

## SILENCE IS GOLDEN . . . EXCEPT IN HEALTH CARE PHILANTHROPY

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### INTRODUCTION

Imagine a forty-year-old woman who has been diagnosed with stage IV colorectal cancer and who has less than a ten percent chance of living five years from the date of her diagnosis. The woman's physician, who specializes in oncology and practices at a hospital affiliated with a major academic medical center, recommends a combination of surgery, chemotherapy, and radiation to treat the woman's cancer. This article addresses the permissible scope of uses and disclosures of the woman's individually identifiable health information that may be made by the hospital and the physician for the purpose of attempting to raise funds for the hospital's own benefit.

If, five years after her diagnosis, the woman is still alive and has no evidence of disease, should the hospital be permitted to select the woman, based on her treatment in the oncology department, her excellent outcome, and her presumed gratitude, to receive a telephone call or a letter at her home requesting a monetary donation that would be used to improve the infrastruc-

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ture of, and the medical technology and human resources available through, the hospital's oncology department? In addition, when the woman visits the hospital for follow-up cancer screenings, should her physician be permitted to initiate private conversations with her regarding the hospital's philanthropic needs? On the other hand, if the woman's condition deteriorates or she dies within five years of her diagnosis, should the hospital be able to use the woman's poor health or the fact of her death to screen her or her family members out from the receipt of philanthropy-related communications? Or, due to legal and ethical concerns associated with patient confidentiality, should the hospital and physician be prohibited from engaging in any of the fundraising activities described in this paragraph?

On January 25, 2013, the federal Department of Health and Human Services ("HHS") issued final regulations ("Final Regulations")<sup>1</sup> modifying the privacy rule ("Privacy Rule")<sup>2</sup> that implements section 264 of the administrative simplification provisions<sup>3</sup> within the Health Insurance Portability and Accountability Act of 1996 ("HIPAA").<sup>4</sup> These Final Regulations changed the answers to some of the questions raised above. More recently, on September 16, 2013, HHS issued a model notice of privacy practices ("Model Notice") that would provide patients with little information regarding how their health care providers use and disclose patient information for fundraising purposes.<sup>5</sup> This article is the first law review article to critique and propose corrections to provisions within the Final Regulations that expand the permissible scope of uses and disclosures of protected health information ("PHI")<sup>6</sup> for fundraising purposes<sup>7</sup> as well as related provisions

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1. Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules under the Health Information Technology for Economic and Clinical Health Act and the Genetic Information Nondiscrimination Act; Other Modifications to the HIPAA Rules, 78 Fed. Reg. 5566, 5700 (Jan. 25, 2013) (to be codified at 45 C.F.R. pts. 160, 164).

2. Privacy of Individually Identifiable Health Information, 45 C.F.R. §§ 164.500–.534 (2013).

3. The Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, § 264, 110 Stat. 1936, 2033 (1996).

4. *Id.* §§ 261–70.

5. U.S. DEP'T HEALTH & HUMAN SERVS., NOTICE OF PRIVACY PRACTICES 3–5 (2013) [hereinafter MODEL NOTICE].

6. OTHER MODIFICATIONS TO THE HIPPA RULES, 78 Fed. Reg. at 5689 (defining PHI with reference to individually identifiable health information with certain exceptions).

7. Technical Corrections to the HIPAA Privacy, Security, and Enforcement Rules, 78 Fed. Reg. 32,466, 32,466 (June 7, 2013) (to be codified at 45 C.F.R. pts. 160, 164).

within the Model Notice that fail to alert patients to these expanded information uses and disclosures.<sup>8</sup>

This article proceeds as follows: Part I reviews the history of the Privacy Rule. Part II examines HHS's regulation of the use and disclosure of PHI for fundraising with a focus on HHS's progressively weakened confidentiality protections. That is, in a proposed rule issued in 1999, HHS would have required prior written authorization from a patient before the patient's health care providers could use or disclose the patient's PHI for fundraising purposes. In a final rule issued in 2000, HHS changed tack, allowing health care providers to use and disclose some limited demographic information about the patient as well as the patient's dates of health care for fundraising purposes without prior written authorization. Other information uses and disclosures still required prior written authorization from the patient. In early 2013, HHS significantly expanded the classes of PHI that health care providers may use and disclose for fundraising without prior patient authorization and, in fall 2013, HHS released its Model Notice, which does not alert patients to these additional information uses and disclosures. Part II of this article carefully charts the diminution of HHS's confidentiality protections in the context of fundraising over the last fourteen years with a special focus on the content of public commentary provided during the notice-and-comment rulemaking process as well as HHS's response to that commentary. Part II thus focuses on the development and current status of the law of grateful patient fundraising and other activities designed to increase philanthropic donations to hospitals and other health care institutions.

Part III of this article examines the growing business of health care philanthropy. Part III explains why health care institutions rely so heavily on philanthropic donations, including because of the expense of medical equipment, inadequate Medicare and Medicaid reimbursement, high uncompensated health care costs, and rising health care compliance costs associated with health care reform. Part III chronicles the ways in which health care institutions attempt to increase revenue through health care philanthropy. Part III focuses in particular on one type of health care philanthropy known as grateful patient fundraising and details

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8. *See infra* Part IV.

the ways in which hospitals and physicians identify and solicit grateful patients.

Part IV of this article examines whether the Final Regulations properly balance an individual's interest in maintaining health information confidentiality with the interest of health care providers in obtaining philanthropic donations. Concluding that the Final Regulations do not properly balance such interests, Part IV argues that prior written authorization should be sought and obtained before any information other than demographic information and dates relating to the provision of health care (collectively, "demographic information") is used or disclosed for fundraising purposes for four reasons. First, patients likely do not expect that their PHI is being used and disclosed for fundraising purposes in exchange for their request for and receipt of health care and the Model Notice does nothing to improve these patient expectations. Second, fundraising is neither a core function of covered entities nor necessary to support a core function of covered entities. Third, a fundraiser who receives and uses non-demographic information to create a targeted fundraising communication or a third party who reads a targeted fundraising communication could easily determine the patient's general health condition or the health care services requested or received by the patient. Fourth, a close examination of the comments received by HHS in response to the proposed rule that preceded the Final Regulations does not reveal a shift in public attitudes regarding the appropriate balance of health information confidentiality and health care philanthropy. Rather, the comments indicate that covered entities would still like to gather, use, and disclose as much information as possible about patients for fundraising purposes and that patients' rights advocates and privacy coalitions still prefer to prioritize patient confidentiality. The fact that covered entities would still like to gather, use, and disclose an expanded class of PHI for fundraising does not mean that philanthropy should, on a normative level, outweigh basic patients' rights. Rather, this article proposes that health information confidentiality and health care philanthropy be balanced through a more express notification of fundraising and prior authorization requirement.

Part V of this article proposes corrections to provisions within the Final Regulations and the Model Notice governing the use and disclosure of PHI for fundraising activities. That is, Part V

proposes a prohibition on health care providers using or disclosing PHI, other than demographic information, for fundraising purposes without prior written notification to and authorization from the patient. Part V offers sample fundraising notification and authorization language that health care providers may incorporate into their informed consent conversations, notices of privacy practices, and authorization forms. Because the Privacy Rule is necessarily limited to the topic of health information confidentiality, Part V also incorporates by reference a complementary set of ethical guidelines proposed in a companion article.<sup>9</sup> These guidelines address and resolve additional ethical issues raised by physician involvement in grateful patient fundraising.

### I. THE PRIVACY RULE: A BRIEF HISTORY

As signed into law by President Clinton on August 21, 1996, HIPAA had several purposes, including improving portability and continuity of health insurance coverage in individual and group markets, combating health care fraud and abuse, promoting the use of medical savings accounts, improving access to long-term care services and insurance coverage, and simplifying the administration of health insurance.<sup>10</sup> The administrative simplification provisions, codified at Subtitle F of Title II of HIPAA, directed HHS to issue regulations protecting the privacy<sup>11</sup> of individually

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9. See Stacey A. Tovino, *Giving Thanks: The Ethics of Grateful Patient Fundraising*, 103 KY. L.J. (forthcoming 2015) [hereinafter Tovino, *Giving Thanks*].

10. The Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (1996).

11. *Id.* § 264(c), 110 Stat. at 2033. Elsewhere, I defined and distinguished the concepts of privacy and confidentiality in the context of advances in functional magnetic resonance imaging. Stacey A. Tovino, *Functional Neuroimaging Information: A Case for Neuro Exceptionalism?*, 34 FLA. ST. U. L. REV. 415, 441–42 (2007) [hereinafter Tovino, *Functional Neuroimaging Information*]. This article uses these same basic definitions and distinctions. That is, in the health care context, “privacy” includes a patient’s interest in avoiding the unwanted collection by a third party of health or other information about the patient. *Id.* at 442. On the other hand, “confidentiality” refers to the obligation of a health industry participant to prevent the unauthorized or otherwise inappropriate use or disclosure of voluntarily given and appropriately gathered health and other information relating to a patient. *Id.* The terms “privacy” and “confidentiality” are frequently confused. Indeed, the Privacy Rule is actually a health information confidentiality rule because it sets limits on how health care providers and other covered entities can use and disclose appropriately gathered PHI. *Id.* at 449. However, I do use the term “Privacy Rule” in this article because that is the name given by HHS and used by the public for the rule. See, e.g., *HIPAA and the Privacy Rule*, PARTNERS HEALTH CARE, <https://healthcare.partners.org/phsirb/hrchipaa.htm> (last visited Apr. 14, 2014); *The Privacy Rule*, U.S. DEP’T HEALTH & HUMAN SERVS., <http://www.hhs.gov/ocr/privacy/hipaa/administrative/privacypolicy/index.html> (last

identifiable health information if Congress failed to enact comprehensive privacy legislation within three years of HIPAA's enactment.<sup>12</sup> When Congress failed to enact privacy legislation by its deadline, HHS incurred the duty to adopt privacy regulations.<sup>13</sup> The original HIPAA statute clarified, however, that any privacy regulations adopted by HHS must be made applicable only to three classes of individuals and institutions: (1) health plans; (2) health care clearinghouses; and (3) health care providers who transmit health information in electronic form in connection with certain standard transactions (each, a "covered entity"; collectively, "covered entities").<sup>14</sup>

HHS responded. On November 3, 1999,<sup>15</sup> and December 28, 2000, HHS issued a proposed and final Privacy Rule regulating covered entities' uses and disclosures of, and requests for, PHI.<sup>16</sup> On March 27, 2002,<sup>17</sup> and August 14, 2002, HHS issued proposed and final modifications to the Privacy Rule.<sup>18</sup> With the exception of technical corrections and conforming amendments,<sup>19</sup> these rules as reconciled remained largely unchanged between 2002 and 2009.

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visited Apr. 14, 2014).

12. § 264(c), 110 Stat. at 2033 ("If legislation governing standards with respect to the privacy of individually identifiable health information . . . is not enacted by the date that is 36 months after the date of the enactment of this Act, the Secretary of Health and Human Services shall promulgate final regulations containing such standards . . .").

13. *See id.*

14. *Id.* § 1172(a), 110 Stat. at 2023. *See generally* Standards for Privacy of Individually Identifiable Health Information, 64 Fed. Reg. 59,918, 59,924 (proposed Nov. 3, 1999) (to be codified at 45 C.F.R. pts. 160–64) (explaining that HHS did not directly regulate any entity that was not a covered entity because it did not have the statutory authority to do so).

15. Standards for Privacy of Individually Identifiable Health Information, 64 Fed. Reg. at 59,918.

16. Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82,462 (Dec. 28, 2000) (to be codified at 45 C.F.R. pts. 160, 164).

17. Standards for Privacy of Individually Identifiable Health Information, 67 Fed. Reg. 14,776 (proposed Mar. 27, 2002) (to be codified at 45 C.F.R. pts. 160, 164).

18. Standards for Privacy of Individually Identifiable Health Information, 67 Fed. Reg. 53,182 (Aug. 14, 2002) (to be codified at 45 C.F.R. pts. 160, 164).

19. *See, e.g.*, Standards for Privacy of Individually Identifiable Health Information, Final Rule; Correction of Effective and Compliance Dates, 66 Fed. Reg. 12,434 (Feb. 26, 2001) (to be codified at 45 C.F.R. pts. 160, 164); Technical Corrections to the Standards for Privacy of Individually Identifiable Health Information Published December 28, 2000, 65 Fed. Reg. 82,944 (Dec. 29, 2000) (to be codified at 45 C.F.R. pts. 160, 164).

