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# MERCATUS GRADUATE POLICY ESSAY

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PROPERTY RIGHTS AND ELECTRONIC HEALTH RECORDS

by Jessica Carges



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**Abstract**

This is an analysis of the current assignment of property rights of electronic health records and patient medical data. The paper focuses on the adverse incentives created by the current structure of property rights and hypothesizes that giving patients and providers co-ownership of medical data will best address concerns about interoperability and privacy, and also result in a number of additional positive benefits. Next the paper describes ways to make stronger patient ownership a reality despite the presence of special interest groups incentivized to block access. The paper concludes with state policy level analysis examining New Hampshire – the only state to currently grant patient ownership over medical data and electronic health record. This paper finds that state governments can follow New Hampshire’s lead and extend co-property rights to patients and providers to improve interoperability and privacy outcomes.

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## **Introduction**

Obtaining medical records is cumbersome and frustrating. Typically, getting copies of hospitalization and patient health records requires contacting the facility, signing a release form, paying fees for each page of the copy and having the materials sent via fax several days or weeks later. Frequently, obtaining access to office visit records is not any easier to acquire.<sup>1</sup> This is despite the fact that many patient records are now stored electronically, making it easier than ever to gain access. The Centers for Medicare and Medicaid Services (CMS) state that electronic health records (EHRs) are, “an electronic version of a patient’s medical history, that is maintained by the provider over time, and may include all of the key administrative clinical data relevant to that person's care under a particular provider, including demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data, genetic data and radiology reports.”<sup>2</sup> The electronically available information provides continuity of care to individual patients, supports planning patient's care and documents clinical notes between patients, care providers, other health professionals and healthcare institutions. Despite all the benefits touted about EHRs, patients still do not have the ability to easily access medical information concerning their own bodies.

Now, imagine a world where patients have their own personal electronic health record available through an app on their own personal smartphone, instead of having to request access through each individual medical provider. Imagine being able to add data through wearable devices and smartphone attachments, or even comment on notes made by your physician. Imagine being able to easily forward the health record to any doctor you wish, so that basic medical tests do not have to be repeated.

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<sup>1</sup> Eric Topol, *The Patient Will See You Now: The Future of Medicine is In Your Hands*, (Basic Books, 2016).

<sup>2</sup> Centers for Medicare & Medicaid Services, “Electronic Health Records,” March 26, 2012.

The vision imagined above is not yet a reality for a variety of reasons, the most glaring being that patients do not own their personal health records. The entities that do have ownership over health records are not properly incentivized to provide patient EHRs openly or freely. The present assignment of property rights in patient medical data has resulted in a number of problems, revolving most around interoperability and privacy. I will argue in this paper that these issues can be mediated by providing patients with stronger and more clearly defined property rights over their medical data. Further, I will show the positive benefits associated with stronger patient-rights. Benefits include higher levels of trust between physicians and patients and increased accountability in personal healthcare. Next I will describe ways to make stronger patient ownership a reality despite the presence of special interest groups who may block access. The paper concludes with state policy level analysis examining New Hampshire – the only state to currently grant patient ownership over medical data and electronic health records.

### **Current Assignment of Health Record Property Rights**

Until the latter half of the 20th century, medical records were maintained on paper, and each provider and medical facility maintained separate records using manual facilities. There was a minimal level of sharing of medical information between healthcare providers. The classic rule of ownership of medical records reflected the analog nature of record keeping at the time; "the paper (physical medium) belongs to the provider and the words (data/information) belong to the patient."<sup>3</sup> Ownership was fairly straightforward, and words on paper were easy to control. However, the physical records were more difficult to share, exchange and manipulate.

The situation has changed dramatically with electronic computing and networking advances since the mid-20th century. Technological advances like the Internet and mobile

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<sup>3</sup> B. Demster, "Data Ownership Evolves with Technology," *Journal of AHIMA*, 83 (9), (2012): 52.

devices have enabled a new level of ease for data creation, proliferation and access. Emerging technologies also raised the value and facilitated innovative ways to use EHRs. For example, new discoveries in molecular biology and genetics created hopes that revolutionary breakthroughs in the treatment of major diseases are imminent.<sup>4</sup> Scientists can now read every letter of life's code, create precisely targeted drugs and tailor the drug use to individual patients.<sup>5</sup> The data can be stored in patient's electronic health records. Access to health records allowed providers to prescribe treatment more accurately. This new technological ability raised the value of owning EHRs. The information stored and maintained in electronic health records can be used for great societal benefit but property rights must be clearly established so that the respective parties know their legal default positions.<sup>6</sup>

In a well-known paper on the evolution of property rights, Harold Demsetz (1967) argues that rights of a resource must become more exclusive and detailed when new technology or other developments raise its expected value.<sup>7</sup> Increasing levels of technology have increased the worth of medical data, and its sale has become a global multi-billion dollar industry.<sup>8</sup> To put it in perspective, hackers make more money selling patient medical data on the black market than selling credit card and social security numbers.<sup>9</sup> Therefore, the initial assignment of property rights becomes ever more important because these rights have a potential market value.<sup>10</sup> But

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<sup>4</sup> T. Eggertsson, "The Evolution of Property Rights: The Strange Case of Iceland's Health Records." *International Journal of the Commons*. 5(1), (2011): 50–65

<sup>5</sup> P. Huber, (2013). "The Cure in the Code: How 20th Century Law is Undermining 21st Century Medicine." (Basic Books, 2013)

<sup>6</sup> Mark Hall, "Property, Privacy and the Pursuit of Integrated Electronic Medical Records," *Wake Forest Univ. Legal Studies*, no. 1334963 (2009).

<sup>7</sup> H. Demsetz, "Toward a Theory of Property Rights," *American Economic Review*, 57 (2), (1967): 347-359.

<sup>8</sup> A. Tanner, "Our Bodies, Our Data: How Companies Make Billions Selling Our Medical Records?" *Beacon Press*, (2017).

<sup>9</sup> C. Humer and J. Finkle, "Your Medical Record is Worth More to Hackers than Your Credit Card," *Reuters*, September 24, 2014, <https://www.reuters.com/article/us-cybersecurity-hospitals/your-medical-record-is-worth-more-to-hackers-than-your-credit-card-idUSKCN0HJ21I20140924>.

<sup>10</sup> Demster, "Data Ownership Evolves with Technology," 52.

with so many sources, operators and users of medical data, the determination of ownership and legal responsibility during various activities is complicated.<sup>11</sup> Is the owner the patient who receives care? Is it the practitioner who gives care? Is it the facility where the care was given? Or is it the organization that pays for the care? This uncertainty, notes Hall and Schulman (2009), is “high on the list of legal and economic barriers to investing in an integrated electronic medical infrastructure.”<sup>12</sup>

In legal theory, ownership is determined by who is entitled to sell a particular item of property.<sup>13</sup> But this definition isn’t as useful in healthcare, since the question of data ownership in medicine is muddled.<sup>14</sup> The amount of human medical data potentially available for data mining is enormous, with thousands of terabytes of data generated annually in North America and Europe. However, the data are buried in heterogeneous databases and scattered throughout the medical care system without any common format or principles of organization. The question of ownership of patient information is unsettled, confusing and the object of recurrent, highly publicized lawsuits and congressional inquiries.<sup>15</sup>

As a result of today's electronic health information environment, no single entity has complete control of medical records or data, additionally no federal law outlines property rights of medical data. Although the Health Insurance Portability and Accountability (HIPPA)

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<sup>11</sup> Y. Babad and A. Lubitch, “Ethical and Legal issues of Privacy and Patient Rights in The Application of Information Healthcare Delivery Systems,” *International Journal of Healthcare Technology and Management*, 12(3-4), (2011): 230-249.

<sup>12</sup> Mark A. Hall and Kevin A. Schulman, “Ownership of Medical Information,” *Journal of the American Medical Association*, 301(12), (2009): 1282.

<sup>13</sup> *Ibid.*, 1282.

<sup>14</sup> K. J. Cios and G. W. Moore, “Uniqueness of Medical Data Mining.” *Artificial Intelligence in Medicine*, 26 (1), (2002): 1-24.

