

# Property, Privacy and the Pursuit of Integrated Electronic Medical Records<sup>1</sup>

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[W]e have a twenty-first-century financial information infrastructure and a nineteenth-century health information infrastructure. Given what is at stake, health care should be the most IT-enabled of all our industries, not one of the least. Nonetheless, the "technologies" used to collect, manage, and distribute most of our medical information remain the pen, paper, telephone, fax, and Post-It note. Meanwhile, thousands of small organizations chew around the edges of the problem, spending hundreds of millions of dollars per year on proprietary clinical IT products that barely work and do not talk to each other. Health care organizations do not relish the problem, most vilify it, many are spending vast sums on proprietary products that do not coalesce into a systemwide solution, and the investment community has poured nearly a half-trillion dollars into failed HIT ["health information technology"] ventures that once claimed to be that solution. Nonetheless, no single health care organization or HIT venture has attained anything close to the critical mass necessary to effect such a fix. This is the textbook definition of a market failure.<sup>2</sup>

## I. Introduction

### A. *The Stubborn Problem*

Medical information is one of the most prominent, puzzling, frustrating and entrenched dimensions of fragmentation in U.S. health care finance and delivery. We each confront this reality every time we go to a new doctor. Each doctor starts a new medical relationship virtually from scratch, as if we've never been examined before. Unless our referring physician has dictated a personal note, the only convenient way to transmit information from our existing medical records is by the patient's own word of mouth, which the doctor enters by hand and then feels the need to painstakingly re-confirm by direct re-examination. Even basic patient identification and family history information is written out and re-entered for each new doctor -- often even when they are practicing in the same medical system. And on, and on, throughout our kaleidoscopic medical system.<sup>3</sup>

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<sup>2</sup> J.D. Kleinke, Dot-Gov: Market Failure And The Creation Of A National Health Information Technology System, 24(5) Health Affairs 1246, 1247-48 (September/October 2005).

<sup>3</sup> For instance, frustration also extends to researchers who are forced to use primitive and cumbersome methods of primary data collection rather than being able to access consolidated information from existing medical records.

The dystopia of health care information automation in the US has frustrated the best and brightest minds for years, if not decades.<sup>4</sup> Widespread attention was first brought to the problem by an Institute of Medicine report in 1991.<sup>5</sup> Since then, an array of prominent organizations and individuals have made it their calling to overcome the barriers that keep health care providers from efficiently accessing and sharing a patient's complete medical record<sup>6</sup> -- but so far to no avail. The costs are staggering – from 100 billion hard dollars each year driven by needless duplication of procedures to perhaps a half trillion softer dollars annually associated with medication errors, lost worker productivity, and, in the most extreme cases, loss of life.<sup>7</sup>

The vision of what IT could bring to health care is well-formed and has been discussed at length.<sup>8</sup> Agreement on where we need to go is universal - from the President, to both Houses of Congress, to both major political parties, to hospitals, physicians, patients, payors, and the business community at large. Therefore, it is a puzzle why more progress has not been made. Only about a quarter of physicians use electronic medical records (EMRs) and fewer than 5% have fully functional systems.<sup>9</sup> Information technology (IT) is more prevalent in some hospital departments, such as radiology and laboratory testing, but fewer than 10% of hospitals have

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<sup>4</sup> See Edward H. Shortliffe, Strategic Action In Health Information Technology: Why The Obvious Has Taken So Long, *Health Affairs*, September/October 2005; 24(5): 1222-1233; Jeff Goldsmith, David Blumenthal, and Wes Rishel, Federal Health Information Policy: A Case Of Arrested Development, 22(4) *Health Aff.* 44 (July 2003); Himmelstein DU, Woolhandler S. Hope and hype: predicting the impact of electronic medical records, 24(5) *Health Aff.* 1121 (Sept. 2005).

<sup>5</sup> Institute of Medicine, *The Computer-Based Patient Record: An Essential Technology for Health Care* (1991).

<sup>6</sup> See, e.g., Dept. Health and Human Services, Health Information Technology Home, <http://www.hhs.gov/healthit/>; National Committee on Vital and Health Statistics, Workgroup On National Health Information Infrastructure, <http://www.ncvhs.hhs.gov/wg-nhii.htm> ; Markle Foundation, Connecting for Health, <http://www.connectingforhealth.com/> ; Robert Wood Johnson Foundation, Project HealthDesign, <http://www.projecthealthdesign.org/> ; California Healthcare Foundation, <http://www.chcf.org/topics/index.cfm?topic=CL108> ; Paul M. Ellwood, Crossing the Health Policy Chasm (February 18, 2003), <http://www.ppionline.org/ndol/print.cfm?contentid=251324>.

<sup>7</sup> These are “net” figures, that is, in excess of the costs of building and maintaining a comprehensive HIT system. Federico Girosi, Robin C. Meili, Richard Scoville, Extrapolating Evidence of Health Information Technology Savings and Costs (RAND Corp. 2005), <http://rand.org/pubs/monographs/MG410/>; Jan Walker, Eric Pan, Douglas Johnston, et al. The Value Of Health Care Information Exchange And Interoperability, *Health Affairs Web Exclusive*, January 19, 2005, <http://content.healthaffairs.org/cgi/content/full/hlthaff.w5.10/DC1>; Hillestad R, Bigelow J, et al., Can electronic medical record systems transform health care? Potential health benefits, savings, and costs, 24(5) *Health Aff.* 1103 (Sept. 2005). See generally Congressional Budget Office, *Evidence on the Costs and Benefits of Health Information Technology* (May 2008), available at <https://www.cbo.gov/ftpdocs/91xx/doc9168/05-20-HealthIT.pdf>

<sup>8</sup> For the latest, see Rodney A. Hayward, Access to clinically-detailed patient information: a fundamental element for improving the efficiency and quality of healthcare, 46(3) *Med Care.* 229 (2008); K.D. Mandl & I.S. Kohane, Tectonic shifts in the health information economy, 358 *N Engl J Med.* 1732 (2008); or any issue of these journals: *International Journal of Medical Informatics*, *Journal of the American Medical Informatics Association*, *Journal of Healthcare Information Management*, *Methods of Information in Medicine*; *BMC Medical Informatics and Decision Making*.

<sup>9</sup> Jha AK, et al., How common are electronic health records in the United States? A summary of the evidence, 25(6) *Health Aff.* w496 (Nov. 2006), <http://www.rwjf.org/pr/product.jsp?id=15315>; Catherine M. DesRoches, et al., Electronic Health Records in Ambulatory Care: A National Survey of Physicians, 359 *New Eng. J. Med.* 50 (2008).

basic systems for physicians to give their treatment instructions by computer (so-called computerized physician order entry (CPOE) systems).<sup>10</sup>

Even though e-health is growing steadily and will soon exist in some form just about everywhere, the electronic systems that are in place rarely interconnect -- a problem that is getting worse rather than better. The RAND Corporation summarizes that “the ability to share information from system to system is poor.” This is because there “is no market pressure to develop HIT systems that can talk to each other.” Instead, the “piecemeal implementation currently under way may actually create additional barriers to the development of a future standardized system because of the high costs of replacing or converting today’s non-standard systems.”<sup>11</sup>

The challenge is how to move an enterprise representing one-sixth of US GDP, with 13 million employees and potentially almost 300 million patients, from a decentralized, fragmented, paper based world, to an integrated, automated, networked world where information follows the patient, information-based tools can aid in decision making and quality, and population health data can be mined to improve the quality and outcome of care for all.

The goal of integrated electronic medical records (I-EMRs) has unqualified support from all quarters, but every effort to achieve it seems to end up stalled at a tactical or practical level. The most well-intentioned individuals driven by a common commitment encounter an all too-consistent pattern. While starting with a grand vision, they invariably encounter resistance in the trenches:

this doctor doesn’t support IT because he’s concerned that automation of health information will de-value the his practice’s resale value, . . . this hospital won’t allow access to their information, . . . these IT vendors won’t interoperate, this business is concerned that its employees will be suspicious of any effort by the employer to encourage employee participation in electronic health systems, this hospital administrator does not believe there is any return on IT investment and therefore won’t allocate the necessary funding to deploying the infrastructure.<sup>12</sup>

And so it goes – more money spent, more lives lost due to error, and more time gone by without making much progress toward the ultimate goal. Already it has been five years since President Bush issued a proclamation that within a decade every American who wants an electronic health record (EHR) will have one. Half of the time allocated to achieving this goal has elapsed – yet few feel that true momentum has developed to make this goal a reality in any foreseeable future.

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<sup>10</sup> David M. Cutler, et al., U.S. Adoption of Computerized Physician Order Entry Systems, 24(6) Health Aff. 1654 (Dec. 2005).

<sup>11</sup> RAND Corporation, Health Information Technology: Can HIT Lower Costs and Improve Quality? (2005) [http://www.rand.org/pubs/research\\_briefs/RB9136/index1.html](http://www.rand.org/pubs/research_briefs/RB9136/index1.html).

<sup>12</sup> Health Record Network, Response to Request for Information on CMS’ Role in Personal Health Records (Aug. 31, 2005).

## B. Private versus Public Solutions

Considering these failures, should the government intervene? Certainly, it should encourage and facilitate I-EMRs through various means,<sup>13</sup> as other countries have done, but in the U.S., the many well-intentioned and amply-supported efforts to create interconnected EMRs through central community planning have failed miserably, owing to the difficulties in meeting all the concerns of all the various stakeholders.<sup>14</sup> If all else fails, perhaps the government will have no choice but to require EHR adoption and integration, but there would be huge opposition to a “command and control” approach.<sup>15</sup> To paraphrase Winston Churchill, Americans usually resort to government mandates only after we’ve tried everything else first. This chapter explores whether there is still any hope for private initiative and market-driven innovation.

An analogy exists in the development of the Internet. Imagine that in 1990 a relatively small group of IT bureaucrats had sought to create the Internet of today. In a world where the penetration of personal computers in the home was very low and access was largely via slow-speed modems, when people still shopped only in stores and catalogues and used the public library for research, communicated only by letters, phones and faxes, etc., our clandestine team of IT bureaucrats would have had to anticipate every need, every implication and every cause and effect that occurs in something as massive and pervasive as the Internet we now know. This group would have needed to resolve every issue of deployment, standards, interoperability, new product design and new business model creation before the “product” was even introduced. Taken as a whole, these tasks would have led to the conclusion that “Internet 2008” could simply not be created. Yet every one of these actions did occur and coordinate, not by design but by market mechanisms, to create an environment that allowed the Internet to rapidly evolve to what we know it to be today.

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<sup>13</sup> The strongest case is to encourage or require some degree of standardization of clinical and/or IT protocols. Discussing current options and proposals, see, e.g., 72 Fed. Reg. 30803 (Oct. 31, 2007); Rosenfeld S, Bernasek C, Mendelson D, Medicare’s next voyage: encouraging physicians to adopt health information technology, 24(5) Health Aff. 1138 (2005); Roger Taylor, Anthony Bower, Federico Giroso, et al. Promoting Health Information Technology: Is There A Case For More-Aggressive Government Action?, 24(5) Health Affairs 1234 (Sept. 2005); David Brailer, Action through Collaboration, 24(5) Health Aff. 1150 (Sept. 2005); Jeff Goldsmith, David Blumenthal, and Wes Rishel, Federal Health Information Policy: A Case Of Arrested Development, 22(4) Health Aff. 44 (July 2003);

<sup>14</sup> Exhaustively cataloguing the many failures, see, e.g., Julia Adler-Milstein, et al., The State Of Regional Health Information Organizations, 27(1) Health Affairs w60 (Dec. 11, 2007), <http://content.healthaffairs.org/cgi/content/abstract/hlthaff.27.1.w60v1> ; Robert H. Miller and Bradley S. Miller, The Santa Barbara County Care Data Exchange: What Happened?, 26(5) Health Affairs w568 (August 1, 2007), <http://content.healthaffairs.org/cgi/content/full/26/5/w568> ; Jonah Frohlich, et al., Lessons Learned From The Santa Barbara Project And Their Implications For Health Information Exchange, 26(5) Health Aff. w589 (September 1, 2007), <http://content.healthaffairs.org/cgi/content/full/26/5/w589>; Bruce Merlin Fried, Gauging the Progress of the National Health Information Technology Initiative: Perspectives from the Field (January 2008) <http://www.chcf.org/topics/view.cfm?itemid=133553>; Joy M. Grossman, Kathryn L. Kushner, Elizabeth A. November, Creating Sustainable Local Health Information Exchanges: Can Barriers to Stakeholder Participation be Overcome? (February 2008) <http://www.hschange.org/CONTENT/970/>;

<sup>15</sup> See, e.g., Kleinke, surpa note \_\_\_, at 1250; Summary of Responses to an Industry RFI Regarding a Role for CMS with Personal Health Records, <http://www.cms.hhs.gov/PerHealthRecords/Downloads/SummaryofPersonalHealthRecord.pdf>.