The nature and scope of the legal duties of confidentiality that applied to covered entities and their business associates (“BAs”)<sup>20</sup> changed significantly over four years ago. On February 17, 2009, President Obama signed the American Recovery and Reinvestment Act (“ARRA”) into law.<sup>21</sup> Division A, Title XIII of ARRA, better known as the Health Information Technology for Economic and Clinical Health Act (“HITECH”), contained certain provisions that required HHS to modify some of the information use and disclosure requirements and definitions set forth in the Privacy Rule as well as the amount of civil penalties that may be imposed on covered entities and BAs who violate the Privacy Rule.<sup>22</sup>

Since ARRA’s enactment, HHS has been busy issuing proposed rules, interim final rules, final rules, and technical corrections that implement HITECH’s required changes to the Privacy Rule. On August 24, 2009, HHS released an interim final rule implementing HITECH’s new breach notification requirements.<sup>23</sup> On October 30, 2009, HHS released an interim final rule implementing HITECH’s strengthened enforcement provisions, including strengthened civil monetary penalties that the federal Office for Civil Rights may, for the first time since the enactment of the HIPAA statute, impose directly on BAs who fail to maintain the

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20. Business associates are defined to include individuals and institutions who: (1) on behalf of a covered entity, but other than in the capacity of a member of the workforce of a covered entity, create, receive, maintain, or transmit PHI for a function or activity regulated by the HIPAA Privacy Rule, and (2) provide, other than in the capacity of a member of the workforce of such covered entity, legal, actuarial, accounting, consulting, data aggregation, management, administrative, accreditation, or financial services to or for the covered entity. See Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules under the Health Information Technology for Economic and Clinical Health Act and the Genetic Information Nondiscrimination Act, 78 Fed. Reg. 5566, 5688 (Jan. 25, 2013) (to be codified at 45 C.F.R. pts. 160, 164).

21. American Recovery and Reinvestment Act of 2009, Pub. L. No. 111-5, 123 Stat. 115 (2009).

22. Health Information Technology for Economic and Clinical Health Act, Pub. L. No. 111-5, § 3001, 123 Stat. 115, 226–32 (2009). Elsewhere, I critiqued HITECH’s imposition of confidentiality requirements directly on BAs and I proposed statutory and regulatory changes to HITECH and the HIPAA Privacy Rule, respectively, that would exempt a class of BAs, including outside counsel, from the confidentiality obligations imposed on other BAs. See Stacey A. Tovino, *Gone Too Far: Federal Regulation of Health Care Attorneys*, 91 OR. L. REV. 813 (2013) [hereinafter Tovino, *Gone Too Far*]. This article builds on my earlier work by further critiquing the Final Regulations in an additional context; that is, in the context of hospitals that wish to use and disclose PHI to raise funds for their own benefit.

23. Breach Notification for Unsecured Protected Health Information, 74 Fed. Reg. 42,740, 42,740 (Aug. 24, 2009) (to be codified at 45 C.F.R. pts. 160, 164); Macon Phillips, *Signed, Sealed, Delivered: ARRA*, WHITE HOUSE BLOG (Feb. 17, 2009, 4:25 PM), <http://www.whitehouse.gov/blog/09/02/17/signed-sealed-delivered-ARRA>.

confidentiality of PHI.<sup>24</sup> On July 14, 2010, HHS released a proposed rule that would modify the HIPAA Privacy, Security, Breach Notification, and Enforcement Rules in accordance with HITECH.<sup>25</sup> On May 31, 2011, HHS released a proposed rule that would modify the HIPAA Privacy Rule's accounting of disclosures requirement.<sup>26</sup> On September 14, 2011, HHS released a proposed rule that would modify the Privacy Rule to provide individuals with the right to receive their laboratory test reports directly from their testing laboratories.<sup>27</sup> On January 25, 2013, HHS released the Final Regulations, which modify the HIPAA Privacy, Security, Breach Notification, and Enforcement Rules in accordance with HITECH.<sup>28</sup> On June 7, 2013, HHS released technical corrections to the Final Regulations.<sup>29</sup> Finally, on September 16, 2013, HHS released the Model Notice designed to assist covered entities in complying with the Final Regulations.<sup>30</sup> This article critiques and proposes further corrections to the fundraising provisions that were set forth in the January 25, 2013 rulemaking, and technically corrected on June 7, 2013,<sup>31</sup> as well as related fundraising provisions within the Model Notice.

The critiques and proposals set forth in this article are illustrative rather than exhaustive. I disagree with many of the changes set forth in the Final Regulations and this article is but one installment in a series of articles criticizing the Final Regulations. Elsewhere, I critiqued HITECH's imposition of confidentiality re-

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24. HIPAA Administrative Simplification: Enforcement, 74 Fed. Reg. 56,123, 56,123 (Oct. 30, 2009) (to be codified at 45 C.F.R. pts. 160, 164).

25. Modifications to the HIPAA Privacy, Security, and Enforcement Rules Under the Health Information Technology for Economic and Clinical Health Act, 75 Fed. Reg. 40,868 (proposed July 14, 2010) (to be codified at 45 C.F.R. pts. 160, 164).

26. HIPAA Privacy Rule Accounting of Disclosures Under the Health Information Technology for Economic and Clinical Health Act, 76 Fed. Reg. 31,426, 31,426 (proposed May 31, 2011) (to be codified at 45 C.F.R. pt. 164).

27. CLIA Program and HIPAA Privacy Rule; Patients' Access to Test Reports, 76 Fed. Reg. 56,712, 56,712 (proposed Sept. 14, 2011) (to be codified at 45 C.F.R. pt. 164).

28. Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules under the Health Information Technology for Economic and Clinical Health Act and the Genetic Information Nondiscrimination Act, 78 Fed. Reg. 5566, 5566 (Jan. 25, 2013) (to be codified at 45 C.F.R. pts. 160, 164).

29. Technical Corrections to the HIPAA Privacy, Security, and Enforcement Rules, 78 Fed. Reg. 32,466, 32,466 (June 7, 2013) (to be codified at 45 C.F.R. pts. 160, 164).

30. MODEL NOTICE, *supra* note 5.

31. Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules under the Health Information Technology for Economic and Clinical Health Act and the Genetic Information Nondiscrimination Act, 78 Fed. Reg. at 5566; Technical Corrections to the HIPAA Privacy, Security, and Enforcement Rules, 78 Fed. Reg. at 32,466.

quirements directly on BAs and proposed a correction that would except certain classes of BAs that are already regulated with respect to their use and disclosure of confidential client information, including state-licensed attorneys who are subject to state bar disciplinary action for the misuse of confidential client information.<sup>32</sup> In addition, on May 31, 2011, HHS released a proposed rule that would modify the Privacy Rule's accounting of disclosures requirement to include an access report requirement.<sup>33</sup> If HHS adopts the access report requirement in final regulations, I will make an administrative law critique of those final regulations as well. This article is well situated between my completed article and my anticipated article as it has a specific and detailed goal; that is, to properly balance a patient's interest in maintaining the confidentiality of his or her health information with the interest of a health care provider in using and disclosing the patient's PHI to raise funds for the provider's own benefit.

Before proceeding towards this goal, a brief summary of the Privacy Rule's theory and approach to health information confidentiality is necessary. The Privacy Rule has as its goal the balancing of the interest of individuals in maintaining the confidentiality of their health information and the interest of society in obtaining, using, and disclosing health information to carry out a variety of public and private activities.<sup>34</sup> To that end, the Privacy Rule regulates covered entities' and BAs' uses of, disclosures of, and requests for individually identifiable health information<sup>35</sup> to

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32. See Tovino, *Gone Too Far*, *supra* note 22, at 814–67.

33. HIPAA Privacy Rule Accounting of Disclosures Under the Health Information Technology for Economic and Clinical Health Act, 76 Fed. Reg. 31,426, 31,429 (proposed May 31, 2011) (to be codified at 45 C.F.R. pt. 164).

34. See Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82,462, 82,464 (Dec. 28, 2000) (to be codified at 45 C.F.R. pts. 160, 164) (“The rule seeks to balance the needs of the individual with the needs of the society.”); *id.* at 82,468 (“The task of society and its government is to create a balance in which the individual's needs and rights are balanced against the needs and rights of society as a whole.”); *id.* at 82,472 (“The need to balance these competing interests—the necessity of protecting privacy and the public interest in using identifiable health information for vital public and private purposes—in a way that is also workable for the varied stakeholders causes much of the complexity in the rule.”).

35. “Individually identifiable health information” is defined as information that is a subset of health information, including demographic information collected from an individual, and: (1) [i]s created or received by a health care provider, health plan, employer, or health care clearinghouse; and (2) [r]elates to the past, present, or future physical or mental health or condition of an individual; the provision of health care to an individual; or the past, present, or future payment for the provision of health care to an indi-

the extent such information does not constitute: (1) an education record protected under the Family Educational Rights and Privacy Act of 1974 (“FERPA”); (2) a student treatment record excepted from protection under FERPA; (3) an employment record held by a covered entity in its role as an employer; or (4) individually identifiable health information regarding a person who has been deceased for more than fifty years.<sup>36</sup> The name given by the Privacy Rule to the subset of individually identifiable health information described in the previous sentence is PHI.<sup>37</sup>

The Privacy Rule requires covered entities to adhere to three different levels of patient permission when using or disclosing PHI for different activities.<sup>38</sup> Again, the varying levels of patient permission reflect HHS’s desire to appropriately balance the interest of individuals in maintaining the confidentiality of their health information with a wide range of societal interests in obtaining, using, and disclosing PHI.<sup>39</sup> A review of the three levels of patient permission is necessary before discussing the level of patient permission that is appropriate for fundraising.

The first level of patient permission is actually no patient permission at all. That is, covered entities may freely use and disclose PHI without any form of prior patient permission for their own treatment,<sup>40</sup> payment,<sup>41</sup> and health care operations activities,<sup>42</sup> as well as certain public policy activities.<sup>43</sup> For example, a

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vidual; and (i) [t]hat identifies the individual; or (ii) [w]ith respect to which there is a reasonable basis to believe the information can be used to identify the individual.

Privacy of Individually Identifiable Health Information, 45 C.F.R. § 160.103 (2013).

36. *Id.* (defining “protected health information”).

37. *Id.* (using the name “protected health information”).

38. *Id.* §§ 164.502–.514 (setting forth the use and disclosure requirements).

39. *See supra* text accompanying note 34.

40. “Treatment” is defined as

the provision, coordination, or management of health care and related services by one or more health care providers, including the coordination or management of health care by a health care provider with a third party; consultation between health care providers relating to a patient; or the referral of a patient for health care from one health care provider to another.

45 C.F.R. § 164.501.

41. “Payment” is defined as the “activities undertaken by . . . a health plan to obtain premiums or to determine or fulfill its responsibility for coverage and provision of benefits under the health plan” as well as the activities of a “health care provider or health plan to obtain or provide reimbursement for the provision of health care.” *Id.*

42. “Health care operations” is defined with respect to a list of activities that are related to a covered entity’s covered functions. *Id.* These activities include, but are not limited to, conducting quality assessment and improvement activities, conducting training

covered general practitioner who wishes to consult with a specialist may disclose PHI to the specialist in order to allow the general practitioner to treat the patient and the Privacy Rule does not require the patient to give his or her prior authorization.<sup>44</sup> Likewise, a covered hospital that treats a patient may send a bill to the patient's insurer to obtain payment for hospital services rendered.<sup>45</sup> Again, the billing may occur without the patient's prior authorization.<sup>46</sup> Similarly, a teaching physician employed by a covered academic medical center may involve medical students in patient care, without patient authorization, to enable the students to learn to practice medicine while under physician supervision.<sup>47</sup> A covered entity that is required by state or other law to disclose PHI to another individual or entity may do so without patient authorization.<sup>48</sup> By final illustrative, but not exhaustive, example, a covered entity may disclose a patient's PHI to a law enforcement officer in certain situations, including when the covered entity suspects that the death of the patient may have resulted from criminal conduct.<sup>49</sup> The theory behind these permissions is that treating patients, allowing health care providers to obtain reimbursement for health care services rendered, training medical students, complying with state law, and alerting law enforcement officers to the suspicion of criminal activity outweigh a patient's interest in maintaining complete confidentiality.

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programs in which medical and other health care students learn to practice health care under supervision, and arranging for the provision of legal services. *Id.*; *see id.* § 164.506(c)(1) (permitting a covered entity to use or disclose PHI for its own treatment, payment, or health care operations).

43. Covered entities may use and disclose PHI for twelve different public policy activities without the prior written authorization of the individual who is the subject of the information. *Id.* § 164.512(a)–(l). These public policy activities include, but are not limited to, uses and disclosures required by law, uses and disclosures for public health activities, disclosures for law enforcement activities, uses and disclosures for research, and disclosures for workers' compensation activities. *Id.* § 164.512(a), (c), (f), (i), (l).

44. *Id.* § 164.501 (defining treatment to include "consultations between health care providers relating to a patient").

