



# THE COMMITTEE ON ENERGY AND COMMERCE

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## *Memorandum*

April 24, 2013

TO: Members, Subcommittee on Oversight and Investigations

FROM: Subcommittee on Oversight and Investigations Staff

RE: Hearing on “Does HIPAA Help or Hinder Patient Care and Public Safety?”

On Friday, April 26, 2013, at 9:00 a.m. in room 2123 of the Rayburn House Office Building, the Subcommittee on Oversight and Investigations will hold a hearing entitled "Does HIPAA Help or Hinder Patient Care and Public Safety?"

On March 5, 2013, the Subcommittee hosted a bipartisan public forum, “After Newtown: A National Conversation on Violence and Severe Mental Illness.” During that forum, parents and psychiatrists raised concerns that the Health Information Portability and Accountability Act’s (HIPAA) privacy rule may interfere with the timely and continuous flow of health information between health care providers, patients, and families, thereby impeding patient care, and in some cases, public safety. This hearing will explore how HIPAA may interfere with patient care and public safety, either through misunderstanding, or proper application, of the law.

## **I. WITNESSES**

Panel 1:

Leon Rodriguez  
Director  
Office for Civil Rights  
Department of Health and Human Services

Professor Mark A. Rothstein  
Herbert F. Boehl Chair of Law and Medicine  
Director, Institute for Bioethics, Health Policy and Law  
University of Louisville School of Medicine

Panel 2:

Dr. Richard Martini, M.D.  
Professor of Pediatrics and Psychiatry  
University of Utah School of Medicine  
Chair, Department of Psychiatry and Behavioral Health  
Primary Children's Medical Center

Carol Levine  
Director  
Families and Health Care Project  
United Hospital Fund

Gregg Wolfe  
Father of a son with mental illness and substance addiction

Edward Kelley  
Father of a son with mental illness

Jan Thomas  
Family impacted by HIPAA

Deven McGraw  
Director of the Health Privacy Project  
Center for Democracy and Technology

## **II. BACKGROUND**

The Health Insurance Portability and Accountability Act (HIPAA) of 1996 (P.L. 104-191) establishes national standards to protect individuals' medical records and other personal health information. These standards include certain individual privacy rights, as well as limitations on the use or disclosure of personal health information (collectively, the "privacy rule").<sup>1</sup> HIPAA applies to health plans, health care clearinghouses, and those health care providers that conduct certain health care transactions electronically (collectively, the "covered entities"). Since 2000, the Department of Health and Human Services (HHS) Director of the Office for Civil Rights (OCR) has been delegated the HHS Secretary's authority to administer and enforce the privacy rule, including the imposition of civil monetary penalties for noncompliance.<sup>2</sup>

Generally, the rule prohibits covered entities from using or disclosing protected health information (PHI), except as expressly permitted or required by the rule. Aside from giving

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<sup>1</sup> The HIPAA privacy rule, and accompanying general administrative and enforcement requirements, are codified at 45 C.F.R. Part 160 and Part 164, Subparts A and E.

<sup>2</sup> Office for Civil Rights; Statement of Delegation of Authority, 65 Fed. Reg. 82381 (Dec. 28, 2000), *available at* <http://www.hhs.gov/ocr/privacy/hipaa/administrative/privacyrule/fedreg.pdf>.

patients the rights to examine and obtain a copy of their health records and to request corrections, the privacy rule sets limits and conditions on the uses and disclosures that may be made of such information without patient authorization. For example, when it comes to disclosures of PHI to family members and friends of the patient, the rule requires covered entities to give the individual the opportunity to object to the disclosure. The privacy rule also permits the use or disclosure of PHI for certain specified law enforcement purposes. For all uses or disclosures of PHI that are not otherwise permitted or required by the rule, covered entities must obtain a patient's written authorization.

Providers handling PHI for *permitted* uses and disclosures, such as for purposes of treatment or payment, can choose whether to use or disclose the information based on their professional ethics and their own best judgment. In fact, the rule aims, where possible, to preserve providers' traditional discretion over the communication of patient information while giving patients the ability to object to the disclosure of their information in certain specified situations. In contrast to the multitude of *permitted* uses and disclosures, the privacy rule specifies only two circumstances when covered entities are *required* to disclose PHI: (1) to the individual who is the subject of the information; (2) to HHS officials investigating potential violations of the rule.

It should be noted that HIPAA provides a Federal floor with respect to the uses and disclosures of PHI. However, the overall scope of the privacy rule may be modified by State law. Health care providers may be subject to State health privacy laws that can be more protective of individually identifiable health information than HIPAA. For example, State laws may prohibit or restrict a use or disclosure that would otherwise be permitted under HIPAA, and provide individuals with heightened access to their own health information.<sup>3</sup>

Studies show that some health care providers apply HIPAA regulations overzealously, leaving family members, caregivers, public health and law enforcement hindered in their efforts to get information.<sup>4</sup> Some experts blame the language of the law itself, noting the broad discretion to disclose information left with health care providers; others point out that many providers do not understand the law, have not trained their staff members to apply it responsibly, or are fearful of the threat of fines and jail terms resulting from noncompliance.<sup>5</sup> Indeed, with growing attention to breaches of confidentiality and increased penalties under the American Recovery and Reinvestment Act-related Health Information Technology for Clinical and Economic Health Act (HITECH), there are concerns that HIPAA compliance anxiety may only grow, further "overshadow[ing] basic principles of communication and good clinical care."<sup>6</sup>

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<sup>3</sup> See Edward C. Liu et al., CONG. RESEARCH SERV., R43040, SUBMISSION OF MENTAL HEALTH RECORDS TO NICS AND THE HIPAA PRIVACY RULE, at 10-11 (Apr. 15, 2013), available at <http://www.crs.gov/Products/R/PDF/R43040.pdf>.