Why is this spontaneous market development not happening for e-health? The primary barriers are not technological.<sup>16</sup> Instead, they are economic.<sup>17</sup> Realizing that the economics of e-health are shaped and driven by basic legal rights in networked medical information, this paper explores whether the law is responsible for, or might be a solution to, the Balkanization of medical information.

## II. The Structure and Economics of Electronic Medical Record Networks

### A. Network Economics

The economics of information networks reveal key reasons why many providers currently do not adopt EMRs and others do not interconnect the EMRs they have. The field of network economics has developed over the past generation to provide us much better understanding of the market dynamics for telecommunications, the internet, credit cards, and other large and complex interconnected services.<sup>18</sup> The core economic characteristic of these networks is that each user gets more benefit the larger the network is. Network effects exist whenever there are increasing returns to scale,<sup>19</sup> meaning that “the utility that a user derives from consumption of a good increases with the number of other agents consuming the good.”<sup>20</sup>

There are obvious network economies in connecting electronic medical records.<sup>21</sup> The more providers who are connected, the more comprehensive and useful is the information for any single patient. And, the more patients that are included, the more likely that providers will agree to participate. More patients and more information also make the network more useful for health services research and public health monitoring. If signing up more people produces more bang for the IT buck, why don't these win-win dynamics snowball into widespread EMR adoption and interconnection?

No one is in a position to build the network who can capture anywhere near its full social benefits.<sup>22</sup> In economic parlance, much of these benefits are externalized. Patients benefit from

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<sup>16</sup> Certainly, there are many practical issues that must be worked out, but they are solvable, at least in principle. See, e.g., Pamela Hartzband & Jerome Groopman, *Off the Record: Avoiding the Pitfalls of Going Electronic*, 358 NEJM 1656 (2008); R.D. Kush, et al., *Electronic health records, medical research, and the Tower of Babel*, 358 N Engl J Med. 1738 (2008); David Brailer, *Action through Collaboration*, 24(5) Health Aff. 1150 (Sept. 2005); W. Ed Hammond, *The Making and Adoption Of Health Data Standards*, 24(5) Health Affairs 1205 (Sept. 2005).

<sup>17</sup> Accord, see *Health Information Technology in the United States: Where We Stand, 2008*, available at <http://www.rwjf.org/files/research/062508.hit.exsummary.pdf>; CBO Report, *supra* note \_\_\_\_.

<sup>18</sup> See generally Yochai Benkler, *The Wealth of Networks: How Social Production Transforms Markets and Freedom* (2006), [http://www.benkler.org/wealth\\_of\\_networks/](http://www.benkler.org/wealth_of_networks/); Michael L. Katz & Carl Shapiro, *Network Externalities, Competition, and Compatibility*, 75 Am. Econ. Rev. 424 (1985); S.J. Liebowitz & Stephen E. Margolis, *Network Effects and Externalities*, in *The New Palgrave Dictionary of Economics and the Law* 671 (Peter Newman ed. 1998).

<sup>19</sup> This sounds similar to “economies of scale,” but those usually refer to decreasing costs. Networks may also have decreasing unit costs, but the term “network effects” refers to increasing benefits per user.

<sup>20</sup> Mark A. Lemley & David McGowan, *Legal Implications of Network Economic Effects*, 86 Cal. L. Rev. 479, 483 (1998).

<sup>21</sup> Congressional Budget Office, *Evidence on the Costs and Benefits of Health Information Technology* (May 2008), available at <https://www.cbo.gov/ftpdocs/91xx/doc9168/05-20-HealthIT.pdf>.

<sup>22</sup> See generally *id.*; Shekelle PG, Morton SC, Keeler EB. *Costs and Benefits of Health Information Technology. Evidence Report/Technology Assessment No. 132.* (April 2006), at 12,

better quality and the public at large benefits from research. Insurers (and other payors) benefit from lower costs, but only for the patients who are their subscribers. And each provider has a stake only in its treatments for its own patients.<sup>23</sup> None of these key actors benefits from all the gains that could be realized by the others, so none stands to accrue most of the rewards from the considerable costs of I-EMR development. (Estimates for a complete, nationwide system range from \$100 billion to \$300 billion.)<sup>24</sup>

Concretely illustrated, if a patient has seen four doctors already and is heading to a fifth, it is only the fifth who will benefit from the first four sharing their information in a useable form. A reciprocal network among them might make sense if they shared patients among each other in roughly equal proportions, but more likely some doctors tend to be senders and others receivers. Therefore, not everyone has the same incentive to invest in interconnected EMRs, and no one has sufficient incentive to pay the costs for the others. Because the networking costs are misaligned with the networking benefits, conversion to EMRs happens only sporadically, and interconnection is rare or incomplete.

More or less the same is true among insurers (or the employers who pay them). Payors might have a greater and more direct economic stake in forcing providers to adopt I-EMRs, but their interest is only in their own subscribers or employees. Typically, each provider belongs to dozen or more managed care networks. Therefore, it would be impractical for insurers or employers to insist on widespread adoption of a particular EMR system within their provider networks, regardless of who might foot the bill for doing so.

In addition, the particular institutional features of health care create negative economic incentives, that is, outright financial penalties, for networking. One benefit to patients of interconnecting is avoiding repeated testing to learn what other doctors already know. But, due to nearly ubiquitous fee-for-service reimbursement, from the doctor's perspective less testing means lost revenues. J.D. Kleinke astutely observes that, in "an industry rife with dirty little secrets, this is health care's dirtiest: . . . not knowing is good for business. . . . [T]he less the hospital knows about [a patient], the more services it can render, the more it can bill his health

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<http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat1b.chapter.6986> ("private return-on-investment (ROI) calculations can provide results that are quite different from those of societal cost-benefit analysis"); Anthony G. Bower, *The Diffusion and Value of Healthcare Information Technology* 62-63 (RAND Corp. 2005), <http://rand.org/pubs/monographs/MG272-1/> (stressing the "network externalities" that arise when each component of the system is under separate ownership).

<sup>23</sup> See CBO Report, *supra* note \_\_\_\_; Health Information Technology in the United States: The Information Base for Progress 44 (2006)

<http://www.rwjf.org/pr/product.jsp?id=15315> ("doctors and hospitals would capture only a small fraction of HIT's potential economic benefits. It has been estimated that as much as 80 percent of the potential savings generated through HIT inure to insurers and health care group purchasers"); Shekelle, et al., *supra* note \_\_\_\_ at 13 ("it does not pay one insurer to subsidize HIT for an entire provider or organization because a substantial portion of the cost savings accrue to other payers").

<sup>24</sup> Jan Walker, Eric Pan, Douglas Johnston, et al. *The Value Of Health Care Information Exchange And Interoperability*. Health Affairs Web Exclusive, January 19, 2005 (\$276 billion); Federico Girosi, Robin C. Meili, Richard Scoville, *Extrapolating Evidence of Health Information Technology Savings and Costs* (RAND Corp. 2005). <http://rand.org/pubs/monographs/MG410/> (\$97 billion). See generally CBO Report, *supra* note \_\_\_\_ (surveying and critiquing studies).



insurer, and the more it will collect.”<sup>25</sup> This is why it is difficult or impossible to make a “business case” for providers’ investment in I-EMRs, based only on the economic return on investment.

Doctors also fear that they will take on more liability exposure for knowing and managing information.<sup>26</sup> The more information they have access to, the more they are potentially responsible for. Increased scope of responsibility with decreased compensation is a recipe for intransigence.

A straightforward remedy for the fragmentation of medical records is for providers to integrate into comprehensive delivery systems. It is no surprise that interconnected EMRs have arisen so far only in integrated systems that operate under fixed, global budgets.<sup>27</sup> The leading U.S. examples are Kaiser-Permanente and the V.A., which have had model EMRs in place for decades.<sup>28</sup> These delivery systems internalize most of the network benefits from adopting I-EMRs since they contain almost all of their patients’ providers. Also, adopting EMRs does not cause negative economies for integrated systems. Reimbursement does not drop under global or capitated payments, and institutional liability does not expand.<sup>29</sup> Moreover, self-contained systems can interconnect EMRs more efficiently by adopting a single set of communications standards and protocols that apply to all of their physicians, who see only patients within the system.

So, clearly, the most effective solution is market or government integration of both health care delivery and financing. In fact, some analysts hope that the benefits of I-EMR will drive more systemic integration, perhaps by pushing toward a single-payor system or back to staff and group model HMOs. But those much larger topics are fanciful hopes that wish away our problem. Certainly, if the lack of I-EMR diffusion is a symptom of our system’s fragmentation, then curing the underlying disease could abate the ailment. But, we know that health care finance and delivery cannot be defragmented just by pressing a button. This book teaches us that fragmentation is chronic and deeply entrenched. Therefore, we need to search for effective ways to manage and mitigate its information management symptoms, along with all its other ills.

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<sup>25</sup> Kleinke, *surpa* note \_\_\_, at 1250-51. See also Robert H. Miller and Christopher E. West, *The Value Of Electronic Health Records In Community Health Centers: Policy Implications*, *Health Affairs* Jan/Feb 2007 26(1):206-214; *Health Information Technology in the United States: The Information Base for Progress* 43 (2006), <http://www.rwjf.org/pr/product.jsp?id=15315>.

<sup>26</sup> Sara Rosenbaum & Michael W. Painter, *When New is Old: Professional Liability in the Information Age*; GAO, *HHS’s Efforts to Promote Health Information Technology and Legal Barriers to Its Adoption*, GAO-04-991R (Aug. 13, 2004), <http://www.gao.gov/new.items/d04991r.pdf>; *Health Information Technology in the United States: The Information Base for Progress* (2006), at chap. 5, p. 45, <http://www.rwjf.org/pr/product.jsp?id=15315>.

<sup>27</sup> See, e.g., D. Rotti, *A Comparison of Information Technology in General Practice in Ten Countries*, 10 *Healthcare Q.* 107 (2007); Ashish K. Jha & David Blumenthal, *International Adoption of Electronic Health Records*, Chapter 7 in *Health Information Technology in the United States: Where We Stand*, 2008, available at <http://www.rwjf.org/files/research/062508.hit.exsummary.pdf>.

<sup>28</sup> Shekelle PG, Morton SC, Keeler EB. *Costs and Benefits of Health Information Technology*. Evidence Report/Technology Assessment No. 132. (April 2006), at 13, <http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat1b.chapter.6986>; GAO, *HHS’s Efforts to Promote Health Information Technology and Legal Barriers to Its Adoption*, GAO-04-991R (Aug. 13, 2004), <http://www.gao.gov/new.items/d04991r.pdf>; Dvid Mechanic, *Rethinking Medical Professionalism: The Role of Information Technology and Practice Innovations*, 86 *Milbank Q.* 327 (2008).

<sup>29</sup> Furthermore, antitrust liability is not a concern for cooperation among providers within an integrated network.

## *B. Partial Integration*

Short of full integration, providers can attempt partial integration by forming a contractual network that shares resources such as medical records. Some hospitals, for instance, are willing to bear or defray IT costs for physicians who adopt their EMR systems. Hospitals' side payments to referring physicians are one way to overcome some of the network externalities that physicians face in providing hospitals treatment information about their patients. These side payments potentially run afoul, however, of Medicare and tax-exemption laws designed to insulate hospitals financially from their referring physicians.<sup>30</sup> This appears to be another instance of the more general phenomenon noted by professor Blumstein, that while these laws welcome or allow full integration among providers, they illogically threaten and therefore retard various contractual arrangements that are transitional states between no integration and complete integration.<sup>31</sup>

For hospital support of physician EMRs, this problem appears to be solved, at least for now. After lawyers and policy officials drew sufficient attention for Congress to mandate action, HHS and IRS responded with rulings that create protective safe-harbors for hospital support of EMR software and training (but not for hardware).<sup>32</sup> These rulings have addressed much of the legal uncertainty that made doctors and hospitals hesitant to share IT resources. However, they have not produced a groundswell of EMR adoption and interconnection. The fundamental reality still exists that, under prevailing reimbursement methods it is not in providers' economic interest to fully automate and interconnect medical information.

