order to determine the applicability of statutes pertaining to mail fraud,<sup>51</sup> copyright infringement,<sup>52</sup> and conversion,<sup>53</sup> as well as the division of matrimonial property in divorce.<sup>54</sup>

Intangibles that courts have deemed to be property in one context or another include shares in a corporation,<sup>55</sup> information in a customer list,<sup>56</sup> Internet domain names,<sup>57</sup> taxi operating licenses,<sup>58</sup> professional football franchises,<sup>59</sup> aviation safety innovations,<sup>60</sup> business franchises,<sup>61</sup> medical degrees,<sup>62</sup> and celebrity status.<sup>63</sup> Intangibles that courts have not deemed to be property include hot news,<sup>64</sup> infor-

<sup>49</sup> See Henry E. Smith, *Property as the Law of Things*, 125 HARV. L. REV. 1691, 1691–92 (2012) (grounding property law in tangible and intangible “things”). *But see* Katrina M. Wyman, *The New Essentialism in Property*, 9 J. LEGAL ANALYSIS 183, 194–98 (2017) (describing ongoing debate among property theorists regarding the extent to which “things” should be considered the gravamen of property law).

<sup>50</sup> See, e.g., *Kremen v. Cohen*, 337 F.3d 1024, 1030 (9th Cir. 2003).

<sup>51</sup> *United States v. Turoff*, 701 F. Supp. 981, 985 (E.D.N.Y. 1988).

<sup>52</sup> *Int’l News Serv. v. Associated Press*, 248 U.S. 215, 234–35 (1918).

<sup>53</sup> See *Greenberg v. Miami Children’s Hosp. Research Inst., Inc.*, 264 F. Supp. 2d 1064, 1074–76 (S.D. Fla. 2003); *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 493 (Cal. 1990); *Palm Springs-La Quinta Dev. Co. v. Kieberk Corp.*, 115 P.2d 548, 551–52 (Cal. Dist. Ct. App. 1941).

<sup>54</sup> See Allen M. Parkman, *Human Capital as Property in Celebrity Divorces*, 29 FAMILY L.Q. 141, 145–46 (1995).

<sup>55</sup> *Payne v. Elliot*, 54 Cal. 339, 342 (1880).

<sup>56</sup> See *Palm Springs-La Quinta Dev. Co.*, 115 P.2d at 551–52 (recognizing cause of action for conversion of real estate developer’s “lead cards”).

<sup>57</sup> *Kremen v. Cohen*, 337 F.3d 1024, 1030 (9th Cir. 2003).

<sup>58</sup> *United States v. Turoff*, 701 F. Supp. 981, 985 (E.D.N.Y. 1988).

<sup>59</sup> *City of Oakland v. Oakland Raiders*, 646 P.2d 835, 837–39 (Cal. 1982).

<sup>60</sup> *G.S. Rasmussen & Assocs., Inc. v. Kalitta Flying Serv., Inc.*, 958 F.2d 896, 903 (9th Cir. 1992).

<sup>61</sup> *Hatfield v. Straus*, 82 N.E. 172, 176 (N.Y. 1907).

<sup>62</sup> *O’Brien v. O’Brien*, 489 N.E.2d 712 (N.Y. 1985).

<sup>63</sup> *Piscopo v. Piscopo*, 557 A. 2d 1040 (N.J. Super. Ct. App. Div. 1989); *Elkus v. Elkus*, 572 N.Y.S.2d 901 (App. Div. 1991); *Golub v. Golub*, 527 N.Y.S.2d 946, 950 (Sup. Ct. 1988).

<sup>64</sup> *Int’l News Serv. v. Associated Press*, 248 U.S. 215, 235 (1918).

mation gleaned from study of an individual's tissue,<sup>65</sup> laundry routes,<sup>66</sup> the right to have an employment agreement renewed,<sup>67</sup> the right to have a restraining order enforced by the police,<sup>68</sup> the government's right to regulate arms sales,<sup>69</sup> and citizens' right to good government.<sup>70</sup>

In *Kremen v. Cohen*,<sup>71</sup> the Ninth Circuit applied a three-part test to determine whether a property interest should be recognized in an intangible—the “medallion” license issued to authorized taxi drivers—for takings purposes. While not all cases determining whether a particular intangible should be invested with the attributes of property are takings cases, takings cases have a well-developed analytical framework exemplified by *Kremen*. In addition, takings cases appear to give the most thought to the actual property-like attributes of the intangible under consideration, whereas cases involving issues such as mail fraud and divorce settlement often focus more on the conduct of the parties.<sup>72</sup> Thus, it is appropriate to consider the framework adopted by courts in takings cases when analyzing more generally whether an intangible such as IHI should be invested with the attributes of personal property.

Of course, current proposals to propertize IHI go beyond even the results of recognition of a property interest for takings purposes. Such proposals seek to invest IHI with all of the rights and benefits of common law property, building a new property regime from scratch. This approach is thus more legislative than judicial, and legislative approaches ideally involve greater refinement and tailoring than judicial recognition of property interests for takings or other limited pur-

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<sup>65</sup> *Greenberg v. Miami Children's Hosp. Research Inst., Inc.*, 264 F. Supp. 2d 1064, 1074–76 (S.D. Fla. 2003) (dismissing a conversion claim based on unauthorized use of donated genetic information); *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 493 (Cal. 1990) (holding no conversion claim existed for unauthorized use of patient's cells and information discovered thereby).

<sup>66</sup> *Olschewski v. Hudson*, 262 P. 43 (Cal. Dist. Ct. App. 1927).

<sup>67</sup> *Bd. of Regents of State Colls. v. Roth*, 408 U.S. 564 (1972) (interpreting “property” for due process purposes).

<sup>68</sup> *Town of Castle Rock v. Gonzales*, 545 U.S. 748, 768 (2005) (interpreting “property” for due process purposes).

<sup>69</sup> *See United States v. Evans*, 844 F.2d 36 (2d Cir. 1988) (interpreting “property” for purposes of applying the federal mail fraud statute, 18 U.S.C. § 1341 (2012)).

<sup>70</sup> *McNally v. United States*, 483 U.S. 350 (1987) (interpreting “property” for purposes of applying § 1341), *superseded by statute*, Pub. L. No. 100-690, 602 Stat. 4181 (1988), *as recognized in Skilling v. United States*, 561 U.S. 358 (2010).

<sup>71</sup> 337 F.3d 1024 (9th Cir. 2003).

<sup>72</sup> *Compare Kremen v. Cohen*, 337 F.3d 1024, 1030 (9th Cir. 2003) (takings), *with Elkus v. Elkus*, 572 N.Y.S.2d 901, 904–05 (App. Div. 1991) (divorce).

poses.<sup>73</sup> Nevertheless, considering the questions that courts have asked regarding the recognition of property interests in particular intangibles for takings purposes is at least a useful first step in the analysis of a property interest in IHI.

Though slightly different tests have been adopted by other courts,<sup>74</sup> the Ninth Circuit's test in *Kremen* is among the most well-articulated and analytically rigorous of takings-type property frameworks. This Article thus considers the case for propertization of IHI in view of the *Kremen* analysis.

*Kremen* provides the following three-part framework for assessing the property-like nature of an intangible: "First, there must be an interest capable of precise definition; second, it must be capable of exclusive possession or control; and third, the putative owner must have established a legitimate claim to exclusivity."<sup>75</sup>

#### A. *Is IHI Capable of Precise Definition?*

Proponents of IHI propertization do not generally speak in terms of protection for an aggregated body of data, as do database protection regulations in Europe and elsewhere,<sup>76</sup> nor in terms of the secrecy of IHI, as does trade secret law.<sup>77</sup> Rather, the "thing" at the root of the proposed IHI property right is information itself. The smallest unit of such property would constitute an individual datum, a single element of IHI: a blood pressure reading on a given date, the results of a particular diagnostic test, or the existence of a known mutation in one's DNA.

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<sup>73</sup> For discussions of proposals for legislative recognition of property interests in different forms of intangibles, see, for example, C. Scott Hemphill & Jeannie Suk, *The Law, Culture, and Economics of Fashion*, 61 STAN. L. REV. 1147 (2009), which proposes protection of fashion designs; J.H. Reichman & Paul F. Uhlir, *A Contractually Reconstructed Research Commons for Scientific Data in a Highly Protectionist Intellectual Property Environment*, L. & CONTEMP. PROBS., Winter/Spring 2003, at 315, which discusses debate over proposed database protection legislation in the United States; and Pamela Samuelson, *Creating a New Kind of Intellectual Property: Applying the Lessons of the Chip Law to Computer Programs*, 70 MINN. L. REV. 471 (1986), which compares protection for computer software to *sui generis* protection for semiconductor layouts.

<sup>74</sup> See, e.g., *Bd. of Regents of State Colls. v. Roth*, 408 U.S. 564, 577 (1972) (describing how the Supreme Court requires a person with a "property interest in a benefit" to "have a legitimate claim of entitlement to it").

<sup>75</sup> *Kremen*, 337 F.3d at 1030 (citing *G.S. Rasmussen & Assocs., Inc. v. Kalitta Flying Serv., Inc.*, 958 F.2d 896, 903 (9th Cir. 1992)).

<sup>76</sup> See, e.g., Directive 96/9/EC of the European Parliament and of the Council of 11 March 1996 on the Legal Protection of Databases, 1996 O.J. (L77) 24–25.

