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Before the

SUBCOMMITTEE ON INVESTIGATIONS AND OVERSIGHT,
HOUSE COMMITTEE ON ENERGY AND COMMERCE

Does HIPAA Help or Hinder Patient Care and Public Safety?

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MR. CHAIRMAN and members of the Subcommittee. My name is Mark Rothstein. I am the Herbert F. Boehl Chair of Law and Medicine and Director of the Institute for Bioethics, Health Policy and Law at the University of Louisville School of Medicine. From 1999-2008, I served as Chair of the Subcommittee on Privacy and Confidentiality of the National Committee on Vital and Health Statistics, the statutory public advisory committee to the Secretary of Health and Human Services (HHS) on health information policy. I am testifying today in my individual capacity.

In my testimony this morning I want to make the following three points. First, the HIPAA Privacy Rule is essential to patient care and public health and safety. Second, exceptions to the HIPAA Privacy Rule permit disclosure of health information for important public purposes. Third, additional measures could enhance the effectiveness of the HIPAA Privacy Rule.

1. The HIPAA Privacy Rule Is Essential to Patient Care and Public Health and Safety

Some people think that the only benefit of health privacy laws is to prevent anxiety, embarrassment, and similar intangible harms to individuals; and that occasionally stigmatization or discrimination can be caused by the disclosure of sensitive health information. Although it is important to protect against these types of harms, it is critical to recognize that the lack of health privacy can interfere with individual health care and endanger public health and safety.

Ever since the Hippocratic Oath, medical codes of ethics have established the duty of physicians -- and later other health care providers -- to maintain the confidentiality of patient health information. Without assurances of confidentiality, patients will be reluctant to divulge sensitive information about their physical and mental health, behavior, and lifestyle that could be vital to

the individual's treatment. The Privacy Rule codifies this crucial requirement for ethical and effective health care. Surveys of patients indicate that many of them, fearful of disclosure of their sensitive health information, currently engage in "defensive practices" by withholding certain information from their health care providers.¹ Any weakening of privacy protections would undoubtedly increase the use of defensive practices.

Health privacy laws also are essential to the protection of public health and safety. To illustrate, this afternoon I will be going back to Louisville. At lunch, I do not want my cook or server to be someone who was reluctant to get treatment for hepatitis A because of privacy concerns; I do not want as my taxi driver someone with chronic tuberculosis who was afraid to get ongoing health treatment; I do not want my flight safety placed at risk by an air traffic controller with a mental health problem or a pilot with a substance abuse disorder who was deterred from obtaining behavioral health care. Confidentiality protections serve to advance both the patient's and the public's interest.

Congress recognized the importance of protecting sensitive health information as early as 1970s, when it enacted the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act and the Drug Abuse Prevention, Treatment, and Rehabilitation Act. As implemented by 42 C.F.R. Part 2, the law protects the confidentiality of alcohol and substance abuse treatment information about any person in a federally assisted program. Congress understood that the public interest in getting individuals into treatment would be thwarted if individuals with substance abuse problems feared they would be subject to, among other things, criminal prosecution for violating state and federal drug laws.

¹ California Healthcare Foundation, Consumers and Health Information Technology: A National Survey 25 (2010).

A similar recognition of the public health consequences of widespread disclosure of sensitive mental health information should guide the nation's mental health information policy. Although we were all deeply saddened by the recent, horrific loss of life caused by some violent, mentally unstable individuals, we should appreciate the potential consequences of new, excessive, mental health reporting requirements. Each year in the U.S. there are over 38,000 suicides and over 700,000 emergency room visits caused by self-inflicted harms.² An estimated 26.2 percent of people in the U.S. have a diagnosed mental disorder in any given year.³ Any steps to lessen confidentiality protections or mandate the unnecessary disclosure of mental health information could lead vast numbers of individuals to forego mental health treatment and potentially result in significantly more suicides, self-inflicted harms, and untreated mental illness.

