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Consent for Disclosure of Health Records: Lessons from the Past

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Summary: A 1998 Maine health privacy law that required written consent for many health disclosures was so unpopular and impractical that the legislature suspended the law shortly after it took effect. Many of the law's requirements for written consent were later replaced with expanded authority for nonconsensual disclosures.

Introduction

When is it appropriate and practical to rely on patient consent to control the use and disclosure of health care information? HIPAA mostly eliminates the need for patients to consent to (“authorize”) disclosures. HIPAA permits covered entities to disclose patient records for treatment, payment, health care operations, and many other purposes without any patient intervention. While nearly all allowable disclosures are permissive and not mandatory under HIPAA, it appears that most covered entities rely on the authority in the HIPAA rule for most disclosures.

Is it possible to adopt a regime that relies more on patient consent? The State of Maine tried to do that in 1999, but the attempt failed miserably.¹ Acting unanimously, the legislature used emergency procedures to put the law on hold shortly after it took effect. It later modified the law substantially to remove some of the requirements for consent.²

The history of the Maine law is worth reviewing. It illustrates the public expectations in the tradeoffs between privacy and convenience. The Maine law was long and complicated. Only those parts relevant to a debate about patient consent are discussed here. The descriptions of the law are simplified here to avoid tripping over irrelevant details. However, the discussion here fairly conveys the issues that arose.

First Law

The original revision to Maine health privacy laws passed in April 1998 after a long and “heavily-lobbied” debate. The heart of the law, for present purposes, was the section on the confidentiality of health care information. A basic provision required written consent for disclosures, with some exceptions.

¹ Laws of Maine, 118th Session, ch. 793, § A-8 (1998) (adding 22 MRSA § 1711-C).

² Laws of Maine, 119th Session, ch. 512, § A-5 (1999) (amending 22 MRSA § 1711-C).

Treatment Disclosures: The law permitted disclosure without consent to a health care practitioner for treatment of the patient in emergency circumstances only. In non-emergency circumstances, the law limited disclosure without consent to activities within the office of the treating practitioner.³ That meant that consent was required for all routine external disclosures for treatment purposes.

Family Disclosures: The law allowed disclosure without consent to a family or household member only when a patient was being treated in an emergency health care facility.⁴ Even then, disclosures were limited to presence and general health condition. All other family disclosures required written consent.

Payment Disclosures: The law did not provide for nonconsensual disclosures for payment purposes.

Other Disclosures: The law allowed nonconsensual disclosures (under varying procedures and standards) in cases of imminent harm, for public health or welfare purposes, to government agencies pursuant to subpoena or statute, for research, for health oversight purposes, for licensing, to employees and contractors of the practitioner, and in some other circumstances.⁵ Most of these disclosures were not relevant to the public controversy that followed.

Public Furor

The public objections that arose centered on the inflexibility of the law to permit disclosures to family, the press, the clergy, and other physicians.⁶

- One legislator spoke about a doctor who was reluctant to share information with another doctor because of the law.⁷

- One press story cited the inability of a family to obtain laboratory results by telephone. A legally blind individual who could not drive to a lab could not get test results.⁸

- Another story reported on a woman who called a hospital 15 miles from her home to check on her grandfather's condition and the hospital refused to give her any information.⁹

³ Laws of Maine, 118th Session, ch. 793, § A-8 (1998) (22 MRSA §§ 1711-C(6)(A)(1) & (2)(a)).

⁴ Laws of Maine, 118th Session, ch. 793, § A-8 (1998) (22 MRSA § 1711-C(6)(C)).

⁵ Laws of Maine, 118th Session, ch. 793, § A-8 (1998) (22 MRSA §§ 1711-C(6)(B), (D) to (K)).

⁶ See Thomas Lee, Newsweek, "Too Much Privacy is a Health Hazard", August 16, 1999 ("In Maine lawmakers tried earlier this year to bar the release of any information without a patient's written consent. The law seemed reasonable at first, but the result was chaos. Doctors caring for the same patient couldn't compare notes without first seeking permission. Clinical labs had to stop giving patients their results over the phone. You couldn't even call a local hospital to find out if a loved one had been admitted. Confidentiality is a vital component of the trust between patients and physicians, and protecting it is worth some inconvenience. But information is the lifeblood of good health care. In short, privacy can be hazardous to your health.").

