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# Ownership of Medical Information

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**W**HO OWNS MEDICAL INFORMATION? THE ONE who gives care, receives care, or pays for care? All of the above? None of the above? Does it really matter?

In the emerging era of electronic health informatics, few other medicolegal questions are more critical, more contested, or more poorly understood. The American Recovery and Reinvestment Act of 2009 allocates up to an estimated \$20 billion to implement clinical information systems,<sup>1</sup> and it aims for the use of electronic health information “for each person in the United States by 2014.” It fails, though, to resolve who owns this massive increase in electronic information. This legal uncertainty presents a major obstacle to integrating and using information about a single patient from various clinicians and hospitals.

Ownership of paper records was never much in doubt. Clinicians and insurers own the tangible vessels in which they store patients’ medical information.<sup>2</sup> But now that digitizing information frees it from particular storage media, confusion reigns.<sup>3</sup> This uncertainty is high on the list of legal and economic barriers to investing in an integrated electronic medical record infrastructure, like that in the Veterans Administration and Kaiser Permanente systems.<sup>4</sup> Some propose moving beyond ownership to decide more directly about stewardship principles that protect and control medical information.<sup>5</sup> But property rights cannot be avoided. They arise spontaneously and they strongly influence, if not determine, what forms of electronic health records predominate and whether effective, comprehensive, and integrated medical information networks can emerge in the United States.

## Legal Basics

Some surface legal issues seem clear. Clinicians, as owners of the paper records they maintain, can give or sell medical records to other clinicians for treatment purposes and block access by anyone except the patient. Patients have rights of privacy and access to their records, but neither federal nor state law explicitly extends property rights to patients. For instance, patients do not have the right to sole possession or to the destruction of their original records. Beyond these

rudimentary points, there are several common misimpressions about ownership.

First, property law is only one of several legal regimes that control rights and responsibilities over economic goods. Three others are contract, tort, and regulatory law. In coarse outline, property rights are enforced against the world, meaning that everyone must respect them, even those who have no relationship with the owner, whereas contract, tort, and regulatory law depend on the relationships or interactions among the particular parties involved.

The effect of other legal regimes may sometimes resemble property law, but the mechanisms of control are distinct. For instance, privacy law (which grows out of tort law) may appear to give patients property-like control, but privacy rights enable patients only to block access, not to sell the information, and privacy governs only clinicians and payers, not anyone else who might possess the information.

Property law is shaped both by fundamental rights and by society’s economic goals. We do not own the air we breathe because one person’s consumption does not deplete another’s. Conferring ownership would only inhibit society’s beneficial use. The same is true for information. In general, information is not owned because one person’s use does not deplete its value for others. Instead, information is regarded as a public good, available to anyone who can use it.

Patent and copyright laws are large exceptions to this general rule. Only by virtue of meeting their particular requirements does one own (to a limited extent) creative or useful information; however, personal medical information generally does not qualify for these protections.

Thus, the straightforward notion of sole and complete ownership often does not apply. Property rights come in bundles of various sizes and compositions. Ownership of houses and cars is subject to the collateral security interests of the lender; land is subject to easements and eminent domain; other assets are owned jointly by spouses or

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business partners. Likewise, multiple parties may have overlapping interests in different (or the same) parts of a patient's medical record. Ownership of intangible property is even more complex. At the extreme, the traditional elements of ownership can become so scanty that a particular bundle of rights no longer qualifies as property but instead is simply an assortment of contractual and other legal rights.

Privacy laws and long-standing professional ethics prevent clinicians from conveying medical information without a patient's permission. Patients, for their part, may insist on having a paper or electronic copy of their medical records if they pay the reasonable costs of copying. These rights of control and access do not function, however, as property rights unless the rights can be transferred or sold. Clinicians cannot sell patients' rights, but can patients sell their own access rights? Perhaps. If so, patients could authorize a representative to access and copy their information for them. This role might be performed, for instance, by a trusted "infomediary" who compiles complete medical records from among many different clinicians for a large group of patients.