2. Exceptions to the HIPAA Privacy Rule Permit Disclosures for Important Public Purposes

The Privacy Rule specifically permits a covered entity to disclose 12 types of health information of importance to the public without the need for a patient's authorization or consent, so long as the disclosures are described in the covered entity's Notice of Privacy Practices. These 12 categories are disclosures: (1) required by law; (2) for public health activities; (3) about victims of abuse, neglect, or domestic violence; (4) for health oversight activities; (5) for judicial and administrative proceedings; (6) for law enforcement; (7) about decedents to coroners, medical examiners, and funeral directors; (8) for cadaveric organ, eye, or tissue donation; (9) for research purposes pursuant to a waiver of authorization, for reviews preparatory to research, and for

² Centers for Disease Control and Prevention, Suicide and Self-Inflicted Injury, www.cdc.gov/nchs/fastats/suicide.htm.

³ National Institute of Mental Health, The Numbers Count: Mental Disorders in America, www.nimh.nih.gov/health/publications/the-numbers-count-mental-disorders-in-america/index.shtml.

research on a decedent's information; (10) to avert a serious threat to health or safety [the subject of the OCR's January 15, 2013 letter to health care providers]; (11) for military and veterans' affairs, national security, and intelligence; and (12) for workers' compensation.⁴ These public purpose exceptions are broadly worded and include various measures to protect public health and safety through the disclosure of protected health information to appropriate federal, state, and local government officials.

Significantly, the public purpose exceptions are permissive. The Privacy Rule does not require any disclosures; the disclosure obligations arise from other sources, such as state public health reporting laws. The effect of the public purpose exceptions is to permit otherwise-required disclosures without violating the Privacy Rule.

3. Additional Measures Could Enhance the Effectiveness of the HIPAA Privacy Rule

Before the Privacy Rule went into effect in April 2003, as well as for the last 10 years, inadequate health professional and patient outreach and education programs have led to a lack of understanding of the Privacy Rule by many affected individuals and covered entities. A common problem is that some uses and disclosures permitted by the Privacy Rule are not allowed by some covered entities, perhaps out of ignorance or an over-abundance of caution.

To take one example, in the early days of the Privacy Rule, many covered entities stopped reporting infectious diseases and other health information to state public health agencies even

⁴ 45 C.F.R. § 164.512.

though such disclosures are expressly permitted by the Privacy Rule.⁵ Although this problem has been largely corrected, there are anecdotal reports of other types of nondisclosure.

A recurring complaint by some patients and their caregivers is that some covered entities invoke the Privacy Rule as an excuse for not making lawful disclosures of health information whenever disclosure is considered inconvenient or burdensome.

The Privacy Rule should be viewed by the public as more than arcane and indecipherable legal provisions sometimes invoked to their detriment. Similarly, the Privacy Rule should be viewed by covered entities as more than a burdensome paperwork regulation whose provisions are only vaguely understood.

The 2013 promulgation of the omnibus amendments to the Privacy Rule make it an appropriate time for HHS to start a new program of public and health care provider education and outreach. Such efforts have been long advocated by the National Committee on Vital and Health Statistics.⁶

Another way in which health privacy and public health and safety could be advanced would be redrafting some of the public purpose exceptions to make them more explicit. For example, the public purpose exception to avert a serious threat to public health or safety includes disclosures required by state laws as a result of the influential *Tarasoff* decision.⁷ In this case, the California Supreme Court held that a psychotherapist who learns of a patient's threat of serious harm or

⁵ National Committee on Vital and Health Statistics, Letter to HHS Secretary Tommy G. Thompson, March 5, 2004, www.ncvhs.hhs.gov/04030512.htm; 45 C.F.R. § 164.512(b).

⁶ National Committee on Vital and Health Statistics, Letter to HHS Secretary Tommy G. Thompson, September 27, 2002, www.ncvhs.hhs.gov/020927lt.htm.

⁷ *Tarasoff v. Regents of the University of California*, 551 P.2d 334 (Cal. 1976).

death to an identifiable victim has a duty to take appropriate steps to reduce the threat, which could include notifying law enforcement and warning the threatened individual.

Unfortunately, in implicitly deferring to state law on a health care provider's duty to avert a serious threat to public health or safety, the Privacy Rule fails to clarify the complicated and inconsistent array of state statutory and case law. An unequivocal, national, unitary standard for such disclosures would clear up a great deal of confusion.

In conclusion, the Privacy Rule is essential to individual health care and public health and safety. Additional efforts to increase understanding of the Privacy Rule by the public and covered entities, as well as revising some of the public purpose exceptions, will enhance the effectiveness of the Privacy Rule.

Thank you for the opportunity to testify.