45. *Id.* (defining payment to include "the activities undertaken by [a] health care provider . . . to obtain . . . reimbursement for the provision of health care").

46. *Id.* § 164.506(c)(1) (permitting a covered entity to disclose PHI for its own payment activities).

47. *Id.* § 164.501 (defining health care operations to include "conducting training programs in which students, trainees, or practitioners in areas of health care learn under supervision to practice or improve their skills as health care providers").

48. *Id.* § 164.512(a)(1) (allowing covered entities to "use or disclose protected health information to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law").

49. *Id.* § 164.512(f)(4).

Under the second level of patient permission, a covered entity may use and disclose a patient's PHI for certain activities, but only if the individual is informed in advance of the use or disclosure and has the opportunity to agree to or prohibit or restrict the use or disclosure.<sup>50</sup> Because the Privacy Rule allows the covered entity to orally inform the individual of (and capture an oral agreement or oral objection to) a use or disclosure permitted by these provisions, this level of patient permission is sometimes referred to as the "oral permission" level, although a more practical written permission also will suffice. Under the Privacy Rule, a covered entity can conduct five sets of information uses and disclosures once the individual who is the subject of the information has been notified and has either agreed or not objected to the information use or disclosure.<sup>51</sup> These five sets of information uses and disclosures include certain uses and disclosures of directory information, such as name, location, general condition, and religious affiliation;<sup>52</sup> certain uses and disclosures that would allow other persons to be involved in a patient's care or payment for care;<sup>53</sup> certain uses and disclosures that would help notify, or assist in the notification of, family members, personal representatives, and other persons responsible for the care of the individual of the individual's location, general condition, or death;<sup>54</sup> certain uses and disclosures for disaster relief purposes;<sup>55</sup> and certain disclosures to family members and other persons who were involved in the individual's care or payment for health care prior to the individual's death of PHI that is relevant to that person's involvement.<sup>56</sup>

Under this second level of patient permission, the hospital room number and the general condition of a patient (e.g., "good," "fair," "poor," "stable") who has given her permission or who has not expressed an objection may be disclosed to a visitor who wishes to visit an identifiable patient in the hospital.<sup>57</sup> Likewise, a woman in labor who wishes her partner to be present for her labor and delivery may orally give permission for her health care

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50. *Id.* § 164.510.

51. *Id.* § 164.510(a)(1).

52. *Id.* § 164.510(a)(1)(i)(A)–(D).

53. *Id.* § 164.510(b)(1)(i).

54. *Id.* § 164.510(b)(1)(ii).

55. *Id.* § 164.510(b)(4).

56. *Id.* § 164.510(b)(5).

57. *Id.* § 164.510(a)(1)–(2).

providers to involve her partner in her care.<sup>58</sup> The theory behind requiring oral permission for these information uses and disclosures is that the patient has an interest in maintaining the confidentiality of her health information; however, the patient also may have an interest in being visited in the hospital, in obtaining assistance with the patient's health care or payment for health care, and being assisted during a disaster. In addition, the patient's family may have an interest in visiting the patient in the hospital, assisting the patient with his or her health care and financial needs, and obtaining assistance during a disaster. The required oral permission reflects the patient's interest in maintaining the confidentiality of his or her health information, but the lack of a requirement for a formal written authorization reflects HHS's desire to make it easy for the patient to ask for or agree to receive help.

The third (and highest) level of patient permission is prior written authorization. In the event that a covered entity would like to use or disclose PHI for a purpose that is not treatment, payment, or health care operations, that does not fall within one of the twelve public policy exceptions, that is not allowed with oral permission, and that is not otherwise permitted or required by the Privacy Rule, the covered entity must obtain the prior written authorization of the individual who is the subject of the information.<sup>59</sup> The Privacy Rule specifies the form of the authorization, including certain required elements and statements that are designed to place the individual on notice of how the individual's PHI will be used or disclosed.<sup>60</sup> This high level of patient permission reflects the value HHS places on a patient's interest in maintaining the confidentiality of her health information compared to other societal interests that are far removed from the core functions of covered entities, such as a health care provider's interest in selling the patient's information to a tabloid magazine or a health plan's interest in disclosing the patient's information to a marketing company to allow the company to market its products and services to the patient.<sup>61</sup>

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58. *Id.* § 164.510(b)(1)(i).

59. *Id.* § 164.508(a)(1).

60. *Id.* § 164.508(c)(1)–(2).

61. *See* Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82,462, 82,514 (Dec. 28, 2000) (to be codified at 45 C.F.R. pts. 160, 164) (“[C]overed entities must obtain the individual's authorization before using or disclosing protected

With this background, Part II of this article examines the history of HHS's regulation of the use and disclosure of PHI for fundraising purposes and identifies HHS's current placement of fundraising activities within these three levels of patient permission. As discussed in more detail in Parts IV and V, this article proposes that HHS move almost all fundraising activities from the first tier to the third tier of patient permission.

## II. THE REGULATION OF THE USE AND DISCLOSURE OF PHI FOR FUNDRAISING

Again, imagine a covered entity that would like to use or disclose a patient's PHI in order to raise funds for the covered entity's own benefit. For example, a general acute care hospital affiliated with a major academic medical center would like to embark on a capital campaign to raise funds to expand the infrastructure of, and technological and human resources available through, the hospital's medical, surgical, and radiation oncology departments. To raise funds, the hospital's major gifts officer would like to access health information in its electronic patient database to select patients who have received medical, surgical, or radiation oncology services, who had favorable health outcomes, and who live in certain zip codes known to be associated with a high median family income, or who have other indicators that suggest wealth.<sup>62</sup> The gifts officer believes that these patients, given their positive health care experiences, may be inclined to donate money to the hospital,<sup>63</sup> and may have the discretionary funds to do so. These types of patients are referred to as "grateful patients" and the solicitation of funds from grateful patients is frequently referred to

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health information for marketing purposes.").

62. See GRENZEBACH, GLIER & ASSOCS., *GRATEFUL PATIENTS: CRITICAL SUCCESS FACTORS FOR NAVIGATING HEALTHCARE'S FASTEST GROWING DONOR SEGMENT 3* (2013) [hereinafter *GRATEFUL PATIENTS*], available at <http://www.donorscape.com/assets/files/Grateful%20Patient%20White%20Paper%20202013.pdf> (providing health care fundraising advice and noting that "City or Zip code is a common method for segmenting large files, since, clearly, there are correlations between geographic areas and relative wealth").

63. See generally *After ARRA, CEs Should Tighten Compliance with Fundraising Rules*, ASS'N FOR HEALTHCARE PHILANTHROPY (May 7, 2009), [http://sharepoint.ahp.org/publicationandtools/News/InTheNew/AHPInNews\\_2009/Pages/AfterARR.aspx?PF=1](http://sharepoint.ahp.org/publicationandtools/News/InTheNew/AHPInNews_2009/Pages/AfterARR.aspx?PF=1) [hereinafter *AHP, After ARRA*] (noting that individuals who have received life-saving treatments and are grateful for such treatments are referred to as "grateful patients" and, "historically, [they are] the highest givers").

as “grateful patient fundraising” or “grateful patient philanthropy.”<sup>64</sup>

After searching its electronic patient database, the gifts officer identifies the woman described in the opening paragraph of this article; that is, the forty-year-old woman who had been diagnosed with stage IV colorectal cancer five years ago, who was given less than a ten percent chance of living five years, and who, five years later, is healthy and disease free after a rigorous combination of surgery, radiation, and chemotherapy.

If the woman’s address is associated with an affluent part of town, or if other demographic indicators or publicly available data<sup>65</sup> reveal actual or probable wealth, the gifts officer may ask the woman’s treating physician to initiate a private conversation with the woman regarding the hospital’s health care philanthropy needs during one of the woman’s follow-up appointments. If the woman’s address or other publicly available data suggests middle- to upper-middle class, but not wealthy, status, the major gifts officer may wish to disclose the woman’s home address to a contracted commercial fundraiser, who will send the woman a letter requesting a monetary donation that would be used to expand the

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64. *Grateful Patients Build*, NONPROFIT TIMES (Sept. 15, 2009), <http://www.nonprofittimes.com/news-articles/grateful-patients-build/> (explaining that grateful patients and their families are typically the largest donor base for healthcare philanthropy); Lindsey Getz, *In Tight Economic Times, Former Patients Become the Focus of Fundraising*, HOSP. & HEALTH NETWORK MAG., Nov. 2008, at 12 (noting that since 2003, forty percent of major gifts received by the University of Kansas Hospital have come from grateful patients or their families); see, e.g., Scott M. Wright et al., *Ethical Concerns Related to Grateful Patient Philanthropy: The Physician’s Perspective*, 28 J. GEN. INTERNAL MED. 645, 645 (2012) (“Philanthropy is a vital source of financial support for academic medical centers, and grateful patients may be the single most important source for substantive philanthropic gifts.”); Page Bullington, *First Steps for Successful Grateful Patient Fundraising*, TARGET ANALYTICS, Apr. 2011, at 1, available at [http://www.blackbaud.com/files/resources/downloads/WhitePaper\\_FirstStepsForSuccessfulGratefulPatientFundraising.pdf](http://www.blackbaud.com/files/resources/downloads/WhitePaper_FirstStepsForSuccessfulGratefulPatientFundraising.pdf) (“For any healthcare institution, an excellent source of new donors can be grateful patients. Programs that reach out to these individuals can form the cornerstones of successful healthcare fundraising operations.”); Dan Lowman, SENIOR VICE PRESIDENT, GRENZBACH GLIER & ASSOCS., *Successful Grateful Patient Fundraising Programs: Practical Steps for Tapping the Fastest Growing Donor Segment in Healthcare* (July 1, 2010), available at <http://www.grenzbachglier.com/assets/files/webinars/GG+A%20Webinar%20-%20successful%20Grateful%20Patient%20programs%20-%207.1.10.pdf> (explaining why grateful patients give more money than do corporations and foundations).

65. See Steven Rum & Scott M. Wright, *A Randomized Trial to Evaluate Methodologies for Engaging Academic Physicians in Grateful Patient Fundraising*, 87 ACAD. MED. 55, 57 (2012) (listing wealth indicators (including annual income, real estate assets, direct stock holdings, pension plan value, and investment data estimations) that may be pulled or estimated from publicly available sources).

resources available to future patients through the hospital's oncology department. If the woman is a Medicaid beneficiary, eligibility for which is tied to low-income and low resources, the hospital may wish to spend no time or resources requesting monetary donations from the woman.

Although the woman described in the preceding paragraphs is fictitious, there are many examples of actual grateful patients who have made significant donations to their hospitals and other health care providers. One well-known example is Annette Bloch, wife of H&R Block co-owner Richard Bloch.<sup>66</sup> The Bloch Cancer Foundation donated \$20 million to a hospital affiliated with the University of Kansas after Annette received treatment for her breast cancer there.<sup>67</sup>

Our hypothetical does raise several legal issues, however. One legal issue is whether a treating physician may initiate a private conversation with the woman regarding the hospital's health care philanthropy needs during one of the woman's follow-up appointments. Since its inception, the Privacy Rule has allowed physicians to converse with patients regarding a range of activities without the patient's prior written authorization or other indication of interest in the activity. For example, the Privacy Rule allows physicians who conduct clinical research to contact their patients for purposes of making them aware of clinical trials in which the patients may wish to participate, even without any prior written authorization or other indication from such patients that they are interested in participating in research.<sup>68</sup> HHS reasons that a physician who contacts a patient for purposes of making the patient aware of a clinical trial relevant to the patient's illness is engaged in "treatment" activities that fall within the first level of patient permission discussed in Part I of this arti-

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66. *Annette Bloch: Advocate, Philanthropist, Survivor*, UNIV. OF KAN. CANCER CTR., <http://www.kucancercenter.org/surviving-cancer/patient-stories/annette-bloch-story> (last visited Apr. 14, 2014).

67. Getz, *supra* note 64, at 12 (describing the donation made by the R.A. Bloch Cancer Foundation to the University of Kansas Hospital).