This is unlikely to happen, though, unless the infomediary can recoup the considerable expenses of compilation by licensing access rights to others. In principle, there is no legal reason this cannot be done.<sup>6</sup> Medical records are not like transplantable organs, inherently too subject to misuse and exploitation to be commercialized. With sufficient legal clarifications and protections, one can imagine a wide range of contractual agreements that license, bundle, or transfer patients' rights of access and control to various parties under various conditions for a variety of applications. For instance, an intermediary could compile a bundle of patients' authorizations to use their information for research or marketing purposes; the compiler could, with patient authorization, then market these databases to permitted users or could transfer the bundled rights to a third-party aggregator and marketer. Some earnings could flow back to patients or compensate participating clinicians. In this way, placing bundled rights to medical information into a stream of commerce could, in theory, direct them toward their highest and best use.

### Transactions in Medical Information

Should patients be allowed to commercialize access to their medical information? No, according to some social theorists. Focused on law's expressive effects or symbolic functions, they believe it is "morally obnoxious . . . anathema" to "commodify" integral aspects of one's personhood, such as genetic information.<sup>7</sup> Social theorists are also concerned about the fairness of marketplace transactions in medical information. One hopes that patients would authorize access on terms they understood and could negotiate, but according to experience from many other realms, this typically will not happen.

In a competing view, the goal of property law is to bundle legal rights in a form that facilitates transactions and maximizes social value.<sup>8</sup> From this economic perspective, the current situation is nearly the worst of 2 worlds.<sup>9</sup> Strong privacy laws and clinicians' economic interests in limiting access to medical records increase barriers to forming integrated electronic records, and uncertainty about property rights decreases the potential returns. This combination of low commercial value with restricted access leaves medical information lying stunted in an undernourished field.

A helpful heuristic is the notion of an "anticommons." Electronic medical information clearly is not an overused "commons." Instead, its problems lie at the opposite end of the economic spectrum, identified a decade ago by legal scholars Heller and Eisenberg.<sup>10</sup> They introduced the contrasting idea of the anticommons to explain the underdevelopment of biomedical innovations (resulting from the "thicket" of too many patent rights). An anticommons arises when individuals can block use or development of a resource. Each adjoining property owner, for instance, can block a potential larger development unless each receives a disproportionate share of the total commercial value. The same is true for multiple patent owners, who must come to terms to build a better mousetrap (or genetically engineered mouse). Thus, conferring more property rights can be counterproductive in some situations.

Networking electronic medical records is a clear example of too many overlapping property rights creating a logjam that blocks rather than spurs investment and development. A comprehensive network of medical records can be formed and used only if many patients, clinicians, hospitals, and payers are willing to contribute and share information. But clinicians, hospitals, and payers have a stake in doing just the opposite: controlling their part of the record for proprietary business purposes.<sup>11</sup> Despite federal funding initiatives, this barrier to integrating patient health records remains.

Multiple stakeholders pursuing a single prize creates problems of coordination and strategic behavior that are difficult to resolve. One solution might be to remove all property rights, turning medical information into a public good. This approach might make the most sense for deidentified forms of information used for research purposes, but many good arguments and practical considerations counsel against taking from clinicians their control of the patient records they create and maintain. Instead, contract and privacy law could give patients the rights to sell access to their records, rights that are superior to the property rights held by clinicians and payers. Also, under contract or regulatory law payers could require or subsidize clinician participation in patient-controlled medical records as part of reimbursement. Recognizing a hierarchy of overlapping rights, with the patient initially in control, may both loosen the logjam of competing interests and stimulate market mechanisms to make much larger investments in using and sharing electronic health information.<sup>6</sup>

## A Possible Path Forward

Some informed stakeholders believe that incentives to integrate and use electronic medical records could greatly facilitate unlocking their economic value.<sup>9,12</sup> Economic value could be created by constructing a clinically useful network of longitudinal patient records or by patients licensing rights of access to their data for research or marketing uses. Caution is needed, however, in any public or commercial enterprise based on access to patients' personal health records. Patients should always retain their core, nonwaivable rights to inspect, copy, and correct medical records. Most prudent would be revocable or term-limited licenses to access personal health information. Being able to back out of an improvident bargain helps to correct market abuses by preventing initial mistakes from having long-term consequences and creates incentives on intermediaries to avoid this end.