⁷ A. Jay Higgins, "State to rework patient privacy law; Legislation's good intentions went awry", Bangor (Maine) Daily News, Jan. 12, 1999.

⁸ Paul Carrier, "[Fever] Builds to Loosen Privacy Law; Legislators Hear of Problems with Maine's Patient-Confidentiality Law", Portland (Maine) Press Herald, March 16, 1999.

- Other complaints centered on the inability of a family to obtain detailed information about diagnosis, treatment, and prognosis when the patient had not signed a release form.¹⁰

- The press complained about the inability to acquire even minimal information about the condition of an accident victim or victim of violent crime.¹¹

- The delivery of flowers to inpatients was disrupted.¹²

- Clergy were unable to learn about patients in the hospital, and priests were concerned about not being able to administer last rights for an unconscious, dying patient if the family could not be reached.¹³

News stories about early implementation of the law showed that there was strong public reaction to the restrictions in the law. Stories included these phrases and quotes:

- A barrage of unintended consequences
- Firestorm of controversy
- Complaints were so overwhelming
- Inundated with phone calls from angry constituents
- Tremendous uprising from the general public
- Case of well-intentioned stakeholders in the medical confidentiality debate going a step too far.
- We erred on the side of confidentiality by keeping medical records too confidential so that patients weren't even able to get any information to their families
- So restrictive it may harm patient care.

It is certainly debatable whether all of the objections were valid. Some of the problems were likely transitory, and some were overstated. Any new privacy law encounters overreactions and misinterpretations that create confusion and misapplication. However, not all of the objections or concerns can be readily dismissed. Perceptions about the law made a great difference, and the public concerns about barriers to health information access were real. The legislature acted with alacrity and unanimity to suspend the law.

The strong public reaction to disclosure restrictions on family, clergy, and press shows that disclosures only with consent are not necessarily what the public wants or expects. The public wants a health care system that responds to the realities of life without too many

⁹ Paul Carrier, "Patient-privacy law suspended; The Maine Legislature votes unanimously to suspend the unpopular law, which limits hospital information, until Oct. 1", Portland (Maine) Press Herald, Jan. 15, 1999.

¹⁰ A. Jay Higgins, "State to rework patient privacy law; Legislation's good intentions went awry", Bangor (Maine) Daily News, Jan. 12, 1999.

¹¹ "Public's Medical Records", Bangor (Maine) Daily News, Jan. 5, 1999.

¹² A. Jay Higgins, "State to rework patient privacy law; Legislation's good intentions went awry", Bangor (Maine) Daily News, Jan. 12, 1999.

¹³ Meredith Goad, "Privacy law raises worry, confusion; Diverse groups seek to loosen new restrictions on disclosing patient information", Portland (Maine) Press Herald, Jan. 1, 1999.

procedural barriers. The public appears to be comfortable giving health care providers discretion over disclosures that are traditional or that ease procedural burdens.

It is also noteworthy that the provisions in the original law allowing nonconsensual disclosures to contractors, agencies, researchers, and others apparently did not attract attention or opposition. It was mostly the disclosure that required consent that drew fire because of the substantive barriers and inconveniences that they erected.

Revised Law

The legislature revised the law in 1999. The new law allows oral consent for disclosure when it is not practical to get written or individual chooses to give oral consent. It also allows an authorization for disclosure to be given by a relative or “adult who has exhibited special concern for the individual and who is familiar with the individual’s personal values.”¹⁴

New or revised nonconsensual disclosures¹⁵ permit disclosure:

- to health care practitioner for diagnosis, treatment, or care. The original “emergency circumstances” limitation was dropped altogether.
- to a family or household member unless expressly prohibited by the patient
- for the reporting of a crime against the practitioner
- to government agencies or in response to subpoenas (previous existing policy was broadened)
- to a person engaged in payment activities, with an expansive definition of payment
- to schools of immunization information
- to make or confirm appointments
- to obtain or convey information about prescription medication or to provide medication under a prescription
- to a member of the clergy of information about the presence of an individual in a health care facility unless expressly prohibited by the patient
- to a member of the media who asks a health care facility about an individual by name, of brief confirmation of general health status unless expressly prohibited by the patient

¹⁴ 22 MRSA § 1711-C(3-B).