<sup>15</sup> *Ibid.*

addresses management of patient data, it merely states that the patients have rights to see and receive copies upon request. It falls short in establishing patients as the owners of their data.<sup>16</sup>

Despite a lack of federal law defining ownership, the states have taken initiative. Only twenty-eight states plus the District of Columbia have neglected to establish laws that assign medical data ownership. In twenty-one states, law has mandated hospitals and/or physicians as owners of patient health records, and only one state – New Hampshire – has granted ownership to the patient.

### **The Problem: Incentivizing Against Interoperability and Privacy**

The murkiness of current property right assignments in the age of electronic health records has led to suboptimal outcomes on issues such as the ability to share and exchange records and patient privacy.

#### *Interoperability*

Interoperability, or the ability to share and exchange patient health records, is a necessary component to achieve the myriad of positive benefits associated with electronic health records. For example, EHR systems can facilitate provider performance measurements, as well as encourage more robust patient monitoring. It allows providers to cross boundaries in order to exchange information and coordinate care across healthcare systems. EHR systems also help promote evidence-based care through standardized electronic order sets, clinical guidelines, and immediate access to medical literature. Patient safety is improved through features such as

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<sup>16</sup> U.S. Department of Health and Human Services, “Individuals’ Right under HIPAA to Access their Health Information,” February 25, 2016,” <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/index.html>.

automated alerts and reminders, and through new predictive analytics that identify potential problems before crises arise.<sup>17</sup>

Health data is surprisingly difficult to move from one place to another. With few incentives for sharing, data hoarding is common.<sup>18</sup> In the United States, despite \$30 billion in government cash incentives to increase interoperability, health data sits in siloes unable to be exchanged or shared. Data hoarding is so pervasive that the U.S. Office of the National Coordinator for Health IT released a report on ‘information blocking,’ a term unique to the U.S. healthcare system.<sup>19</sup>

Lack of interoperability is persistent because the U.S. healthcare system is extremely fragmented, with no one overarching operator or vendor currently capable of standardizing how information is collected, stored, shared or analyzed. Additionally, a majority of individuals receive medical care from multiple providers that cut across different healthcare systems. Utilizing multiple doctors or hospitals reduces the ability of patients to have easy and singular access, since medical data is scattered throughout the healthcare system.<sup>20</sup> For example, anyone over the age of sixty-five in the United States sees, on average, seven doctors across four practices per year.<sup>21</sup> Further, different providers use different EHR systems for data collection and recording, and these different systems operate utilizing different identifiers or programming

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<sup>17</sup> S. Silow-Carroll, J. N. Edwards and D. Rodin, “Using Electronic Health Records to Improve Quality and Efficiency: The Experiences of Leading Hospitals,” *Issue Brief Commonwealth Fund*, 17, (2012):1-40.

<sup>18</sup> Leonard J. Kish and Eric J. Topol, "Unpatients-Why Patients Should Own their Medical Data," *Nature Biotechnology*, 33 (9), (2015): 921-924.

<sup>19</sup> The Office of the National Coordinator for Health Information Technology (ONC), “Report to Congress April 2015: Report on Health Information Blocking,” April 9, 2015, [http://healthit.gov/sites/default/files/reports/info\\_blocking\\_040915.pdf](http://healthit.gov/sites/default/files/reports/info_blocking_040915.pdf).

<sup>20</sup> Topol, *The Patient Will See You Now*.

<sup>21</sup> Institute of Medicine, “Best Care at Lower Cost: The Path to Continuously Learning Health Care in America,” *The National Academy Press*, (2013).

languages. Thus, even if medical records were interoperable, communication would still be hindered, since different systems rarely share the same language.

Another reason electronic health records are difficult to share and exchange is because EHR vendor companies often own the right to control or deny access to medical data. HIPAA provides that a doctor cannot withhold medical records from patients, pending payment for care. However, vendors can deny access by building a clause into contracts with doctors that explicitly states that the vendor has no responsibility to accommodate patient rights directly.<sup>22</sup> Meaning, a patient's life can literally hang in the balance while their doctor is prevented from accessing records to provide care, transferring the information to another provider, or giving the record to the patient if an EHR vendor decides to reject access.<sup>23</sup>

Niam Yaraghi, Ph.D., a fellow at the Brookings Institution Center for Technology Innovation, writes that EHR vendors have taken patient data “hostage.” That’s because even though EHR vendors receive a government cash incentive to encourage exchange of medical records, vendors are claiming their systems cannot be interoperable without making costly fixes to technical problems.<sup>24</sup> “This prevents physicians from sharing their patient records with other doctors,” Yaraghi says. “This is like T-Mobile claiming that its users cannot make calls to AT&T customers.”<sup>25</sup> In many cases, it is written into business contracts that access to the EHR can be immediately discontinued upon nonpayment, allegations of misuse or in the company's “sole

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<sup>22</sup> K. Royal, “Who Owns Patient Medical Records?” *Journal of Urgent Care Medicine*, (2017), <https://www.jucm.com/owns-patient-medical-records/>.

<sup>23</sup> Ibid.

<sup>24</sup> N. Yaraghi, “Electronic Health Record Vendors Take Patient Data Hostage: What Should We Do?” *Brookings Institute*, June 29, 2016, <https://www.brookings.edu/blog/techtank/2015/02/24/electronic-health-record-vendors-take-patient-data-hostage-what-should-we-do/>.

<sup>25</sup> Ibid.

discretion” if someone with access may jeopardize confidentiality. Yet, contracts may not address how the doctors can access records if needed in an emergency.<sup>26</sup>

Additionally, the EHR industry is controlled by a handful of relatively large companies with systems aimed at specialized providers. If medical records were easily exchangeable between vendor systems, large EHR companies would lose out on market share. Hence, by helping the smaller players, interoperability is a direct threat to the larger companies’ business models.<sup>27</sup> Larger EHR companies do not want to assist their customer’s in moving to services at another competing company.

Epic Systems, for example, a private company based in Verona, Wisconsin, is the industry leader. Epic controls close to half of all American medical records. Led by founder Judy Faulkner, Epic also appears to be the leading obfuscator when it comes to transferring records and interoperability. The company has developed App Orchard, a portal for outside vendors to sell apps that dig into Epic’s electronic records in order to find and sell medical data. However, the app charges four cents per message, which adds up quickly when millions or billions of electronic messages would be required to complete a typical transaction.<sup>28</sup> Epic might cap fees at 30 percent of the outside vendor’s revenue, but the revenue gained from selling medical data is still massive. Losing the ability to charge for that access to medical data would undermine Epic’s business model. Therefore, the current incentive structure is not conducive to encouraging interoperability. Instead, it encourages EHR companies to view increased interoperability as unnecessary increased competition.

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<sup>26</sup> Royal, “Who Owns Patient Medical Records?”

<sup>27</sup> Carlos Casarez, "EHR Interoperability: Why Is It So Difficult?" *CareCloud*, March 20, 2013.

<sup>28</sup> Andy Kessler, "Siri, Am I About to Have a Heart Attack?" *The Wall Street Journal*, January 10, 2017, <https://www.wsj.com/articles/siri-am-i-about-to-have-a-heart-attack-1484007412>.

Large hospital systems and physician practices have their own motives for idling on interoperability as well. Allowing access to all medical records through a health information exchange makes it easier for patients to transfer records and care instructions to other providers.<sup>29</sup> If it is easier to shop around for the perfect general physician, instead of staying with a current physician, competitive barriers between medical practices are lowered.

For example, one study examined the effect of caps on fees associated with acquiring personal medical records on the likelihood that patients switch medical providers.<sup>30</sup> Capping the fees resulted in lower barriers of acquisition for patient records. Not surprisingly, the study found that patients from states that adopted caps on copy fees were significantly more likely to switch doctors.<sup>31</sup>

While in many cases patients would not have the luxury of time to shop around for physicians, increased interoperability could still be viewed as increasing unnecessary competition. It can thus be argued that some medical providers, particularly large hospital or medical centers, may attempt to protect their market share by blocking the ability to easily change providers. However, it should be acknowledged that this is a moot point if the doctor in question is seen as competent and well liked. A patient is less likely to shop around for another doctor when the doctor shows superior skill, knowledge, bedside manner and personable traits.<sup>32</sup> Another way to increase the chances of increasing patient loyalty is by increasing access to patient medical records.<sup>33</sup> Inferior physicians however, will still have an incentive to fight against any changes that may increase competition.