Even if providers were to integrate IT, the following diagram<sup>33</sup> depicts broader network externalities: information systems built around medical treatment needs may fail to take account of the broader set of concerns encompassed by patient health and population health.

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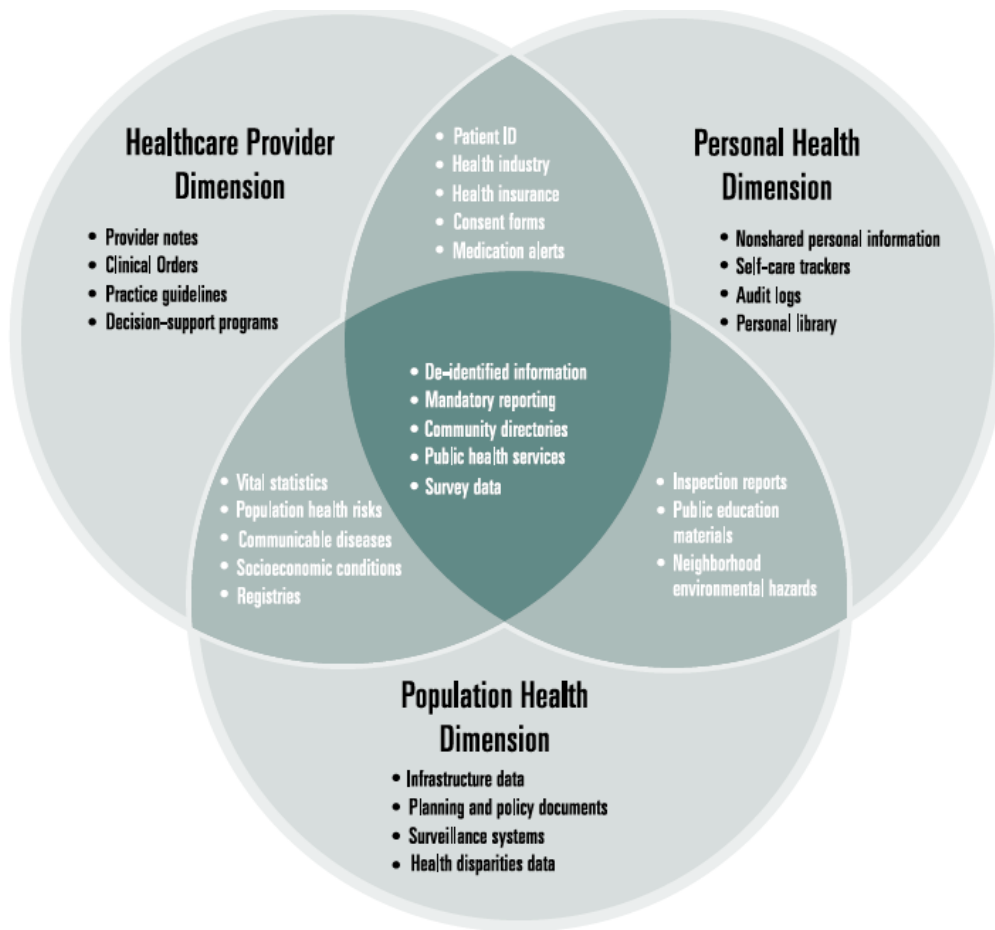
<sup>30</sup> GAO, HHS's Efforts to Promote Health Information Technology and Legal Barriers to Its Adoption, GAO-04-991R (Aug. 13, 2004), <http://www.gao.gov/new.items/d04991r.pdf>; Sara Rosenbaum, Phyllis C. Borzi, Lee Repasch, Charting the Legal Environment of Health Information, George Washington University School of Public Health (May 2005), <http://www.rwjf.org/files/research/Legal%20Environment%20Long%20Version.pdf>.

<sup>31</sup> James Blumstein, The Fraud and Abuse Statute in an Evolving Healthcare Marketplace: Life in the Health Care Speakeasy, 22 Am. J.L. & Med. 205 (1996).

<sup>32</sup> 71 Fed. Reg. 45110, 45140 (Aug. 8, 2006); IRS Memorandum dated May 11, 2007, <http://www.irs.gov/pub/irs-tege/ehrdirective.pdf>.

<sup>33</sup> From National Committee on Vital and Health Statistics, Personal Health Record Systems 12 (U.S. Department of Health and Human Services, 2006), <http://www.ncvhs.hhs.gov/0602nhirpt.pdf>.





I

The network externalities of provider-centric models have given rise to alternatives centered on insurers or employers,<sup>34</sup> but these too have their limitations. First, patients and providers may not trust payors sufficiently to contribute to and use their systems. Second, and more fundamentally, because most private doctors and almost all non-federal hospitals have patients from many different insurance plans, insurance-based models clearly fail to overcome fragmentation. Why should one insurer pay for an information system covering 10% of a doctor's patients that can be used for free on all patients? But, how is a doctor supposed to cope with a dozen different information systems?

In the end, both providers and payors face the fractured reality that an information system centered on a particular affinity group (providers, employers, or insurers) cannot efficiently interconnect all of a patient's relevant information. Therefore, we must look

<sup>34</sup> See, e.g., K.D. Mandl & T.S. Kohane, Tectonic shifts in the health information economy, 358 N Engl J Med. 1732 (2008).

elsewhere for ways to structure electronic medical networks that will capture (or internalize) the primary social benefits.<sup>35</sup>

### C. Patient-Centered Models

The emerging model for I-EHRs is patient-centric.<sup>36</sup> Under this model, each patient will have a life-time of digitized medical and health information at his fingertips and those of his providers. Providers will contribute to and use this record, but it will be controlled by patients and maintained by third parties on behalf of patients.<sup>37</sup> At the moment, a widely-discussed development is popular internet portals such as Microsoft or Google hosting secure data repositories that patients control and providers use. Other options include memory cards or chips that patients carry with them (or perhaps even have implanted) for easy access and continual updating.

Aside from the technological challenges, these models raise practical concerns that are formidable.<sup>38</sup> Who has the “legal” version of the record that existed at any given point? Will patients trust the host institutions? Will doctors trust and use the information in records of uncertain provenance? Do privacy laws apply? To address these problems, others propose a trustee model that places a patient-controlled record in the hands of some type of trustworthy and expert “infomediary” or “records bank.”<sup>39</sup>

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<sup>35</sup> Outlining competing and overlapping models, see generally Connecting for Health, Financial, Legal and Organizational Approaches to Achieving Electronic Connectivity in Healthcare (Oct. 2004), [http://www.connectingforhealth.org/assets/reports/flo\\_sustain\\_healthcare\\_rpt.pdf](http://www.connectingforhealth.org/assets/reports/flo_sustain_healthcare_rpt.pdf); David Blumenthal, Expecting the Unexpected: Health Information Technology and Medical Professionalism, in \_\_\_\_\_ D. Rothman & D. Blumenthal eds. (2009); Lisa Sprague, Personal Health Records: The People’s Choice? (National Health Policy Forum, Nov. 2006) [www.nhpf.org/pdfs\\_ib/IB820\\_PHRs\\_11-30-06.pdf](http://www.nhpf.org/pdfs_ib/IB820_PHRs_11-30-06.pdf); Altarum, Environmental Scan of the Personal Health Record (PHR) Market (October 31, 2006), [http://www.dhhs.gov/healthit/ahic/materials/meeting11/ce/EnvScan\\_PHRmarket.pdf](http://www.dhhs.gov/healthit/ahic/materials/meeting11/ce/EnvScan_PHRmarket.pdf); Nicolas P. Terry & Leslie P. Francis, Ensuring the Privacy and Confidentiality of Electronic Health Records, 2007 U. Ill. L. Rev. 681; Nicolas P. Terry, To HIPAA, a Son: Assessing the Technical, Conceptual, and Legal Frameworks for Patient Safety Information, 12 Widner L. Rev. 137 (2005); National Committee on Vital and Health Statistics, Personal Health Record Systems. U.S. Department of Health and Human Services (2006), <http://www.ncvhs.hhs.gov/0602nhiiirpt.pdf>.

<sup>36</sup> The seminal report is Connecting for Health, The Personal Health Working Group Final Report (Markle Foundation, June 2003) [http://connectingforhealth.org/resources/final\\_phwg\\_report1.pdf](http://connectingforhealth.org/resources/final_phwg_report1.pdf). See also Robert Steinbrook, Personally controlled online health data--the next big thing in medical care?, 358 N Engl J Med. 1653 (2008); Lisa Sprague, Personal Health Records: The People’s Choice? (National Health Policy Forum, Nov. 2006) [www.nhpf.org/pdfs\\_ib/IB820\\_PHRs\\_11-30-06.pdf](http://www.nhpf.org/pdfs_ib/IB820_PHRs_11-30-06.pdf). For a skeptical view, see Nicolas P. Terry, Personal Health Records: Directing More Costs and Risks to Consumers?, forthcoming 2009.

<sup>37</sup> For examples and detailed descriptions, see id.; Carol Cronin, Personal Health Records: an Overview of What Is Available To the Public, AARP Research Report (May 2006), [http://www.aarp.org/research/health/carequality/2006\\_11\\_phr.html](http://www.aarp.org/research/health/carequality/2006_11_phr.html); Altarum, Environmental Scan of the Personal Health Record (PHR) Market (October 31, 2006), [http://www.dhhs.gov/healthit/ahic/materials/meeting11/ce/EnvScan\\_PHRmarket.pdf](http://www.dhhs.gov/healthit/ahic/materials/meeting11/ce/EnvScan_PHRmarket.pdf); <http://www.informatics-review.com/records.html>; [http://www.myphr.com/resources/phr\\_search.asp](http://www.myphr.com/resources/phr_search.asp).

<sup>38</sup> See Sprague, *supra* note \_\_\_\_; Terry, *supra* note \_\_\_\_.

<sup>39</sup> Agency for Healthcare Research and Quality, National Health Data Stewardship, 72 Fed. Reg. 30803 (Oct. 31, 2007); A. Shabo, A global socio-economic-medico-legal model for the sustainability of longitudinal electronic health records, 45(3 & 5) Methods Inf Med. 240-5, 498-505 (2006); T.R. Knapp, J. Walter. C.P. Renaudin, Property rights and privacy principles, 14(4) J Healthc Inf Manag. 83 (2000); Paul T. Kostyack, The emergence of the Healthcare Information Trust, 12 Health Matrix 393 (2002); Judah Thornewill, Robert J. Esterhay, Capitalizing the NHIN-A Strategy for Funding an Integrated Nationwide Network of Community HIEs, 32(3) J.

We are not lacking for innovative ideas and alternative models. Which ones ultimately end up prevailing and in what forms will be determined not only by how well they work, but also by the basic legal framing of competing rights in and to medical information and its economic value. Some of these models assume that medical information is a public good. Others assume that patients have ultimate ownership and control. Some assume that medical information will change hands in exchange for money; others assume an admirable degree of non-remunerated cooperation, based on a variety of motives.

Increasingly, participants in and observers of the HIT sector recognize that monetizing medical information in some form is necessary in order to align interests and overcome the economic barriers to forming I-EMRs. One leading group of diverse experts,<sup>40</sup> for instance, concluded that a “critical path to enabling a market” for I-EMRs is “[e]nabling consumers to monetize their medical data” by giving them “economic interests . . . from providing access to their data.”<sup>41</sup> But, is this allowed, and in what circumstances? Because the law’s uncertainty over ownership and control of medical information is widely regarded as a major barrier to effective networking of EMRs, policy analysts consider the legal status of medical information to be a critical question at or near the top of issues needing resolution.<sup>42</sup> All parties are looking to the law to define the ownership, control, and commercialization potential of medical information. How these issues are resolved ultimately will determine which information network models are economically viable and what form they will take.

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Healthcare Info. Mgt., 18 (2007); Edmund F. Haislmaier, Health Care Information Technology: Getting the Policy Right, Heritage Foundation WebMemo #1131 (June 16, 2006); <http://www.heritage.org/Research/HealthCare/wm1131.cfm>; Health Record Banking Alliance, <http://www.healthbanking.org>.

