

## REMARKS: A LEGISLATOR'S LAMENT: WHEN WILL WE TAKE BACK OUR ELECTRONIC IDENTITIES?

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You can look at the issues raised today as a state legislator, doctor, policy wonk, law student, judge, or business. Let's start from the perspective of the individual patient and consumer.

This person right now lives in a world, sanctioned by no less an authority than the U.S. Supreme Court, where the most private and personal medical and drug prescription information is available for use in the marketplace for fundraising purposes or to market drugs to doctors.

Detailed profiles of this patient's medical and prescription history have been assembled and may be used to track this individual over time, following her every medical move. While names are supposed to be removed, the de-identification methods are known to be susceptible to code-breaking. And, the ready availability of personal information from other sources—such as credit card information from websites and birth dates from a Facebook account or airline frequent-flier website—can be mined to assemble a detailed and personalized medical profile, the existence and use of which would shock most people.

While the discussion in *Sorrell v. IMS Health Inc.* and the Legislature's data-mining laws focused on this information whizzing around electronically, and its use to create prescriber profiles to aid in drug-marketing efforts, this same information in hard copies has shown up in dumpsters improperly disposed of by pharmacies,<sup>1</sup> left behind on the Boston subway,<sup>2</sup> and posted inadvertently on public websites.<sup>3</sup>

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† The author thanks the many state legislators across the country who have bucked the pressures of powerful financial interests to advocate for more effective protection of patients' and health providers' personal and professional information

1. Jeremy Jojola, *Dumpster Full of Medical Records Found Outside Pharmacy*, 9NEWS.COM (Feb. 12, 2012, 9:59 PM), <http://www.9news.com/dontmiss/248924/630/Dumpster-full-of-medical-records-found-outside-pharmacy>.

2. Carey Goldberg, *MGH Settles for \$1M After HIV Patient Records Lost on Subway*, COMMONHEALTH (Feb. 24, 2011, 4:53 PM), <http://commonhealth.wbur.org/2011/02/mass-general-privacy>.

3. *Texas: Personal Data Posted Accidentally*, N.Y. TIMES, Apr. 12, 2011, [http://www.nytimes.com/2011/04/12/us/12brfs-PERSONALDATA\\_BRF.html?\\_r=2](http://www.nytimes.com/2011/04/12/us/12brfs-PERSONALDATA_BRF.html?_r=2).

As an individual, there is basically nothing you can do about it. Every time I go to a medical provider for treatment or a checkup, to receive care, I have to sign a waiver saying that I understand my HIPAA rights and authorize the sharing of my personal information for HIPAA-approved purposes. I know HIPAA allows marketing and fundraising uses, so I specifically write on every waiver that I do not authorize use or sharing of any of my information except for purposes directly related to and necessary for providing my health care. Does this accomplish anything? Of course not.

Then I take my prescription to the pharmacy to fill it. Even if I refuse the special rewards card that saves money with future coupons, because I know this card is a way of tracking my purchases, and even if I purchase my medicine with cash instead of a credit card, I know my personal information is being sold, transferred, and matched up for purposes that have nothing to do with providing me medical treatment.

*That information is a commodity with tremendous value.* And I have no say over how it can be used and derive no financial benefit from its purchase and sale many times over—even though from a legal point of view, the individual patient is supposed to have the strongest case for privacy protections.

Nor do prescribers whose prescription records are mined have any say in how this information is used—and after *Sorrell*, it is hard to know if there is any legally recognized privacy right for those prescribers. Nonetheless, the information thus collected and manipulated reveals medical judgments and practice details through detailed profiles of prescribing behavior; and, it is sold into the marketplace, potentially *compromising the confidentiality and integrity of the doctor-patient relationship.*

I am choosing my words with care. The information we are talking about is a commodity. I cannot agree with the Supreme Court that it is speech. It is personal, private information that carries with it an expectation of privacy. It is information that when data-mined turns into a proprietary product that is neither public nor free. This information that you and I so freely hand over, because we have no alternative if we want access to medical care, now underpins more than one multi-billion-dollar business. Let me read a quote: “The capacity of technology to find and publish personal information, including records required by the government, presents serious and unresolved issues with respect to personal privacy and the dignity it seeks to secure.”<sup>4</sup>

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4. *Sorrell v. IMS Health Inc.*, 131 S. Ct. 2653, 2672 (2011).