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<sup>29</sup> Casarez, "EHR Interoperability."

<sup>30</sup> L. C. Baker, M. K. Bundorf and D. P. Kessler, "Expanding Patients' Property Rights in Their Medical Records," *American Journal of Health Economics*, (2015).

<sup>31</sup> Ibid.

<sup>32</sup> M. Turley et al. "Association Between Personal Health Record Enrollment and Patient Loyalty," *American Journal of Managed Care*, 18 (7), (2012): e248-53.

<sup>33</sup> Turley et al. "Association Between Personal Health."

## *Privacy*

Privacy is the foundation of “informational self-determination,” defined as the ability of a person to control the flow of their personal information. This self-determination can be achieved in two ways: anonymity and fair information practices.<sup>34</sup> Anonymity prevents disclosure of information, but it is difficult to achieve. Fair information practices control the collection, storage, dissemination and distribution of information, and thus have an ethical component. Ethical principles are “a particular system of principles and rules concerning duty and behavior.”<sup>35</sup> Privacy provides individuals with a private anonymous physical or virtual space under their control, including their living accommodation, body and personal information. It asserts that certain aspects of personal life may become public only with the permission of the affected person.<sup>36</sup> The HIPAA privacy rule sets boundaries on the use and release of health records, establishes safeguards to protect the privacy of health information and holds violators accountable.<sup>37</sup>

Despite this rule, a surprising number of organizations receive information about patients’ health records, often without a patient’s knowledge or consent. Marketing firms, pharmaceutical companies and hackers are more likely to see patient’s medical records than the patients themselves.<sup>38</sup> And while that data is made anonymous, only direct identifiers like names, addresses and social security numbers are taken out.<sup>39</sup> With big data it is becoming increasingly

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<sup>34</sup> I. Goldberg, A. Hill and A. Shostack, “Trust, ethics, and privacy,” *Boston University Law Review* 81 (2001).

<sup>35</sup> *Ibid.*, 407.

<sup>36</sup> Y. Babad, & A. Lubitch, “Ethical and Legal Issues of Privacy and Patient Rights in the Application of Information Healthcare Delivery Systems,” *International Journal of Healthcare Technology and Management* 12, no. 3-4 (2011): 230-249.

<sup>37</sup> “What does the HIPAA privacy rule do?” U.S. Department of Health and Human Services, accessed May 2017, <https://www.hhs.gov/hipaa/for-individuals/faq/187/what-does-the-hipaa-privacy-rule-do/index.html>.

<sup>38</sup> B. Sadan, “Patient Data Confidentiality and Patient Rights.” *International Journal of Medical Informatics* 62, no. 1 (2001): 41-49.

<sup>39</sup> T. Brase, “Congress Has Exposed Patients' DNA to Prying Eyes,” *Wall Street Journal*, August 28, 2017, <https://www.wsj.com/articles/sharing-medical-data-is-noble-but-not-without-patients-consent-1503960932>.

easy to match the remaining data, including zip code, birthday and gender to an individual identity.<sup>40</sup> For example, a few years ago Harvard researchers examined about 600 anonymized profiles from a genome-research project. By comparing profiles against public records and voter data, researchers were able to identify nearly half of these people by name.<sup>41</sup> Meanwhile, there were over 112 million records breached by hackers in 2015 alone.<sup>42</sup>

The application of the computer program Elensy, which made headlines in 1998, reveals how the lack of privacy in personal health information can be abused. Two Washington DC pharmacy chains, CVS and Giant Foods, sent patient prescription records to a database marketing firm, Elensy. Elensy mailed patients reminders to refill prescriptions as well as information about new drugs. Until they received a letter, patients did not know that their medical information had been shared.<sup>43</sup> The pharmacy chains canceled the program after media coverage ignited public outrage.

Pam Dixon, executive director of the World Privacy Forum, said such inappropriate behavior among medical staff is rare, and most organizations work hard to comply with the law.<sup>44</sup> But once a medical file is breached or a patient's information is leaked, it can be too late.<sup>45</sup> Dixon said, "my concern is in the rush to digitize all of our records that sometimes privacy goes by the wayside."<sup>46</sup> Complaints regarding invasions of privacy to the U.S. Department of Health

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<sup>40</sup> Jordan Robertson, "Your Medical Records are for Sale," *Bloomberg Business Week*, August 8, 2013.

<sup>41</sup> L. Sweeney, A. Abu and J. Winn, "Identifying Participants in The Personal Genome Project by Name," *Data Privacy Lab, Harvard University* (2013).

<sup>42</sup> Dan Munro, "Data Breaches in Healthcare Totaled Over 112 Million Records in 2015," *Forbes*, December 31, 2015, <https://www.forbes.com/sites/danmunro/2015/12/31/data-breaches-in-healthcare-total-over-112-million-records-in-2015/#1c4c30157b07>.

<sup>43</sup> Sadan, "Patient Data Confidentiality," 41-49.

<sup>44</sup> "Electronic Health Records," World Privacy Forum, Retrieved April 13, 2017, <https://www.worldprivacyforum.org/category/electronic-health-records/>.

<sup>45</sup> S. Abram, "Invasion of Medical Records, Hospital Privacy on Rise," *Los Angeles Daily News*, November 16, 2014, <https://www.dailynews.com/2014/11/15/invasion-of-medical-records-hospital-privacy-on-rise/>.

<sup>46</sup> *Ibid.*

and Human Services have been rising. In 2013 there were 12,915 complaints filed across the nation, nearly double the number filed in 2004.<sup>47</sup>

More recently, the 21<sup>st</sup> Century Cures Act, which passed in December of 2016, weakened patients' privacy rights.<sup>48</sup> The law allowed government-funded researchers to collect and even share patients' medical and genetic information without their consent. This is done through "information commons": a government-regulated pool of data accessible to all health researchers, regardless of background, training or motive.<sup>49</sup> While making data for medical research easier to acquire is a noble goal, the new law doesn't give patients in government funded research any method to opt out of data sharing. Unless ways can be found to balance the privacy rights of individuals against the legitimate needs of such institutions for patient information, healthcare outcomes suffer as patients may become less willing to seek care or withhold sensitive personal information.<sup>50</sup>

Unfortunately, patients reported perceptions of the value health information technology suggest a lack of trust. It is particularly evident in how patients view the security of private medical data as well as the prevalence of hackers. A 2016 survey of 12,090 consumers conducted by Black Book Surveys reveals that the prevalence of hacking has had an impact on how people view health information technology. Fifty-seven percent of consumers with a provider visit this past year report being skeptical of the overall benefits of health information technologies such as patient portals, mobile apps and electronic health records. The patients

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<sup>47</sup>Ibid.

<sup>48</sup> *21<sup>st</sup> Century Cures Act, U.S. Code 42 (2016) §§ 201 et seq.*

<sup>49</sup> Brase, "Congress Has Exposed Patients' DNA."

<sup>50</sup> John Glaser, "Protecting Our Medical Information: Rights, Responsibilities and Risks" (Testimony before the Committee on Labor and Human Resources, US Senate, October 28, 1997).

reported that this is mainly due to recently reported data hacking and a perceived lack of privacy protection by providers.<sup>51</sup>

More importantly, patient behavior is altered by concerns related to lack of privacy and medical data hacking. Due to the concerns, the survey found that in 2016, eighty-nine percent of consumers with provider visits report withholding health information during visits. Sixty-nine percent of patients confirm their belief that their current primary care physician does not demonstrate enough technology prowess for them to trust divulging all their personal information.<sup>52</sup>

### **The Solution: Stronger Patient Property Rights**

#### *Alleviating Interoperability and Privacy Problems*

The current assignment of property rights over health records has assisted in creating a framework that incentivizes EHR systems to refuse exchange of information, or charge a steep price tag to do so. In addition, patients are offered inadequate protection or guarantee of privacy. One potential solution, is to give the people who are most directly harmed by these issues – the patient – stronger ownership over their own health records.