<sup>77</sup> See, e.g., Economic Espionage Act, Pub. L. No. 104-294, 110 Stat. 3488 (1996) (codified as amended at 18 U.S.C. § 1839(3)(a) (2012) (requiring that for information to be considered a trade secret, "the owner thereof has taken reasonable measures to keep such information secret")).

But can such data be precisely defined at the individual level? One nettlesome question is *when* an ownable datum of IHI is created. That is, if one owns a piece of property, it is important in many contexts (e.g., transfer, encumbrance, bankruptcy, divorce, inheritance) to know when the property came into existence. For example, suppose that you wake up one morning with a fever of 104° and a large, red sore on your forehead. At least two important new pieces of health information about you have been created. Is your awareness of these health data required to instantiate them, or do they have an independent and objective existence? Or suppose when you wake up you realize that you have a fever, yet you do not own a thermometer. You do not know that your fever is 104° until your temperature is taken at your primary care provider's office a few hours later. When does your temperature become an ownable piece of property: when your fever struck last night, when you awoke feeling unwell, when your temperature was taken, or when a clerk entered your temperature into a medical record?

Conscious awareness of property is generally not required for it to exist. You may own a piece of land in fee simple with no knowledge of the gold deposits beneath it, yet under the common law of property the gold is indisputably yours. Yet even when the acquirer of property is not consciously aware of the precise nature of the property, it is generally not difficult to define what the property is and when ownership of the property passed to the acquirer. Even works of great originality do not constitute copyrighted works of authorship until they are fixed in a tangible medium of expression (e.g., written, recorded, or electronically stored).<sup>78</sup>

So what of IHI? Is your unrecorded temperature in the middle of the night a datum that qualifies as property when no human, yourself included, is aware of it? If the basis for treating IHI as property derives from one's inherent right to own all information about oneself, then it seems that unfixed, unknown information should, indeed, be considered property. Yet the practical difficulties associated with this extreme version of ownership are significant. For example, how many data are created during the night while you suffer from feverish dreams? Is a new piece of IHI property created every hour? Every minute? Every second? A veritable Zeno's paradox emerges in the fruitless attempt to define the property interests inherent in this simple fact. Such considerations tend to refute the character of

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<sup>78</sup> 17 U.S.C. § 102(a) (2012); *see id.* § 101 ("A work is 'fixed' in a tangible medium of expression when its embodiment . . . is sufficiently permanent or stable to permit it to be perceived, reproduced, or otherwise communicated for a period of more than transitory duration.").

unknown, unfixed IHI as “capable of precise definition” under the *Kremen* standard.

### B. *Is IHI Capable of Exclusive Possession or Control?*

Even if it is possible to identify IHI in a manner “capable of precise definition,” problems emerge under the second *Kremen* factor, which asks whether the right is “capable of exclusive possession or control.”<sup>79</sup> The exclusive possession and control requirement harkens back to the Blackstonian notion of property as “that 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.”<sup>80</sup> Today of course there are many limitations on the property owner’s “sole and despotic dominion,” as a host of governmental regulations concerning the environment, health and safety, illegal activity, and public functions, as well as private covenants, duties, and the like limit what we may and may not do with our property. Yet, even with these important caveats, a fundamental attribute of property remains the right to exclude others from its enjoyment.

But how does such exclusion occur? Physical property may be locked away or hidden. Intangibles like money and financial accounts can be secured behind electronic firewalls and entrusted to intermediaries such as banks. Can the same be said of IHI? At the outset, much information about one’s health can only be learned by the outside world if the individual discloses it directly (“I feel dizzy”) or consents to its discernment by a third party, usually a healthcare provider (e.g., an eye exam, a blood draw, an MRI). Thus, prior to the discernment of an element of IHI by a third party, it seems capable of exclusive possession or control.

But how excludable is this information once it is disclosed? In economic terms, once information is communicated, it is difficult, if not impossible, to contain.<sup>81</sup> Thus, once a physician measures a patient’s pulse or views an x-ray image of his chest, she is prohibited by applicable law from disclosing it to others, but can she be prevented from knowing or using that information in the future?<sup>82</sup> As

<sup>79</sup> *Kremen v. Cohen*, 337 F.3d 1024, 1030 (9th Cir. 2003) (citing *G.S. Rasmussen*, 958 F.2d at 903).

<sup>80</sup> 2 WILLIAM BLACKSTONE, COMMENTARIES \*2. Some scholars have challenged the absolutist nature of exclusivity that has generally been ascribed to Blackstone. See, e.g., Wyman, *supra* note 49, at 219 n.108.

<sup>81</sup> See Charlotte Hess & Elinor Ostrom, *Introduction: An Overview of the Knowledge Commons*, in UNDERSTANDING KNOWLEDGE AS A COMMONS: FROM THEORY TO PRACTICE 8–9 (Charlotte Hess & Elinor Ostrom eds., 2007).

<sup>82</sup> A physician may, of course, have ethical or legal duties not to disclose patient health information. But while the violation of these duties may give rise to other forms of liability



explained by Glenn Cohen, it may be both practically difficult and generally unwise to allow such a right to exclude:

When a physician who is a textbook author writes up a case study of a disease . . . that is a composite of what he has learned from the twenty patients he has seen with the disorder, must he specifically ask each of the patients for his or her consent? Imagine that it is not twenty patients, but at the end of his career, it is every patient he has ever treated, thousands or tens of thousands; must he seek consent from each individual patient in order to use the knowledge he has gleaned? . . . My primary care physician . . . has undoubtedly seen thousands of patients in his career so far . . . . When he treats me, it is not only my expectation but indeed my fervent hope that he uses that prior experience in helping to treat me. If I were to say to him, “Thank you very much for the help on the bronchitis today, doctor, but I want your solemn pledge that you will forget everything you learned in this encounter and never use that knowledge to help another patient,” I know of no physician who would agree to this, were it even possible.<sup>83</sup>

This discussion suggests that IHI may not be amenable to exclusive possession and control as conceptualized under *Kremen*.

### C. Does an “Owner” of IHI Have a Legitimate Claim to Exclusivity?

The third *Kremen* factor requires consideration of whether a putative property owner has a legitimate claim to exclusive control over the proposed item of property.<sup>84</sup> As explained by the Supreme Court in *Board of Regents of State Colleges v. Roth*, “[t]o have a property interest . . . a person clearly must have more than an abstract need or desire for it. He must have more than a unilateral expectation of it. He must, instead, have a legitimate claim of entitlement to it.”<sup>85</sup>

In *G.S. Rasmussen & Associates, Inc. v. Kalitta Flying Services, Inc.*, the Ninth Circuit, drawing on the Supreme Court’s Fifth Amendment takings jurisprudence, explicitly refers to the “reasonable investment-backed expectations” of a prospective property owner in deciding whether or not the owner had a legitimate claim to exclusivity in an aviation safety certification.<sup>86</sup> Based in large part on the “considerable time and effort in research and design” expended by

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for the physician, they do not themselves prevent the use or dissemination of the disclosed information by others once they have received it. *See Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 496–97 (Cal. 1990).

<sup>83</sup> Cohen, *supra* note 43, at 214–15 (citations and emphasis omitted).

<sup>84</sup> *Kremen*, 337 F.3d at 1030.

<sup>85</sup> 408 U.S. 564, 577 (1972).

<sup>86</sup> 958 F.2d at 903 n.13 (citing *Ruckelshaus v. Monsanto Co.*, 467 U.S. 986, 1005 (1984)).

the would-be property owner, the Ninth Circuit recognized his property interest.<sup>87</sup> Likewise, the court in *Kremen* found that domain name registrants expend “substantial time and money to develop and promote websites that depend on their domain names.”<sup>88</sup> These expenditures supported a “legitimate claim to exclusivity” by domain name registrants, and the court accordingly recognized a property interest in domain name registrations.<sup>89</sup>

In the case of IHI, however, the individual who is the source of the information typically expends little or no effort to create it. IHI is largely descriptive information about an individual, not information that the individual spent time, effort, or money to develop. In most cases, this information is discovered and recorded by skilled professionals (physicians, pathologists, medical examiners) who then analyze it without material assistance from the individual. As a result, IHI is more characteristic of something that an individual has an “abstract need or desire” to own, rather than something as to which the individual possesses a legitimate expectation of exclusive control.<sup>90</sup>

Cohen’s discussion as explained in Section I.B, above, illustrates why, in many contexts, a rational patient would not seek to enforce exclusivity against a physician who has obtained IHI from her, even if she could. In addition to individual self-interest, social welfare considerations limit the legitimacy of an individual’s assertion of exclusive rights over IHI. For example, as discussed elsewhere, individual ownership of IHI could impede public health research, monitoring, and response by preventing physicians from communicating important

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<sup>87</sup> *Id.* at 903.

<sup>88</sup> *Kremen*, 337 F.3d at 1030.

<sup>89</sup> *Id.* at 1030.