<sup>4</sup> See Jane Gross, *Keeping Patients' Details Private, Even From Kin*, N.Y. TIMES, July 3, 2007, available at <http://www.nytimes.com/2007/07/03/health/policy/03hipaa.html?pagewanted=all> [hereinafter Gross, N.Y. TIMES].

<sup>5</sup> *Id.*

<sup>6</sup> See Carol Levine, *Understanding HIPAA: What It Protects and What It Permits*, CARE MANAGEMENT, Feb./Mar. 2013, available at <http://www.uhfnyc.org/assets/1073>.

Two of the most frequently – but far from the only – misunderstood and/or misapplied HIPAA privacy rule sections are 164.510(b), “Uses and Disclosures for Involvement in the Individual’s Care and Notification Purposes” and 164.512, “Law Enforcement, Duty to Warn.”

Generally, under Section 164.510(b), a covered entity “may. . .disclose to a family member, other relative, or a close personal friend of the individual, or any other person identified by the individual, the protected health information directly relevant to such person’s involvement with the individual’s care or payment related to the individual’s health care” – as well as the individual’s location, general condition, or death – except in situations where the patient has expressly objected. Perhaps not surprisingly, leaving such disclosure to the discretion of medical staff – from doctors and nurses to hospital clerks – some of whom lack a solid understanding of HIPAA – has often resulted in the unnecessary withholding of important information from those who could benefit from it.<sup>7</sup> In fact, unnecessary secrecy is a “significant problem,” says Mark Rothstein, former chairman of a subcommittee advising HHS on health information policy, including the HIPAA privacy rule.<sup>8</sup> Rothstein adds, “It’s drummed into them that there are rules they [health care providers] have to follow without any perspective. So, surprise, surprise, they approach it in a defensive, somewhat arbitrary way.”<sup>9</sup>

Section 164.512 of HIPAA permits the use or disclosure of PHI in certain circumstances outside of the health care context, including for law enforcement purposes and to avert a threat to health or safety. Consistent with applicable law and standards of ethical conduct, a health care provider may use or disclose PHI if the provider in good faith believes it is necessary to prevent or lessen a serious or imminent threat to the health or safety of a person or the public, and where the disclosure is to a person reasonably able to prevent or lessen the threat (e.g., law enforcement official, family member, school administrator). In fact, one of the President’s post-Newtown executive action involved clarifying that Federal law does not prohibit health care providers from reporting threats of violence to law enforcement authorities. Implementation of this executive action took the form of a January 15, 2013, letter from the OCR Director, Leon Rodriguez, to health care providers in which he reminded them of HIPAA’s duty to warn provision, which permits the disclosure of patient information to avert threats to health or safety.<sup>10</sup>

The problems that HIPAA misinterpretation poses for patient care and public safety were highlighted at the Subcommittee’s March 5, 2013, bipartisan public forum discussing the link between severe mental illness and violence. At this forum, the Committee heard powerful stories from parents with children who have schizophrenia and other forms of serious mental illness, including about their interactions with the mental health system. Complications raised by health care providers’ inconsistent – and sometimes incorrect – application of HIPAA were a common thread across these parents’ experiences with the mental health system, *regardless* of their access to health insurance or their ability to pay for care. Yet, concerns stemming from the misinterpretation of HIPAA are not merely present in cases of mental illness – where the inability to recognize one’s condition (referred to by some as *anosognosia*) and resulting refusal

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<sup>7</sup> Gross, N.Y. TIMES.

<sup>8</sup> *Id.*

<sup>9</sup> *Id.*

<sup>10</sup> See DEP’T OF HEALTH AND HUMAN SERVS., MESSAGE TO OUR NATION’S HEALTH CARE PROVIDERS (Jan. 15, 2013), available at <http://www.hhs.gov/ocr/office/lettertonationhcp.pdf>.

of treatment are commonplace – but can and do occur in all types of medical situations, directly impacting upon the quality and timeliness of an individual’s long-term medical care.

The inability of families and caregivers to obtain crucial health information affecting the care of a loved one can have tragic consequences. For example, at the March 5, 2013, forum, the father of a son with severe mental illness and a history of self-destructive behavior cited the unwillingness of his son’s mental health care providers to share with him their concerns about the potential recurrence of such tendencies and dangers arising out of possible discontinuance of treatment as an important contributing factor in his son’s later suicide. On the opposite extreme, misinterpretations of HIPAA have resulted in farcical scenarios, such as when birthday parties in nursing homes in New York and Arizona were canceled for fear that revealing a resident’s date of birth could be a violation.<sup>11</sup>

### **III. ISSUES**

- What is the role of OCR in educating health care workers, patients, patients’ families, friends, caregivers and law enforcement about the HIPAA privacy rule?
- What kind of information sharing does the HIPAA privacy rule (1) require, (2) permit, and/or (3) prohibit health care workers, patients, patients’ families, friends, caregivers and law enforcement from engaging in?
- What are the ways in which HIPAA has been improperly interpreted or applied so as to stymie an individual’s access to PHI, and how does this impact patient care and public safety?
- Does HIPAA interfere with patient care and public safety when properly applied?
- What is the role of families and/or family caregivers in the treatment of individuals with long-term medical conditions, including severe mental illness?

### **IV. STAFF CONTACTS**

If you have any questions regarding this hearing, please contact Sam Spector at (202) 225-2927.

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<sup>11</sup> Gross, N.Y. TIMES.