The traditional definition of property rights, as told by Armen Alchian in *The Concise Encyclopedia of Economics* is, “the exclusive authority to determine how a resource is used, whether that resource is owned by government or by individuals. Society approves the uses selected by the holder of the property right with governmental administered force and with social ostracism.” Private property goes on to include the right to service the resource, determine its

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<sup>51</sup> Heather Landi, "Survey: Patients Skeptical of Health IT Due to Privacy, Security Concerns." *Healthcare Informatics Magazine*, January 3, 2017.

<sup>52</sup> Landi, “Survey: Patients Skeptical of Health IT Due to Privacy, Security Concerns.”

use, and delegate, rent or sell any portion of the right. Patients who lack formalized property rights over their own health records should be entitled to private ownership, because they paid, even if indirectly, for tests, scans, office visits and hospitalizations.<sup>53</sup>

In 22 states, medical care providers also legally have a claim to ownership rights of medical records. Providers are the experts who determine what information is relevant to put on record and what tests are necessary. Most often, providers have significantly more knowledge of patient's medical conditions than the patients themselves. Michael Bossenbroek, JD, a partner in Wachler & Associates, reveals that another reason physician's often lay claim over medical records is how those records are treated in a medical practice sale or the sale of a partnership interest. "Implicit in those transactions is that part of the value I'm bringing to the practice are my patient relationships, and the records that come with them."<sup>54</sup> More traditionally, the paternalistic argument that patients are not smart enough to understand the information and therefore they will become confused, anxious and misunderstand their conditions without proper context and knowledge is put forth as a definitive reason for neglecting sole patient ownership of records. Thus, doctors and other healthcare professionals must serve as interpreters of medical data. In this case, medical data ownership is transferred over to them to ensure patient protection from themselves.<sup>55</sup>

However, sole ownership of electronic health records granted to physicians will not alleviate the earlier stated problems of incompatible EHRs and inadequate privacy protection. Medical providers are not incentivized to share patient records easily, and could actively make doing so more difficult as to avoid unnecessary competition. And, while the Hippocratic Oath

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<sup>53</sup> Topol, *The Patient Will See You Now*.

<sup>54</sup> K. Terry, "Patient records: The Struggle for Ownership." *Medical Economics*. December 10, 2015.

<sup>55</sup> Topol, *The Patient Will See You Now*.

takes patient-doctor confidentiality very seriously, physicians have little power or knowledge as to best practices to prevent data breaches of the electronic software system that stores EHRs. The people who would care most about these issues, and therefore would be driven to ensure these problems are most likely alleviated, are the patients themselves. Granting stronger property rights to patients over their own health records encourages patients to demand increased access, exchange, and privacy in a way that no other interest group could.

Given the uniqueness of the healthcare field and the rampant information asymmetries that exist between patients and providers, a more robust assignment of property rights may involve co-ownership, rather than comprehensive rights given to one party or the other. Patients can own their medical data, but these data will need to be managed by the treating institutions and physician.<sup>56</sup>

Co-ownership also protects against some difficult situations that may arise in the case of sole patient granted property rights. Patients may make it extremely difficult for medical providers to make important health decisions by refusing to allow anyone, including their own doctors, to obtain medical record access. If a patient destroyed their own records, they could place their own health in jeopardy should an emergency arise. If a patient's health records are lost or stolen, it is the patient who is liable instead of an EHR vendor, and the patient may not have the resources, time, or know-how to recover their own file. Vulnerable populations, including the under educated, homeless, patients with mental disabilities, undocumented immigrants and others may be expected to shoulder responsibilities while lacking the necessary resources to do so on their own.

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<sup>56</sup> Sadan, "Patient Data Confidentiality."

Having a medical provider act as a trustee of patient's health records relieves the pressure and problems of full responsibility mentioned above. Granting patients co-ownership of their own health records empowers patients to move health records around as they please. A new system of patient-initiated control of health records, managed and overseen by physicians and providers could be the key to a successful system. Such a system could "loosen the logjam of competing interests and stimulate market mechanisms to make much larger investments in using and sharing electronic health information."<sup>57</sup> EHRs, while still being able to charge fees for service, would be properly incentivized to compete against each other to cater to patient needs. As a result, companies may focus more on pleasing and providing services directly to patients. For example, user friendly apps could securely store EHRs on individual's smartphones.

Sadan, et al. (2001) agrees, saying "co-ownership and co-documentation is part of the solution. We believe that a cooperative approach will help maintain greater accuracy of personal medical data and delegate the power to the patient to decide when and to whom to give authorization for its use by a third party and for research."<sup>58</sup> Hodge et al. describe three ways in which the quality and reliability of personal medical information can be directly influenced by the extent to which the privacy of personalized medical data is protected: (1) fair information practice, including the right to access and to amend medical records; (2) assurances of privacy between physician and patient – these enhance the patient's trust and thus enable freer disclosure of health information; and (3) better safeguarding of privacy and patient ownership of data.<sup>59</sup>

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<sup>57</sup> Hall and Schulman, "Ownership of Medical Information."

<sup>58</sup> Sadan, "Patient Data Confidentiality," 41.

<sup>59</sup> J.G. Hodge Jr, L.O. Gostin and P.D. Jacobson, "Legal Issues Concerning Electronic Health Information," *Journal of the American Medical Association* 282 (1999): 1466–1471.

*Improving Health Outcomes, Accountability, and Trust*

Every patient is unique. Even if they have the same disease, no two patients have the same manifestations, conditions, or the same qualitative and quantitative outcomes. Nor do patients have the same resources to reach their personal health goals.<sup>60</sup> Developing a system that encourages open patient participation and communication with medical providers would improve patient outcomes. Granting patients stronger property rights encourages them to become more actively involved in their own healthcare. Studies on patient access to records and patient-held records, a feature of increased patient property rights over medical data, indicate that access and possession of records reassures patients, improves communication with their doctors, increases trust and patient compliance and, no less importantly, improves the quality of the medical data.<sup>61</sup>

Clinical notes, one part of a patient's electronic health record, are often confusing or require expert assistance to understand. Traditionally, notes are handwritten, often illegible, and there is no way of knowing whether the records are complete.<sup>62</sup> Medical data are rarely simple, straightforward or objective. Thus, simply granting patient access to view clinical notes cannot take place without a parallel effort to help the patient achieve a better understanding of the content of those notes. Providers will be tasked with explaining the nuances of medical decisions and of the complexity in the interpretation of medical information.<sup>63</sup>

The digitization of medical information, and access to that information, will drive information ownership in the future. In a research study called Open Notes, first published in

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<sup>60</sup> S. Toombs, *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient* (Norwell, MA: Kluwer Academic, 1992).

<sup>61</sup> M.L. Gilhooly and S.M. McGhee, "Medical Records: Practicalities and Principles of Patient Possession," *Journal of Medical Ethics* 17, no. 3 (1991): 138–14; D.P. Stevens, R. Stagg and I.R. Mackay, "What Happens when Hospitalized Patients See Their Own Records," *Annals of Internal Medicine* 86, no. 4 (1977): 474–477; S.C. Porter et al. "Parents as Direct Contributors to the Medical Record: Validation of their Electronic Input," *Annals of Emergency Medicine* 35, no.4 (2000): 346–352.

<sup>62</sup> Sadan, "Patient Data Confidentiality."

<sup>63</sup> L.L. Weed, "Medical Records that Guide and Teach," *New England Journal of Medicine* 278 (1968): 593–599.