68. U.S. DEPT HEALTH & HUMAN SERVS., CLINICAL RESEARCH AND THE HIPAA PRIVACY RULE 4 (2004), *available at* [http://privacyruleandresearch.nih.gov/pdf/clin\\_research.pdf](http://privacyruleandresearch.nih.gov/pdf/clin_research.pdf) ("To contact potential study participants, a researcher may do so, without Authorization from the individual, under the following circumstances: . . . [A] covered health care provider may discuss treatment alternatives, which may include participating in a clinical trial, with the patient as part of the patient's treatment or the covered entity's health care operations.").

cle.<sup>69</sup> Therefore, the Privacy Rule requires no prior written authorization or other indication of interest from the patient.<sup>70</sup>

The Privacy Rule also allows physicians to initiate private face-to-face conversations with patients regarding available health-related and non-health related products and services without any authorization or other indication that the patient may be interested in purchasing or acquiring such products or services.<sup>71</sup> HHS reasons that the Privacy Rule was not intended to police private communications between physicians and patients.<sup>72</sup> HHS also reasons that patients who do not want products and services marketed to them can simply respond that they are uninterested during the face-to-face conversation.<sup>73</sup>

The same general rule applies to fundraising. That is, the Privacy Rule does not prohibit a physician from initiating a private, face-to-face conversation with a patient regarding the hospital's

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69. *See id.*

70. *See id.*

71. *See* Privacy of Individually Identifiable Health Information, 45 C.F.R. § 164.508(a)(3)(i)(A) (2013) (“[A] covered entity must obtain an authorization for any use or disclosure of protected health information for marketing, except if the communication is in the form of . . . [a] face-to-face communication made by a covered entity to an individual . . . .”); *see also* Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82,462, 82,545 (Dec. 28, 2000) (to be codified at 45 C.F.R. pts. 160, 164) (“First . . . [the Privacy Rule] permits a covered entity to use or disclose protected health information without individual authorization to make a marketing communication if the communication occurs in a face-to-face encounter with the individual. This provision would permit a covered entity to discuss any services and products, including those of a third-party, without restriction during a face-to-face communication. A covered entity also could give the individual sample products or other information in this setting.”).

72. *See* Standards for Privacy of Individually Identifiable Health Information, 67 Fed. Reg. 53,182, 53,190 (Aug. 14, 2002) (to be codified at 45 C.F.R. pts. 160, 164) (“The Department does not intend to police communications between doctors and patients that take place in the doctor’s office.”).

73. *See id.* (“In [the face-to-face] context, the individual can readily stop any unwanted communications, including any communications that may otherwise meet the definition of ‘marketing.’”); *see also* *Frequently Asked Questions*, U.S. DEP’T HEALTH & HUMAN SERVS., <http://www.hhs.gov/ocr/privacy/hipaa/faq/marketing/289.html> (last updated Mar. 14, 2006) (asking, “Are health care providers required to seek a prior authorization before discussing a product or service with a patient, or giving a product or service to a patient, in a face-to-face encounter?” and answering, “No. In face-to-face encounters, the HIPAA Privacy Rule allows *covered entities* to give or discuss products or services, even when not health-related, to patients without a prior authorization. This exception prevents unnecessary intrusion into the doctor-patient relationship”); *id.* (asking, “When is an authorization required from the patient before a provider or health plan engages in marketing to that individual?” and answering, “The HIPAA Privacy Rule expressly requires an authorization for uses or disclosures of protected health information for ALL marketing communications, except in two circumstances: 1. When the communication occurs in a face-to-face encounter between the covered entity and the individual . . . .”).

health care philanthropy needs. The Privacy Rule also would not prohibit a physician in that same setting from directly asking a patient for a donation that would benefit the hospital. As a practical matter, no confidentiality concerns are raised because no other person would be present for the conversation.

Thus, in our hypothetical, the Privacy Rule as it is currently written would not prohibit the oncologist from initiating a private conversation with the woman regarding the hospital's health care philanthropy needs during one of the woman's follow-up appointments. Again, HHS believes that the Privacy Rule was not designed to interfere with private communications between physicians and their patients.<sup>74</sup> Although I agree that private, face-to-face conversations do not raise confidentiality issues because no other person is present for the conversation, I argue in a companion article that significant physician involvement in grateful patient fundraising can risk conflicted physician decision making, health care resource allocation injustices, financial exploitation, and breach of privacy.<sup>75</sup> I manage these concerns by proposing in that companion article ethical guidelines governing physician involvement in grateful patient fundraising.<sup>76</sup>

A second legal issue relates to situations in which PHI would be used or disclosed for fundraising activities beyond a private, face-to-face, physician-patient conversation. For example, many hospitals also would like their employed, affiliated, or contracted development officers, major gift officers, institutionally-related foundation officers, and business associates to be able to use or disclose PHI in order to call patients on the telephone or mail letters to patients requesting donations. To select the patients who would receive telephone calls or mailed letters, many hospitals (and their affiliates and contractors) would like the ability to search electronic patient databases by certain criteria, such as treating physician, department of service, health outcome, and zip code, to try to identify grateful patients who have the financial ability to give. HHS has gone back and forth in proposed and final regulations over the past fourteen years regarding what, if any, information may be used by health care providers and their employed, affiliated, and contracted fundraisers to target patients

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74. See *supra* notes 72–73 and accompanying text.

75. See *Tovino, Giving Thanks, supra* note 9.

76. *Id.*

for receipt of fundraising communications. This article argues that HHS's current position, which allows sensitive PHI to be used and disclosed without prior patient authorization for fundraising purposes, insufficiently protects patient confidentiality.

#### A. *The 1999 Proposed Rule*

In its first proposed Privacy Rule, published on November 3, 1999 ("1999 Proposed Rule"), HHS would have required covered health care providers to obtain a patient's formal written authorization before using or disclosing any of the patient's PHI for fundraising: "Uses and disclosures of protected health information for which individual authorization is required include, but are not limited to, the following . . . [u]se or disclosure for fundraising purposes."<sup>77</sup> HHS explained in the preamble to the 1999 Proposed Rule that fundraising was sufficiently unrelated to treatment and payment, the core functions of hospitals and other covered entities, and therefore prior patient authorization should be required.<sup>78</sup>

#### B. *The 2000 Final Rule*

Over a year later, on December 28, 2000, HHS issued its first final Privacy Rule ("2000 Final Rule") and changed its approach to fundraising.<sup>79</sup> The 2000 Final Rule allowed covered entities to internally use and externally disclose to BAs and institutionally related foundations certain classes of PHI for fundraising purpos-

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77. See Standards for Privacy of Individually Identifiable Health Information, 64 Fed. Reg. 59,918, 60,055 (proposed Nov. 3, 1999) (to be codified at 45 C.F.R. pts. 160–64); see also Mary Chris Jaklevic, *Another Battle: HIPAA Threatens Doc Referrals in Soliciting Donations*, MOD. HEALTHCARE, May 6, 2002, at 14 [hereinafter Jaklevic, *Another Battle*] ("A stricter version of the regulations proffered by the Clinton administration and opposed by the industry would have forbidden hospitals from using patient data for fund raising.").

78. See Standards for Privacy of Individually Identifiable Health Information, 64 Fed. Reg. at 59,941 ("[W]e determined that it would be helpful to identify activities that, in our opinion, are sufficiently unrelated to the treatment and payment functions to require a [sic] individual to authorize use of his or her information. We want to make clear that these activities would not be prohibited, and do not dispute that many of these activities are indeed beneficial to both individuals and the institutions involved. Nonetheless, they are not necessary for the key functions of treatment and payment and therefore would require the authorization of the individual before his/her information could be used. These activities would include but would not be limited to: . . . The use or disclosure of information for fund raising purposes.").

79. See Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82,462 (Dec. 28, 2000) (to be codified at 45 C.F.R. pts. 160, 164).

es without prior authorization.<sup>80</sup> That is, covered entities were allowed to use or disclose demographic information about an individual as well as dates relating to the provision of health care to an individual for the purpose of raising funds for the covered entity's own benefit without obtaining prior authorization from the individual.<sup>81</sup> In the 2000 Final Rule, HHS imposed five requirements on fundraising efforts engaged in without prior authorization. First, the fundraising must be for the covered entity's own benefit.<sup>82</sup> That is, a covered entity could not use or disclose an individual's PHI to help a second organization raise funds for the second organization's benefit.<sup>83</sup> Second, the covered entity must include a statement in a document called a notice of privacy practices informing individuals that their PHI may be used and disclosed for fundraising purposes.<sup>84</sup> Third, the covered entity must include in its fundraising communications a description of how individuals may opt out of receiving further fundraising communications.<sup>85</sup> Fourth, the covered entity must make reasonable efforts to ensure that individuals who opt out of receiving future fundraising communications are not sent such communications.<sup>86</sup> Finally, the PHI used or disclosed by the covered entity must be limited to demographic information and dates of health care.<sup>87</sup> Other information, such as an individual's diagnosis, the specific treatments provided to the individual, the name of the individual's treating physician, or the name of the hospital department in which the individual received health care, could not be used or disclosed without prior authorization.<sup>88</sup> Covered entities that ad-

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80. *Id.* at 82,514 ("In the final rule, we narrow the circumstances under which covered entities must obtain the individual's authorization to use or disclose protected health information for fundraising purposes.").

81. *Id.*

82. *Id.* at 82,820 ("A covered entity may use, or disclose . . . the following [PHI] for the purpose of raising funds for its own benefit . . .").

83. *Id.* at 82,514 ("Any use or disclosure for fundraising purposes that does not meet the requirements . . . requires authorization. Specifically, covered entities must obtain the individual's authorization to use or disclose [PHI] to raise funds for any entity other than the covered entity. For example, a covered entity must have the individual's authorization to use [PHI] about the individual to solicit funds for a non-profit organization that engages in research, education, and awareness efforts about a particular disease.").

84. *Id.* at 82,820.

85. *Id.*

86. *Id.*

87. *Id.* ("A covered entity may use, or disclose . . . the following [PHI] for its own benefit, without an authorization . . . (i) Demographic information relating to an individual; and (ii) dates of health care provided to an individual.").

88. *See, e.g.,* Christopher Cloud, *Fund Raising Hits a Privacy Barrier: HIPAA Rule*

hered to these requirements were considered to be engaged in “health care operations” within the first level of patient permission described in Part I of this article; thus, no prior authorization was required.<sup>89</sup>

The fundraising approach HHS selected in its 2000 Final Rule appears to have been shaped in large part by the comments HHS received during the notice-and-comment rulemaking process. According to HHS, many commenters argued that it would be “time consuming and costly” for non-profit health care providers to obtain prior patient authorization for fundraising.<sup>90</sup> These commenters argued that an authorization requirement could “lead to a decrease in charitable giving.”<sup>91</sup> Comments such as these perhaps explain HHS’s removal of the authorization requirement that was proposed in the 1999 Proposed Rule.

The limitations HHS imposed on permissible fundraising activities in its 2000 Final Rule also appear to have been shaped by public comment. According to HHS, numerous commenters explained that they did not need access to all PHI, just patient names, addresses, and telephone numbers, to carry out fundraising, and that the use or disclosure of other information by covered entities could “unnecessarily intrude[] on individual privacy.”<sup>92</sup> In addition, several commenters explained that “disease or condition-specific letters requesting contributions, if opened by the wrong person, could reveal personal information about the in-

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*Will Force Healthcare Organizations to Rethink Development Outreach*, MOD. HEALTHCARE, Jan. 13, 2003, at 21 (“Unless a patient signs a special authorization, the HIPAA privacy rule will limit fund-raisers’ access to a patient’s name, address, age, gender, insurance status and the date the individual was treated. Many analysts interpret the privacy rule to mean that fund-raisers cannot access information about the doctor or practice area where a patient was treated.”); Mary Chris Jaklevic, *Healthcare Donations Surge*, MOD. HEALTHCARE, Sept. 10, 2001, at 34 [hereinafter Jaklevic, *Healthcare Donations Surge*] (explaining that under the 2000 regulations, development officers will not have access to patient medical data for fundraising; “[f]or example, fund-raisers could not determine which patients received cancer care, and therefore would be likely candidates to hit up for funding of a new linear accelerator”).

89. See Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. at 82,546 (“[I]n the final rule we define fundraising on behalf of a covered entity to be a health care operation.”); *id.* at 82,804 (defining health care operations to include “[c]onsistent with the applicable requirements of § 164.514 . . . fundraising for the benefit of the covered entity”).

90. *Id.* at 82,716.

91. *Id.* at 82,718 (“We agree with commenters that our proposal could have adversely effected charitable giving, and accordingly make several modifications to the proposal.”).

92. *Id.*

tended recipient.”<sup>93</sup> These comments perhaps explain HHS’s requirement in the 2000 Final Rule that only demographic information and dates of health care could be used or disclosed for fundraising.