Additional protections can be established by enforcing standards of data stewardship<sup>5</sup> and by embedding safeguards in the software architecture of any such system. Some experts criticize privacy law for failing to reach beyond clinicians and payers to wherever personal health information might exist,<sup>13</sup> but others believe that privacy law has inhibited the growth of networked electronic records by creating too many potential technical objections under the threat of serious legal penalties.<sup>14</sup> Those who host personal health records can (as they have done) bind themselves to enforceable protections that replicate the substance of privacy regulations without mirroring their complexity.<sup>15</sup>

Patient-controlled health records offer one potential solution to many of the problems encountered in creating institution-based longitudinal medical records. No matter which path is taken toward a national goal, clear but adaptable laws are needed so that stakeholders can assign economic value to the access, control, and use of the medical information contained in electronic health record networks.

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## REFERENCES

1. Herszenhorn DM. A smaller, faster stimulus plan, but still with a lot of money. *New York Times*. February 14, 2009:A11.
2. Stearns PV. Access to and cost of reproduction of patient medical records: a comparison of state laws. *J Leg Med*. 2000;21(1):79-108.
3. Waller AA, Alcantara OL. Ownership of health information in the information age. *J AHIMA*. 1998;69(3):28-38.
4. Safran C, Bloomrosen M, Hammond WE, et al; Expert Panel. Toward a national framework for the secondary use of health data: an American Medical Informatics Association White Paper. *J Am Med Inform Assoc*. 2007;14(1):1-8.
5. Bloomrosen M, Detmer D. Advancing the framework: use of health data—a report of a working conference of the American Medical Informatics Association. *J Am Med Inform Assoc*. 2008;15(6):715-722.
6. Hall MA, Schulman KA. Property, privacy and the pursuit of integrated electronic medical records. In: Elhauge E, ed. *Our Fragmented Health Care System: Causes and Solutions*. New York, NY: Oxford University Press. In press.
7. Suter SM. Disentangling privacy from property: toward a deeper understanding of genetic privacy. *George Washington Law Rev*. 2004;72(4):737-814.
8. Smith HE. Intellectual property as property: delineating entitlements in information. *Yale Law J*. 2007;116(8):1742-1822.
9. Haismaier EF. Health care information technology: getting the policy right. Heritage Foundation WebMemo #1131. June 16, 2006. <http://www.heritage.org/Research/HealthCare/wm1131.cfm>. Accessed February 23, 2009.
10. Heller MA, Eisenberg R. Can patents deter innovation? the anticommens in biomedical research. *Science*. 1998;280(5364):698-701.
11. Congressional Budget Office. Evidence on the costs and benefits of health information technology. May 2008. <https://www.cbo.gov/ftpdocs/91xx/doc9168/05-20-HealthIT.pdf>. Accessed February 23, 2009.
12. PCHRI. 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). 2006. Accessed February 23, 2009.
13. Hoffman S, Podgurski A. In sickness, health, and cyberspace: protecting the security of electronic private health information. *Boston College Law Rev*. 2007; 48(2):331-386.
14. Fried BM. Gauging the progress of the National Health Information Technology Initiative: perspectives from the field. <http://www.chcf.org/topics/view.cfm?itemid=133553>. Updated January 2008. Accessed February 23, 2009.
15. Altarum. Review of personal health record (PHR) service provider market: privacy and security: January 5, 2007. [http://www.hhs.gov/healthit/ahic/materials/01\\_07/ce/PrivacyReview.pdf](http://www.hhs.gov/healthit/ahic/materials/01_07/ce/PrivacyReview.pdf). Accessed February 23, 2009.