<sup>90</sup> For similar reasons, even the old property law chestnut—Locke’s labor theory—fails to support the legitimacy of an individual’s claim to exclusive control over her IHI. Locke begins with the premise that one owns one’s body and the fruits of his labor. JOHN LOCKE, *TWO TREATISES OF GOVERNMENT* 111 (Ian Shapiro ed., Yale Univ. Press 2003) (1690) (“[E]very man has a property in his own person: this nobody has any right to but himself. The labour of his body, and the work of his hands, we may say, are properly his.”). But as Glenn Cohen notes, information *about* a person (what color shirt he is wearing, how she reacts to a particular medication) is not *the person* and is thus not captured within the initial premise of Locke’s theory. Cohen, *supra* note 43, at 212–14. Moreover, because a person expends no effort (labor) to generate health information about herself, Locke’s argument that one should own the fruits of one’s labor also fails with respect to such data. *Id.*; see also Cohen, *supra* note 3, at 1380–81 (casting doubt on Lockean justifications for recognizing a property right to personal data); Spinello, *supra* note 42, at 37 (same); Jacob S. Sherkow, Letter to the Editor, *Whose Genes Are They Anyway?*, N.Y. TIMES (Feb. 19, 2007), <https://www.nytimes.com/2007/02/19/opinion/19genes.html> (“Imagine . . . a medical patient had a gene that could cure AIDS, but he prevented researchers from studying it because it came from his body. He didn’t “invent” his genes . . . . Should society be able to compel him to make his genes available for scientific study?”).

health-related observations (e.g., outbreaks of infectious diseases, new strains of flu, previously unknown symptoms, adverse drug reactions) to public health authorities and by preventing public health authorities from using and acting upon that information.<sup>91</sup> In addition, the assertion of exclusive rights to data about oneself is likely to impede socially valuable biomedical research.<sup>92</sup> Though *Kremen* and related cases frame the legitimacy analysis in economic terms and generally do not speak in terms of balancing of social interests, the legitimacy of one's claim to own a particular thing should, at least in part, reflect the social costs and benefits of that ownership. Thus, the legitimacy of individual ownership of IHI may also be challenged on the basis of its potential social harm.

## II

### IHI AS PERSONAL PROPERTY

As discussed in Part I above, serious questions exist regarding the characterization of IHI as personal property under the *Kremen* test. But even if not recognized as property by the courts, the legislature may create new forms of property through *sui generis* legislation.

In the debate over propertization of IHI, little has been said about what, precisely, an IHI property system would look like. Non-legal advocates appear to view the terms “property” and “ownership” as self-evident and not in need of further elaboration or refinement. For example, Hu-manity seeks to “bestow the legal characteristics of property ownership to inherent human data” without explaining what these characteristics should be.<sup>93</sup> And while these statements may be discounted as mere advocacy, even the enacted statutory language of some states that have sought to propertize genetic data<sup>94</sup> is woefully imprecise. For example, Colorado provides, without further elaboration, that “[g]enetic information is the unique property of the individual to whom the information pertains;”<sup>95</sup> and Georgia provides, with equal brevity, that “[g]enetic information is the unique property of the individual tested.”<sup>96</sup> These and other state statutes contain no limitations or constraints on the scope of the property right that is

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<sup>91</sup> See, e.g., Rodwin, *supra* note 43, at 599–607; Contreras & Nordfalk, *supra* note 43, at 194.

<sup>92</sup> See *supra* notes 81–83 and accompanying text.

<sup>93</sup> Hu-manity.co, <https://hu-manity.co> (last visited Apr. 18, 2019); see also Kish & Topol, *supra* note 19, at 924 (identifying the author's goal as “urgently seek[ing] to promote ownership of one's medical data” without explanation of proposed legal mechanisms).

<sup>94</sup> See *supra* note 8 and accompanying text.

<sup>95</sup> COLO. REV. STAT. ANN. § 10-3-1104.7(1)(a) (West 2019).

<sup>96</sup> GA. CODE ANN. § 33-54-1(1) (West 2019).

purportedly created, nor does the limited case law that has developed under these cases shed any light on these critical questions.<sup>97</sup> Thus, this Article examines how IHI would be propertized under a traditional framework for personal property at a doctrinal level not previously addressed in the literature. Doing so reveals significant, and possibly intractable, structural issues with the attempt to propertize IHI in this manner.

### A. *Alienation and Divisibility*

In addition to the right to exclude discussed in Part I above, another fundamental right enjoyed by property owners is the ability to alienate (transfer or sell) their property.<sup>98</sup> The right of alienation has long been viewed as one of the most important rights associated with property, and courts have gone to great lengths to avoid even consensual restrictions of an owner's right to alienate.<sup>99</sup> Indeed, some scholars have proposed that property rights be recognized in IHI precisely to *encourage* the creation of trading markets in such data.<sup>100</sup>

Yet as Baron points out, some may object to the fact that the recipient of their IHI (e.g., a healthcare provider) may freely transfer that IHI to others (e.g., research institutions, pharmaceutical companies, insurers—all subject to applicable regulatory restrictions).<sup>101</sup> To counteract the effect of free alienability by downstream possessors of personal data, scholars have proposed modified formulations of the right to alienate that derive from the inherent divisibility of property rights.<sup>102</sup> Divisibility of property rights manifests itself in different

<sup>97</sup> See, e.g., *Cole v. Gene by Gene, Ltd.*, No. 1:14-cv-00004, 2017 WL 2838256, at \*5 (D. Alaska June 30, 2017) (denying a motion to dismiss suit brought under similar Alaska statute because the disclosure of plaintiff's DNA test results without his consent "is sufficiently 'concrete' so as to confer Article III standing").

<sup>98</sup> JESSE DUKEMINIER ET AL., *PROPERTY* 232–33 (8th ed. 2014). Cf. Susan Rose-Ackerman, *Inalienability and the Theory of Property Rights*, 85 COLUM. L. REV. 931, 932–33 (1985) (describing limited circumstances in which property should be subject to restraints on alienation).

<sup>99</sup> RESTATEMENT (FIRST) OF PROP. § 489 cmt. A (AM. LAW INST. 1944); see, e.g., *Mountain Brow Lodge No. 82 v. Toscano*, 64 Cal. Rptr. 816, 817 (Dist. Ct. App. 1967) ("Conditions restraining alienation, when repugnant to the interest created, are void." (quoting CAL. CIV. CODE § 711)).

<sup>100</sup> See *supra* note 24 and accompanying text.

<sup>101</sup> Baron, *supra* note 40, at 382 ("[I]ndividuals rarely understand the kind and range of uses that might later be made of the information they are selling. In the context of personal information, alienability, ordinarily thought to be welfare-enhancing, becomes something more like a trap for the unwary."); see also OR. PUB. HEALTH DIV., *supra* note 8, at 8 (citing free alienability as a factor weighing against recognition of property rights in genetic data).

<sup>102</sup> See Henry E. Smith, *Property as Platform: Coordinating Standards for Technological Innovation*, 9 J. COMPETITION L. & ECON. 1057, 1061 (2013) ("Much of what property does, in terms of setting up things and defining rights over them, involves fragmentation

concurrent uses and estates in real property as well as intellectual property.<sup>103</sup> Thus, like a copyrighted book or musical composition, personal data could be licensed only for specified uses that are amenable to the owner.<sup>104</sup>

The divisibility of uses for health information is clearly desired by some, as evidenced by recent litigation. In *Greenberg v. Miami Children's Hospital Research Institute, Inc.*, the plaintiffs who provided genetic information to a research institution claimed that they consented to its use for genetic research, but not for commercial exploitation or patenting.<sup>105</sup> In their case against Arizona State University, the Havasupai Indian tribe argued that its members' consent to diabetes research did not extend to schizophrenia or human migration research.<sup>106</sup> And the plaintiffs in *Beleno v. Lakey* argued that their consent to the use of their children's DNA for birth defect screening did not extend to epidemiological or other research.<sup>107</sup>

While none of these cases explicitly recognized a property interest in IHI, the ability to subdivide and specify uses of biomedical data, particularly genetic information, already exists to some degree under government regulations. For example, the National Library of Medicine's Database of Phenotypes and Genotypes (dbGaP) has for years permitted research studies to specify multiple "consent groups" that limit future use of data to narrowly defined purposes,<sup>108</sup> though

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and separation. . . . [S]eparation is the key to entity property . . . ."); Litman, *supra* note 3, at 1299–1300 (discussing problems with free alienability of personal data outside the health context).

<sup>103</sup> See 17 U.S.C. § 201(d)(2) (2012) ("Any of the exclusive rights comprised in a copyright, including any subdivision of any of the rights specified by section 106, may be transferred . . . and owned separately."). Thus, a copyrighted book may be licensed separately in different geographical regions, for distribution in hardcover, paperback, and audiobook forms, for translation into different languages, for use in film and television, and in product and apparel merchandising.

<sup>104</sup> See, e.g., Cohen, *supra* note 3, at 1428–29 (proposing a property interest in personal information resembling copyright protection); Schwartz, *supra* note 3, at 2094–98 (2004) (proposing limited "hybrid inalienability" for personal information); see also Baron, *supra* note 40, at 382–83 (discussing Schwartz and Cohen proposals).

<sup>105</sup> 264 F. Supp. 2d 1064, 1075 (S.D. Fla. 2003).

<sup>106</sup> See *Havasupai Tribe v. Ariz. Bd. of Regents*, 204 P.3d 1063, 1066 (Ariz. Ct. App. 2008), discussed in Contreras, *supra* note 42, at 22–23.

<sup>107</sup> See *Beleno v. Lakey*, 306 F. Supp. 3d 930, 936–37 (W.D. Tex. 2009), discussed in Contreras, *supra* note 42, at 21–22.