Certainly not everyone agreed with HHS’s approach to fundraising in the 2000 Final Rule. Joel Simon, Director of Gift Planning at the charitable foundation of Greater Baltimore Medical Center, responded to the final rule by criticizing its limitations on ways of searching for grateful patients: “You need to find the needle in the haystack of 240,000, and HIPAA took away our magnet.”<sup>94</sup>

### C. *The 2009 HITECH Legislation*

The federal government’s approach to fundraising held steady until ARRA began working its way through Congress in early 2009. On January 28, 2009, an amendment to ARRA proposed to the House would have struck fundraising from the definition of “health care operations,” thereby removing fundraising from the first level of patient permission and moving it to the third; that is, covered entities would be required to obtain prior written authorization for all uses and disclosures of PHI for fundraising.<sup>95</sup> The amendment, which was unsuccessful, was patient advocates’ final pre-ARRA attempt to give more weight to health information confidentiality than to health care philanthropy.<sup>96</sup>

Less than three weeks later, on February 17, 2009, President Obama signed ARRA, including HITECH, into law.<sup>97</sup> HITECH

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93. *Id.*

94. Jaklevic, *Healthcare Donations Surge*, *supra* note 88, at 34.

95. See 155 CONG. REC., H702 (daily ed. Jan. 28, 2009) (proposing to amend ARRA by stating: “Fundraising.—Fundraising for the benefit of a covered entity shall not be considered a health care operation for purposes of section 164.501 of title 45, Code of Federal Regulations”).

96. See AHP, *After ARRA*, *supra* note 63 (“Prior to final passage of ARRA, there was a pitched battle between ardent patient privacy advocates and those representing health care providers and employers about the extent to which the existing protections should be strengthened. . . . [Patient] [a]dvocates convinced House members to toss the word ‘fundraising’ . . . . [Then, the Association for Healthcare Philanthropy] and other organizations launched a lobbying effort, saying the Office for Civil Rights had told them that in six years it had received no complaints of privacy violations related to fundraising. The [philanthropy] groups were victorious, and the House-Senate conference committee removed the sentence dealing with fundraising but retained the restrictions on marketing.”).

97. Ed Jones, *ARRA’s HITECH Privacy Provisions Apply HIPAA Security Rule to*

contained two consecutive provisions that specifically addressed fundraising and directed HHS to make certain changes to the Privacy Rule's fundraising provisions. The first provision required HHS to provide by rule that "any written fundraising communication that is a healthcare operation . . . shall, in a clear and conspicuous manner, provide an opportunity for the recipient of the communications to elect not to receive any further such communication."<sup>98</sup> In the second provision, HITECH stated: "When an individual elects not to receive any further such communication, such election shall be treated as a revocation of authorization . . . ."<sup>99</sup>

The two statutory provisions were curious for several reasons. First, HHS already required individuals be provided the opportunity to elect not to receive further fundraising communications, so the only new requirement in the first provision was that the opportunity given to the individual to opt out must be "clear and conspicuous."<sup>100</sup> The statutory requirement for a "clear and conspicuous" opportunity to opt out was unusual for federal health law. That is, Congress usually sets broad policy mandates in legislation and HHS usually establishes detailed implementation procedures in regulations.<sup>101</sup> Here, Congress included in its legislation detailed implementation provisions addressing the manner of information presentation.

Moreover, the second HITECH provision did not really make sense. Since individuals were not required to authorize covered entities to use their limited demographic information and dates of health care for fundraising under the 2000 Final Rule, HITECH's requirement that a patient's election not to receive further communications be treated as a revocation of such authorization was odd.<sup>102</sup>

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*Business Associates*, HIPAA.COM, <http://www.hipaa.com/2009/02/arras-hitech-privacy-provisions-apply-hipaa-security-rule-to-business-associates/> (last visited Apr. 14, 2014).

98. Health Information Technology for Economic and Clinical Health Act, Pub. L. No. 111-5, § 13406(b), 123 Stat. 115, 269 (2009).

99. *Id.*

100. *Id.*; see AHP, *After ARRA*, *supra* note 63 (reporting that a HIPAA attorney thought it unusual for HITECH to have "such specific implementation details, typically left up to rules issued by federal agencies" especially when "the new provision essentially repeats requirements in the privacy rule").

101. *See id.*

102. *See, e.g.*, Letter from Claudia A. Looney, Senior Vice President of Dev., Children's Hosp. of L.A., to U.S. Dep't of Health & Human Servs. 2 (Aug. 25, 2010) ("The use of the

#### D. *The 2010 Proposed Rule*

After President Obama signed HITECH into law, the health care industry eagerly awaited HHS's interpretation of the curious HITECH provisions.<sup>103</sup> On July 14, 2010, HHS released a proposed rule ("2010 Proposed Rule") that would modify the Privacy Rule in accordance with HITECH.<sup>104</sup> In the preamble preceding the proposed rulemaking, HHS highlighted the extent to which the rulemaking would strengthen confidentiality protections in the context of fundraising by imposing new limitations on the use and disclosure of PHI for fundraising.<sup>105</sup> Later in the rulemaking, in a section designed to highlight the benefits that would flow to individuals as a result of the rulemaking, HHS mentioned again the extent to which it was strengthening confidentiality protections by imposing restrictions on fundraising.<sup>106</sup>

Indeed, part of HHS's 2010 Proposed Rule would have strengthened individuals' confidentiality protections in the context of fundraising. As required by HITECH, HHS proposed to strengthen an individual's ability to recognize the opportunity to opt out of receiving future fundraising communications by requiring the opt-out language to be presented to individuals in a "clear and conspicuous" manner.<sup>107</sup> Although not required by HITECH, HHS also proposed to require that the method for an individual to

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term 'authorization' is confusing in the context of an 'opt-out.' Revocation of authorization for an opt-out seems to require using a legal document similar to the HIPAA Authorization Form currently used by fundraisers when there is need to use or disclose . . .").

103. See, e.g., Judd A. Harwood, *Have You Seen My HIPAA Regulations*, BIRMINGHAM MED. NEWS BLOG (Nov. 21, 2012, 7:52 AM), <http://birminghammedicalnews.blogspot.com/2012/11/have-you-seen-my-hipaa-regulations.html> (referencing the health care industry's long wait for the Final Regulations); Bill Mountcastle, *HIPAA Rule Brings about Favorable Changes to Fundraising*, HEALTH PHILANTHROPY SERVS. GRP. (Mar. 26, 2013), [http://www.health-philanthropy.com/index.php?option=com\\_lyftenbloggie&view=entry&category=bloggies&id=5%3Ahipaa-rule-brings-about-favorable-changes-to-fundraising&Itemid=15](http://www.health-philanthropy.com/index.php?option=com_lyftenbloggie&view=entry&category=bloggies&id=5%3Ahipaa-rule-brings-about-favorable-changes-to-fundraising&Itemid=15) (stating that the Final Regulations give "long-awaited clarification regarding the use of health information for hospital fundraising").

104. See Modifications to the HIPAA Privacy, Security, and Enforcement Rules Under the Health Information Technology for Economic and Clinical Health Act, 75 Fed. Reg. 40,868 (proposed July 14, 2010) (to be codified at 45 C.F.R. pts. 160, 164).

105. See *id.* at 40,869 ("These provisions . . . [establish] new limitations on the use and disclosure of protected health information for . . . fundraising purposes . . .").

106. *Id.* at 40,909 ("Also, individuals' rights with respect to fundraising communications would be strengthened.").

107. *Id.* at 40,896, 40,922 ("With each fundraising communication sent to an individual under this paragraph, a covered entity must provide the individual with a clear and conspicuous opportunity to elect not to receive any further fundraising communications.").

elect not to receive further fundraising communications not pose an “undue burden” or be “more than nominal.”<sup>108</sup> In the preamble to the 2010 Proposed Rule, HHS encouraged covered entities to “consider the use of a toll-free phone number, an e-mail address, or similar opt out mechanism that would provide individuals with a simple, quick, and inexpensive way to opt out of receiving future communications.”<sup>109</sup> HHS also explained its belief that requiring individuals to opt out by sending a letter through the U.S. mail would constitute an undue burden.<sup>110</sup> HHS further proposed that a covered entity not be able to condition treatment or payment on an individual’s choice with respect to receiving fundraising communications.<sup>111</sup> This proposal, HHS believed, would implement the curious language in HITECH that an election by an individual not to receive further fundraising communications be treated as a revocation of authorization.<sup>112</sup> HHS’s final proposal designed to strengthen confidentiality protections in the context of fundraising was a proposal that covered entities not be able to send fundraising communications to an individual who had elected not to receive such communications.<sup>113</sup> Before, covered entities only had to make “reasonable efforts” to ensure that those individuals who had opted out of receiving fundraising communications were not sent such communications.<sup>114</sup> Now, covered entities would be expected to actually abide by an individual’s request not to receive further fundraising communications.<sup>115</sup>

In addition to these proposals that were highly touted as increasing confidentiality protections in the context of fundraising,<sup>116</sup> HHS also quietly solicited public comment on other provisions that would decrease confidentiality protections. That is, HHS solicited public comment on whether to expand the classes of PHI that a covered entity may use and disclose for fundraising

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108. *See id.*

109. *Id.* at 40,886.

110. *Id.*

111. *Id.* at 40,896, 40,922 (proposing 45 C.F.R. § 164.514(f)(1)(ii)(C)).

112. *Id.* at 40,896–97.

113. *Id.* at 40,897, 40922–23.

114. *Id.* at 40,897 (internal quotation marks omitted); *see also supra* text accompanying note 86.

115. *See* Modifications to the HIPPA Privacy, Security, and Enforcement Rules Under the Health Information Technology for Economic and Clinical Health Act, 75 Fed. Reg. at 40,897.

116. *See supra* text accompanying note 105.

purposes from just demographic information and dates of health care to other information, including the name of the hospital department that provided health care services to the individual.<sup>117</sup> Explaining its solicitation of public comment on this topic, HHS cited concerns expressed by some covered entities that additional classes of information were needed to successfully engage in grateful patient fundraising.<sup>118</sup>

#### E. *The 2013 Final Rule*

Almost four years after President Obama signed HITECH into law, HHS issued its Final Regulations implementing HITECH. Published on January 25, 2013,<sup>119</sup> and technically corrected on June 7, 2013,<sup>120</sup> the Final Regulations contain both expected and surprising provisions that increase and decrease confidentiality protections in the context of fundraising, respectively.

As expected, and as required by HITECH, HHS added a requirement that the opportunity to elect not to receive further fundraising communications be clear and conspicuous: “With each fundraising communication made to an individual under this paragraph, a covered entity must provide the individual with a clear and conspicuous opportunity to elect not to receive any further fundraising communications.”<sup>121</sup> Although not required by HITECH, HHS also added other provisions it had proposed that

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117. See Modifications to the HIPAA Privacy, Security, and Enforcement Rules Under the Health Information Technology for Economic and Clinical Health Act, 75 Fed. Reg. at 40,897 (“In addition to the above modifications proposed in response to the HITECH Act, we also solicit public comment on the requirement at § 164.514(f)(1) which limits the information a covered entity may use or disclose for fundraising demographic information about and dates of health care service provided to an individual.”).

118. *Id.* (“Since the promulgation of the Privacy Rule, certain covered entities have raised concerns regarding this limitation, maintaining that the Privacy Rule’s prohibition on the use or disclosure of certain treatment information without an authorization, such as the department of service where care was received and outcomes information, harms their ability to raise funds from often willing and grateful patients.”).

119. See Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules under the Health Information Technology for Economic and Clinical Health Act and the Genetic Information Nondiscrimination Act, 78 Fed. Reg. 5566, 5700 (Jan. 25, 2013) (to be codified at 45 C.F.R. pts. 160, 164).

120. See Technical Corrections to the HIPAA Privacy, Security, and Enforcement Rules, 78 Fed. Reg. 32,466, 32,466 (June 7, 2013) (to be codified at 45 C.F.R. pt. 160, 164).

121. See Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules under the Health Information Technology for Economic and Clinical Health Act and the Genetic Information Nondiscrimination Act, 78 Fed. Reg. at 5700; see also *id.* at 5618 (summarizing HITECH’s new fundraising language).

supported an individual's ability to opt out of receiving further fundraising communications. For example, HHS finalized the provision requiring the opt-out method not to pose an undue burden or exceed a nominal cost.<sup>122</sup> HHS also finalized the provision it had proposed prohibiting covered entities from making fundraising communications to individuals who had opted out of receiving further communications.<sup>123</sup> Moreover, HHS finalized the provision prohibiting covered entities from conditioning "treatment or payment on [an] individual's choice with respect to the receipt of fundraising communications."<sup>124</sup> Although not in the Final Regulations, HHS also clarified in the preamble to the Final Regulations that covered entities must not use or disclose more than the minimum amount of information necessary to accomplish their fundraising activities.<sup>125</sup> All four of these regulatory provisions plus the preamble clarification may be viewed as increasing the confidentiality protections available to individuals who wish not to have their PHI used or disclosed for fundraising purposes.