<sup>40</sup> These were participants invited to a conference at Harvard Medical School, from academia, government, and industry. The conclusions described here were those of the business model discussion group at the conference.

<sup>41</sup> PCHRI 2006, the Harvard Medical School Meeting on Personally Controlled Health Record Infrastructure. [http://www.pchri.org/2006/presentations/pchri2006\\_track\\_output.pdf](http://www.pchri.org/2006/presentations/pchri2006_track_output.pdf). Accord Edmund F. Haislmaier, Health Care Information Technology: Getting the Policy Right, Heritage Foundation WebMemo #1131, June 16, 2006 <http://www.heritage.org/Research/HealthCare/wm1131.cfm>, (“The best way to induce patients and providers to share the individual data they create is to help them unlock the value of that data and share in the benefits derived from letting others use it.”).

<sup>42</sup> Stressing the importance of legal resolution of property interests, see, e.g., Edmund F. Haislmaier, Health Care Information Technology: Getting the Policy Right, Heritage Foundation WebMemo #1131, June 16, 2006 <http://www.heritage.org/Research/HealthCare/wm1131.cfm>; Altarum, Environmental Scan of the Personal Health Record (PHR) Market 20 (October 31, 2006), [http://www.dhhs.gov/healthit/ahic/materials/meeting11/ce/EnvScan\\_PHRmarket.pdf](http://www.dhhs.gov/healthit/ahic/materials/meeting11/ce/EnvScan_PHRmarket.pdf) (“Ultimately, legal ownership of the PHR and its data is a core unresolved issue, and will likely require further clarification at the state and federal levels.”); Rodwin, supra note \_\_\_; Sara Rosenbaum, Phyllis C. Borzi, Lee Repasch, Charting the Legal Environment of Health Information, George Washington University School of Public Health 29 (May 2005) <http://www.rwjf.org/files/research/Legal%20Environment%20Long%20Version.pdf> (“questions regarding ownership must be resolved at an extremely early stage of the process”); Nicolas P. Terry, Legal Barriers to Realizing the Public Good in Clinical Data, in Institute of Medicine, Clinical Data as the Basic Staple of Health Learning (2009); Barbara Harty-Golder, EMR Ownership Questions, Medical Laboratory Observer, July 2007; C. Safran, M. Bloomrosen, W.E. Hammond, et al., Toward a national framework for the secondary use of health data: an American Medical Informatics Association White Paper, 14 J Am Med Inform Assoc. 1 (2007), <http://www.jamia.org/cgi/content/abstract/14/1/1>.

### III. Property and Privacy Rights in Medical Information

“Your original medical record is property of [the hospital], but the information in it belongs to you.”<sup>43</sup>

The AMA [advocates] that physicians own [their electronic medical data]. . . . [William A. Hazel Jr., MD, a member of the AMA's Board of Trustees] said this is a concern because "there is tremendous economic value to the cumulative data in terms of analyzing patterns," and without clear physician ownership, third-party vendors could reap the profits.<sup>44</sup>

Because data is generated only by a patient-provider interaction, the most reasonable legal approach is to recognize both parties' claims to co-ownership of the resulting data. If other parties, such as a payer, are involved, then they too have a reasonable claim to ownership of that portion of the information that is generated by their involvement. . . . [The system] should be governed by a legal structure which recognizes that virtually all health system data is 'co-owned' by two or more parties.<sup>45</sup>

[A] serious impediment to a comprehensive approach in the U.S. is the lack of clarity in this country about the nature of the interest that individuals have in information about themselves: Is it a commodity interest, a consumer protection interest, a personal dignity interest, a civil right interest, all of the above, or no interest at all? . . . Without a coherent conception about the nature of a person's interest in personal data, it is difficult to design a legal regime to protect this interest appropriately.<sup>46</sup>

#### A. *Legal Uncertainty as a Barrier*

Who owns medical information? Patients, providers, both of the above, or no one? The law provides incomplete, unclear, and somewhat inconsistent answers. But does this matter? According to one version of the “Coase Theorem,” ownership in theory does not affect social welfare as long as transaction costs are roughly equivalent either way.<sup>47</sup> Regardless of how the law makes the initial assignment of ownership, the parties are free to reallocate their rights and responsibilities by agreement however will best achieve their goals. But there is at least one important proviso to this Theorem: property rights must be clearly established so that the respective parties know their legal default positions.<sup>48</sup> As revealed by the preceding quotations, this condition clearly is not met here. The relevant parties are in a quandary over who owns or

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<sup>43</sup> [www.bannerhealth.com](http://www.bannerhealth.com). See also [http://www.myphr.com/what/who\\_owns\\_info.asp](http://www.myphr.com/what/who_owns_info.asp) (“Your physical health record belongs to your healthcare provider, but the information in it belongs to you”); N.H. REV. STAT. ANN. x 332-I:1 (“All medical information contained in the medical records in the possession of any health care provider shall be deemed to be the property of the patient.”).

<sup>44</sup> Kevin B. O'Reilly, AMA to set guidelines on control of record data, *Am Med. News*, Nov. 28, 2005.

<sup>45</sup> Edmund F. Haislmaier, *Health Care Information Technology: Getting the Policy Right*, Heritage Foundation WebMemo #1131, June 16, 2006, available at <http://www.heritage.org/Research/HealthCare/wm1131.cfm>

<sup>46</sup> Pamela Samuelson, *Privacy as Intellectual Property?*, 52 *Stan. L. Rev.* 1125, 1170-71 (2000).

<sup>47</sup> Richard S. Murphy, *Property Rights In Personal Information: An Economic Defense Of Privacy*, 84 *Geo. L.J.* 2381, 2387, 2403, 2395, (1996) (applying Coase's theorem to property rights in personal information);

<sup>48</sup> If legal positions are uncertain, parties can still attempt simply to stake a claim, forcing a negotiation toward a contractual settlement that determines respective rights, but such contracts bind only the immediate parties, and the process of negotiation is an expensive barrier. Establishing clear property rights a priori therefore greatly facilitates contractual transfer of these rights. Licensing of intellectual property rights is an obvious case in point.

controls what and so they do not know for sure what needs to be done to construct any particular information network model.<sup>49</sup> Moreover, even if they were sure, the initial assignment of rights determines *private* welfare to a great extent since these rights form the parties' initial endowments that confer bargaining power. Accordingly, it matters a great deal to real-world actors who has exactly what rights in different aspects of medical record information.

Medical information has considerable commercial value. “[A] well-established multimillion-dollar business exists that utilizes secondary health data as its primary resource,”<sup>50</sup> for purposes such as marketing to physicians or conducting medical research.<sup>51</sup> Legal uncertainty or agnosticism over valuable property rights can spark a land grab that hoards rather than develops these productive assets. Once one party stakes its ownership claim, then so must all the other competing parties, for fear of being trumped. But, fencing off the terrain of medical information destroys the commons that might have supported valuable public goods. Witness the A.M.A.'s proclamation quoted above that physicians own the medical information they collect.<sup>52</sup> Likewise, the Center for Studying Health System Change observed that hospitals' greatest concern with I-EMRs is “losing competitive advantage by relinquishing control of ‘their’ data. They view[] clinical data as a key strategic asset, tying physicians and patients to their organization.”<sup>53</sup>

Legal logjams also arise from privacy protections. Medical privacy is important, but we may be protecting it to a fault. The risk of infringing patients' privacy rights gives providers another reason to be isolate their medical records.<sup>54</sup> In one empirical study, economists at the University of Virginia and M.I.T. found that “state privacy laws make hospitals 33 percent less

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<sup>49</sup> See, e.g., C. Safran, M. Bloomrosen, W.E. Hammond, et al., Toward a national framework for the secondary use of health data: an American Medical Informatics Association White Paper, 14 J Am Med Inform Assoc. 1, 7-8 (2007), <http://www.jamia.org/cgi/content/abstract/14/1/1> (posing several scenarios involving networked medical information where the first and primary question raised is “who owns the data”).

<sup>50</sup> C. Safran, M. Bloomrosen, W.E. Hammond, et al., Toward a national framework for the secondary use of health data: an American Medical Informatics Association White Paper, 14 J Am Med Inform Assoc. 1 (2007), <http://www.jamia.org/cgi/content/abstract/14/1/1>.

<sup>51</sup> Robert Steinbrook, For sale: physicians' prescribing data, 354 N Engl J Med. 2745 (2006); Judah Thornewill, Robert J. Esterhay, Capitalizing the NHIN-A Strategy for Funding an Integrated Nationwide Network of Community HIEs, 32(3) J. Healthcare Info. Mgt., 18 (2007).

<sup>52</sup> Supra note \_\_\_\_.

<sup>53</sup> Joy M. Grossman, Kathryn L. Kushner, Elizabeth A. November, Creating Sustainable Local Health Information Exchanges: Can Barriers to Stakeholder Participation be Overcome? 5 (February 2008), <http://www.hschange.org/CONTENT/970/>.

<sup>54</sup> See Health Information Technology in the United States: The Information Base for Progress (2006), at Chap. 5, p. 45, <http://www.rwjf.org/pr/product.jsp?id=15315> (based on an extensive literature review, the “actual or perceived legal burden of compliance with” privacy regulations is a barrier to EHR adoption); Bruce Merlin Fried, Gauging the Progress of the National Health Information Technology Initiative: Perspectives from the Field 12 (January 2008) <http://www.chcf.org/topics/view.cfm?itemid=133553> (many leaders and experts in the HIT community “believe that the resulting series of state and federal privacy policies hinders the flow of personal health information.”); Connecting for Health, Financial, Legal and Organizational Approaches to Achieving Electronic Connectivity in Healthcare (Oct. 2004), [http://www.connectingforhealth.org/assets/reports/flo\\_sustain\\_healthcare\\_rpt.pdf](http://www.connectingforhealth.org/assets/reports/flo_sustain_healthcare_rpt.pdf); Joy M. Grossman, Kathryn L. Kushner, Elizabeth A. November, Creating Sustainable Local Health Information Exchanges: Can Barriers to Stakeholder Participation be Overcome? 5 (February 2008) <http://www.hschange.org/CONTENT/970/>.



likely to choose [HIT] software that is easily compatible with neighboring hospitals.”<sup>55</sup> Notably, the deterrence comes directly from dampening network benefits that would accrue by sharing electronic data among hospitals: “the enactment of state privacy laws restricting the transfer of medical information from hospitals inhibits network effects that would have otherwise promoted hospital adoption of EMR.”<sup>56</sup> The high prices paid for patient-anonymized data about physicians’ prescribing behaviors demonstrates that, in the absence of privacy restrictions, vibrant markets in medical information can develop quickly and easily.

The legal threat from privacy laws may be based more on the perception of legal exposure than on its reality. A comprehensive analysis of all 113 relevant legal cases found no real cause for concern.<sup>57</sup> Nevertheless, the perception of legal risk appears to be genuine,<sup>58</sup> perhaps due simply to uncertainty over the possible effects of these complex laws. Uncertainty costs played a major role, for instance, in one of the most visible attempts and dramatic failures to establish an I-EMR system among local providers in Santa Barbara. There (according to the National Coordinator for Health Information Technology), privacy laws “were major issues from the outset. More money was spent on attorneys’ fees than on technology, consulting, or any other line item,” because “[a]ny number of lawyers would draw different conclusions from the federal and state privacy rules that were spread across many chapters of code and among many agencies.” Therefore, it was “difficult for fifteen provider-leaders of the Santa Barbara Project to understand or agree on what they could or should do under these rules.”<sup>59</sup>

The oppressive aura of privacy laws is one reason that non-provider-based models for I-EMR networks are emerging so strongly (as noted above). If centralized medical records are maintained by someone who is not involved in health care finance or delivery, they are not subject to the same privacy strictures. Some analysts call for expanding the federal privacy rule to cover anyone who possesses identifiable patient information,<sup>60</sup> but the impact of existing privacy laws should be studied more carefully before making this potentially crippling jump.

From the economic perspective of investing in medical information, the lack of clear property rights plus the presence of strong privacy protections is the worst of both worlds. Privacy protections increase the costs of developing I-EMRs and uncertain property rights

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<sup>55</sup> Amalia R. Miller and Catherine Tucker, Privacy Protection and Technology Diffusion: The Case of Electronic Medical Records 4 (February 5, 2008), available at <http://ssrn.com/abstract=960233>.