<sup>108</sup> For example, in the Alzheimer's Disease Sequencing Project (ADSP) hosted on dbGaP, there are six different "consent groups" with different usage restrictions, including use solely for Alzheimer's Disease research, research on any neurodegenerative diseases, any research conducted by nonprofit entities, any health/medical/biomedical purposes, and purposes excluding the study of population origins or ancestry. NAT'L INST. ON AGING GENETICS OF ALZHEIMER'S DISEASE DATA STORAGE SITE, CONSENT LEVEL GUIDELINES 1 (2019).

the effectiveness of these restrictions, which have no practical means of monitoring or enforcement, is questionable.<sup>109</sup> Today, however, data intermediaries seek to enable this type of divisibility through the Blockchain, allowing individuals to specify, on a case-by-case basis, the permitted uses for their IHI—a technological approach that could well succeed.<sup>110</sup>

But even if technologically feasible, the infinite divisibility of IHI uses poses both practical and ethical challenges. At a practical level, restricting the use of IHI to particular types of studies limits both the value of the data for research and the capacity for broad-ranging investigation and discovery. Researchers, let alone consumers, have little idea what new avenues of research will emerge from existing studies, and constraining the use of data to only one disease category or metabolic pathway could handicap future research.<sup>111</sup> Moreover, the selective exclusion of certain research areas from data usage permissions has the potential to bias research and skew results (so-called “consent bias”).<sup>112</sup>

In a more pernicious vein, allowing individuals to exercise autonomy by selecting permitted uses of their IHI can lead to both implicit and explicit discrimination. For example, should individuals who harbor animus toward members of particular population groups (e.g., based on race, ethnicity, gender, or sexual orientation) be permitted to exclude the use of their IHI in research or public health interventions beneficial to those groups? To put it more bluntly, should a homophobe be permitted to allow the licensing of his or her IHI for research on cancer, but not on HIV? Should a racist be permitted to allow research on melanoma, but not on Tay-Sachs disease (which disproportionately affects Jewish populations)?<sup>113</sup> From the

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<sup>109</sup> See Jorge L. Contreras, *Leviathan in the Commons: Biomedical Data and the State*, in *GOVERNING MEDICAL KNOWLEDGE COMMONS*, 19, 31–32 (Katherine J. Strandburg, Brett M. Frischmann & Michael J. Madison eds., 2017) (questioning the effectiveness of NIH policing and enforcement of policies regarding dbGaP).

<sup>110</sup> See Kish & Topol, *supra* note 19; Roberts, Pereira & McGuire, *supra* note 16, at 19. As long ago as 2010, a governmental advisory panel encouraged the development of data “tagging” technology that would enable individuals to embed elements of their health records with privacy and usage preferences. PRESIDENT’S COUNCIL OF ADVISORS ON SCI. AND TECH., *REALIZING THE FULL POTENTIAL OF HEALTH INFORMATION TECHNOLOGY TO IMPROVE HEALTHCARE FOR AMERICANS: THE PATH FORWARD* 78 (2010).

<sup>111</sup> For example, considering the Alzheimer’s data discussed in note 108, *supra*, data tagged for use only in Alzheimer’s research could not be used for cardiac research if, years later, a link were discovered between genetic markers for Alzheimer’s and heart disease.

<sup>112</sup> See Contreras, *supra* note 42, at 30, 46 (reviewing literature on consent bias); Roberts, *supra* note 5, at 1141 (same).

<sup>113</sup> While prohibitions could be put in place to prevent blatant attempts to discriminate against protected classes, such prohibitions would be difficult to manage if expressed in terms of medical conditions, rather than racial, ethnic, or religious categories.

standpoint of social justice, enabling such discrimination would be abhorrent, no matter how deeply individuals desire to exercise their autonomy in this regard.

### B. Valuation and Compensation

Closely associated with the right to alienate one's property is the right to be paid for it.<sup>114</sup> Indeed, as discussed in the Introduction, charging for the use of IHI appears to be one of the driving forces behind recent efforts to propertize IHI. Yet difficult questions emerge regarding the amount of consideration that can, or should, be charged for IHI. It is often the huge disparity between what unwitting research subjects receive (nothing) and the profits generated from discoveries enabled by their tissue and IHI that shapes popular attitudes toward compensation for medical discoveries. Among the issues on which the media focused in the story of Henrietta Lacks was the total absence of compensation to Lacks's descendants in view of the huge profits earned by companies commercializing her cell line.<sup>115</sup> But, of course, even if Henrietta Lacks had been capable of negotiating with her physicians over the use of her cells, neither she nor they would have had any way of knowing their true value *ex ante*.<sup>116</sup>

It is this uncertainty regarding the value of any individual element of IHI that makes proposed transactional systems questionable. Because the true value of an individual's IHI will often remain unknown until years after the contribution, the vast majority of IHI elements will simply be tiny pieces of a huge, population-wide mosaic.

For these reasons, no individual with disproportionately valuable IHI can realistically hope to receive its true value up-front. Thus, if an individual wishes to share in the profits of a blockbuster drug or the next HeLa cell line, he or she will require some form of profit sharing or "reach-through" royalty arrangement<sup>117</sup> with downstream users

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<sup>114</sup> Of course, having a property interest in something is not a strict requirement for being compensated for its use. Issues of compensation could just as easily arise in connection with an individual's conditional consent to provide a blood sample to a data gathering company. However, given the emphasis placed by the new crop of data intermediaries on compensating individuals for "their" data, this discussion is an important part of the overall propertization picture.

<sup>115</sup> Matthew C. Nisbet & Declan Fahy, *Bioethics in Popular Science: Evaluating the Media Impact of the Immortal Life of Henrietta Lacks on the Biobank Debate*, 14 *BMC MED. ETHICS* 1, 5–6 (2013) (noting that seventy-two percent of media accounts analyzed described compensation as an ethical issue in the Lacks story).

<sup>116</sup> In fact, the unique "immortal" character of her cells was only discovered accidentally, and never mentioned to Lacks during her lifetime. See SKLOOT, *supra* note 7, at 40–42, 89–107.

<sup>117</sup> Reach-through royalties are contractual arrangements under which the owner of a patented research tool (e.g., a reagent or molecular probe) seeks to collect royalties on

(pharmaceutical and medical device manufacturers, healthcare providers, etc.).<sup>118</sup> Yet pharmaceutical manufacturers and biotech companies have, by and large, proven unwilling to pay reach-through royalties even to the developers of groundbreaking research tools.<sup>119</sup> It thus seems unrealistic to expect that these firms will commit to make reach-through payments to data intermediaries or millions of individual IHI owners when the contribution of any given element of IHI to an eventual drug or biomedical product is likely to be minuscule, difficult to track, and many years away.<sup>120</sup>

In this scenario, the result of IHI proprietization is likely to be the distribution of trivial payouts to a large number of individuals,<sup>121</sup> while the new data intermediaries profit through the collection of transaction fees.<sup>122</sup> And the estimated multi-billion-dollar global “market” in IHI?<sup>123</sup> A steep new tax on biomedical research and drug development that will most likely be passed along to the consumer in the form of higher healthcare costs.<sup>124</sup>

What’s more, participation in the IHI marketplace is not mandatory. Every individual will be able to decide whether or not the fees offered for sharing her IHI adequately compensate her for the

discoveries made using the research tool, but which are not themselves covered by the patents on the tool. See Alfred C. Server, Nader Mousavi & Jane M. Love, *Reach-Through Rights and the Patentability, Enforcement, and Licensing of Patents on Drug Discovery Tools*, 1 HASTINGS SCI. & TECH. L.J. 21, 23 (2009).

<sup>118</sup> Data intermediaries such as Invitae are reported to have offered to share their profits with individual IHI owners. See Roberts, Pereira & McGuire, *supra* note 16, at 18. However, such profit sharing will not result in a windfall to the individual unless the intermediary has a profit sharing arrangement with its data customer (the pharmaceutical manufacturer or healthcare vendor), which, as discussed above, seems unlikely.

<sup>119</sup> See, e.g., Fiona Murray, *The Oncomouse that Roared: Hybrid Exchange Strategies as a Source of Distinction at the Boundary of Overlapping Institutions*, 116 AM. J. SOC. 341, 361–68 (2010) (describing DuPont’s failure to extract reach-through royalties on the Harvard-invented oncomouse).

<sup>120</sup> One notable, but small, exception is PXE International (PXEI), a patient advocacy group that uses contractual mechanisms (not property law) to ensure that contributors of DNA and tissue samples are compensated for their use. See Sharon F. Terry et al., *Advocacy Groups as Research Organizations: The PXE International Example*, 8 NATURE REV. GENETICS 157, 157 (2007).

<sup>121</sup> See Brown, *supra* note 17 (noting the meager payouts offered by health data companies).

<sup>122</sup> See Cutler, *supra* note 10 (“[A]ny flat compensation would likely not be very much . . .” (quoting Hank Greely, director of Stanford University’s Center for Law)); Roberts, Pereira & McGuire, *supra* note 16, at 19 (“[T]he most equitable compensation model would be to pay each person equally for sharing data.”); see also Angrist, *supra* note 14, at 45; *supra* notes 27–28 and accompanying text.

<sup>123</sup> See Merken & Elfin, *supra* note 10.