As it did in its 2010 Proposed Rule, in the Final Regulations HHS made much of the way these new provisions would increase confidentiality in the context of fundraising. On the first page of the preamble to the Final Regulations, HHS explained that it was "[s]trengthen[ing] the limitations on the use and disclosure of protected health information for . . . fundraising purposes."<sup>126</sup> HHS stated several times thereafter that the Final Regulations "establish new limitations on the use and disclosure of protected health information for . . . fundraising purposes."<sup>127</sup>

Notwithstanding the emphasis HHS gave to its heightened confidentiality protections in the context of fundraising, the Final Regulations also contained somewhat surprising provisions that allow covered entities to expand the classes of PHI that may be used or disclosed for fundraising purposes.<sup>128</sup> In addition to demo-

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122. *See id.* at 5700.

123. *Id.*

124. *Id.*

125. *Id.* at 5622.

126. *Id.* at 5566.

127. *Id.* at 5568.

128. *Id.* at 5620 ("We generally adopt the proposals in the final rule, as well as allow certain additional types of protected health information to be used or disclosed for fundraising purposes.").

graphic information (including name, address, other contact information, age, gender, and date of birth) and dates of health care provided to an individual, the Final Regulations now allow covered entities to use and disclose information relating to the department of service from which the individual received care, as well as information regarding the individual's treating physician and health outcomes.<sup>129</sup> HHS explained that department of service information, treating physician information, and outcome information were the three categories of information most frequently identified by commenters as necessary for targeting fundraising communications to potentially grateful patients.<sup>130</sup>

Although the Final Regulations do not provide further detail about these three classes of PHI, HHS clarifies in its preamble language that department of service information includes information about the general department from which the patient received treatment, such as the cardiology department, the oncology department, or the pediatrics department.<sup>131</sup> As far as outcome information, HHS clarifies in the preamble that covered entities would be permitted to use and disclose any information regarding the death of the individual or any other sub-optimal result of treatment or services in order to screen out certain individuals for the receipt of fundraising communications.<sup>132</sup>

In the preamble to the Final Regulations, HHS did not specifically identify the exact number of commenters who persuaded them to expand the classes of PHI that could be used or disclosed for fundraising.<sup>133</sup> A careful reading of the preamble suggests that they received more comments in favor of expanding the classes of PHI that could be used or disclosed for fundraising than comments opposed to such expansion. In one part of the preamble, HHS provides: "[T]he vast majority of commenters supported allowing the use or disclosure of additional protected health information for fundraising."<sup>134</sup> Later, HHS explained that "a small

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129. *Id.* at 5700; *see also id.* at 5622 ("[T]his final rule also allows covered entities to use and disclose department of service information, treating physician information, and outcome information for fundraising purposes.").

130. *Id.* at 5622.

131. *Id.*

132. *Id.*

133. *See infra* Part IV for a detailed discussion of the number and contents of the comments received by HHS.

134. Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules under the Health Information Technology for Economic and Clinical Health Act

minority of commenters opposed allowing the use of additional protected health information to target fundraising efforts, citing privacy concerns with doing so.”<sup>135</sup>

In summary, HHS changed tack with respect to its approach to fundraising three times in the last decade and a half. In its 1999 Proposed Rule, HHS would have required prior written authorization for all PHI uses and disclosures for fundraising. That is, in 2000, HHS initially classified fundraising as requiring the third (and highest) level of patient permission: prior written authorization. Over a year later, in its 2000 Final Rule, HHS decided to impose fewer confidentiality restrictions on PHI used and disclosed for fundraising by allowing two classes of PHI (i.e., demographic information related to an individual and dates of health care provided to an individual) to be used and disclosed for fundraising without prior written authorization. That is, in 2000 HHS classified the use and disclosure of these two classes of PHI as “health care operations” within the first level of patient permission, requiring no prior written authorization. Thirteen years later, in 2013, HHS in its Final Regulations removed additional confidentiality restrictions on the use and disclosure of PHI for fundraising by allowing additional classes of PHI (i.e., department of service, treating physician, and outcome information) to be used and disclosed for fundraising without prior written authorization. That is, HHS increased the number of information uses and disclosures that fall within the first level of patient permission, thus requiring no prior written authorization. The question is whether the current approach is appropriate. As discussed in more detail in Parts IV and V, I believe it is not.

### III. THE BUSINESS OF HEALTH CARE PHILANTHROPY

To determine whether HHS’s current approach to fundraising is appropriate, an individual’s interest in maintaining the confidentiality of his or her health information must be balanced against a health care provider’s interest in obtaining, using, and disclosing PHI for fundraising purposes. This balancing requires

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and the Genetic Information Nondiscrimination Act, 78 Fed. Reg. at 5620. According to HHS, “These commenters stated that the use of additional protected health information would streamline their fundraising efforts and ensure that individuals were sent communications about campaigns that would be meaningful to their experiences.” *Id.*

135. *Id.*

a careful examination of the business of health care philanthropy, including the many benefits.

In 2012, the most recent year for which data is available, charitable giving in all industries totaled \$316.23 billion.<sup>136</sup> Approximately three-quarters of that amount—\$228.93 billion in 2012—came from individuals; that is, non-corporations and non-foundations.<sup>137</sup> Charitable giving to health organizations, the subject of this article, totaled \$28.12 billion in 2012.<sup>138</sup> Historically, more than three-quarters of the amount given to health organizations has come from individuals.<sup>139</sup>

Philanthropy has helped found, build, and maintain some of the country's oldest and finest healthcare institutions. New Orleans's historic Charity Hospital "was founded as a result of a creative estate plan of Jean Lois, a French seaman, in 1735."<sup>140</sup> Los Angeles's famous Cedars-Sinai Medical Center "was dedicated, in 1902, through the generosity of the city's Jewish community."<sup>141</sup> San Francisco's French Hospital, "California's oldest existing hospital, was established by a relief society" founded for the purpose of serving the sick and furnishing assistance to individuals without resources, among other purposes.<sup>142</sup>

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136. See Mark Hrywna, *Giving Gains, Estimated at \$316.23 Billion for 2012*, NONPROFIT TIMES (June 18, 2013), <http://www.thenonproffitimes.com/news-articles/giving-gain-estimated-at-316-23-billion-for-2012/>; *Giving USA: Charitable Donations Grew in 2012, But Slowly, Like the Economy*, LILLY FAMILY SCH. OF PHILANTHROPY (June 18, 2013), <http://www.philanthropy.iupui.edu/news/article/giving-usa-2013> [hereinafter Giving USA].

137. See *Giving USA*, *supra* note 136.

138. See *id.* For an overview of numbers reported by other sources and for previous years, see Rum & Wright, *supra* note 65, at 55 (reporting that charitable giving to the health care industry, including academic medical centers, health systems, and community hospitals, totaled \$4.8 billion in 2009); Michael L. Bentz et al., *Fundraising and Philanthropy in Plastic Surgery: An Essential Tool for Academic Excellence*, 127 PLASTIC RECONSTRUCTIVE SURGERY 2108, 2108 (2011) (reporting that educational institutions, including academic medical centers, received approximately seventeen percent of total charitable giving and that health initiatives received seven percent of total charitable giving); Getz, *supra* note 64, at 12 (reporting that the total amount donated to hospitals was \$7.9 billion in 2006 and \$8.3 billion in 2007).

139. See, e.g., Lowman, *supra* note 64, at 3 (providing data from 2008 and noting that of the \$8.6 billion in donations given to health care institutions, eighty-five percent of those donations came from individuals; that is, non-foundations and non-corporations).

140. Edie E. Zusman et al., *Philanthropy Funding for Neurosurgery Research and Program Development*, 73 NEUROSURGERY 177, 177 (2013).

141. *Id.*

142. *Id.*

The largest known gift to an American health care institution is the \$400 million gift given in 2007 by businessman Denny Sanford to the Sioux Valley Hospitals & Health System, located in Sioux Falls, South Dakota.<sup>143</sup> The health system has since been renamed Sanford Health.<sup>144</sup> Other illustrative major gifts to American health care institutions include the \$75 million given by the Schmidt Family Foundation to Boca Raton Community Hospital in Florida,<sup>145</sup> the \$60 million gift given by A.B. Hudson to Shriners Hospital for Children,<sup>146</sup> the \$4 million gift given by Richard M. and Yvonne Hamlin to Summa Health System in Ohio,<sup>147</sup> and the \$100 million regularly raised through gifts each year to New York University's Langone Medical Center.<sup>148</sup>

Philanthropic donations support a wide variety of health care initiatives and related educational missions.<sup>149</sup> In the context of academic medical centers, which typically include a medical school and at least one affiliated teaching hospital,<sup>150</sup> philanthro-

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143. See Kelby Krabbenhoft, *Philanthropy: A Priceless Lesson in Healthcare Leadership—The Sanford Health Story*, 24 FRONTIERS HEALTH SERVS. MGMT. 3, 4 (2008) (describing how Denny Sanford's \$400 million gift to support the institution that was renamed Sanford Health "(the largest known gift to an American healthcare organization)" came about); Loren Shook, *Building a Culture of Philanthropy from the Inside Out*, 24 FRONTIERS HEALTH SERVS. MGMT. 23, 23 (2008) (discussing the \$400 million Sanford Health gift); Susan Kreimer, *Mega Gifts Let Hospitals Rapidly Expand Their Missions*, HOSPS. & HEALTH NETWORKS, Mar. 2007, at 26 (discussing the \$400 million Sanford Health gift).

144. See *About Us*, SANFORD LUVERNE, <http://www.sanfordluverne.org/about/> (last visited Apr. 14, 2014) (noting that the Sioux Valley Health System was renamed Sanford Health after Danny Sanford's \$400 million gift).

145. See Stephanie Strom, *Florida: \$75 Million Donated to Hospital*, N.Y. TIMES, Jan. 31, 2007, at A15 ("The Boca Raton Community Hospital announced that it had received \$75 million from the Schmidt Family Foundation, one of the largest gifts given to a hospital. The money will help underwrite a new academic medical center focusing on hospital safety.").

146. See Tammy Robins, *Shriners Hospitals for Children Receives \$60 Million Donation Largest Donation in Organization's History*, LADUE-FRONTENAC PATCH (Missouri), (Oct. 16, 2011), <http://ladue-frontenac.patch.com/groups/around-town/p/shriners-hospitals-for-children-receives-60-million-d7e9224de9b>.

147. See *Summa Health System Receives Largest Philanthropic Gift in Organization's History*, SUMMA HEALTH SYS. (July 23, 2013), <http://www.summahealth.org/pressroom/all-news/2013/summa-health-system-receives-largest-philanthropic-gift-in-organizations-history>.

148. See *Grateful Patients Build*, *supra* note 64.

149. See Park H. Haussler, *Philanthropy for Patient Care*, HEALTHCARE FIN. MGMT., Dec. 1982, at 6.

150. Cf. Joseph V. Simone, *Understanding Academic Medical Centers: Simone's Maxims*, 5 CLINICAL CANCER RES. 2281, 2281 (1999) (describing the educational and patient care components of an academic medical center).

py has historically supported educational efforts,<sup>151</sup> research programs,<sup>152</sup> clinical initiatives,<sup>153</sup> and building or other academic infrastructure support.<sup>154</sup>

In the non-academic health care setting, health care buildings, including whole hospitals as well as wings, departments, wards, units, and centers of hospitals, have been the traditional beneficiaries of philanthropic efforts.<sup>155</sup> Historically, giving also has funded the acquisition and maintenance of expensive medical equipment, including x-ray machines, computed tomography scanners, magnetic resonance imaging scanners, and positron emission tomography scanners.<sup>156</sup> Several decades ago, when third-party payers reimbursed health care primarily on a retrospective cost basis,<sup>157</sup> donations designed to cover daily operating costs, such as the cost of a patient's daily hospital bed charge, were discouraged because such donations (viewed by accountants and auditors as reductions in costs) were required to be reported to third party payers and subtracted from the reimbursement requested by the health care provider.<sup>158</sup> In the 1980s and 1990s, as

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151. See Bentz et al., *supra* note 138, at 2111. Educational expenses include hard copy and computer based learning materials, resident travel for presentation of papers and teaching course attendance, visiting professorships, named lectureships, and international surgery mission efforts, among others. *Id.*

152. *Id.* Research programs include "basic science, translational, and clinical research programs." *Id.* at 2111 tbl.3.

153. *Id.*

154. *Id.* Building and academic infrastructure support include the development or improvement of buildings or areas within buildings, the purchase or donation of pieces of equipment, chairs, professorships, and/or program directorships. *See id.* at 2111.

155. See Haussler, *supra* note 149, at 6 ("Bricks and mortar . . . have been the primary beneficiaries of charitable giving.").

156. See Les Cave et al., *Philanthropy Makes a Difference: CHRISTUS Health Reaps the Benefits of Its Successful Community Efforts in Southern Texas*, HEALTH PROGRESS, Jan.-Feb. 2008, at 44 ("Many philanthropists are attracted to the idea of making contributions to build new buildings and acquire high technology like CAT Scans, MRIs and Cath labs, especially if this 'health care' comes complete with naming rights."); Haussler, *supra* note 149, at 6 ("[E]quipment and other capital acquisitions have been the primary beneficiaries of charitable giving.").

