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How To Consolidate Patchwork of Health Information Confidentiality Laws

by Dennis Melamed

Legislative mandates to generate reports and statistics almost always evoke yawns if they are noticed at all. And possibly no detail could be smaller and more obscure than the requirement in the huge economic stimulus package for HHS to report its statistics on HIPAA privacy and security enforcement as part of the multibillion-dollar plan to computerize medical records.

So why bother mentioning it?

Because these statistics could create the foundation for rationalizing our fragmented system of privacy laws and regulations and at least provide some baby teeth for enforcement.

Bear with me for a moment or two.

No discussion of electronic health information can occur without at least a cursory bow in the direction of patient rights, which is immediately followed by the lamentation that the "devil is in the details." One of these details is the lamentable failure of HHS' Office for Civil Rights to respond to the majority of HIPAA privacy and security complaints that fall out of its jurisdiction. (For the purposes of this discussion, I'll put aside the serious issues afflicting the Office of e-Health Standards and Services at CMS and the transparency of its activities.)

From the moment the HIPAA medical privacy rule went into effect in April 2003 through Dec. 31, 2008, OCR received a total of 41,107 complaints, according to the agency's statistics. Of those, only 11,587, or 28%, fell within the scope of OCR's HIPAA jurisdiction and required the agency to respond, according to OCR.

That left the remaining 72%, or 29,520 complaints. To be sure some were frivolous or filed too late.

But were they all nutty?

Over the years, I've sought some kind of analysis or number from OCR regarding these complaints and whether they might have fallen under the jurisdiction of another agency or department.

To no avail.

Instead, OCR stuck by its claims that these complaints were "resolved." That approach allowed OCR to claim an 85% complaint resolution rate.

If by "resolved," the agency meant "ignored," I suppose it was right. But that doesn't sound as good.

Wide, Confusing Array of Privacy Laws

This failure is unfortunate on many levels.

As one of the few agencies in government required to investigate complaints over the handling of personal information, OCR had and still has the opportunity to provide some insight into patients' health information concerns.

Instead, OCR created a "dead letter" office for privacy complaints.

OCR could have treated legitimate complaints as ones that were actionable, but simply misplaced. It could

have referred them to other agencies and departments. It could have at least counted them.

OCR already refers complaints that might have criminal implications to the Department of Justice. And even here, no one knows what DOJ has done with these complaints. For that matter, OCR will not say how many complaints were kicked back to its offices. There has not been one federal criminal prosecution that invoked HIPAA in any way that came from the OCR complaint system. We know this because the U.S. attorneys never mentioned it, and we can be reasonably certain that OCR would have mentioned it as part of its educational approach to HIPAA compliance.

If OCR had referred these non-HIPAA complaints to the appropriate authorities, the federal government -- in a small way -- could have reduced the patchwork of privacy laws at least to the extent that citizens did not have to guess where to go for enforcement.

The well-recognized but studiously avoided reality is that health information is governed by a wide array of other laws including the Americans with Disabilities Act, the Family Medical Leave Act, the Gramm-Leach-Bliley Act, the Fair Credit Reporting Act, the Family Educational Records and Privacy Act, the Food, Drug and Cosmetic Act, the Rehabilitation Act, as well as a vast array of state laws.

This fact is so well known that it seems that it is dismissed as trite or something to be tolerated but unaddressed. Mention this fact in some venues and you can almost hear people's eyes rolling. So we have a highly fragmented system of laws governing health information. Does that necessarily mean enforcement of those laws has to be fragmented and isolated as well?

It is also useful to remember that many HIPAA experts recognize that the public has little incentive to file complaints. Patients can't sue anyone in federal court using HIPAA, and state courts have almost exclusively based their decisions on state law when patients go to court over perceived abuses.

That could mean that many of the 29,520 complaints were from people who were motivated, but simply guessed wrong on where to file their complaints. That doesn't sound like a responsive government, seeking to assure its citizens that their personal information will be protected when we computerize medical records.

Complaints Should be Referred

So in the spirit of the Obama administration's proclaimed commitment to more transparency and better service to its citizens, I have this simple and inexpensive proposal:

Go ahead and require formal reports on HHS's enforcement of HIPAA, but also require OCR to refer cases that fall outside of its HIPAA jurisdiction.

This does not need a law. It can be accomplished by establishing a process under a Presidential Executive Order or by a directive from the Office of Management and Budget, which is responsible for privacy and security compliance as well as department budgets.

The system could operate in several ways. The basic structure, however, would require the involvement of the HHS inspector general.

Complaints received by OCR that are deemed by OCR to be outside of its jurisdiction would go to the HHS inspector general for vetting and possible referral to other agencies. There should be no bureaucratic turf war; these would be complaints already dismissed by OCR; and the inspector general already is required to audit agency operations.

Referrals Could Be Illuminating

This information could be revealing in many ways. For example, these referrals could help us better understand which sectors are having problems with managing health information and better understand where health information resided and was flowing. Moreover, we may learn that hospitals and doctors' offices are not where the major problems of patient confidentiality reside.

Would it be useful to learn that a large percentage of those 29,520 were complaints against employers or educational institutions or drug companies or supermarkets or political parties?

In my more ambitious moments, I envision that taking steps to examine and act upon the non-HIPAA

complaints could serve as a pilot for creating an intergovernmental referral system that would involve other federal and state agencies with authority over the use and disclosure of personal information.

Why make the public guess about a system that confuses even the most sophisticated of us?

This kind of approach should not be so difficult, particularly if we are trying to create an electronic health record system that promises to coordinate information among an equally formidable number of health care providers and insurers.

And it all could start with a simple report.

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