<sup>124</sup> See Cohen, *supra* note 3, at 1388 (“[D]ata privacy opponents argue that increased protection would impose unreasonable costs on routine consumer transactions—costs that consumers themselves ultimately will have to bear.”).



attendant loss of privacy. And if every IHI owner receives the same modest fee for her data, then the wealthier the individual, the more likely she is to forego the payment and retain her data as private. The result would be a skewing of collected IHI toward lower-income individuals (i.e., those who value the modest fee more highly than their privacy). This skewing has the potential both to distort the results of IHI research and also to target disadvantaged communities unfairly.<sup>125</sup>

### C. *The Silent Majority—Unstewarded Data*

If a personal property interest in IHI is recognized, it would presumably be recognized with respect to everyone, whether or not they have appointed a data intermediary or downloaded an IHI app. At the outset, and even over the long term, it is likely that only a fraction of the population will avail itself of the technological means to control and convey their IHI. A significant segment of the population (probably skewed toward lower socioeconomic status and educational attainment) could thus lack the means to authorize the use of their IHI and thereby profit from it.<sup>126</sup>

Today, as patients have no property interest in IHI, healthcare providers are free to convey this “unstewarded” information to biomedical researchers and public health officials at their discretion, subject to applicable privacy and research regulations.<sup>127</sup> In a world of propertized IHI, however, this flexibility will disappear. Any unauthorized conveyance of IHI would constitute a conversion. Thus, under a propertized IHI regime, far less information could be available for research and public health uses. The data gaps arising from such selection bias could skew research results and prevent findings relevant to omitted populations.<sup>128</sup>

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<sup>125</sup> Professor Richard Posner poses a similar scenario in arguing that the Bureau of the Census should not be required to purchase information from the general populace, and that data should not be owned by individuals more generally. Richard A. Posner, *The Right of Privacy*, 12 GA. L. REV. 393, 397–98 (1978).

<sup>126</sup> See, e.g., Megan Pricor, Harriet J.A. Teare & Jane Kaye, *Equitable Participation in Biobanks: The Risks and Benefits of a “Dynamic Consent” Approach*, FRONTIERS PUB. HEALTH (Sept. 5, 2018), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6133951> (noting that participants in biomedical research are generally biased toward “white, middle-class, higher-educated people in most Western countries, to the exclusion of indigenous groups, the socially-disadvantaged and the culturally and linguistically diverse”).

<sup>127</sup> For example, the HIPAA Privacy Rule contains strict limitations on a healthcare provider’s ability to disclose or share personally identifiable health information. 45 C.F.R. §§ 160, 164 (2012).

<sup>128</sup> See INST. OF MED., BEYOND THE HIPAA PRIVACY RULE: ENHANCING PRIVACY, IMPROVING HEALTH THROUGH RESEARCH 209 (Sharyl J. Nass et al. eds., 2009) (discussing selection bias arising from individual unwillingness to consent to research); Contreras,

### D. Perpetual Duration

As a general matter, property lasts forever. A chattel retains its character as *somebody's* property so long as it exists. As IHI is relatively indestructible and difficult to abandon, propertized IHI would, absent some statutory limitation,<sup>129</sup> have perpetual duration.

A perpetual IHI property right could be problematic in a number of ways. First, a particular datum may exist within the research establishment for a long time. For example, researchers in the 1950s collected data regarding the effects of radiation exposure on survivors of the Hiroshima and Nagasaki nuclear detonations.<sup>130</sup> This data has been used for decades in countless studies and radiation safety assessments.<sup>131</sup> Studies cite and build upon one another. It is unlikely that researchers conducting a radiation study today could point to any specific use of original Hiroshima data, yet prior generations of studies upon which they may rely undoubtedly made use of this original data. Is the expectation of today's data propertization proponents that original data owners (and their heirs) would continue to profit from work done generations after an initial study was completed? The difficulty of tracking this data through successive generations of studies that do not make use of primary data, but instead rely on prior studies' results and conclusions, is mind-boggling.

The degree of complexity increases with respect to population and epidemiological studies. For example, a nationwide study of lung cancer incidence would involve health data not only from lung cancer patients, but also from unaffected individuals (control groups).<sup>132</sup> An entire population is implicated in many such studies.<sup>133</sup> Is the expectation that every person, ill or healthy, who "contributed" to the scientific understanding of a particular disease or condition profit in some way from the result of such studies (e.g., a lung cancer treatment developed decades later)? Because traditional property interests do not disappear even as they become smaller parts of the overall data, the complexity involved in such an undertaking could be intractable.

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*supra* note 42, at 30–31 (noting the impact of selection bias on underrepresented communities).

<sup>129</sup> See *infra* Section III.A.2 (discussing potential durational limitations for IHI property).

<sup>130</sup> See Yukiko Shimizu et al., *Radiation Exposure and Circulatory Disease Risk: Hiroshima and Nagasaki Atomic Bomb Survivor Data, 1950-2003*, *BMJ*, Jan. 14, 2010, at 1.

<sup>131</sup> See, e.g., *id.*

<sup>132</sup> See Patricia M. de Groot, *The Epidemiology of Lung Cancer*, 7 *TRANSLATIONAL LUNG CANCER RES.* 220 (2018) (detailing a national study of lung cancer in the United States).

<sup>133</sup> See, e.g., *id.*

### *E. Orphan Data and the Dead Hand*

The survival and inheritance of property after the original owner's death exacerbate the problems inherent in a perpetual form of property. That is, unless the proposed rules regarding IHI terminate ownership at the death of the original data subject,<sup>134</sup> rights in a deceased individual's IHI would naturally flow to his or her estate. Does each of a decedent's heirs succeed to an undivided joint ownership interest in the decedent's IHI? Given the intangible nature of this property, how will they even know what property they have inherited? If the task of identifying and managing this inherited property is difficult for the decedent's heirs, it is even more difficult for the many hospitals and research institutions that will use that information (e.g., if the decedent happened to be part of that nationwide lung cancer study). How would a drug company that sought to develop a lung cancer therapy identify, let alone compensate, the scattered heirs of every individual counted in the study? This problem is akin to that experienced with "orphan" works—books and other copyrighted materials that are old but still covered by copyright, and as to which the copyright owner(s) cannot be located.<sup>135</sup> These works, which are often out of print and difficult to obtain, languish in a no-man's land in which they cannot be reprinted or digitally reproduced and are thus excluded from the store of human knowledge.<sup>136</sup>

Even more challenging is the original (deceased) owner's right to exercise control over the use of his or her IHI after death. This is the traditional property law issue of "dead hand" control—the ability of deceased property owners to dictate, either through a will or trust instrument, how their property may be used long after their deaths.<sup>137</sup> Today, this type of control has gradually crept into policies regarding certain types of IHI. For example, donors of tissue, DNA, and genetic data may have limited rights through the exercise of informed consent to control and limit the use of these resources after death.<sup>138</sup> The

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<sup>134</sup> See *infra* Section III.A.2 (describing fixed durations for IHI).

<sup>135</sup> See U.S. COPYRIGHT OFFICE, ORPHAN WORKS AND MASS DIGITIZATION: A REPORT OF THE REGISTER OF COPYRIGHTS (2015).

<sup>136</sup> See Olive Huang, *U.S. Copyright Office Orphan Works Inquiry: Finding Homes for the Orphans*, 21 BERKELEY TECH. L.J. 265, 265 (2006).

<sup>137</sup> See, e.g., LEWIS M. SIMES, PUBLIC POLICY AND THE DEAD HAND 2 (1955).

<sup>138</sup> The National Institute of Health's (NIH) 2014 Genomic Data Sharing (GDS) policy provides that individual consent is required in connection with research conducted on any human genetic material obtained using NIH funding, whether or not the data is anonymized, and whether the donor is living or deceased. See Final NIH Genomic Data Sharing Policy, 79 Fed. Reg. 51,345, 51,347 (Aug. 28, 2014); see also Jorge L. Contreras, *NIH's Genomic Data Sharing Policy: Timing and Tradeoffs*, 31 TRENDS GENETICS 55, 55 (2015). Some state informed-consent laws and institutional ethical guidelines regarding informed consent also impose requirements regarding deceased individuals. See NAT'L

National Bioethics Advisory Commission has opined that if an individual restricts the use of his or her genetic material while alive, those restrictions should continue to apply after death.<sup>139</sup> The recognition of traditional common law property rights in IHI would extend this dead-hand control to all IHI, creating significant barriers to data reuse even when new applications or research avenues are discovered.

### III

#### POTENTIAL LIMITATIONS AND EXCEPTIONS FOR IHI PROPERTY

As discussed in Part II above, the application of a traditional personal property regime to IHI could result in a range of unexpected and undesirable consequences: taxing administrative systems and yielding negligible financial benefits to individuals, while increasing healthcare costs and potentially stifling biomedical research and public health monitoring. Nevertheless, property theorists might dismiss these threats as illusory—property need not impose such burdens if it is suitably limited and constrained. After all, “property” today is a flexible concept rife with limitations, exceptions, and exclusions.<sup>140</sup> Newer property systems, such as those developed under federal statutes governing patents and copyrights, as well as judicially crafted limitations and exceptions to common law property regimes, contain a broad range of modifications to an absolute conception of property. These are broadly referred to as “limitations and exceptions.”<sup>141</sup> Such limitations and exceptions could conceivably be applied to a new property system for IHI—either through statutory enactment or judicial decisionmaking—to mitigate the worst effects of “long and strong” property protection described in Part II. This Part considers the nature and viability of such limitations and exceptions in the context of propertized IHI.

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BIOETHICS ADVISORY COMM’N, RESEARCH INVOLVING HUMAN BIOLOGICAL MATERIALS: ETHICAL ISSUES AND POLICY GUIDANCE 29 (1999).

<sup>139</sup> See NAT’L BIOETHICS ADVISORY COMM’N, *supra* note 138, at 49. See generally Contreras, *supra* note 42, at 26–27 (discussing dead-hand control over genetic material and data).