157. See, e.g., LOUIS C. GAPENSKI, FUNDAMENTALS OF HEALTHCARE FINANCE 70 (2d ed. 2013) (explaining that cost-based reimbursement involves a third-party payer who agrees to reimburse the health care provider for the actual costs incurred in providing health care to the insured population; cost-based reimbursement is retrospective in the sense that reimbursement is based on the actual services that were delivered to the patient in the past).

158. See Haussler, *supra* note 149, at 6 ("Since the beginning of cost-based reimbursement, the industry has discouraged the endowment of free beds, or the underwriting of operation costs. In our efforts to 'maximize' reimbursement, we have noted that any reduction of cost shares the gift with third-party payors, and we have concluded in most cases

third-party payers moved towards prospective payment systems,<sup>159</sup> the health care industry began to change its approach to philanthropy, including by encouraging donations that could be put towards daily operating expenses.<sup>160</sup>

Today, health care institutions engage in fundraising to support an even wider variety of health care initiatives and related educational missions. Academic medical centers continue to engage in fundraising to satisfy educational needs, research programs, clinical initiatives, and building and infrastructure support.<sup>161</sup> Nonprofit health care organizations engage in fundraising to provide resources to their community-based hospitals and clinics and to improve access to health care and other services for the uninsured and under-insured.<sup>162</sup> Many private health care foundations use philanthropy to serve the economically poor and under-served, including women, children, and seniors who live in the community served by the foundation.<sup>163</sup> Health care philanthropy is also used to improve the public's health through preven-

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that it is not the intention or desire of the donor to have such sharing.”).

159. A prospective payment system may be defined as a payment system in which the rates paid by third-party payers are determined by the payer before health care services are provided and in which payments are not directly related to a health care provider's costs or charges. *See* GAPENSKI, *supra* note 157, at 71–72.

160. *See* Cave et al., *supra* note 156, at 44 (“And, of course, with the reimbursement challenges hospitals and acute care face today, it often is essential to raise money through philanthropy to supplement the limited insurance and patient payments received.”); Haussler, *supra* note 149 at 6 (“Now is the time for the healthcare industry to consider a change in approach to philanthropy. Two reasons point to this conclusion: Cost-based reimbursement will be soon a relic of the past and, [t]here are unmet patient and institutional financial needs. As the healthcare industry moves into the competitive marketplace, reasonable provision for capital expansion, education and operations must be built into the charge structure. . . . Funding from gifts and bequests for payment of specific patient charges can be a means through which an institution may reduce uncollectible accounts, thereby strengthening the bottom line.”).

161. Bentz et al., *supra* note 138, at 2111; *see also* Rum & Wright, *supra* note 65, at 55 (“At academic health centers and hospitals, these monies help to fund varied needs including capital projects, research programs, educational initiatives, financial aid, and endowments. These gifts clearly support the tripartite academic health center mission of patient care, research, and education.”); Wright et al., *supra* note 64, at 645 (“Philanthropic contributions to academic medical centers from grateful patients support research, patient care, education, and capital projects.”).

162. *See, e.g.,* Cave et al., *supra* note 156, at 44 (“[T]he [CHRISTUS] fund's intent is to provide resources to community-based, not-for-profit organizations whose vision, mission and goals are consistent with those of CHRISTUS Health. Creating access to health care and other services for the uninsured and under-insured in communities served by CHRISTUS Health gives specificity to the grants awarded.”).

163. *See, e.g., id.* at 47 (noting that the St. Joseph's Community Foundation located in Paris, Texas, “focuses on programs that serve the economically poor and under-served, women and children and seniors . . .”).

tion and wellness programs and through the offering of basic health care and disease management for individuals without health insurance.<sup>164</sup> Health care philanthropy is used to support a wide range of medical specialties and patient care needs, including neurosurgery,<sup>165</sup> obstetrics and gynecology,<sup>166</sup> plastic surgery,<sup>167</sup> psychiatry,<sup>168</sup> and rare diseases,<sup>169</sup> among others. In short, health care philanthropy now supports a variety of medical specialties and health care needs in a broad range of communities and settings. That is, health care philanthropy has moved well beyond its historic purpose of providing financial support of hospital “bricks and mortar.”<sup>170</sup>

Philanthropy is said to be one of the only ways that some health care institutions can survive in the current health care environment, which is characterized by expensive medical technologies, high uncompensated health care costs, inadequate Medicare and Medicaid reimbursement, and rising health care compliance costs associated with health care reform.<sup>171</sup> In addition, philan-

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164. See *id.* at 45 (“[The intent of philanthropy can be] to improve the public’s health through prevention and wellness programs or . . . to offer primary care and disease management for uninsured.”).

165. See Zusman et al., *supra* note 140, at 177 (“In times of fiscal and political uncertainty, philanthropy has become an increasingly important mechanism for building, maintaining, and expanding neurosurgical research programs.”).

166. See Frank A. Chervenak et al., *Ethics: An Essential Dimension of Soliciting Philanthropic Gifts from Donors*, 203 AM. J. OBSTETRICS & GYNECOLOGY 540, 540 (2010) (“Obstetrics and gynecology continues to experience fiscal pressures that challenge its core missions. In such an increasingly economically unforgiving environment, philanthropy will become a major source of revenue.”).

167. See, e.g., Bentz et al., *supra* note 138, at 2108 (addressing the need for fundraising in the context of academic plastic surgery).

168. See Herbert Pardes & Constance E. Lieber, *Philanthropy for Psychiatry*, 163 AM. J. PSYCHIATRY 766, 766–67 (2006) (“With reduced public funding and limited foundation support, patient-inspired philanthropy serves as an invaluable alternative to cover much of the deserted areas of social need,” including academic psychiatry. “[P]hilanthropy should not be an area in which mental illness is given short shrift by provider and fundraising organizations”).

169. See, e.g., Elie Dolgin, *Advocates to Bring Rare Disease Philanthropy Under One Umbrella*, 16 NATURE MED. 837, 837 (2010) (discussing rare disease philanthropy).

170. Cave et al., *supra* note 156, at 44, 47.

171. See, e.g., Ass’n of Healthcare Philanthropy Int’l Conference, *With Health-Care Reforms, Hospitals Need Philanthropy More*, FUND RAISING MGMT., Dec. 1993, at 47 (stating that philanthropy is necessary due to the financial pressures brought about by health care reform); *Frequently Asked Questions*, HUNTINGTON HOSP., <http://www.huntingtonhospital.com/Main/GivingFAQ.aspx> (last visited Apr. 14, 2014) (“While Huntington Hospital has a number of income sources, including insurance reimbursements and investment income, the hospital is heavily dependent on private support from this community to maintain our level of excellence.”).

thropy is said to be one of the most vital and important sources of revenue and financial support for health care institutions because it is frequently unrestricted and can be used in any area of high organizational or institutional need.<sup>172</sup>

Today, health care philanthropy is a big business supported by attorneys,<sup>173</sup> consultants,<sup>174</sup> data connection organizations,<sup>175</sup> and professional associations.<sup>176</sup> Services offered by health care philanthropy experts include grateful patient fundraising seminars,<sup>177</sup> webinars,<sup>178</sup> and workshops,<sup>179</sup> as well as blog posts ad-

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172. Rosalyn Stewart et al., *Success in Grateful Patient Philanthropy: Insights from Experienced Physicians*, 124 AM. J. MED. 1180, 1184 (2011) (“Patient philanthropy can be especially transformative because it is often unrestricted, thereby allowing for new and creative ventures.”); Wright et al., *supra* note 64, at 649 (“Grateful patient philanthropy is an essential part of keeping academic medical centers (AMC) moving forward . . . because it is often unrestricted, and can allow for innovation in areas of high institutional need.”); see also Zusman et al., *supra* note 140, at 178 (“For years, some neurosurgeons have eschewed philanthropy, but the profession must now view it as an important source of revenue.”).

173. Adam H. Greene & Kristen R. Blanchette, *Time to Take Advantage of HIPAA Omnibus Rules “Good News”: Fundraising, Research, and Student Immunization Records*, DAVIS WRIGHT TREMAINE LLD (Apr. 2, 2013), <http://www.dwt.com/Time-to-Take-Advantage-of-HIPAA-Omnibus-Rules-Good-News-Fundraising-Research-and-Student-Immunization-Records-04-02-2013/> (“The Omnibus Rule now also permits the use of department of service, treating physician, outcome information, and health insurance status.”). Bob Belfort, a partner at Manatt, Phelps & Phillips, explains that many of his hospital clients have an interest in targeting fundraising communications based on the nature of the health care services received by the patient and the identity of the patient’s physician. See *HIPAA Final Rule Brings Changes to Marketing, Fundraising*, HEALTHCARE FIN. NEW (Mar. 11, 2013), <http://www.healthcarefinancenews.com/news/hipaa-final-rule-brings-changes-marketing-fundraising>. Many of Belfort’s hospital clients also have physicians on their medical staffs “make personal appeals to the patients.” *Id.* Belfort admits that, “I don’t know whether patients will have a negative reaction to getting solicitations that indicate fundraisers have looked at their data in more detail.” *Id.*

174. See, e.g., *Healthcare*, GRETZENBACH, GLIER & ASSOCIATES, <http://www.grenzebachglier.com/healthcare.html> (last visited Apr. 14, 2014) (marketing themselves as “[c]onsultants in [p]hilanthropic [m]anagement” and listing dozens of health care industry clients including academic medical centers, hospitals, research institutes, and hospices, among others); *Foster Physician Engagement*, THIRD SECTOR STRATEGY, <http://www.thirdsectorstrategy.com/physicians.html> (last visited Apr. 14, 2014) [hereinafter *Foster Physician Engagement*] (“Third Sector Strategy provides training and resources to engage and enable physicians to be vital partners for philanthropy.”).

175. See, e.g., *Healthcare Funding Solutions*, HARRIS CONNECT, <http://www.bcharris.com/images/HarrisConnectHealthcarefundraisingsolutions.pdf> (last visited Apr. 14, 2014) (marketing itself as the “leader in grateful patient fundraising”).

176. See, e.g., *Who We Are*, ASS’N FOR HEALTHCARE PHILANTHROPY, <http://sharepoint.ahp.org/publicationandtools/News/mediakit/Documents/AHPFactSheet.pdf> (last visited Apr. 14, 2014) [hereinafter AHP, *Who We Are*] (advertising that “AHP is the leading authority for standards, knowledge, and leadership in health care philanthropy”).

177. See, e.g., *AFP International Conference on Fundraising*, ASS’N OF FUNDRAISING PROF’LS, <http://www.afpnet.org/Professional/content.cfm?ItemNumber=3097&navItemNumber=550> (last visited Apr. 14, 2014) (advertising various conferences with seminars host-

dressing best practices in hospital fundraising generally and grateful patient fundraising in particular.<sup>180</sup> The Association for Healthcare Philanthropy (“AHP”) is the largest professional organization dedicated exclusively to assisting charitable efforts in health care organizations.<sup>181</sup> AHP provides education and information to “chief development officers . . . major gift officers, annual campaign managers, event coordinators . . . grant writers,” and other development personnel in all sectors of the health care industry including health care systems, academic medical centers, general acute care hospitals, specialty hospitals, long-term care facilities, hospices, institutionally related foundations, and advocacy groups, among others.<sup>182</sup> “AHP’s 5,000 members represent more than 2,200 health care facilities in the United States and Canada.”<sup>183</sup>

Understandably, AHP is very much in favor of HHS’s current approach to fundraising. Following the January 25, 2013, release of the Final Regulations, the President and Chief Executive Officer of AHP stated:

[T]he most positive element in the [Final Regulations] is that health care providers and their institutionally-related foundations can obtain and use department of service information in order to focus appeals, communications and outreach to those donors and prospects most likely to be interested in supporting the specific program related to that area of treatment. Reinstating this provision among the

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ed by the Association of Fundraising Professionals).

178. See, e.g., *Developing a Multichannel Grateful Patient Program to Identify Major Donor Prospects*, ASS’N OF FUNDRAISING PROF’LS, <http://afp.peachnewmedia.com/store/seminar/seminar.php?seminar=14929> (last visited Apr. 14, 2014) (advertising a webinar for purchase); *Recording Information: Grateful Patient Fundraising Webinar*, HARRIS CONNECT, <http://www.bcharrispub.com/patientfundraising?campaign=WODGP> (last visited Apr. 14, 2014).