<sup>56</sup> Id. at 21.

<sup>57</sup> Sara Rosenbaum, et al., Does HIPAA Preemption Pose a Legal Barrier To Health Information Transparency and Interoperability?, 16(11) Health L. Rep. (BNA) 1 (March 22, 2007) [http://www.gwumc.edu/sphhs/healthpolicy/chsrp/downloads/BNA\\_HIPAA\\_Privacy\\_Preemption\\_031907.pdf](http://www.gwumc.edu/sphhs/healthpolicy/chsrp/downloads/BNA_HIPAA_Privacy_Preemption_031907.pdf).

<sup>58</sup> The Georgetown study, id. at 2, for instance, concluded that “misunderstandings about the breadth, scope, and content of HIPAA’s basic rules, and the flexibility that covered entities have to design their own privacy policies appear to contribute to the perception that HIPAA and its preemption provisions may impede the development of interoperable and transparent health care information systems.”

<sup>59</sup> David J. Brailer, From Santa Barbara To Washington: A Person’s And A Nation’s Journey Toward Portable Health Information, 26(5) Health Aff., w581, w587 (September 1, 2007) <http://content.healthaffairs.org/cgi/content/full/26/5/w581>.

<sup>60</sup> E.g., National Committee on Vital and Health Statistics, Personal Health Record Systems. U.S. Department of Health and Human Services 21 (2006), <http://www.ncvhs.hhs.gov/0602nhirpt.pdf>; Sharona Hoffman & Andy Podgurski, In Sickness, Health, and Cyberspace: Protecting the Security of Electronic Private Health Information, 48 B.U. L. Rev. 331 (2007).



decrease the returns. How these barriers and uncertainties are resolved could determine the kinds of networks that will emerge and how efficiently they can form. Accordingly, this section sorts out who owns or controls exactly what, of both the pure information content of medical records and their physical embodiment. The tangible-intangible distinction is critical: the property regime that potentially applies to the paper or computer files that store medical records differs considerably from the intellectual property rights in their information content. We start with the latter.

### *B. Patients Lack Intellectual Property Rights in their Medical Information*

People frequently ask: Is medical information the patient's property or the provider's? Framing the question this way fails to leave open the possibility that often no one owns information, even when it is important and valuable. According to intellectual property scholar Pam Samuelson, "the traditional view in American law has been that information as such cannot be owned by any person."<sup>61</sup> Statutorily created property rights in certain types of information (via patents or copyright) are exceptions to this general rule, created to induce the production of new information with the expectation that it will be freely available to all after ownership expires.

These general understandings about creative and technical ideas also apply to everyday information about people. Scholars have explained at length that people do not own the information they reveal about themselves when they shop in stores, browse the internet, or set forth into any other public arena. Some analysts have argued for creating a species of intellectual property covering valuable information about ourselves, but courts and legislatures have not heeded these calls. One property law scholar explains that, "neither property nor torts theory recognizes individuals' rights in their [personal] information. At the heart of that nonrecognition is a view that personal information is no one's until collected . . ." Instead, personal information is like a wild animal, "not owned by anyone until captured."<sup>62</sup>

These basic rules also govern medical information. As explained by the High Court of Australia in a case involving a patient's access to her own medical records, it "is only in a loose metaphorical sense that any knowledge as such can be said to be property."<sup>63</sup> Privacy law gives patients the right to control access to their medical information, and patients have rights to inspect, copy, and correct their medical records. While these privacy and access rights can be enforced in ways similar to property rights, properly characterized they are not actually property rights that can readily be bought and sold.<sup>64</sup> Privacy and access rights arise out of the special relationship patients have with their providers and so they are enforceable only against those providers, not against the world at large.

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<sup>61</sup> Supra note \_\_\_\_, at 1130-31.

<sup>62</sup> Vera Bergelson, *It's Personal but Is It Mine? Toward Property Rights in Personal Information*, 37 U.C. Davis L. Rev. 379, 403 (2003).

<sup>63</sup> *Breen v. Williams*, 186 C.L.R. 71, 128 (per Gummow J.) (Australia 1996) (quoting Federal Comm'r of Taxation v. *United Aircraft Corp.*, 68 C.L.R. 525, 534 (Australia 1943)). See also Marc A. Rodwin, *Patient Data: Professionalism, Property & Policy*, in \_\_\_\_\_, David Rothman & David Blumenthal, eds. (2009) (the law "does not give patients exclusive ownership rights in this information, [n]or does the law grant exclusive property rights in patient data to other parties to have access to this information."). Likewise

<sup>64</sup> See *Estate of Finkle*, 90 Misc.2d 550, 552, 395 N.Y.S.2d 343, 344 (N.Y.Sur. 1977).

For other types of personal information, lack of ownership leaves the information in the public domain where commercial or other productive uses can be made by anyone who cares to invest the resources in collecting and compiling it. (Witness phone books, for instance.) In contrast, because providers strongly guard the privacy of medical information, it remains out of circulation even though it is not, strictly speaking, owned. This combination of no ownership plus limited access leaves medical information lying dormant in an abandoned and fallow field (reminiscent of the former absence of phone books in the old Soviet bloc). Lacking any legal rights that clearly can be monetized, patients have no market mechanism for overcoming network externalities. Patients may control their medical information, but have no ready way to transfer their rights.<sup>65</sup>

As developed below, propertizing medical information could stimulate increased flow of medical information into more useful forms by giving the stakeholders rights of access and control they can buy and sell. But, we also must beware that expanding stakeholders' legally-protected economic rights could cause even more constipation. As we will learn shortly, there is a faint path between the extremes of too few and too many property rights in medical information. To see this more clearly, we next turn to providers' rights in their medical records.

### *C. Providers and Insurers have Tangible Property Rights in their Medical Records*

Although medical information, per se, is not property, medical records are. The adage "possession is nine-tenths of the law" applies with full force to patients' records. Those who possess and compile medical records own their tangible embodiment -- whether paper or electronic.<sup>66</sup> Medical records in any form are recognized as key assets in a physician's practice, which can be assigned an express economic value and sold as part of the business.<sup>67</sup> This does not mean, however, that health care providers can own a patient's medical information per se. Owning a book does not equate with owning its intellectual content. A property interest in a

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<sup>65</sup> Although there is no reason in legal theory that they could not transfer their rights, possible ways of doing so have not been tested in the market or in court, so we do not know for sure. One reason they have not been tried is the absence of any legal recognition on the part of third parties to further license or sell these rights. In other words, we might have some confidence that one-step transfers to an immediate party are permitted, but we have good reason to doubt or question whether downstream transfers and commercialization of patients' access rights would currently be allowed. This downstream uncertainty perhaps explains why this route has never been explored.

<sup>66</sup> Estate of Finkle, 90 Misc.2d 550, 552, 395 N.Y.S.2d 343, 344 (N.Y.Sur. 1977) ("the vast majority of states hold 'that medical records are the property of the physician or the hospital and not the property of the patient.'") (quoting Gotkin v. Miller, 379 F.Supp. 859, 866-867 (E.D.N.Y.1974), aff'd. 514 F.2d 125 (2d Cir. 1975)); Nicolas P. Terry & Leslie P. Francis, Ensuring the Privacy and Confidentiality of Electronic Health Records, 2007 U. Ill. L. Rev. 681, 709 ("It is generally accepted that doctors own the medical records they keep about patients."); Taylor Burke, Joy Pritts, & Sara Rosenbaum, Patient Health Records Law in the Age of Health Information (Dec. 2007) ("Traditionally, state laws have treated the 'physical' patient health record as the property of the health care provider who created it."); Paul V. Stearns, Access to and cost of reproduction of patient medical records: A comparison of state laws, 21 J Leg Med. 79, 98 (2000).

<sup>67</sup> See Joy M. Grossman, Kathryn L. Kushner, Elizabeth A. November, Creating Sustainable Local Health Information Exchanges: Can Barriers to Stakeholder Participation be Overcome? 11 (February 2008) <http://www.hschange.org/CONTENT/970/> ("Institutions and provider practices treat health data as a business asset over which these organizations can exert property rights"). Cf. Vera Bergelson, It's Personal but Is It Mine? Toward Property Rights in Personal Information, 37 U.C. Davis L. Rev. 379, 404, 411 (2003) (in variety of legal and business contexts, courts and commercial practices consistently regard customer lists as property).

patient's medical record means only that one owns the particular embodiment and not the pure information content.

This distinction is easy to obscure when medical records are in electronic rather than paper form, but the distinction is no more difficult to maintain than that between the copyright holder in music, art, literature or software and the purchasers of digitized copies of each of these. Because information is intangible, a doctor's or hospital's ownership of medical records does not foreclose or interfere with others' ownership of different embodiments of the same information. The same is true for medical information that anyone else might lawfully compile.

Multiple ownership of different pieces of a patient's medical history, however, makes it difficult for anyone to assemble a complete record. Balkanization among providers and insurers creates what legal scholars have termed an "anticommons" problem - one in which competing rights holders foreclose each other from productive use of a shared resource.<sup>68</sup> The term "anticommons" is meant to contrast with the more familiar "tragedy of the commons."<sup>69</sup> When no one owns a shared resource and there are competing uses -- as when ranchers share a common pasture -- then it frequently happens that the resource is depleted, to everyone's detriment (for instance, by overgrazing). Medical (or any other kind of) information does not present a commons problem because its use is nonrivalrous.<sup>70</sup> Multiple users do not deplete information; indeed, multiple users may enhance the information's value. But instead, overlapping interests in a patient's medical information creates the opposite problem: the inability of anyone to compile and use a complete record.

More than one stakeholder having the right to block or exclude others from using or developing a good is a classic anticommons situation. Each of a patient's health care providers and insurers owns a piece of the patient's complete medical treatment and health history and therefore each has the ability to exclude others from forming or using the complete record. Since the complete record has greater value than the sum of its parts, there is value to be gained in gathering all the pieces together, but no single provider or insurer can accomplish this.

Conceivably, an organizer could pay all necessary providers and insurers to induce their cooperation, but this would raise significant issues under the state and federal privacy laws addressed above. Patients can give permission to reveal or release medical information, but privacy laws deter using this legal authority to build repositories that can be shared with others for a fee. These laws make it cumbersome to share medical information with others. They also cloud whether a patient's permission can include selling access to medical information. Even if law does not strictly prohibit this, it does not clearly allow it, and public policy advocates often disfavor commodifying or monetizing medical information.<sup>71</sup>

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<sup>68</sup> See Marc A. Rodwin, *PATIENT DATA: PROFESSIONALISM, PROPERTY & POLICY* (2009).

<sup>69</sup> The seminal article is Michael Heller, *The Tragedy of the Anticommons: Property in Transition from Marx to Markets*, 111 *Harv. L. Rev.* 621 (1998).

<sup>70</sup> Richard A. Posner, *The Right of Privacy*, 12 *Georgia Law Rev.* 393 (1978).

<sup>71</sup> See, e.g., National Committee on Vital and Health Statistics, *Personal Health Record Systems*. U.S. Department of Health and Human Services 19 (2006), <http://www.ncvhs.hhs.gov/0602nhiiirpt.pdf> (expressing concern that "relying entirely on market forces to determine the nature and direction of PHR systems could cause personal health information to be exploited for its economic value without adequate consumer controls.").

If these uncertainties could be resolved, we would still face a more fundamental problem. Multiple stakeholders in a single prize creates problems of coordination and strategic behavior that are difficult to solve through private ordering.<sup>72</sup> Where the prize is a network benefit -- one whose value depends on the number of joiners -- later joiners sometimes obtain or confer more value than early ones, creating an obvious disincentive to join at all.<sup>73</sup> Real estate developers know this as the hold-out problem. In HIT, one form of this dynamic is the reluctance to join until technology standards are settled, for fear the early systems will soon become outmoded. Elsewhere, we can see other analogies in the “thickets” or “stacking” of multiple intellectual property interests in different aspects of a complex new technology or an entertainment production.<sup>74</sup> In these various situations, divided ownership or control of a common good makes it extremely difficult to assemble the pieces of the pies even though the collective benefits would be well worth the costs.