<sup>140</sup> See Kevin Gray & Susan F. Gray, *Private Property and Public Propriety*, in PROPERTY AND THE CONSTITUTION 11, 15 (Janet McLean ed., 1999) (“The ideology of property as uncontrolled exclusory power is nowadays just as untenable as is the dichotomous distinction between the domains of the private and the public.”); Wyman, *supra* note 49, at 186–87 (arguing that a contemporary theory of property is “malleable”).

<sup>141</sup> See, e.g., COPYRIGHT LAW IN AN AGE OF LIMITATIONS AND EXCEPTIONS 11–15 (Ruth L. Okediji, ed., 2017) (defining limitations and exceptions and giving a broad overview of their significance).

### A. *General Limitations and Exceptions Borrowed from IP Law*

Limitations and exceptions to the scope and effect of property rights exist in many areas of property law, particularly intellectual property.<sup>142</sup> Although IHI does not easily fit into any existing category of intellectual property, certain limitations and exceptions that exist under various intellectual property regimes may be useful to consider when fashioning a property regime for IHI.

#### 1. *Fixation—Limiting IHI Property to Medical Records*

As discussed in Section I.A.1, defining the moment when an element of IHI is created can be difficult. One simplifying approach may be borrowed from copyright law, which requires that a work of authorship be fixed in a tangible medium before a copyright is recognized in it.<sup>143</sup> Under this reasoning, propertized IHI could be limited to information that is recorded, most likely in an individual's medical record.<sup>144</sup> Such a fixation requirement would address some of the complexities that arise when trying to define IHI with sufficient precision. In fact, several commentators who have considered the propertization of IHI have focused largely on ownership and control of electronic medical records.<sup>145</sup>

But should the existence of an external artifact be the crucial factor in determining whether IHI is property? What is a medical record after all? In the traditional sense, it is a manila folder with a multicolored label that resides in a doctor's filing cabinet. Today, most of these folders are electronic and housed in a central server run by a health maintenance organization (HMO) or health plan. But what about the heart rate and activity records measured by a Fitbit device and stored in the "cloud"? Or the daily record that one keeps of her caloric intake, jogging regimen, or blood pressure? Or the prescription records generated by a local pharmacy? Or the DNA markers identi-

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<sup>142</sup> See, e.g., Daniel J. Gervais, *Making Copyright Whole: A Principled Approach to Copyright Exceptions and Limitations*, 5 U. OTTAWA L. & TECH. J. 1, 3 (2008) (detailing the history of limitations and exceptions in copyright at the international level).

<sup>143</sup> See *supra* note 78 and accompanying text.

<sup>144</sup> Professor Yaniv Heled has suggested, as an alternative, that IHI could be recognized as an element of property once reduced to a form in which it may be communicated to others—an "articulability" requirement. Thus, one's temperature would not become an element of IHI property until measured by some means that would allow it to be communicated to another person, which might be earlier than it is recorded in a recognized medical record. E-mail from Yaniv Heled, Assoc. Professor of Law, Ga. State Univ. Coll. of Law, to author (Apr. 26, 2019) (on file with the author).

<sup>145</sup> See, e.g., Kish & Topol, *supra* note 19, at 922 (discussing ownership and control of medical records); Baron, *supra* note 40, at 369–70 (analyzing the roles of ownership and control vis-à-vis medical records); Rodwin, *supra* note 43, at 593 (same).

fied by a direct-to-consumer genomic testing company like 23andMe or AncestryDNA? Or the chemical reaction that occurs within a home pregnancy kit? Is all of this information part of a medical record? Is it property?

Under copyright law, the fixation requirement is said to be necessary “because only fixed works are at risk of misappropriation by copying.”<sup>146</sup> Copyrighted works must thus be fixed “to ‘eas[e] problems of proof of creation and infringement.’”<sup>147</sup> These considerations do not seem particularly relevant to IHI, and the imposition of a fixation requirement on proptertized IHI seems to draw a somewhat arbitrary distinction between data that, in the eye of the individual, is otherwise the same.

What’s more, the imposition of a requirement that IHI be fixed in a tangible medium to be recognized as property, while making IHI property more tractable, also cuts against the moral and intuitive bases for proptertizing IHI in the first place. That is, if an individual’s claim to own information about herself arises from principles of autonomy and self-actuation, why should it matter whether or not that information is fixed in a tangible artifact?

## 2. *Limited Duration*

As discussed above in Section II.D, additional problems with treating IHI as personal property arise from the perpetual duration of personal property. These problems include dead-hand control, difficulties of administering inherited IHI, and the diminishing value of IHI over time. However, it might be possible to mitigate some of these issues if IHI property were given a finite and limited duration, as are many forms of intellectual property.

Under the federal statutes that authorize them, patents last for twenty years from the date of filing,<sup>148</sup> while copyrights in works made for hire have durations of ninety-five years and those in other works last for the life of the author plus seventy years.<sup>149</sup> The right of publicity under state law, which gives an individual the exclusive right to exploit his or her persona commercially, is extinguished in many states either upon death or the passage of a particular time period.<sup>150</sup> Like

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<sup>146</sup> See Evan Brown, *Fixed Perspectives: The Evolving Contours of the Fixation Requirement in Copyright Law*, 10 WASH. J.L. TECH. & ARTS 17, 18 (2014).

<sup>147</sup> *Kim Seng Co. v. J & A Importers, Inc.*, 810 F. Supp. 2d 1046, 1051, 1054 (C.D. Cal. 2011).

<sup>148</sup> 35 U.S.C. § 154 (2012).

<sup>149</sup> 17 U.S.C. § 302 (2012).

<sup>150</sup> See JENNIFER E. ROTHMAN, *THE RIGHT OF PUBLICITY: PRIVACY REIMAGINED FOR A PUBLIC WORLD* 3 (2018).

these rights, IHI property could also be given a defined duration based on the life of the individual or some other measure. Such a limited duration would eliminate at least some of the administrative complexities raised by the inheritance of IHI property from one generation to the next though, like many of the limiting proposals made here, would also limit the compensation that would be received for use of that IHI.<sup>151</sup>

### 3. *Exhaustion and First Sale*

The doctrines of patent exhaustion and copyright first sale provide that the use and sale of patented articles and copies of copyrighted works may not be restricted after the first authorized sale of such articles and works.<sup>152</sup> By the same token, some form of exhaustion could be imposed on IHI property so that after the initial “sale” of data by the individual or his or her intermediary, further rents could not be charged on downstream uses of that data. Such a limitation would facilitate downstream scientific research using data that has already entered the “stream of commerce,” as further consent would not be required from the individual IHI owner. Like limitations on the duration of IHI property, exhaustion may limit the compensation payable with respect to IHI over time.

#### B. *IHI-Specific Limitations and Exceptions*

The unique nature of IHI suggests that additional limitations and exceptions could be imposed on IHI property.

##### 1. *Prohibitions on Compensation*

Even if IHI is property, it is not a foregone conclusion that it should be sold on the open market. As observed by Judge Mosk, dissenting in *Moore v. Regents*, “some types of personal property may be sold but not given away, while others may be given away but not sold, and still others may neither be given away nor sold.”<sup>153</sup> And as law professor Neil Richards recently commented about personal data, “Not everything works better when we put dollar . . . figures on it.”<sup>154</sup>

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<sup>151</sup> In addition, the expiration of IHI property upon death would remove pathology and autopsy findings from the scope of the property right, again leading to inconsistent treatment of data and recordkeeping and tracking challenges.

<sup>152</sup> See *Impression Prods., Inc. v. Lexmark Int'l Inc.*, 137 S. Ct. 1523, 1535 (2017) (patent exhaustion); *Kirtsaeng v. John Wiley & Sons, Inc.*, 568 U.S. 519, 524–25 (2013) (copyright first sale).

<sup>153</sup> *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 510 (1990) (Mosk, J., dissenting).

<sup>154</sup> Cutler, *supra* note 10 (quoting Washington University School of Law Professor Neil M. Richards).

Thus, while several state and federal statutes recognize individual property rights in human body parts,<sup>155</sup> they also restrict an individual's right to sell (but not to donate) them.<sup>156</sup> Likewise, individuals may not sell themselves into slavery. Pregnant women may not sell their fetuses. And payments to healthy "volunteers" who participate in medical experimentation must remain modest so as not to exert undue influence over their willingness to participate.<sup>157</sup> Thus, the compensation that individuals may receive for the exercise of property-like rights with respect to their bodies and persona is regulated in a variety of contexts and could also be limited in the case of IHI. Such pecuniary restrictions, of course, would eliminate the incentive motivating many of the aspiring data intermediaries mentioned above in the Introduction.

## 2. *Limiting Rights to Exclude After De-Identification*

Others have proposed recognizing an individual property interest only in IHI that is personally identifiable—in other words limiting individual rights to exclude with respect to IHI after it has been "de-identified" or "anonymized."<sup>158</sup> This approach could limit the impact of IHI propertization on socially beneficial research and public health activity, as it would allow public use of de-identified information (most biomedical research does not require knowledge of an individual's name or address).

However, eliminating individual ownership of non-identifiable IHI somewhat defeats the purpose of the propertization proposition, as it would prevent individuals from being paid for the use of their data in some of its most lucrative applications (e.g., drug discovery).