2012, three highly regarded medical centers in the United States – Geisenger in rural Pennsylvania, Harborview in Seattle, and Beth Israel Deaconess in Boston – participated in an experiment testing the impact of patients having rapid access to their office visit notes. Over 100 primary care physicians and more than 22,000 patients participated in the study. The study demonstrated that immediate access to clinical notes resulted in more engaged and satisfied patients and stronger relationships between patients and doctors.<sup>64</sup>

Specific results from the surveys conducted during the study indicated that 99 percent of patients wanted access to clinical note in the future, and nearly 90 percent of patients would select future care based on having Open Note access. Reading the notes increased patient understanding and instilled them with a sense of control, improved adherence to the plans that were discussed at the visit, and enhanced trust of their physicians.<sup>65</sup> Among the patients in the Open Notes trial who reviewed their notes, roughly 75 percent reported better recall of care plans, better self-care, a clearer understanding of their conditions, and a sense of control over their healthcare.<sup>66</sup>

Notably, over 60 percent of patients improved their adherence to medications compared to a baseline of 50 percent in control groups.<sup>67</sup> When it comes to managing chronic diseases and pain, sticking to medication is important. An improvement in adherence to medication leads to a direct improvement in health outcomes. With access to notes, care partners of chronically ill

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<sup>64</sup> T. Delbanco et al., “Inviting Patients to Read their Doctors’ Notes: A Quasi Experimental Study and a Look Ahead,” *Annals of Internal Medicine* 157, no. 7 (2012): 461-471.

<sup>65</sup> J. Thew, “Opening Up About Medical Records: OpenNotes Gives Patients Access to Provider Notes,” HL7 Health, January 28, 2014, <http://healthstandards.com/blog/2014/01/28/open-notes/>

<sup>66</sup> Bell et al., “OpenNotes: How the Power of Knowing Can Change Health Care.” Catalyst, October 12, 2017, <https://catalyst.nejm.org/opennotes-knowing-change-health-care/>

<sup>67</sup> Delbanco et al., “Inviting Patients to Read their Doctors’ Notes,” 461-471; M. Coren, “You Can Now Find out What Your Doctor is Writing Down in That File,” *Fast Company*, July 23, 2013.

patients can also help avert potentially complex and costly problems, including poor medication adherence, inaccurate medication lists, and preventable hospital readmissions.<sup>68</sup>

Furthermore, the study revealed that increased patient control, involvement, and access to medical records did not notably inconvenience physicians. Doctors learned to modulate their notes on certain issues such as mental health, substance abuse, obesity and cancer where they might offend or carelessly upset patients. Doctors also learned to avoid acronyms like SOB, which doctor's use for shortness of breath, but which the patient can easily misinterpret. Providing access to clinical notes did not significantly increase email traffic for the physicians. While some patients required interaction after having read a note, others found their questions answered.<sup>69</sup> Overall, there was no net increase in time demanded of physicians.<sup>70</sup>

The study was so successful that it has become standard practice at the three centers where research was conducted.<sup>71</sup> In fact, the program has expanded. Today, more than 11 million patients in the United States have easy access to their notes through what has become a standard-of-care "movement."<sup>72</sup> Doctors reported that access to notes makes patients better prepared for the consent. Patients may be more prepared to participate in decision-making once they are fortified with a deeper understanding of their health conditions and treatment options. Moreover,

### *The Legal Case for Stronger Patient Property Rights*

Property right assignment matters greatly in determining legal access and control over patient electronic health records. U.S. court cases highlight the effects of murky or complete lack of

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<sup>68</sup> Bell et al., "OpenNotes: How the Power of Knowing Can Change Health Care."

<sup>69</sup> Topol, *The Patient Will See You Now*.

<sup>70</sup> Delbanco et al., "Inviting Patients to Read their Doctors' Notes," 461-471.

<sup>71</sup> Ibid.

<sup>72</sup> Bell et al., "OpenNotes: How the Power of Knowing Can Change Health Care."

patient rights for accessing their own medical records. In the examples that follow, patients are blocked from fully accessing their own data due to the lack of legal rights on the books.

In *Gotkin v. Miller*, a New York federal district court held that there is no constitutionally protected property right interest in a person's medical records in the state of New York. The district court said that the deciding factor for any property right was New York statutory law, but the court was unable to locate an enactment that recognized a patient's right to access his or her medical records. The state courts found that medical records belonged to the physician or hospital.<sup>73</sup> Thus, the court concluded that the plaintiffs did not show sufficient property interest to entitle them to protection under the purview of the fourteenth amendment.

In *Wallace v. University Hospitals of Cleveland*, the lower court of Ohio held that “a patient has a property right in the information contained in the record and as such is entitled to a copy of it.”<sup>74</sup> However, on appeal the patient's right of access was significantly restricted to only those records that, in the hospital's judgment, were in the “beneficial interest” of the patient to inspect.<sup>75</sup> Because the patient did not have property rights over their own records, the patient was barred from having a say in their care.

In 2007, Vermont instated The Prescription Confidentiality Law that required doctors’ consent before their prescription records could be used to market prescription drugs. It was in response to the Vermont Medical Society’s unanimous resolution that the sale and marketing use of doctors’ prescribing practices without consent is “an intrusion into the way physicians practice medicine.”<sup>76</sup> Many pharmacies sell records that reveal which doctors prescribe which drugs, as

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<sup>73</sup> 379 F. Supp. 859, 860-65 (E.D.N.Y. 1974), *aff'd*, 514 F.2d 125 (2d Cir. 1975).

<sup>74</sup> 164 N.E.2d at 918.

<sup>75</sup> 170 N.E.2d at 261-262.

<sup>76</sup> “Supreme Court Strikes Down Vermont Prescription Privacy Law,” Hunton Andrews Kurth LLP, n.d., accessed May 15, 2017, <https://www.lexology.com/library/detail.aspx?g=e7bcb93b-c16e-4885-827a-c7a11f103c4e>.

well as the age and gender of the patient receiving the drug, without the consent of the doctor or patient. Companies like IMS Health buy patient records and sell them to drug companies. The drug companies then use the data to target certain doctors with marketing for the newest and most expensive drugs. Vermont's law required that doctor's consent before their prescribing practices could be used for marketing.

After conflicting hearings at the state level, the case went to the U.S. Supreme Court. The Supreme Court rejected the Vermont law that requires doctors' consent before their prescription records can be used to market prescription drugs. The Court held that the law violates the First Amendment rights of pharmaceutical companies and data miners who brought suit in 2007. This ruling occurred despite the support for the law from 35 states, organizations representing over 100,000 doctors, and consumer groups, and privacy experts. In a decision authored by Justice Kennedy, the Court stated that Vermont's law impermissibly "disfavors marketing," and "disfavors specific speakers, namely pharmaceutical marketers."<sup>77</sup> Justice Breyer, joined by Justices Ginsburg and Kagan, would have upheld the law because, in their view, the evidence showed that it would advance Vermont's interests in protecting public health and privacy.<sup>78</sup>

Today's laws also hinder protection of privacy. Consider the Supreme Court's unanimous 2012 decision in *U.S. vs. Jones*.<sup>79</sup> "It may be necessary," Justice Sonia Sotomayor wrote in a concurring opinion, "to reconsider the premise that an individual has no reasonable expectation of privacy in information voluntarily disclosed to third parties." Although that case was about law-enforcement surveillance, Justice Sotomayor's warning that the current privacy laws are "ill-

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<sup>77</sup> *Sorrell v. IMS Health Inc.*, 131 U.S. 2653, 10-779 (2011).

<sup>78</sup> "Supreme Court Strikes Down Vermont Prescription Privacy Law."

<sup>79</sup> *United States v. Jones* 615 F.3d 544, affirmed (2012).

suited to the digital age” applies equally to patient medical records.<sup>80</sup> Without explicit legal property rights, patient’s will continue to lack access, control, and privacy.

### **Next Steps: How to Increase Adoption of Stronger Patient Property Rights**

It is idealistic to assume that all persons in political roles seek only to further some common good, with total disregard to their own self-interest.<sup>81</sup> If this were the case, then politicians may adopt stronger patient medical rights simply due to an increase in the overall common good of society. However, adopting stronger patient property rights will take more than the support of benevolent politicians. There are numerous special interest groups who would lobby the government against instating stronger patient rights. Public Choice theory takes the tools and methods of economic theory and applies them to the political or governmental sector. The analysis *relates* the behavior of individual actors in the governmental sector – the behavior of people in their various capacities as voters, candidates for office, elected representatives, or as bureaucrats – to the sum of outcomes that could be observed.<sup>82</sup> In order to increase adoption of stronger patient property rights, the influence of special interest groups must be acknowledged and overcome.