As individuals we are powerless to contain this use of our personal information. My amendment of the standard HIPAA waiver is a protest act without legal or practical effect. So we as individuals look to our government, whether legislatures or the courts, to look out for us. And here they have failed us. Congress has enacted medical privacy laws that are full of holes, and state efforts to fill the gaps were shot down by the Supreme Court in *Sorrell*. Here, the Court failed to protect the public interest by elevating non-speech to the realm of protected First Amendment speech—extending for the first time heightened scrutiny to a commercial transaction it considers speech (regardless as to whether the Court *said* it was deviating from *Central Hudson*).<sup>5</sup>

*Sorrell* has implications for the continued viability of FDA restrictions on pharmaceutical marketing. For example, restrictions on off-label promotion are defended as “truthful speech” even though the FDA has not approved the particular use of the drug.<sup>6</sup>

It also seems to call into question the federal and state “do not call” lists, the Driver Protection Privacy Act, and laws limiting the sale of information about video rental choices. And what about the “Restore Online Shoppers’ Confidence Act” signed into law by President Obama, which prevents “data pass”—online merchants’ passage of billing data to others to facilitate aggressive marketing and streamlined purchase of add-ons that a consumer had not intentionally purchased?<sup>7</sup>

I would say the *Sorrell* decision is also of great concern because it comes at the very time when there is a national shift to electronic medical records, which will put vast amounts of private medical information, much more than the prescription records the *Sorrell* case turned on, into online databases. This country is wholly unprepared to protect this expanded electronic database from both technical and practical, as well as legal, perspectives.

Where do we go from here? Well, I would not give up on the states in Northern New England just yet.

New Hampshire, which rarely strays far from its license plate motto “Live Free or Die,” has the first-in-nation distinction of having enacted the first prescription privacy law, sponsored by Representative Cindy

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5. *Id.* at 2663.

6. Thomas M. Burton, *The Free Speech Pill: Drug Firms See Opening to Push for End to Off-Label Marketing Ban*, WALL ST. J., Nov. 3, 2011, <http://online.wsj.com/article/SB10001424052970203707504577012382844711146.html>; see also Sharon Treat, *Will the Drug Industry Get Its Heart's Desire and Soon Be Able to Market Off-Label and Every Other Way?*, NAT'L LEGIS. ASS'N ON PRESCRIPTION DRUG PRICES (Nov. 4, 2011), <http://www.reducedrugprices.org/read.asp?news=6314>.

7. Restore Online Shoppers Confidence Act, Pub. L. No. 111-345, § 3, 124 Stat. 3618, 3619 (2010).

Rosenwald.<sup>8</sup> That is not the only law unique to New Hampshire. We will not get into guns, taxes, or political primaries. Let us stick to medical records.

New Hampshire law states: “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>9</sup> “Health care provider” is defined to include pharmacists.<sup>10</sup> This same law addresses data security better than most and specifically prohibits disclosure of protected health information by unattended fax, voicemail, or any other non-secure method.<sup>11</sup> *If these records are the property of the patient and not of the pharmacist, then New Hampshire law may in fact give to the individual patient and consumer the power to say no to non-medical uses of those records.*

And then we have the recently enacted Maine law, PL 2011, Chapter 347, “An act to increase health care quality through the promotion of health information exchange and the protection of patient privacy.”<sup>12</sup> This law requires a health information exchange to provide an “individual protection mechanism” for individuals to opt out of participating in the exchange or to opt out of allowing any health care information to be disclosed to a health care practitioner or health care facility.<sup>13</sup> This language is far more protective of privacy than the language in regulations proposed by the Center for Medicare & Medicaid Services to implement the health exchanges under the Affordable Care Act, which track HIPAA.

And what about Vermont’s Green Mountain Care? A single-payer health system could set the rules for its own activities and simply require prescription record protection in a Request For Proposal with an insurer or as part of its own rules of the road.

Likewise, other states could establish prescription privacy protections within the rules of the health exchanges under the Affordable Care Act. States that choose to have a hands-on exchange likely will be able to go well beyond CMS and HHS rules and provide greater levels of privacy protection. States already do this under HIPAA, and the partnership model the federal government is proposing under the Affordable Care Act lends itself to such state-by-state modifications.

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8. New Hampshire Prescription Confidentiality Act, ch. 328, 2006 N.H. Laws 328 (codified at N.H. REV. STAT. ANN. §§ 318:47-f, -g, 318-B:12 (2006)).

9. N.H. REV. STAT. ANN. § 332-I:1(I) (2011).

10. *Id.* § 332-I:1(II)(b).

11. *Id.* § 332-I:4(III).

12. 2011 Me. Legis. Serv. 712 (West).

13. ME. REV. STAT. ANN. tit. 5, § 19203(11) (2011).

I would not bet against the data-mining industry and Big Pharma on this one. These industries have clout, both economic and political. It is hard to imagine this Supreme Court upholding laws that go to the heart of these industries' business models and profits. On the other hand, people are very sensitive about maintaining privacy around medical issues and their bodies. In an era where "don't touch my junk"<sup>14</sup> has struck a chord with many, perhaps people may finally stand up and fight back against the ubiquitous electronic intrusion into every aspect of their lives.

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14. *DON'T TOUCH MY JUNK* John Tyner - ORIGINAL TSA FULL Encounter, YOUTUBE (Nov. 15, 2010), [http://www.youtube.com/watch?v=-UqM56e-kRA&feature=plcp&context=C31b5482UDOEgsToPDskLXIBXVy91vXTROmAA\\_xsVA](http://www.youtube.com/watch?v=-UqM56e-kRA&feature=plcp&context=C31b5482UDOEgsToPDskLXIBXVy91vXTROmAA_xsVA) (containing footage from CNN).