This tragedy of the anticommons explains, for instance, the lack of interoperability among EMRs even when they do exist. A comprehensive survey by the influential Markle Foundation concluded that providers’ ownership of medical records is a barrier to I-EHRs because “providers treat patient information as a highly proprietary asset that serves as a means of differentiation from the competition. . . . As a result, IT vendors compete without data standards and healthcare data becomes institution-based and compartmentalized.”<sup>75</sup> According to another report, “the momentum [toward electronic records] is so great that the effort could be at risk of fragmenting, with companies and institutions producing a dizzying array of personally controlled health records. ‘The danger is that they each create their own system and every American now has the opportunity to have 17 personally controlled records rather than one.’”<sup>76</sup>

Overcoming fractured ownership is critical to constructing a functioning I-EMR system. Imagine, for instance, that the country had tried in the 1950s to assemble its current interstate highway system out of thousands of separate segments that were privately owned. The coordination problems would be immense, and the holdout problems insurmountable. Imagine also if local nuisance ordinances gave any neighboring resident a right to object if traffic noise or pollution were a bother. Obviously, a smooth flowing, interconnected highway system could never form under these legal and economic conditions, yet these essentially are the conditions that afflict medical information. Health care providers and payors own each local segment of the envisioned information highway, and patients are the affected parties whose permission is needed for access. The resulting anticommons phenomena for I-EMRs are severe.

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<sup>72</sup> F. Scott Kieff & Troy A. Paredes, *Engineering a Deal: Toward a Private Ordering Solution to the Anticommons Problem*, 48 B.C. L. Rev. 111 (2007).

<sup>73</sup> Mark A. Lemley, *Private Property*, 52 Stan. L. Rev. 1545, 1553 (2000).

<sup>74</sup> Kieff & Paredes, *supra* note \_\_; Michael A. Heller & Rebecca S. Eisenberg, *Can Patents Deter Innovation? The Anticommons in Biomedical Research*, 280 Science 698 (1998); Mark A. Lemley & Carl Shapiro, *Patient Holdup and Royalty Stacking*, 85 Tex. L. Rev. 1991 (2007).

<sup>75</sup> *Connecting for Health, Financial, Legal and Organizational Approaches to Achieving Electronic Connectivity in Healthcare* (Oct. 2004), [http://www.connectingforhealth.org/assets/reports/flo\\_sustain\\_healthcare\\_rpt.pdf](http://www.connectingforhealth.org/assets/reports/flo_sustain_healthcare_rpt.pdf).

<sup>76</sup> *Personally Controlled Health Records: Are They the Next Big Thing?*, Focus: News from Harvard Medical, Dental, and Public Health Schools (Oct. 27, 2006), [http://focus.hms.harvard.edu/2006/102706/information\\_technology.shtml](http://focus.hms.harvard.edu/2006/102706/information_technology.shtml) (quoting a Harvard professor who is an expert on HIT).

#### *D. Patients' Rights of Access are Necessary but not Sufficient*

Can law loosen this logjam? Property theorists warn that, once anticommons conditions are created, they can be very difficult to undo. One possible solution is a hierarchy of rights, whereby providers' interests are subsidiary to a patient's. If a patient could command his providers to cooperate with a medical record compiler, then a well motivated and informed patient might be able to break through the thicket of providers' and insurers' competing interests.

A blunt way to confer this authority would be to declare that patients have ultimate ownership of their medical records and that providers' interests are merely "custodial," holding them in trust for the benefit of their patients. Trusteeships and bailments are certainly well known in law, and this is essentially the legal characterization being adopted by non-health care hosts of patient-controlled personal health records (such as Microsoft and Google). However, mere custodianship does not fit the law's current understanding of providers' true ownership of their medical records.<sup>77</sup> The next section explores whether patients *should* be given an intellectual property interest in their medical information, but presently the law decidedly does *not* do so.

Short of ownership, though, the law does give patients a right to inspect, copy, and correct their medical information. (In other words, a provider's property right to exclude others is good against all the world except the patient.) Prior to HIPAA, this access right was (and still is) embodied in a host of state statutes,<sup>78</sup> and it is part of providers' common law fiduciary duties arising from their professional relationships with patients.<sup>79</sup> The federal privacy rule makes this right to access medical records universal, including the right to receive medical information in the form or format requested if that is "readily" done.<sup>80</sup>

A patient's access right to information is very useful for our purposes. It could accomplish what needs to happen in order to create a consolidated medical record, and it can be

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<sup>77</sup> Perhaps providers were legal custodians in an earlier time. See, e.g., *Pyramid Life Ins. Co. v. Masonic Hospital Ass'n of Payne County, Okl.*, 191 F.Supp. 51, 54 D.C.Ok. (1961) ("the keeper of the records is only the custodian and not the owner of that information constituting the medical records of the patient. The patient has a property right in the information appearing or portrayed on the records . . ."). Custodianship fit the practice, prior to photocopy machines, of transferring the original record rather than a copy whenever it was needed for legal or other medical purposes. "Medical Records," in *Encyclopedia of Everyday Law*, [www.enotes.com/everyday-law-encyclopedia/medical-records](http://www.enotes.com/everyday-law-encyclopedia/medical-records). Once photocopying became the norm, however, providers insisted on retaining the original – consistent with their claim of its ownership. This history suggests the possibility of returning to a concept of custodianship once medical records become primarily electronic and therefore no special legal importance is attached to possession of the "original." See Shabo, *supra* note \_\_\_\_.

<sup>78</sup> See generally Comment, *Patient Access To Medical Records In Washington*, 57 Wash. L. Rev. 697 (1983); Paul V. Stearns, *Access to and cost of reproduction of patient medical records: A comparison of state laws*, 21 J Leg Med. 79 (2000); Center on Medical Records Right and Privacy, Georgetown University, <http://ihcrp.georgetown.edu/privacy/publications.html>.

<sup>79</sup> See *Cannell v. Medical and Surgical Clinic, S.C.*, 21 Ill.App.3d 383, 315 N.E.2d 278 (Ill.App. 1974) ("the fiducial qualities of the patient-physician relationship require disclosure of medical data to a patient or his agent on request"). Similarly, *Murphy v. Godwin*, 303 A.2d 668 (Del. Super. 1973) held that a physician has a legal duty to assist a patient with completing insurance application forms, based on "recognized incidents of the doctor-patient relationship."

<sup>80</sup> Joy Pritts, *Altered States: State Health Privacy Laws and the Impact of the Federal Health Privacy Rule*, Yale Journal of Health Policy, Law and Ethics, Spring 2002).

exercised by a patient's representative. One major hitch is the cost of exercising this right. The Privacy Rule permits providers to charge reasonable fees for the costs of copying (including labor) and for preparing a summary or explanation.<sup>81</sup> One study found that hospitals' fees "range very widely, from \$2-55 for short records of 15 pages to \$15-585 for long ones of 500 pages."<sup>82</sup> A potential solution for the fee problem is insurance reimbursement.<sup>83</sup> Health plans that sponsor I-EMRs could require provider cooperation as a condition of membership in the network, or they could pay a modest fee or supplement for doing so voluntarily, recapturing some or all of any net costs through supplemental premiums.<sup>84</sup>

Assisting patients and providers in compiling a comprehensive medical record does not solve all of our problems, however. It is not possible to capture many of the social or network benefits of this compilation unless the compiler or custodian has the right to sell access to their information under terms controlled by the patient. Patients can allow a compiler to exercise their access and control rights on their behalf, but these custodial rights are personal and fiduciary; therefore patients cannot transfer them in a form that can be easily retransferred or monetized. As developed more below, we are not contemplating irrevocable or absolute transfers, only transfers in a form similar to a license for use that the patient can revoke at any time, but even this limited license for nonexclusive and temporary use cannot clearly be put into the stream of commerce under current law.

Thus, we return to the issue of network externalities discussed above: optimal incentives for I-EMRs will not exist unless an entity (or person) can capture and distribute much<sup>85</sup> of the economic value for a group of providers, insurers and patients.<sup>86</sup> Law can facilitate the compilation of a patient's entire medical treatment and health history from among multiple independent records holders, and can reward doctors for using consolidated records -- if only someone is willing to pay the costs of doing this. These costs can be considerable, however,<sup>87</sup> which means that the compiler must be in a position to reap and distribute some economic reward from this endeavor by sublicensing or reselling its limited rights. Thus, Heritage Foundation scholar Edmund F. Haislmaier has it right, that "an explicit mechanism for monetizing the value of medical information and passing that value back to the data owners is a major advantage . . . . The best way to induce patients and providers to share the individual data they create is to help them unlock the value of that data and share in the benefits derived from

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<sup>81</sup> 45 CFR 164.524. However, the fee may not include costs associated with searching for and retrieving the requested information.

<sup>82</sup> Fioriglio G, Szolovits P. Copy fees and patients' rights to obtain a copy of their medical records: from law to reality. AMIA Annu Symp Proc. 2005;:251-5.

<sup>83</sup> See generally Kleinke, *supra* note \_\_\_, at 1258 ("The government has the ability to catalyze the creation and deployment of an HIT infrastructure by wedding that infrastructure to all of its reimbursement policies"); Dave Hansen, Rise of the e-mandates: Soon, you may not have a choice, *Am. Med. News*, Dec. 17, 2007.

<sup>84</sup> One analysis estimates the annual costs for providers' assistance would be less than \$50 per subscriber. Judah Thornewill, Robert J. Esterhay, Capitalizing the NHIN: A Strategy for Funding an Integrated Nationwide Network of Community HIEs, 32(3) *J. Healthcare Info. Mgt.*, 18, 21 (2007).

<sup>85</sup> We say "much" rather than "most" or "all" because the compiler need only capture its costs plus a reasonable profit margin, which might be considerably less than the full economic value if an I-EMR creates a large consumer surplus, as many analysts believe it would. See Brett M. Frischmann & Mark A. Lemley, *Spillovers*, 107 *Colum. L. Rev.* 257, 300 (2007).

<sup>86</sup> We mean to leave open the very real possibility that several or many different I-EMR networks could co-exist.

<sup>87</sup> Estimates for a complete, nationwide I-EMR system range from \$100 billion to \$300 billion. Note \_\_\_ *supra*.



letting others use it.”<sup>88</sup> Currently, law either prohibits this, or it does not clearly permit this, for any of the existing permutations of property and privacy rights.

Property rights are one (but not the only) means to monetize information. In other arenas of intellectual property law, it is naive to think that enough people will invest enough of their creative talents and scientific ingenuity primarily for public good, so we give them patents and copyrights. Similarly, if patients were given ownership of their complete medical treatment and health histories, they could license to compilers their rights to that information in a propertized form that could be more fully developed and commercialized. These third parties could then form contracts or partnerships with others who use or contribute to the databases (including doctors and insurers).

Locating these initial rights with patients in no way determines the eventual locus or form of ensuing medical records networks. Instead, the idea is to create a market mechanism for rewarding those who control access to medical information, in order to place those rights in a stream of commerce that can carry them to their highest and best use. In a proper legal environment, these blood vessels will grow where they need to go. The following section explores this idea. It draws from the vigorous academic debate over whether personal information collected through commercial transactions or internet browsing should be protected by either property law or privacy law regimes.

#### **IV. Should Patients Have Property Rights?**

“There is nothing which so generally strikes the imagination, and engages the affection of mankind, as the right of property.” - Sir William Blackstone<sup>89</sup>

Entrenched and competing property rights by health care providers and insurers, coupled with patients’ privacy rights, have locked out much of the potential value of networked medical information. We have described this architectural fragmentation in the economic terms of network externalities and the tragedy of the anticommons. Those who own this information are not in a position to capture its full value, and those who are in such a position are not clearly permitted to purchase and sell rights to the information.

Absent outright government compulsion, the fluidity needed to efficiently assemble countless scattered pieces of medical information into an I-EMR could be achieved in a variety of ways. Here, we focus on giving patients either property rights or other legal rights to all of their medical information in a form that they can transfer to a data assembler, for deployment into various productive uses. There are numerous variations on the precise institutional arrangements that could accomplish this transfer and deployment.<sup>90</sup> Rather than obsessing over particular institutional arrangements, here we focus on the core rights that patients should possess in order to enable their participation in the necessary financial rewards.

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<sup>88</sup> Edmund F. Haislmaier, Health Care Information Technology: Getting the Policy Right, Heritage Foundation WebMemo #1131 (June 16, 2006) <http://www.heritage.org/Research/HealthCare/wm1131.cfm>.

<sup>89</sup> 2 Commentaries on the Laws of England 1-2 (1978).