¹⁵ Id. at § 1711-C(6).

· to a member of the public who asks a health care facility about an individual by name, of the room number of the individual and brief confirmation of general health status unless expressly prohibited by the patient.

Overall, the changes to the law allowed health care practitioners a great deal of additional discretion to make disclosures without patient consent, including disclosures for treatment and payment activities. Nonconsensual disclosures for what HIPAA later called *health care operations* were also expanded. The changes also made it easier to provide consent by adding oral consent as a new category and by allowing family members to authorize disclosures. The 1999 Maine amendments greatly expanded the types of nonconsensual disclosures that practitioners could make.

Conclusion

The 1999 revisions to the Maine health privacy law moved away from consent for disclosure and remain largely the same today. Some of the provisions have been affected by the HIPAA health privacy rule.¹⁶ Nevertheless, any provision of Maine law – or any other state law – that provides a greater degree of privacy protection remains in force today. HIPAA did not change or undermine any state’s consent requirements.

The Maine experience appears to have influenced HIPAA. The HIPAA provisions for disclosure of information to providers for treatment, to family members and caregivers, to clergy, and to the media are quite similar to the revised Maine law. While the HIPAA provisions created some confusion and some problems, most difficulties were transitional. There is little evidence today of significant patient objections to HIPAA’s disclosures for treatment, payment, family, clergy, and media. The Maine “laboratory experiment” suggests strongly that patients do not want too many consent requirements.

Reliance on consent raises other problems not addressed in the Maine debate. Prior to HIPAA, the health care system relied on broad disclosure consent forms that patients were asked or required to sign every time they visited a health care provider. However, any *informed consent* was in name only. Consent forms were not informative, patients rarely knew what they were signing, and consent was often a prerequisite to seeing a doctor. That type of consent was neither informed nor consensual.¹⁷

If a consent regime were in place today, patients would be still obliged to sign one or more consent forms as a condition of interfacing with the health care system. Insurers and health care providers would demand that patients grant them broad authority to make disclosures. Patients who need care or insurance would have no choice but to comply. It is far from clear that

¹⁶ The health privacy rules issued by the Department of Health and Human Services under the authority of the Health Insurance Portability and Accountability Act (HIPAA) can be found at 45 CFR Parts 160 & 164).

¹⁷ For a discussion of the *paradox of informed consent*, see Robert Gellman, *The Privacy of Health Information and the Challenge for Data Protection*, Eighth International Conference of the Observatory "Giordano Dell'Amore" on the Relations Between Law and Economics, Stresa, Italy (May 1997), at <http://bobgellman.com/rg-docs/rg-health-consent-97.pdf>.

greater use of consent for routine treatment, family, or payment disclosures would be meaningful, consensual, or actually protective of privacy.

This is not to say that all of the nonconsensual disclosures that the HIPAA health privacy rule allows are fine as is. In many instances, stronger standards and better procedures would provide better protections for privacy. For example, law enforcement officials should not be able to obtain health records without making a written request.

Further, HIPAA's provision granting patients the right to request restrictions on use or disclosure is meaningless in its current form because covered entities have no obligation to consider or respond to patient requests. Few covered entities will accept patient requests. Patients have the right to object (opt-out) to some disclosures (to family members, for facility directories, and for fundraising). HIPAA could do more to enhance the patient's role in controlling some disclosures.

If we look toward future developments, such as greater use of electronic health record technology and health networks, providing patients with a greater role in some disclosures should be possible. Some of the practical objections to patient consent for activities like research would disappear if a health network were designed to allow patients to express preferences through opt-in or opt-out choices. Other patient choices should be accommodated as well, including options that would allow patients to limit use of sensitive health information.

The challenge is to find a practical way to allow patients to make the choices they want in an acceptable way that does not undermine their expectations for a workable health care system.

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