#### *The Power of Special Interest Groups*

Interest groups act as a barrier to achieving legislative success on stronger patient property rights. Groups include EHR vendors, pharmaceutical companies, and marketing conglomerates have in keeping access out of patient’s hands. These industries rely on medical data and are incentivized to keep access to data through monopoly control. Monopoly control is accomplished

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<sup>80</sup> Ibid.

<sup>81</sup> J. M. Buchanan, “Politics Without Romance: A Sketch of Positive Public Choice Theory and its Normative Implications,” *The Theory of Public Choice II*, (1984): 11-22.

<sup>82</sup> Buchanan, “Politics Without Romance.”

through rent seeking. Companies lobby the government in order to maintain exclusivity over a specific action; in this case, they maintain legal exclusivity over the control of electronic health records and medical data.

According to The Center for Responsive Politics, a nonprofit and nonpartisan research group that tracks the effects of money and lobbying on elections and public policy, the healthcare sector is one of the most powerful lobbying groups in the United States. From 1998-2017, healthcare lobbying groups – including physicians and other health professionals, pharmaceutical companies, and HMOs – spent over \$7.5 billion.<sup>83</sup> Pharmaceutical and health products are the single largest industry spender on lobbying, with over \$3.5 billion paid during the same time period.<sup>84</sup> EHR vendors have been steadily increasing their share of government lobbying. Since 1990, the EHR vendor companies that have spent the most on lobbying include McKesson (\$17.8 million), Cerner (\$2.4 million), Allscripts Inc. (\$2.4 million) and Epic (\$380,000).<sup>85</sup>

IMS Health, a marketing company that won three court cases in 2007 to block state government's attempts to establish patient or provider consent before medical data can be sold, engaged in rent seeking as well. The graph below depicts IMS Health lobbying spending over time. Spending peaked in 2007, the same year IMS Health was engaged in the court battles with three different states.<sup>86</sup> While recently its lobbying numbers have slightly declined, IMS Health still maintains a consistent presence in order to influence government policy.

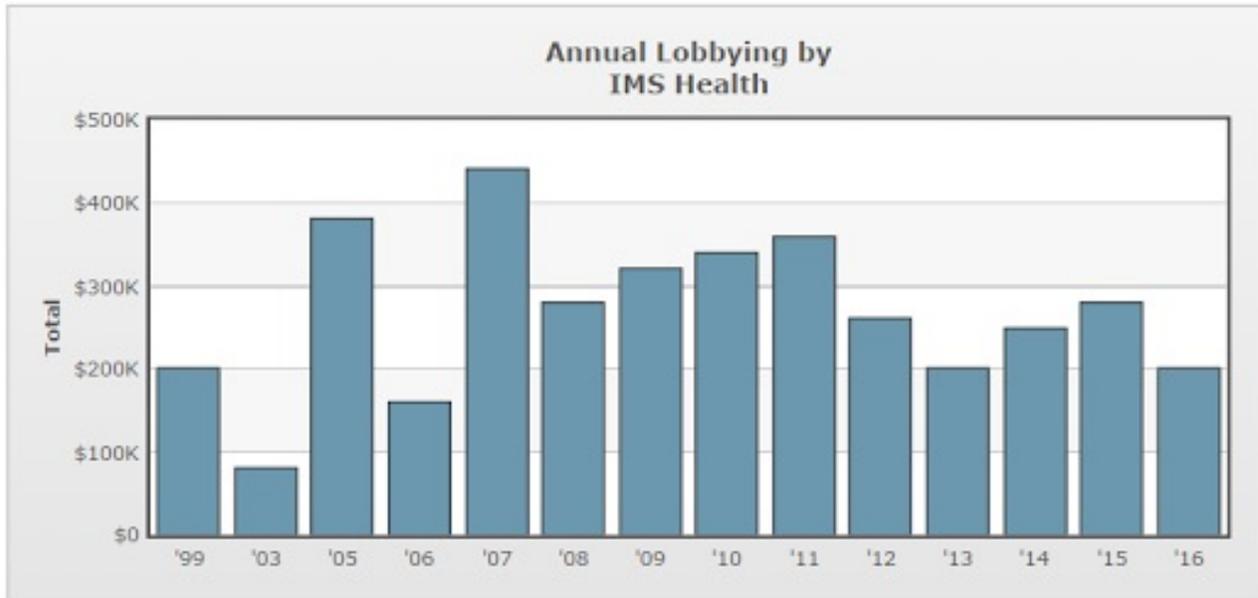
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<sup>83</sup> "IMS Health," The Center for Responsive Politics, n.d., accessed May 16, 2017, <https://www.opensecrets.org/lobby/clientsum.php?id=D000026587>

<sup>84</sup> Ibid.

<sup>85</sup> Ibid.

<sup>86</sup> Ibid.



Source: Center for Responsive Politics, Open Secrets IMS Health. Accessed May 16, 2017  
<https://www.opensecrets.org/lobby/clientsum.php?id=D000026587>

Data on campaign contributions ignore some of the more direct ways that strong interest groups can influence the policy process. Powerful companies can find a way to directly influence policy by serving as consultants and providing expert testimony to the federal government. Expert testimony in public hearings can be used to influence the government to adopt certain policies that would explicitly benefit a private company, often at the expense of less powerful interest groups. Industry testimony can serve as another form of rent seeking.

One example, in 2009 the American Recovery and Reinvestment Act (ARRA) established a Health Information Technology Policy Committee, which makes recommendations on creating a policy framework for the development and adoption of a nationwide health information technology infrastructure. The ARRA includes provisions that set government standards for the exchange of patient medical information. Judy Faulkner, CEO of electronic health record company Epic, was appointed to this board in 2009 and has served every year

since.<sup>87</sup> The board's 2015 report to Congress requested cash payment incentives in order to encourage interoperability between EHR systems. The federal government has been using cash payments to EHR vendors since 2010, resulting in billions of dollars but limited results in terms of interoperability. It isn't a coincidence that Epic would greatly benefit from receiving cash incentives. Without spending any money on direct lobbying, Epic influenced policy outcomes.

The same health information technology advisory board, of which Epic's CEO is a committee member, supplied the U.S. Department of Health and Human Services (HHS) with recommendations on how it can advance priority health IT capabilities in a variety of 'accountable care' arrangements. The recommendations included setting high data requirements. Specifically, the board asked the HHS to "increase vendor accountability by ensuring products not only send data, but can also receive and process data."<sup>88</sup> This allowed Epic to create artificial demand for their services. Smaller and newer companies could not compete with the requirements of the legislature, closing the door on a wide variety of competition in the EHR system market.

The recommendation was approved July 8, 2014 by the advisory board, and enacted by HHS under the Medicare EHR Incentive Program's 2014 Edition Health Information Technology Certification Criteria. During the year 2014, Epic supplied certified technology to over 30 percent of healthcare professionals participating in the Medicare EHR incentive program.<sup>89</sup> Epic achieved the largest market share of any EHR vendor – Epic's systems are used

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<sup>87</sup> "Profile: Judy Faulkner," *Forbes*, accessed August 29, 2017, <https://www.forbes.com/profile/judy-faulkner/>.

<sup>88</sup> Paul Tang and Joe Kimura, "Advanced Health Models and Meaningful Use Workgroup" (presentation to the Health IT Policy Committee, Washington, D.C., October 10, 2017).

<sup>89</sup> "Certified Health IT Developers and Editions Reported by Health Care Professionals Participating in the Medicare EHR Incentive Program: Health IT Quick-Stat #30," Office of the National Coordinator for Health Information Technology, accessed July, 2017, <https://dashboard.healthit.gov/quickstats/pages/FIG-Vendors-of-EHRs-to-Participating-Professionals.php>.

by 52,000 more providers compared to the next closest competitor.<sup>90</sup> Judy Faulkner's influence in Congress and major government agencies augments the effect Epic has through formal lobbying. Other vendors like competitors Allscripts Inc, Cerner and McKesson spend considerably more lobbying dollars in attempt to offset Epic's inside connections.

### *The Role of Providers*

In contrast to the reach that medical companies have, patients are significantly less organized and less able to raise the same amount of lobbying funds or command enough influence over policymakers. However, there are still a number of viable routes to stronger patient property rights.