<sup>90</sup> See note \_\_\_ supra.

The analysis here is drawn primarily from the vigorous debate among legal scholars over ownership and protection of personal information revealed through consumer transactions or internet browsing. The explosive growth of technologies for capturing this information and in hidden markets for trading it brought anxious attention to how and whether consumers should be given more control over their personal information.<sup>91</sup> The issues we face here, though, differ in at least one critical respect. Personal information in non-medical settings is not protected by any existing privacy laws, whereas medical information is. Therefore, the legal policy problem for non-medical information is how to restrict the otherwise free flow and use of such information. Our problem is just the opposite: the privacy of medical information is amply protected when in the hands of care providers and insurers. Property or other legal rights are needed to dislodge that information into more productive circulation, while keeping in place appropriate safeguards. Needing only to protect information puts the property debate in a much different light than also needing to produce more value from it. Nevertheless, the fully developed scholarly debate over property rights in general personal information sheds considerable light on the competing arguments for “proptertizing” medical information.

#### *A. Arguments In Favor of Property*

When law has confronted similar issues, legislatures have created intellectual property rights such as copyright and patents, as exceptions to the general rule that information is in the public domain. These legal rights serve the focused instrumental goal of generating private incentives to invest time, energy and resources into creating, discovering and/or developing valuable information.<sup>92</sup> Should a similar approach be used for medical information?<sup>93</sup> Even though incentives are not needed to create it (since it is created when patients seek treatment),<sup>94</sup> financial rewards are needed to compile and transform it into useful forms. Property rights are an ideal way to bundle patients’ rights into a legal form that can be monetized and put into a stream of commerce. Fully realizing the economic potential of valuable assets is, in modern times, property law’s primary purpose. “We deem something property in order to facilitate its transfer.”<sup>95</sup>

Even when non-economic values loom large, some civil rights advocates favor property protections because of their strength and resonance in our legal system.<sup>96</sup> For instance, civil libertarian George Annas advocates giving people property rights in their own DNA in order to protect infringements from commercial interests.<sup>97</sup> Propertization opponent Sonia Suter

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<sup>91</sup> See generally Symposium, 32 Conn. L. Rev. 809-948 (2000); Symposium, 52 Stan. L. Rev. (2000); Paul M. Schwartz, Property, Privacy, and Personal Data, 117 Harv. L. Rev. 2055 (2004); Bergelson, *supra* note \_\_\_\_, at 414-19 (2003).

<sup>92</sup> See Samuelson, *supra* note \_\_\_\_, at 1140.

<sup>93</sup> Analogously, some states (OR, FL, CO, GA) have given people property rights in their genetic information, to serve the instrumental goal of preventing others from capitalizing on and exploiting this information. Sonia Suter, Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy, 72 George Washington Law Rev. 737, 747 (2004).

<sup>94</sup> Rodwin, *supra* note \_\_\_\_.

<sup>95</sup> Litman, *surpa* note \_\_\_\_, at 1296.

<sup>96</sup> *Id.* at 1290.

<sup>97</sup> George J. Annas, L.H. Glantz, L & P.A. Roche, Drafting the Genetic Privacy Act: Science, Policy and Practical Considerations, 23 J. Law, Med. & Ethics 360-66 (1995).

concedes that property “has always been a powerful tool to protect important interests because it is familiar and effective. Property has teeth and ‘symbolic force.’”<sup>98</sup>

The other extreme to propertization is depropertization – that is, placing such information in the public domain. That route is unappealing for a variety of reasons. Providers’ and insurers’ existing property rights would be eliminated. That might pose significant constitutional issues and would spark strong political opposition. Moreover, since privacy protections would remain, public domain access would still be very limited. And, any economic benefits derived from this information would not flow back to patients. Conferring additional and superior property rights to patients appears to be a more feasible and appropriate route.

This route is also supported by the seminal economic theory developed by Calabresi and Melamed.<sup>99</sup> Their classic article<sup>100</sup> outlines the general criteria by which society should prefer a property regime over a liability (or, in our case, regulatory) regime for determining access to and use of valuable resources. In general, property rules are preferable when markets determine best uses more efficiently than courts (or, in our case, regulatory agencies). Markets are generally preferred in economic arenas unless “market valuation of the entitlement is deemed inefficient,” or when a liability (or regulatory) rule “facilitates a combination of efficiency and distributive results which would be difficult to achieve under a property rule.”<sup>101</sup>

In medical settings, these obviously are large questions that demand wide-ranging analysis, but much of that can be short-circuited by observing that we do not face an all-or-nothing choice. Medical privacy law already contains much (and perhaps too much) of the normative content missing from property law. The issue, then, is whether this field should be overwhelmingly normative – under a legal regime that specifies most of the allowable and unallowable uses – or instead should have a less-normative zone that permits individuals more leeway to decide what uses to make of their medical information and what value those uses should have. Adding property rights to privacy protections would move us in that direction.

Privacy laws are concerned mainly with controlling access to information rather than putting medical information to innovative uses. Therefore, they do not embrace a set of norms and practices that countenance financial transactions. Privacy laws facilitate the ready release of information only for narrow and specific treatment purposes. Thus, they primarily express negative liberties –the rights to exclude, limit and refuse. Property law, in contrast, embraces a broader set of positive liberties: the rights to use, transfer, develop, etc.

Also, privacy rights grow out of the special nature of the relationships in medical care delivery between patient and care providers.<sup>102</sup> Therefore, they are enforceable only against the

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<sup>98</sup> Supra note \_\_\_\_, at 751.

<sup>99</sup> We owe this insight to Bergelson, supra note \_\_\_\_, at 417. See also Thomas W. Merrill & Henry E. Smith, *The Property/Contract Interface*, 101 *Colum. L. Rev.* 773 (2001).

<sup>100</sup> Guido Calabresi & Douglas Melamed, *Property Rules, Liability Rules, and Inalienability: One View of the Cathedral*, 85 *Harv. L. Rev.* 1089 (1972).

<sup>101</sup> *Id.* at \_\_\_\_.

<sup>102</sup> Suter, supra note \_\_\_\_, at 773. Stressing the relational (as opposed to transactional) basis of health care law generally, see Mark A. Hall & Carl E. Schneider, *Where is the "There" in Health Law? Can It Become a Coherent*

particular providers who generate and possess this information. It is difficult to anticipate and specify all the conditions that would be needed to allow the free flow of medical information since this depends on who possesses and controls the information and on its variety of potential uses. The same is true for specifying necessary protections. Building these rights and protections into the legal status of the information itself is therefore an advantage. The other option is for freedoms and protections to derive only from the origins or location of the information – that is, a patient’s particular relationship with the person who holds the information.

Property law addresses these enforcement concerns by creating rights that tend to “run with the chattel,” in other words, that are enforceable against the world at large and not just against particular parties based on their relationship with the patient.<sup>103</sup> Also, property law provides a strong legal basis for seeking injunctive remedies against infringements.<sup>104</sup> To these extents, property law might confer more extensive rights than privacy law alone.

Finally, property law invokes a fairly standard bundle of protections that are well-established and understood in the law, rather than requiring specification and interpretation of each stick in the bundle. This relative simplicity and ease of recognition facilitate productive development. Using examples from for the former Soviet bloc, property law scholar Michael Heller concludes that productive use “emerges more successfully in resources that begin transition [into a newly created market economy] with a single owner holding a near-standard bundle of market legal rights.”<sup>105</sup> It is always possible to craft more tailored legal specifications that fit a particular subject area more exactly, but perfection should not be pursued to the detriment of workable improvements. Property law theorist Henry Smith explains that using existing legal bundles can ultimately be more efficient because they are recognizable and so conserve on information costs: legal “lumpiness has its advantages” because “the on/off quality of [property law] allows complexity to be managed through modularity.”<sup>106</sup>

### *B. Arguments Against Property*

There are several substantial arguments against giving patients property rights in their medical information. Many privacy advocates view propertization of personal information as “morally obnoxious . . . anathema” because of the law’s expressive or symbolic function.<sup>107</sup> They feel that property law connotes a crass commercial attitude about information that inherently has deeply emotional and existential human significance. Sonia Suter articulates this position most forcefully. In her view, medical information is “integral to the self” because it “is

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Field? 14 Health Matrix 101 (2004); Wm. M. Sage, Some Principles Require Principals: Why Banning “Conflicts of Interest” Won’t Solve Incentive Problems in Biomedical Research, 85 Tx. L. Rev. 1413 (2007).

<sup>103</sup> Explaining this “in rem” character of property rights, see Henry Hansmann and Reinier Kraakman, Property, Contract and Verification, 31 J. Leg. Stud. 373 (2002).

<sup>104</sup> Samuelsson, supra note \_\_\_, at 1149.

<sup>105</sup> Heller, supra note \_\_\_, at 631.

<sup>106</sup> Henry E. Smith, *Intellectual Property as Property: Delineating Entitlements in Information*, 116 Yale L.J. 1742 (2007). See also Thomas W. Merrill & Henry E. Smith, Optimal Standardization in the Law of Property, 110 Yale L. J. 1 (2000).

<sup>107</sup> See Samuelson, supra note \_\_\_, at 1143 (reviewing, but not embracing, this position).

*about us in very central and personal ways.*<sup>108</sup> Rather than protecting “the wholeness of the self and of relationships through which the self flourishes,” property “by definition, commodifies and disaggregates the parts from the self.” Therefore, “conceptualizing [medical] information as property distorts and impoverishes our understanding of the dignitary, personhood interests we have in this information and the nature of relationships we hope will be built around and through its disclosure.”<sup>109</sup>

Those who stress the special significance of personal medical information are adamantly opposed to governing its use primarily through marketplace norms. Intellectual property scholars are rightly concerned that reducing the exchange of information to purely transactional legal analysis will produce commercial practices that give people little or no choice over what becomes of their vital information. According to Jessica Litman, the assumption “that initial legal ownership of [information] would enable individuals to restrain their downstream use by negotiating conditions of use before disclosing them . . . seems to be inspired by a fairy-tale picture of easy bargaining in cyberspace through the use of intelligent agents. . . . That’s nonsense.”<sup>110</sup> Mark Lemley agrees that, “from a privacy perspective, an intellectual property right that is regularly signed away may turn out to be less protection than we want to give individuals. To do any good, the right might have to be inalienable and waivable only in certain limited circumstances.”<sup>111</sup>

These concerns have pressing salience for access to and control of medical information, but the default rules of property law strongly favor allowing property owners to permanently relinquish all of their rights to a purchaser. Alienability is the “raison d’être of property” rights<sup>112</sup> because this is the legal characteristic that makes valuable assets easily exchangeable. Although actual commercial practices embrace many less absolute transactional forms such as leasing and licensing, property law strongly disfavors mandatory restraints on full alienation.<sup>113</sup>

Full alienability conflicts sharply with the values we associate with personal medical information. It is inconceivable that we would embrace a legal regime allowing patients to forever relinquish rights to access and control their medical information, yet this is one of the core elements in property law’s classic bundle of rights. In general, medical information law should have a strong normative content – specifying permitted and impermissible uses and modes of obtaining consent. Privacy law does this to a considerable extent, but property law is adamantly neutral (for the most part).

This clash could be avoided by constructing a more limited bundle of property rights -- as intellectual property law usually does (for instance, by limiting the length of those rights), or as patent law specially does (in a variety of ways) to take account of the importance of medical

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<sup>108</sup> Suter, *supra* note \_\_\_, at 773

<sup>109</sup> *Id.* at 749, 798.

<sup>110</sup> Jessica Litman, *Information Privacy/Information Property*, 52 *Stan. L. Rev.* 1283, 1297 (2000).

<sup>111</sup> Mark A. Lemley, *Private Property*, 52 *Stan. L. Rev.* 1545, 1551 (2000). Accord Murphy, *supra* note \_\_\_, at 2413; Paul M. Schwartz, *Property, Privacy, and Personal Data*, 117 *Harv. L. Rev.* 2055, 2077 (2004).

<sup>112</sup> Litman, *supra* note \_\_\_, at 1295.