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<sup>155</sup> This was not always the case, and does not apply to all body parts or in all contexts. See, e.g., LORI ANDREWS & DOROTHY NELKIN, *BODY BAZAAR: THE MARKET FOR HUMAN TISSUE IN THE BIOTECHNOLOGY AGE* (2001) (providing examples of cases where courts have determined that individuals did not have a property interest in biological materials that had been separated from their body); Alix Rogers, *Owning Geronimo But Not Elmer McCurdy: The Unique Property Status of Native American Remains*, 60 B.C. L. REV. (forthcoming 2019) (manuscript at 35–36) (on file with author) (discussing how remains of Native Americans were deemed property of the federal government under the Antiquities Act of 1906).

<sup>156</sup> See National Organ Transplant Act, 42 U.S.C. § 274e (2012); National Conference of Commissioners on Uniform State Laws, Revised Uniform Anatomical Gift Act (2006).

<sup>157</sup> See U.S. Food & Drug Admin., *Payment and Reimbursement to Research Subjects - Information Sheet*, <https://www.fda.gov/RegulatoryInformation/Guidances/ucm126429.htm> (last visited Apr. 18, 2019) ("Other than reimbursement for reasonable travel and lodging expenses, IRBs should be sensitive to whether other aspects of proposed payment for participation could present an undue influence, thus interfering with the potential subjects' ability to give voluntary informed consent. Payment for participation in research should be just and fair.").

<sup>158</sup> See Hall, *supra* note 24, at 661.



What's more, there is little theoretical justification for altering the property status of an element of IHI based on whether or not it can be traced back to an individual, particularly given both continuing advances in technology that make the re-identification of individuals from genetic data increasingly feasible<sup>159</sup> and the recognition that identifiable data (i.e., that which is informed by the full panoply of a subject's phenotypic and demographic characteristics) is often more valuable for research than aggregate or anonymized data.<sup>160</sup> This type of limitation thus seems to be of limited value.

### 3. *Authorizing the Use of Orphan IHI*

As discussed above in Section II.E, IHI that cannot be traced to a particular owner—"orphan" IHI—could be condemned to a state of limbo in which it is not usable because the owner is not available to consent to its use. The difficulties that orphan IHI could present to both biomedical research and public health monitoring are substantial. To mitigate this problem, several measures could be adopted. First, a legal rule could be established simply to permit the use of orphan IHI for specified purposes (e.g., research and public health).<sup>161</sup> Second, more discretionary licensing of orphan IHI could be managed by the government, possibly on a royalty-bearing basis with funds set aside for eventual claims by IHI owners.<sup>162</sup> In both cases, the potential user could be required to use reasonable efforts to identify the owner of the IHI.<sup>163</sup>

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<sup>159</sup> See Contreras, *supra* note 42, at 34 ("Perhaps the most critical shortcoming of deidentified data exceptions is the growing realization that true deidentification of genetic data may, in fact, be difficult or impossible to achieve."); Jennifer Couzin-Frankel, *Trust Me, I'm a Medical Researcher*, 347 SCIENCE 501, 502 (2015) (discussing increasing technological capability to re-identify individuals from DNA data).

<sup>160</sup> See Lisa M. Austin & David Lie, *Safe Sharing Sites*, 94 N.Y.U. L. REV. (forthcoming 2019) (manuscript at 6) ("[S]trategies to mitigate the risk of re-identification affect the accuracy of the data.").

<sup>161</sup> See, e.g., U.S. COPYRIGHT OFFICE, *supra* note 135, at 47–48 (discussing exception-based usage of orphan works). Cf. James Boyle, *(When) Is Copyright Reform Possible?*, in COPYRIGHT LAW IN AN AGE OF LIMITATIONS AND EXCEPTIONS 206, 222–25 (Ruth L. Okediji, ed., 2017) (describing proposal in European Union to permit certain uses of orphan works).

<sup>162</sup> See, e.g., U.S. COPYRIGHT OFFICE, *supra* note 135, at 48–49 (discussing government licensing model). Cf. Boyle, *supra* note 161, at 222–25 (describing proposal in Europe to allow limited licensing).

<sup>163</sup> See, e.g., U.S. COPYRIGHT OFFICE, *supra* note 135, at 56–59 (discussing "good faith diligent search" for authors of orphaned works); Boyle, *supra* note 161, at 223 (proposing a diligent search for authors of orphaned works "scale[d]" to the nature of the project involved").

#### 4. *Public Health Exceptions*

Because IHI plays a critical role in public health monitoring and intervention, it would be reasonable to permit public health authorities to use IHI (not just orphan IHI, as discussed above, but all IHI) without the express permission of the owner under certain circumstances. The circumstances under which such a public health exception would apply could range from emergency situations (e.g., tracking outbreaks of infectious diseases or food-borne illnesses) to any public health activity (e.g., national health surveys or broad epidemiological studies) to any legitimate public or private health-related research. Along this spectrum, one would expect increasing resistance from propertization advocates to exceptions that permitted private sector pharmaceutical companies to profit from research on IHI without the consent of (and payment to) IHI owners. However, excluding such private sector researchers from this exemption could hinder socially beneficial research. Moreover, it could further disempower, and result in worsened health outcomes for, disadvantaged communities and individuals who lack the expertise, desire, or wherewithal to control the use of their IHI. Thus, if IHI is to become a form of property, the broadest possible public health exceptions should be recognized.

#### C. *Other Regulation of IHI Property*

Sections II.A and II.B above discuss the imposition of different limitations on the scope and enforceability of IHI property, overcoming some of the problems (social welfare, efficiency, and administrability) that might be caused by the recognition of unrestricted property rights in IHI. In addition to these limitations and exceptions, it might also be possible to impose rules about the use of IHI property that do not directly affect its character as property but which also seek to overcome some of these problems.

In some cases, these regulations already exist. For example, the Genetic Information Nondiscrimination Act of 2008 (GINA) prohibits discrimination based on individual genetic data by certain employers and health insurers.<sup>164</sup> While the scope of GINA is not all-encompassing, it is a good first step toward preventing abuse of IHI by potential users.<sup>165</sup> In addition, in response to the issue of unstewarded IHI,<sup>166</sup> the government could appoint a data steward or ombudsman

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<sup>164</sup> Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 2(5), 122 Stat. 881, 882–83 (2008) [hereinafter GINA] (codified as amended in scattered sections of 29 and 42 U.S.C.).

<sup>165</sup> For potential expansions of GINA, see Contreras, *supra* note 42, at 45–46.

<sup>166</sup> See *supra* Section II.C.

to represent the interests of individuals who fail to appoint a data agent or representative.<sup>167</sup> Ancillary measures such as these, together with the limitations and exceptions to IHI property discussed in Sections III.A and III.B above, could mitigate some of the worst effects of IHI propertization.

#### IV AGAINST IHI PROPERTY

While each of the measures described above in Part III could alleviate problems caused by property-based systems for IHI, each of them could also be said to move the proposed system from a pure property regime toward a system of governmental regulation.<sup>168</sup> For example, limiting the alienability of certain forms of property is possible, but, as noted by Baron, “the resulting powers retained by owners might not have the consolidated, *in rem* qualities that, in the eyes of some property theorists, make property distinct.”<sup>169</sup> While an absolutist version of property is clearly not required in order for property rules to operate effectively, the creation of a new form of property that is at the outset subject to a raft of limitations and exclusions raises the question whether its treatment as property is actually needed. As Jessica Litman argued nearly two decades ago, recognizing a property interest in personal data would offer no more than “illusory protections.”<sup>170</sup>

More importantly, property is a powerful legal construct that, even with enumerated limitations and exceptions, confers on its owners a host of rights and powers developed over centuries. While this Article has sought to identify some of the most obvious ways in which propertized IHI might cause social harm, systemic inefficiency, and administrative headaches, it cannot predict every potential problem that will occur down the road. Thus, the limitations and exceptions proposed here, even if adopted one and all, cannot guarantee that propertized IHI will operate as expected, or in the public interest. The creation of a new property system *sui generis*, with all of

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<sup>167</sup> Cf. U.S. COPYRIGHT OFFICE, *supra* note 135, at 48–49 (discussing potential governmental representatives for orphan copyrighted works).

<sup>168</sup> See *United States v. Evans*, 844 F.2d 36, 42 (2d Cir. 1988) (“[T]he line between regulation and property is difficult to draw with scientific precision . . .”).

<sup>169</sup> See Baron, *supra* note 40, at 372, 384 (“It may be that we can create a novel legal regime . . . to deal with the problems particular to information. But at some point, the departure of that regime from existing models of property might raise the question of whether the regime deserves the name ‘property’ at all.”).

<sup>170</sup> Litman, *supra* note 3, at 1302.

the attendant rights associated with property, inherently creates risks of unforeseen consequences.

To use a time-worn analogy, property can be analogized to a bundle of sticks.<sup>171</sup> When a new type of property is created, all of the sticks—the right to exclude, the right to alienate, the right to use, and so on—spring into being. We can eliminate or trim some of these rights and powers at the outset with carefully crafted limitations and exceptions. But even in the best of circumstances, this is a *subtractive* process—we begin with a nearly infinite bundle of sticks and eliminate those that cause systemic harm. But even the most farsighted social planner cannot foresee every possible abuse or inefficiency that could arise as technology and social structures evolve, especially in the fast-moving area of healthcare technology. And once something is defined as property, vested with constitutional protection against further taking by the state, curtailing it further—whether through legislative or judicial pruning—becomes difficult if not impossible.