Doctors have held much political sway through rent seeking, and they are one of the most highly respected professions in society. Through the American Medical Association (AMA), a voluntary association of physicians, doctors have influenced policies ranging from Medicare to the Affordable Care Act by lobbying and contributing millions of dollars to politicians. Since 1998, AMA lobbying has never fallen below the \$6 million mark, which is a higher level of spending than every EHR vendor company.<sup>91</sup>

Physicians could be incentivized to push for stronger patient property rights. Many studies, including the Open Notes investigation, have shown that increased electronic communication between physicians and patients improves health outcomes, quality of clinical note taking, and trust between patient and provider.<sup>92</sup> By advocating on their behalf for increased access to medical records, providers would be advocating for higher quality healthcare.

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<sup>90</sup> Ibid.

<sup>91</sup> "IMS Health", The Center for Responsive Politics.

<sup>92</sup> Susan Dentzer, "Rx for the 'Blockbuster Drug' of Patient Engagement," *Health Affairs*, February, 2013, <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2013.0037>; A. Schickedanz et al., "Access, Interest, and Attitudes Toward Electronic Communication for Health Care Among Patients in The Medical Safety Net," *Journal*

A 2012 Kaiser Permanente study examined the association between patient portal usages – in which secure e-mail between physicians and patients is a key functionality – and membership retention. Patients with direct access to medical records and open communication with their doctors via the portal were 2.6 times more likely to remain with the same provider than were nonusers.<sup>93</sup> Loyalty increases when patients feel empowered to communicate with their physicians. While stronger property rights may incentivize patients to shop around more if they dislike their doctor, these results prove that competent doctors need not fear. Providers are incentivized to support stronger property rights in order because rights encourage increases in patient retention as well as profits.

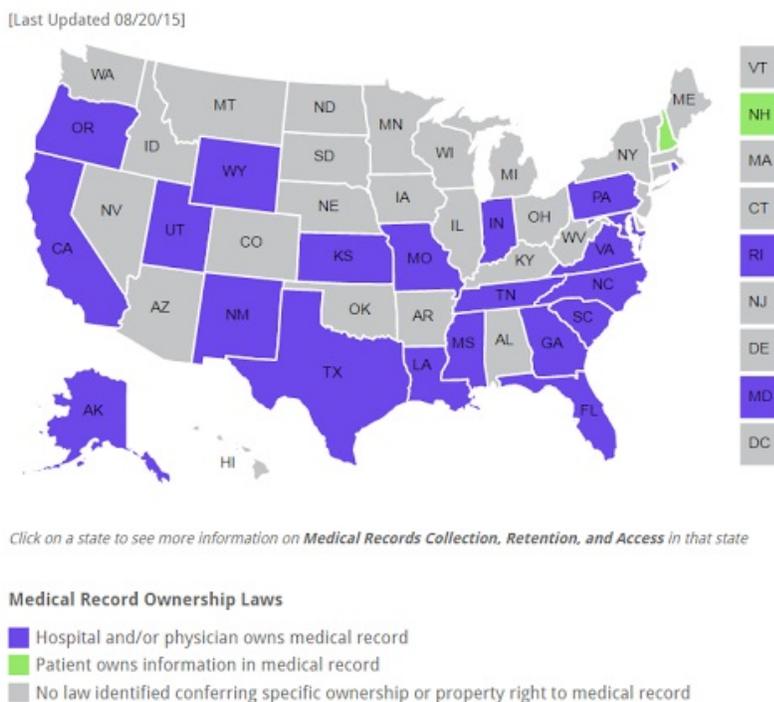
Medical providers constitute a more politically powerful and better organized group than grassroots patient organizations. Doctors could use this power to encourage policy changes at the political level. Furthermore, if providers and patients maintained lawful co-ownership over medical records, then EHR vendors, marketing conglomerates, and large pharmaceutical companies would no longer have the upper hand. The current billion-dollar industry that relies on selling medical records would need patient and/or provider consent before sales. Co-ownership of EHRs and medical data would serve as a check to the power wielded by EHR vendors, who would no longer be legally able to hold data hostage. Increasing control of medical data for patients leads to positive benefits for providers. Providers can be the spark that changes the system by using the AMA to lobby and leverage their influence to continue to advocate on behalf of patients.

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*of General Internal Medicine* 28, no. 7 (2013): 914-20.; R. Tagalicod, “Stage 2: Engaging Patients in their Health Care,” *CMS* Last Modified September, 2013, [http://www.cms.gov/eHealth/ListServ\\_Stage2\\_EngagingPatients.html](http://www.cms.gov/eHealth/ListServ_Stage2_EngagingPatients.html).  
<sup>93</sup> Turley et al., “Association Between Personal Health Record Enrollment and Patient Loyalty.”

## Patient Property Rights: Variation in State Law

At the state level, there are many nuances to property right law regarding medical records and EHRs. New Hampshire is currently the only state which defines medical records and electronic health records as patient property, but specifies that patients own only the information conveyed in the records and not the means by which it is stored. Wyoming is currently the only state that grants ownership of the physical conveyance (paper or digital) of the medical record to the physician and/or the healthcare facility in which he/she practices. Furthermore, 20 states have laws that specify hospital and/or physician owned medical records, and 28 states plus the District of Columbia have no law conferring specific ownership or property right to medical records. The graph below visualizes these results.<sup>94</sup>



Source: Health Information and Law, George Washington University, Hirsch Health Law and Policy Program and the Robert Wood Johnson Foundation. Accessed May 16, 2017, <http://www.healthinfolaw.org/comparative-analysis/who-owns-medical-records-50-state-comparison>

<sup>94</sup> “Who Owns Medical Records: 50 State Comparison.” Health Information & the Law, n.d., accessed May 15, 2017, <http://www.healthinfolaw.org/comparative-analysis/who-owns-medical-records-50-state-comparison>.

### *Case Study: New Hampshire*

IMS Health won a case regarding access to patient medical data and doctor prescription data in New Hampshire. The case decreed that stated providers did not need to give consent in order for patient drug and prescribing data to be taken and sold for research and marketing purposes. The ruling in New Hampshire was made in 2007, three years before the Patient Bill of Rights was passed. The Patient Bill of Rights awarded property rights over electronic health record data to patients. While no recent court cases have occurred, the updated law gives explicit direction regarding patient consent to share medical data: “Written authorization is required for the use or disclosure of patient identifiable medical information for sales or marketing purposes. The New Hampshire definition of ‘marketing’ is broader than the federal HIPAA definition; the State definition includes communications about health-related products or services.”<sup>95</sup> IMS Health has not challenged the most recent legislation. As it stands, the people of New Hampshire must give written authorization before their medical data is used for sales and marketing purposes. In other states, written authorization is not necessary.

Examining the health impact of patient property rights for medical records in New Hampshire is admittedly difficult, and there is limited literature currently available. There are also omitted or confounding variables which are difficult to identify and measure, but which may play an important role in determining health outcomes in the state. But, as the only state to currently grant patients the right at all, any insights gleaned from this natural experiment are valuable.

New Hampshire’s Patient Bill of Rights was established in 2010, and the state law explicitly states:

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<sup>95</sup> “New Hampshire Statutes Related to Health Information Privacy,” New Hampshire Department of Health and Human Services, n.d., accessed May 15, 2017, <https://www.dhhs.nh.gov/hie/documents/laws.pdf>.

The patient shall be ensured confidential treatment of all information contained in the patient's personal and clinical record, including that stored in an automatic data bank, and the patient's written consent shall be required for the release of information to anyone not otherwise authorized by law to receive it. Medical information contained in the medical records at any facility licensed under this chapter shall be deemed to be the property of the patient.<sup>96</sup>

There are two main legal differences between New Hampshire and the rest of the country as a result of this law. First, patients cannot, under any circumstances, be denied access to their medical records. Secondly, patients' written consent is needed before medical information is released. In other states, patients can be denied access to medical records for a variety of reasons and medical data can be released without specific patient consent.