<sup>113</sup> Samuelson, *supra* note \_\_\_, at 1145.

uses.<sup>114</sup> But, the more sticks that are removed or shortened, the less compelling becomes the argument for pursuing a bundling approach at all. As Mark Lemley observes, “a properly designed right would look rather more like a system of regulation than a system of property rights.”<sup>115</sup>

HIT system architecture could be designed creatively to reduce the complexity of a non-bundled regulatory regime.<sup>116</sup> The detailed limits required by regulators or desired by contracting parties could be specified and enforced efficiently by embedding them in the software that operates I-EMRs. The technological sophistication of electronic systems makes it possible to protect individual rights at a much more granular level than traditional regulatory or contracting systems. Thus, according to Jonathan Zittrain, the “expression of rights through a trusted system may allow for ‘baby-splitting’ among interests that is not feasible in more traditional regimes. For example, in place of the stalemate over who should ‘own’ a record, a welldefined self-enforcing rights architecture could allow information sharing without having to ultimately resolve matters in as coarse a way as ‘owner’ or ‘nonowner.’”<sup>117</sup>

Still, if any kind of property regime were adopted for medical information, additional lines would need to be drawn between this type of information and other personal information, over which there are no property rights. The balance of opinion among property scholars opposes propertizing personal information generally, and the arguments of the minority so far have not convinced lawmakers to the contrary. For medical information, there are good reasons to find the propertization arguments more compelling, but if we accepted those arguments we would then need to differentiate the two realms of personal information, which adds an additional element of complexity.

However, much the same is true for any type of intellectual property regime. Because property is not inherent in information, when creating intellectual property it is always necessary to define and justify what is protected from what is not. In part, we have undertaken this chore already for medical information by defining special privacy protections. Similar definitions could also describe the scope of patients’ property rights. However, property law definitions would likely differ from those in existing privacy law because, as noted above, the latter arise from special fiduciary responsibilities of health care providers and they have somewhat different aims. Excavating these additional layers is another reason to pause before leaping into a property regime.

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<sup>114</sup> For instance, patents on medical procedures cannot be enforced against physicians, Aaron Kesselheim & Michelle Mello, *Medical-Process Patents: Monopolizing the Delivery of Health Care*, 355 *New Eng. J. Med.* 2036 (2006), and the government can issue “compulsory licenses” for patented drugs during medical emergencies. Simone A. Rose, *On Purple Pills, Stem Cells, and Other Market Failures: A Case for a Limited Compulsory Licensing Scheme for Patent Property*, 48 *How. L.J.* 579 (2005). Also, drug developers receive extensions of their patent periods to account for the delay in FDA review prior to marketing, and they may infringe the patents of their competitors in order to pursue testing needed for FDA review.

<sup>115</sup> Lemley, *supra* note \_\_\_, at 1556. For instance, Vera Bergelson, *supra* note \_\_\_, at 439, proposes and explicates a complicated scheme for personal information generally under which people would “would own this information during their lifetime, subject to a (i) non-exclusive automatic inalienable license to the original collector and (ii) limited non-exclusive automatic license to the general public.”

<sup>116</sup> Jonathan Zittrain, *What the Publisher Can Teach the Patient: Intellectual Property and Privacy in an Era of Trusted Privication*, 52 *Stanford Law Rev.* 1201 (2000).

<sup>117</sup> *Id.* at 1246.



Finally, property rights might frustrate the very goals they seek, by inhibiting the public goods value of medical information. Creating more property rights may not be the best solution to an anticommons problem that was created in part by too many property rights in the first place. “An intellectual property law governing personal data would result in the creation of literally billions of new intellectual property rights every day; economics wisely counsels us not to expect frictionless licensing in this circumstance.”<sup>118</sup> The internet, for instance, owes its spectacular success to the fact that its basic structure and elements are all in the public domain.<sup>119</sup> Imagine how its development might have stalled or been severely stunted if key elements were protected by copyrights or patents.

For medical information, Professor Marc Rodwin makes an impressive argument that conferring property rights would interfere with important public goods, such as assembling research databases and engaging in public health monitoring.<sup>120</sup> His focus is primarily on de-identified data rather than the personalized medical records we consider here, but his objections must be considered carefully. If patients had property rights, would the government have to pay them “just compensation” for any “taking” of medical information for public purposes? We are not constitutional scholars, but we presume not if the information is not identifiable to the patient, since any property interest resides in patient-specific information. Government presumably would not take identifiable information except for public health purposes under its police power, as now happens without constitutional objection. Any newly created or expanded property rights would be against the backdrop of these long-standing government practices and polices and therefore could be made subject to them. Still, creating new property rights might give patients more legal power than they currently possess to refuse uses (or demand payments) for either public or private purposes.

### *C. Common Ground*

Whichever route we pursue, it will not result in a pure legal regime. As with any other type of intellectual property, because these legal rules are specially constructed to serve an instrumental purpose, we cannot avoid a fairly sui generis set of rules, especially considering the unique importance attached to medical information. Therefore, in the end it may not matter a great deal whether the bundle of rights in medical information is built stick by stick, starting with simple contract and privacy rights, or reconstructed from a larger existing set of property rights. This can be seen in the broader debate over personal information generally. Some scholars favor a special bundle of property rights,<sup>121</sup> others favor a special set of tort rules,<sup>122</sup> and still others feel that contract rights are sufficient if properly enforced.<sup>123</sup> Despite these differences, what is

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<sup>118</sup> Lemley, *supra* note \_\_\_\_, at 1553.

<sup>119</sup> Mark A. Lemley & David McGowan, *Legal Implications of Network Economic Effects*, 86 *Cal. L. Rev.* 479, 540 (1998).

<sup>120</sup> Rodwin, *supra* note \_\_\_\_. See also Litman, *supra* note \_\_\_\_, at 1294 (“When we recognize property rights in facts, we endorse the idea that facts may be privately owned and that the owner of a fact is entitled to restrict the uses to which that fact may be put. That notion is radical.”).

<sup>121</sup> E.g., Bergelson; Schwartz (advocating a “hybrid inalienability regime” that allows sale of personal info but only if there is a default rule (with opt-out) that restricts further transfers).

<sup>122</sup> E.g., Samuelson; Litman.

<sup>123</sup> E.g., Zittrain; Lemley.

common (albeit far from identical) among them is a set of shared concerns about the important interests that require legal protection and facilitation.

Drawing from this common ground, we suggest the following principles to guide construction of patients' rights to license access to their own medical information:

1. People should be able themselves, or through their agents, to authorize access to and use of their medical information for financial rewards, and these licenses should be transferable.

Without clear recognition of this core entitlement, network externalities will not be captured sufficient to give anyone in the health care finance and delivery system (as it is currently structured) enough incentive to invest in the construction of I-EMRs. Conferring rights of access and use should not be demandable as an absolute condition of providing or insuring health care services. However, positive or negative incentives can be offered as long as they are not unconscionable.<sup>124</sup>

2. Default rules should be set with some degree of paternalism toward protecting patients' interests, in order to take account of the cognitive and other limitations on consent involving vital medical information.

For instance, default rules can be set in a way that forces more choice and more information. Usually, to minimize transaction costs legal default rules are set in an "opt-out" fashion according to what most parties would accept when fully informed, so that these rules apply unless otherwise specified. However, if a substantial minority strongly dislikes the majority option, there may be good reason to adopt a more protective default rule that requires parties to affirmatively opt in to the majority position. Otherwise, the net social condition might be suboptimal if the default position is offered only on a take-it-or-leave-it basis, with no real choice or with a technical choice but inadequate notice.<sup>125</sup>

3. Some rights or protections should be nonwaivable (or inalienable) and should follow the information, regardless of agreement or provenance.

For instance, patients should always retain their basic rights to inspect, copy and correct medical records, and patients should have a nonwaivable right to revoke any permissions they give for access or use. Being able to back out of an improvident bargain helps to correct for market flaws by preventing initial mistakes from having long-term consequences.<sup>126</sup> This power also gives market participants a strong incentive to conform their behavior to patients' expectations. Further protections can be had by overseeing the "infomediaries" that assemble and process medical information and by embedding safeguards in the software architecture of the system. These protective mechanisms can originate either from regulators or entrepreneurs.

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<sup>124</sup> Accord, Bergelson, *supra* note \_\_\_\_, at 447.

<sup>125</sup> Murphy, *supra* note \_\_\_\_, at 2412-16.

<sup>126</sup> Schwartz, *supra* note \_\_\_\_, at 2105-06.

4. Patients' rights to control or sell their medical information should be limited to data that can be linked to them personally.

If information is anonymized (or "deidentified") so that it cannot reasonably be connected to anyone in particular, the individual's claim to the value of the information ceases, as does the need for strong legal protections. Recognizing this limit will foster more public goods from medical research and public health monitoring.

## V. Summary and Conclusion

Because information by its nature can be used by many people at once without depletion, it does not suffer from the same "tragedy of the commons" problems as does tangible property.<sup>127</sup> Therefore, property rights are not needed to allocate access. Instead, conferring ownership or control of information can block its beneficial use. Therefore, information, generally speaking, is usually regarded as being in the public domain unless there are good reasons in public policy to propertize it. In other areas of intellectual property, that reason is to provide an economic incentive to discover or create information that otherwise might not exist.<sup>128</sup> For medical information, there is quite a distinct reason: overcoming system fragmentation.

Deeply fractured health care finance and delivery presents two daunting economic challenges that must be solved to fashion the interconnected electronic information systems missing from most other important social arenas. Fragmentation creates *network externalities* that prevent any one actor from realizing much of the social benefits to be derived from I-EMRs. No actor -- including the government -- has sufficient incentives to make the necessary investments. Solutions to the network economics problems can be imagined, but they are barred by a patchwork of laws that either frustrate well-intentioned efforts to integrate information, or that give individual stakeholders the power and incentive to block integration. Medical care providers, for instance, have inherent control of medical information owing to their ownership of the tangible embodiment of medical records and their legal obligations to protect its privacy. Also, owing to reimbursement systems and legal uncertainties, doctors and hospitals lack sufficient incentives or authority to share their records with each other. These phenomena can be usefully thought of as examples of a "tragedy of the *anticommons*."

Absent government mandates or actual integration of our kaleidoscopic finance and delivery system, the only way to loosen this economic and legal constipation is to permit transfer payments among the various stakeholders that control valuable medical information. This can be accomplished in a variety of ways, such as through reimbursement systems and the reform of "fraud and abuse" laws. Here, though, we focus principally on ordinary property and contract laws that would allow patients to license their rights of access and use, under appropriately protective rules and institutions. These rules can be constructed either as a newly-designed form of intellectual property, or as a specially-constructed set of contractual and privacy rights.

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<sup>127</sup> Litman, *supra* note \_\_\_\_, at 1294.

<sup>128</sup> See Samuelson, *supra* note \_\_\_\_, at 1140.

The previous section outlines the pro's and con's of the two general approaches and describes the common ground between them. Property rights are bundled, powerful, recognizable and market-enabling, but they also are coarse, crass, greed-inducing and possibly obstructive. Contract rights coupled with regulatory protections are malleable, fine-grained, situational and normative, but they also are complex and potentially oppressive, and they tend to be enforceable only against particular parties based on their relationship with patients.

Common ground between these approaches can be formed by agreeing that patients' rights to medical information should be tradable in some form that can be monetized, but that special protections and institutions are needed to prevent marketplace abuses. These include giving patients a nonwaivable right to terminate permission to access and use their information, and making their rights to inspect, copy and correct medical information inalienable. A public or private coordinating institution is needed to protect patients and ensure adequate market conditions, but the choice of that institution should not dictate the ultimate structure of medical information networks.

In all of this, we are informed by certain basic lessons that can be learned from a review of the academic literature on property rights generally. Economic and social rights can suffer from too little or too much legal protection, creating either insufficient or excessive incentives for investment, leading to suboptimal development or social harms from excess development. Also, legal protections can exist in a variety of different forms. Thus, for property rights in medical information, we can think of legal protections being arrayed on a spectrum from strong to nonexistent, for each of a variety of stakeholders and potential uses. Rights to medical information can be overlapping (or nonexclusive) as long as there is a clear hierarchy of rights that gives one party ultimate control.

The problem broadly conceived, then, is to find the right mix and forms of property rights among patients, providers, researchers and compilers to maximize the social benefits of I-EMRs while minimizing social or individual harms -- but to do this without making the rules so complex that they are unmanageable, unintelligible, or unreliable. Clear but adaptable rules are needed so that stakeholders can make heterogeneous decisions that sort out which of several competing models for I-EMRs works best, and in what combination. This is a tall order, but it must be filled since legal uncertainty is itself a major deterrent to more productive use of medical information.