One need look no further than patent law to appreciate the controversy and legal uncertainty that can be generated when legislative enactments can be construed as taking vested property rights away from their owners without compensation (in this case, the enhanced patent review and revocation procedures introduced under the 2011 America Invents Act<sup>172</sup>). In just a few short years, this debate has resulted in no fewer than two Supreme Court decisions<sup>173</sup> and an outpouring of legal scholarship and commentary.<sup>174</sup> And these issues

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<sup>171</sup> Ownership rights in property are often described as a bundle of rights or, metaphorically, a bundle of sticks, in which each “stick” represents a separate legal entitlement with respect to the property. *See, e.g.*, *Kaiser Aetna v. United States*, 100 S. Ct. 383, 391 (1979) (noting that the right to exclude is “one of the most essential sticks in the bundle of rights that are commonly characterized as property”); THOMAS W. MERRILL & HENRY E. SMITH, *PROPERTY: PRINCIPLES AND POLICIES* 17 (3rd ed. 2017) (“Property is a ‘bundle of rights’ or ‘bundle of sticks.’”); JOHN G. SPRANKLING & RAYMOND R. COLETTA, *PROPERTY: A CONTEMPORARY APPROACH* 25 (2d ed. 2012) (“[P]roperty is often described as a *bundle of rights* or, more informally, a *bundle of sticks*.”).

<sup>172</sup> Leahy-Smith America Invents Act, Pub. L. No. 112-29 (2011) (codified as amended at 35 U.S.C. §§ 311–19, 321–29 (2012)).

<sup>173</sup> *See Oil States Energy Servs., LLC v. Greene’s Energy Grp., LLC*, 138 S. Ct. 1365, 1368 (2018) (“[T]he decision to *grant* a patent is a matter involving public rights—specifically, the grant of a public franchise. Inter partes review is simply a reconsideration of that grant, and Congress has permissibly reserved the PTO’s authority to conduct that reconsideration.” (emphasis in original)); *SAS Institute Inc. v. Iancu*, 138 S. Ct. 1348, 1354 (2018) (holding that when a party challenges multiple claims of an issued patent, the Patent Trial and Appeal Board can either institute review as to all challenged claims or none of them, but not just some of the challenged claims).

<sup>174</sup> *See, e.g.*, Gregory Dolin & Irina D. Manta, *Taking Patents*, 73 WASH. & LEE L. REV. 719 (2016); Camilla A. Hrdy & Ben Picozzi, *The AIA Is Not a Taking: A Response to Dolin & Manta*, 72 WASH. & LEE L. REV. ONLINE 472 (2016); Greg Reilly, *The Constitutionality of Administrative Patent Cancellation*, 23 B.U. J. SCI. & TECH. L. 377 (2017); *see also*

affect only a handful of inventors whose patents have been challenged in administrative proceedings. IHI property, in contrast, would be owned by every individual in the population—creating orders of magnitude more claimants than have been affected by any prior government taking, and making any post-recognition limitation of the scope of IHI practically impossible.

For these reasons, some commentators, including the author, have proposed that, rather than propertizing IHI, we continue to regulate individual health data through a combination of governmental rulemaking designed to protect individual privacy and autonomy, supplemented by individual tort remedies for abuses by researchers and other handlers of IHI.<sup>175</sup> Unlike propertization, this approach is *additive* in nature. Regulations and remedies can be created individually in a tailored manner as needs become apparent, rather than wholesale through the recognition of a generalized IHI property interest.

Fortunately, the principal elements of such a regulatory/liability system already exist. Federal research regulations today impose numerous restrictions on research involving IHI, such as permitting research without the individual's consent only if data has been de-identified.<sup>176</sup> Individual privacy in personal data is protected today both through private tort law remedies<sup>177</sup> as well as agency policing and enforcement.<sup>178</sup> While many feel that existing privacy protection

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Adam Mossoff, *Patents as Constitutional Private Property: The Historical Protection of Patents Under the Takings Clause*, 87 B.U. L. REV. 689 (2007) (discussing the issues before passage of the AIA).

<sup>175</sup> See, e.g., Contreras & Nordfalk, *supra* note 43, at 183 (“[P]roperty rule frameworks are inadequate and inappropriate for the governance of human health data. Instead, we support a combination of regulatory governance coupled, in some circumstances, with private liability remedies.”); Spinello, *supra* note 42, at 41 (“Instead of relying on property rights, privacy and autonomy should be safeguarded by strongly enforced laws that protect genetic information by informed consent and tight regulations governing the disclosure of such information . . . .”); see also Contreras, *supra* note 42, at 39–48 (reviewing existing and potential rules for regulating the use of genetic data); Litman, *supra* note 3 (arguing that tort and regulation approaches are superior to property for the protection of individual data generally).

<sup>176</sup> See 45 C.F.R. §§ 160, 164 (2012); Evans, *Barbarians*, *supra* note 44, at 658 (arguing that many protections sought to be achieved through property law already exist in the regulatory frameworks that govern medical records and research); Leslie E. Wolf et al., *The Web of Legal Protections for Participants in Genomic Research*, 29 HEALTH MATRIX 1, 75 (2019); see also *id.* at 77–90 (discussing state laws protecting medical privacy beyond HIPAA).

<sup>177</sup> See Wolf, *supra* note 176, at 63 (explaining that a violation of HIPAA can form the basis of a state tort law claim).

<sup>178</sup> The U.S. Federal Trade Commission (FTC), which is authorized to police unfair and deceptive business practices, has monitored the collection and use of consumer data by online vendors. See FED. TRADE COMM’N, PRIVACY & DATA SECURITY UPDATE: 2016, at 1 (2017); FED. TRADE COMM’N, PRIVACY ONLINE: FAIR INFORMATION PRACTICES IN THE ELECTRONIC MARKETPLACE 1 (2000).

is not strong enough, numerous proposals have been made to strengthen protection along these lines.<sup>179</sup> Patients whose healthcare providers violate existing norms of professional ethics and care with regard to the treatment and handling of IHI have remedies under state medical practice laws and tort law.<sup>180</sup> Laws such as GINA supplement traditional protections by prohibiting discrimination using genetic data.<sup>181</sup> Access to IHI and even payment for data usage can be achieved through well-understood contractual mechanisms without resorting to property law.<sup>182</sup>

Thus, it is possible to construct legal frameworks based on contract, data privacy, non-discrimination, and research ethics rules that protect core values without the direct application of property law to IHI.<sup>183</sup> And given the complexities and inherent risks in creating a new form of *sui generis* property, this approach may be preferable even to an IHI property regime that appears at the outset to be appropriately limited and constrained.

### CONCLUSION

While the recognition of personal property interests in IHI appeals to notions of individual autonomy, privacy, and distributive justice, the implementation of a workable property system for IHI presents significant challenges. First, IHI does not fit recognized judicial criteria for recognition as personal property, as IHI defies convenient definition, it is difficult to possess exclusively, and the justifications for its exclusive control are at best contested. If IHI property were structured along the lines of traditional common law property, as suggested by propertization advocates, such sweeping and perpetual rights could impose prohibitive costs on socially valuable

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<sup>179</sup> See, e.g., GEORGE J. ANNAS, LEONARD H. GLANTZ & PATRICIA A. ROCHE, *THE GENETIC PRIVACY ACT AND COMMENTARY* 66 (1995) (proposing legislation to enhance genetic privacy); Clayton et al., *supra* note 1, at 7–10 (concluding that existing legal privacy protections are inadequate and should be enhanced); Roche & Annas, *supra* note 1, at 393 (describing the need for greater privacy protection for genetic information).

<sup>180</sup> See, e.g., *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 502 (1990) (holding that physician violated fiduciary duties to patient by exploiting tissue samples and data without consent); Litman, *supra* note 3, at 1310–12 (discussing the use of tort law to achieve privacy protection); Jessica L. Roberts, *Genetic Conversion* (Mar. 15, 2019) (working draft), [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=3357566](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3357566) (discussing *Moore* and fiduciary claims).

<sup>181</sup> GINA, *supra* note 164; see also Contreras, *supra* note 42, at 45 (discussing the expansion of GINA as one of several alternatives to propertization of IHI).

<sup>182</sup> See *supra* note 120 (discussing contractual approach taken by PXEI); Reichman & Uhlir, *supra* note 73 (describing how contractual mechanisms can serve to limit use of data).

<sup>183</sup> For a detailed discussion of specific remedies arising from these forms of liability, see Contreras & Nordfalk, *supra* note 43.

research and public health activity and result in an unmanageable system that would not address many of the autonomy and distributional concerns fueling the drive toward propertization. If IHI property were instead to include limitations and exceptions on scope, duration, and enforceability, as do some forms of intellectual property, some of these problems could be overcome.

Nevertheless, there are inherent risks associated with creating a new type of property in which owners are given broad rights of control and then relying on enumerated exceptions to mitigate the worst effects of that control, especially when rights are distributed broadly across the entire population and constitutional constraints make their subsequent refinement practically impossible. Moreover, embedding a host of limitations and exceptions into a new property system simply to avoid the worst effects of propertization begs the question whether a property system is needed at all, particularly when existing contract, privacy, and anti-discrimination rules already exist to protect individual privacy and autonomy in this area, and when one of the principal results of propertizing IHI may simply be to enrich would-be data intermediaries with little net benefit to individuals or public health. For all of these reasons, this Article recommends that the propertization of IHI be rejected in favor of sensible governmental regulation of research using IHI coupled with existing liability rules to compensate individuals for violations of their privacy.