#### *How New Hampshire Granted Patient Property Rights*

Despite the power of rent seeking from the various competing entities vying for control and access of medical data, New Hampshire managed to implement a patient-centered law. The first ever Patient Bill of Rights evolved out of the National Welfare Rights Organization (NWRO), a grass-roots consumer organization that formed during the 1960s.<sup>97</sup> The organization drafted a document containing twenty-six demands, which was the first comprehensive statement of "patient rights" from the consumers' perspective. Included were provisions for grievance procedures, community representation on hospital governing boards, nondiscrimination on the

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<sup>96</sup> NH Rev Stat XI § 151-21 (2014).

<sup>97</sup> Laurens H. Silver, "The Legal Accountability of Nonprofit Hospitals," in Clark C. Havighurst, ed., *Regulating Health Facilities Construction* (Washington, D.C.: American Enterprise Institute, 1974): 183–200.

basis of source of payment, restrictions on transfers, provisions on privacy and confidentiality, and prompt attention to patients' requests for nursing assistance.<sup>98</sup>

The Patient Bill of Rights took on a new life in 1972, when the American Hospital Association adopted their own bill of rights based on the premise that "[the] traditional physician–patient relationship takes on a new dimension when care is rendered within an organizational structure ... the institution itself also has a responsibility to the patient."<sup>99</sup> Then in 1992, provisions on access to medical records and use of advance directives were added. Although the list remains vague, incomplete, and lacks an enforcement mechanism, it moves in the direction of increased patient rights. While the grass root, patient revolution campaign has been successful in implementing Patient Bill of Rights across states, patient-oriented property rights may be better realized through the help of a different and more politically powerful group.<sup>100</sup>

### *The Results*

Stronger patient property rights for electronic health records have increased and improved sharing and access of medical data in the state of New Hampshire. Since the law was enacted, it is relatively easy and often free of charge for patients who reside in the state to obtain access to their medical records. At present, 91 percent of hospitals in the state grant access to a patient portal. Three smaller hospitals don't offer access. Comparatively, the nationwide average for

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<sup>98</sup> Ibid.

<sup>99</sup> American Psychiatric Association, *Rights of the Mentally Disabled: Statements and Standards*, (American Psychiatric Pub, 1984): 6-7.

<sup>100</sup> The following states have implemented a Patient Bill of Rights: Arizona, California, Illinois, Kentucky, Maryland, Massachusetts, Michigan, Minnesota, New Hampshire, New York, Pennsylvania, Rhode Island and Vermont.

hospitals granting this technology and access is 50 percent.<sup>101</sup> Patients can request access to their medical records, input family history, refill pharmacy prescriptions, and view lab results through these online systems. Many online systems also allow parents to keep track of their children or elderly family member's records.

While not all systems are the same, New Hampshire residents have easy access to a substantial amount of their personal medical information compared with the average person. "Without patient engagement, we won't make the progress we need to reduce costs and be more efficient in the way we provide care. Portals are a great way to get patients and their families engaged," said Denise Purington, CIO of Elliot Health System, one of the largest hospital systems in New Hampshire.<sup>102</sup> Purington claimed doctors love patient portals because they can communicate with patients without back-and-forth phone calls.<sup>103</sup>

Dartmouth-Hitchcock, the other large hospital system in the state, also created an extensive online EHR portal for its patients. The system is called My D-H and launched in 2011, the year after the Patient Bill of Rights was enacted. The portal, available for free to any New Hampshire resident, is an easy-to-navigate online site and mobile application that contains patient medical history, medications, lab and diagnostic testing results, pharmacy refill request capability, hospital admissions, immunizations, after visit summary, office notes, appointments and referrals. Both the app and the online website allow patients to contact their healthcare team, renew prescriptions, check lab and radiology results, review after visit summaries and manage appointments. My D-H even encourages patients to inquire with questions, especially if medical

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<sup>101</sup> "Market Disruption Imminent as Providers Adopt Patient Portal Technology," *HITECH Answers*, September, 2013, <https://www.hitechanswers.net/market-disruption-imminent-hospitals-physicians-aggressively-adopt-patient-portal-technology/>.

<sup>102</sup> E. Cohen, "An App A Day..." December, 2013, <http://millyardcommunications.com/index.php?src=news&submenu=hospitalitynews&srctype=detail&category=News&refno=4113>

<sup>103</sup> Ibid.

language is confusing – however health articles are linked throughout the medical record specific to patient test results, lab values and conditions in order to make medical education and inquiry as easy as possible.

While published formal studies in peer-reviewed journals that look at improvements in health outcomes due to New Hampshire’s property right change have yet to materialize, many patient and providers are singing the praises of the increase in patient involvement. "By participating in the portal, patients will gain a better understanding of their health overall, but especially about the current, active issues: what's going on now, how it's treated, medications, and so on. Patients who are informed and engaged in their care have the best prospects for recovery and health maintenance," said Dr. Chris Barsotti, an emergency medicine physician and physician informaticist. "This technology is about improving communication between patients and their physicians, and vice-versa. It gives us a way to stay in touch outside of the exam room and helps ensure that we stay focused on our shared goal of the patient's good health."<sup>104</sup>

### **Limitations and Further Inquiry**

Due to the lack of outside literature available on all possible factors that affect stronger patient property rights, there are numerous issues that have not been addressed in this paper. First, patients may respond negatively to seeing sensitive health information displayed in their medical chart. For instance, if a physician included notes that mention obesity, smoking, alcohol addiction or mental health issues, the provider could be punished by the patient with a bad review, or the patient may seek out another doctor entirely. On the other hand, if a patient is readily able to read that they are in perfect health, it might lead to increasingly risky behavior.

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<sup>104</sup> "Patient Portals give access to Medical Info," *Manchester Journal*, August 2014, <http://www.manchesterjournal.com/stories/patient-portals-give-access-to-medical-info,85928>.

For example, a patient with low cholesterol might think that eating an excessive amount of french fries is perfectly fine given their relative good health, and may even increasingly engage in this behavior. Both of these are risks associated with stronger patient property rights of medical records, but could be addressed with open dialog between patients and providers.

Further limitations of this paper's assessment are related to tort issues, liability, and knowledge of how data will be used. For example, teachers do not want to be judged by evaluations and prefer to put information in context before it is made public. Providers may feel the same way about easily sharing their office notes and treatment records. People act differently when they are being recorded, or when they feel their actions are public. However, this scrutiny can lead to better outcomes. In fact, giving patients the ability to double check medical treatment via easily accessible medical records is one reason why EHRs have been shown to reduce medical error. Co-ownership of medical records between providers and patients should also help alleviate any apprehension, since providers will still have a say in how the information is disseminated.

Finally, as any data system becomes more open, the threat of privacy and hacking issues increases. Raising permission requirements and limiting access to medical data can combat privacy problems. However, this could come at a cost. How permission requirements impact the ability for researchers to access data, which is then used to create new treatments, is not currently known. Giving patient's stronger property rights could have a negative impact on the medical research community, and further inquiry into this topic is necessary.

## **Conclusion**

The current property right assignment has resulted in a lack of interoperability and privacy. Strong special interest groups, including EHR vendor companies, large hospital systems,

pharmaceutical companies and marketing conglomerates benefit from the current property rights system. Their position incentivizes rent seeking behavior in order to continue obtaining large profits from the status quo. Fundamentally changing the system so that patients have stronger property rights over medical data will limit rent seeking behavior and encourage the many beneficial outcomes discussed above.

State governments can play a big role in instigating the necessary change. Following the example of New Hampshire, individual state legislatures can extend co-property rights to patients and providers. Providers, who would benefit greatly from the new arrangement, need to recognize the faults in the current system and use their powerful lobbying presence to advocate on the behalf of patients. While there are limitations and weaknesses to a policy advocating stronger patient property rights, it is clear the current system is in desperate need of change.

Stronger patient property rights will lead to better healthcare outcomes and quality of service for patients. Rapid access to office visit notes has led to improvement in ability to recall care plans, better self-care, a clearer understanding of conditions, and patients who feel more in control of their healthcare. Perhaps more importantly, case studies have shown that actual health outcomes improve. Additionally, several studies have proven that increased access and possession of records reassures patients, improves communication with doctors, and improves the quality of medical data. When patients become collaborators in care, quality of care increases.