179. See, e.g., *Foster Physician Engagement*, *supra* note 174.

180. See, e.g., Tom Wilson, *Best Practices in Grateful Patient Fundraising*, MAJORGIFTSGURU, <http://majorgiftsguru.com/2009/05/best-practices-in-grateful-patient.html> (last visited Apr. 14, 2014).

181. *About Us*, ASS’N FOR HEALTHCARE PHILANTHROPY, [http://www.ahp.org/Home/About\\_Us/Home/About\\_Us/About.aspx?hkey=5ed66e69-b202-401f-8aa1-3dfa14bdb488](http://www.ahp.org/Home/About_Us/Home/About_Us/About.aspx?hkey=5ed66e69-b202-401f-8aa1-3dfa14bdb488) (last visited Apr. 14, 2014) [hereinafter AHP, *About Us*]; AHP, *Who We Are*, *supra* note 176.

182. AHP, *Who We Are*, *supra* note 176.

183. AHP, *About Us*, *supra* note 181. Regional and state health care philanthropy associations also exist; see, e.g., NEW ENGLAND ASS’N FOR HEALTH CARE PHILANTHROPY, <http://www.neahp.org> (last visited Apr. 14, 2014); OHIO ASS’N FOR HEALTHCARE PHILANTHROPY, <http://www.ohioahp.us> (last visited Apr. 14, 2014).

professionals in health care will assist in efficiency and growth for health care philanthropy, which better serves communities.<sup>184</sup>

Experts in health care philanthropy, including AHP, strongly recommend grateful patient fundraising.<sup>185</sup> Indeed, grateful patients are said to be the most important source of financial donations to the health care industry.<sup>186</sup> A grateful patient may be defined as a patient, or a family member of a patient, grateful for the health care received by the patient and from whom an individual or institutional health care provider would like to solicit funds.<sup>187</sup> The simple theory behind grateful patient fundraising is that patients who are grateful for the health care they have received may be more willing to make philanthropic contributions compared to less satisfied patients and individuals who have no relationship with the soliciting health care institution.<sup>188</sup>

Grateful patient fundraising can be conducted at two different points in time: when the patient is in the hospital or other health care institution as an inpatient or outpatient or after the patient has been discharged or has returned home.<sup>189</sup> During the first

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184. *Modifications to HIPAA Help Fundraisers Improve Efficiency*, WEALTHENGINE (Mar. 5, 2013), <http://www.wealthengine.com/blog/2013/modifications-hipaa-help-fundraisers-improve-efficiency> (internal quotation marks omitted).

185. Bullington, *supra* note 64, at 1; Dianna Dilworth, *Past Patients an Untapped Fundraising Source: Survey*, DIRECT MARKETING NEWS (July 30, 2007), <http://www.dmnews.com/past-patients-an-untapped-fundraising-source-survey/article/98021/>.

186. *See, e.g.*, Anthony N. DeMaria, *Philanthropy and Medicine*, 48 J. AM. C. CARDIOLOGY 1725, 1725 (2006) (“Perhaps the greatest source of philanthropy is the grateful patient.”); Rum & Wright, *supra* note 65, at 55 (footnote omitted) (“In 2009, gifts from individuals to academic health centers, health systems, and community hospitals in the United States totaled \$4.8 billion. A substantial proportion of this total—nearly \$1 billion—came from grateful patients.”); Stewart et al., *supra* note 172, at 1180 (“Support from grateful patients is the single most important source for substantive philanthropic gifts in medicine.”).

187. *See* Bentz et al., *supra* note 138, at 2109.

188. *See* GRATEFUL PATIENTS, *supra* note 62, at 4 (“Anecdotal evidence indicates that positive patient experiences lead to increased giving. While much study remains to be done on the exact interaction between patient satisfaction, medical outcomes, and donor behavior, medical environments . . . appear to support better philanthropic outcomes.”); *Grateful Patient Program*, CLARK MEM’L HOSP., <http://www.clarkmemorial.org/patient-services/grateful-patient-program/> (last visited Apr. 14, 2014) (“We’re often asked by patients who have such an experience if there’s a way they can express their gratitude and appreciation for the care they or a family member received. That’s why we started the Grateful Patients & Family Program. . . . Through our Grateful Patient & Family Program, you can express your appreciation for the special care you or your loved ones received through a special donation to the Clark Memorial Hospital Foundation.”).

189. *See* Bullington, *supra* note 64, at 3 (explaining that organizations can conduct daily patient visits and/or send fundraising communications through the mail after patient discharge).

time period, solicitations may be made in person during a private conversation between a patient and an institutional representative or the patient's physician. During the second time period, solicitations may be mailed, e-mailed, telephoned, or conducted in person during a meeting or at a fundraising event.

According to health care philanthropy experts, timing is everything. Soliciting funds from a patient who is sick and lying in a hospital bed or from a patient who has been waiting to see a physician for several hours is likely to be unsuccessful.<sup>190</sup> Patients have reported frustration with solicitations made very shortly after health care services are rendered, including one case where a patient received a philanthropic solicitation two weeks after making a single visit to a hospital for a mere physician consultation.<sup>191</sup> Fundraising experts further advise that philanthropic communications not be scheduled at the same time as hospital and other health care bills are to be received by the patient.<sup>192</sup> A majority of first-time patient gifts are made within a year and a half of an inpatient stay, however, waiting years after the patient has been discharged home and all hospital bills have been paid is not recommended either.<sup>193</sup>

#### IV. CONFIDENTIALITY ISSUES RAISED BY GRATEFUL PATIENT FUNDRAISING

With this background regarding the benefits of health care philanthropy and the practice of grateful patient fundraising, this article can now assess the confidentiality issues raised by grateful patient fundraising. In the health care context, confidentiality may be defined as the obligation of a health industry participant to prevent the unauthorized or otherwise inappropriate use or disclosure of voluntarily given and appropriately gathered health

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190. See Lowman, *supra* note 64, at 10 ("Bad idea: Ask for a gift while a person is lying in a hospital bed, has been sitting in your waiting area for 2 hours, etc.").

191. See DeMaria, *supra* note 186, at 1725 ("[T]he concept that seeking medical care may automatically trigger a request for a donation does seem to straddle the fine line between appropriate and unseemly.").

192. See Bullington, *supra* note 64, at 4 ("Messaging and length of time between discharge and solicitation should be tested. You do not want your grateful patients to receive their solicitation letters the same day they receive their bills. Working with the billing department can help alleviate overlap in this area.").

193. See Lowman, *supra* note 64, at 10 ("But time is limited—the vast majority of first-time patient gifts come within 18 months of an in-patient visit.>").

information relating to a patient.<sup>194</sup> Grateful patient fundraising raises confidentiality issues because patients voluntarily provide health and other information about themselves to treating physicians and hospital support personnel in order to obtain a diagnosis and treatment. When a physician or other hospital representative uses or discloses that information for a purpose unrelated to treatment, the question becomes whether the use or disclosure is appropriate without prior patient notification and permission. That is, has a physician or other hospital representative who used or disclosed a patient's information for fundraising violated the patient's right to confidentiality?

As discussed in Part II of this article, the Privacy Rule now allows covered entities to use and disclose demographic information, insurance information, treating physician information, department of service information, and health outcome information for fundraising purposes without patient authorization.<sup>195</sup> As discussed in more detail below, this article argues that authorization should be sought and obtained before any information other than demographic information and dates relating to the provision of health care (collectively, "demographic information") is used or disclosed for fundraising purposes because: (1) patients likely do not expect that their PHI is being used and disclosed for fundraising purposes in exchange for their request for and receipt of health care and HHS's new Model Notice does nothing to improve patient expectations in this regard; (2) fundraising is neither a core function of covered entities nor necessary to support a core function of covered entities; (3) a fundraiser who receives and uses non-demographic information to create a targeted fundraising communication, or a third party who reads a targeted fundraising communication, could easily determine the patient's general health condition or the health care services requested or received by the patient; and (4) a close examination of the comments received by HHS in response to its 2010 Proposed Rule do not indicate a shift in public attitudes regarding the appropriate balance of confidentiality and philanthropy. Rather, the comments indicate that covered entities still would like to gather, use, and disclose as much information as possible about patients

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194. See Tovino, *Functional Neuroimaging Information*, *supra* note 11, at 441–42.

195. Privacy of Individually Identifiable Health Information, 45 C.F.R. § 164.514(f)(1)(i)–(vi) (2013).

for fundraising purposes and that patients' rights advocates and privacy coalitions still prefer to prioritize patient confidentiality. The fact that covered entities would still like to gather, use, and disclose an expanded class of PHI for fundraising does not mean that philanthropy should, on a normative level, outweigh basic patients' rights. Rather, this article proposes that health information confidentiality and health care philanthropy be balanced through a more express notification of fundraising and prior authorization requirement. Each of these four arguments will be discussed in turn.

First, one test federal and state lawmakers have used to determine whether health care providers may use and disclose PHI for a particular purpose without prior patient authorization is whether a patient would reasonably expect that his or her PHI would be used and disclosed for such purpose.<sup>196</sup> For example, HHS believes that most patients expect that when they present to their primary care physician with a suspected broken arm, or to their obstetrician with a suspected pregnancy, that the primary care physician or obstetrician will share information with radiologists and laboratories as necessary to provide or confirm a diagnosis.<sup>197</sup> For this reason, the Privacy Rule does not require the

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196. See, e.g., Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82,462, 82,625 (Dec. 28, 2000) (to be codified at 45 C.F.R. pts. 160, 164) (stating that in the context of patient expectations regarding the use and disclosure of PHI for biomedical and behavioral research: "A large number of commenters, however, indicated that they did not expect that individually identifiable health information about themselves would be used for research purposes without their authorization. Therefore, we retain more stringent protections for research disclosures without patient authorization"); Standards for Privacy of Individually Identifiable Health Information, 67 Fed. Reg. 14,776, 14,782-83 (proposed Mar. 27, 2002) (to be codified at 45 C.F.R. pts. 160, 164) (stating that in the context of whether one covered entity is permitted to disclose PHI to a second covered entity for the recipient entity's health care operations: "The Department believes that this limitation is necessary in order to protect the privacy expectations of the individual. An individual should expect that two providers that are providing treatment to the individual, and the health plan that pays for the individual's health care, would have protected health information about the individual for health care operations purposes. However, an individual would not expect a health plan with which the individual has no relationship to be able to obtain identifiable information from his or her health care provider"); Texas Medical Records Privacy Act, TEX. HEALTH & SAFETY CODE § 181.005(c)(1) (West 2012) (obligating the Executive Commissioner of the Texas Health and Human Services Commission, who is responsible for administering the Texas Medical Records Privacy Act, to consider "the lives of individuals in th[e State of Texas] and their expectations of privacy").

197. See Standards for Privacy of Individually Identifiable Health Information, 64 Fed. Reg. 59,918, 59,940 (proposed Nov. 3, 1999) (to be codified at 45 C.F.R. pts. 160-64) ("Our proposal is intended to make the exchange of protected health information relatively easy for health care purposes and more difficult for purposes other than health care. For indi-

primary care physician or the obstetrician to obtain the patient's prior written authorization before disclosing information to the radiologist or the laboratory.<sup>198</sup> HHS also believes that most patients with health insurance expect (and perhaps hope) that their health care providers will bill their insurers for health care services rendered so that the patients will not have to pay out of pocket for their health care services. Again, the Privacy Rule does not require a health care provider to obtain prior written authorization from a patient before disclosing the patient's PHI to the insurer for payment or reimbursement purposes.<sup>199</sup>

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viduals, health care treatment and payment are the core functions of the health care system. This is what they expect their health information will be used for when they seek medical care."); *see also* Standards for Privacy of Individually Identifiable Health Information, 67 Fed. Reg. 53,182, 53,208 (Aug. 14, 2002) (to be codified at 45 C.F.R. pts. 160, 164) ("In developing the Privacy Rule, the Department balanced the privacy implications of uses and disclosures for treatment, payment, and health care operations and the need for these core activities to continue. The Department considered the fact that many individuals expect that their health information will be used and disclosed as necessary to treat them, bill for treatment, and, to some extent, operate the covered entity's health care business."); *Uses and Disclosures for Treatment, Payment, and Health Care Operations*, U.S. DEPT HEALTH & HUMAN SERVS., <http://www.hhs.gov/ocr/privacy/hippa/understanding/coveredentities/usesanddisclosuresfurtpo.html> (last visited Apr. 14, 2014) ("Many individuals expect that their health information will be used and disclosed as necessary to treat them, bill for treatment, and, to some extent, operate the covered entity's health care business. To avoid interfering with an individual's access to quality health care or the efficient payment for such health care, the Privacy Rule permits a covered entity to use and disclose protected health information, with certain limits and protections, for treatment, payment, and health care operations activities.").

198. *Id.*; *see also* Privacy of Individually Identifiable Health Information, 45 C.F.R. § 164.506(c)(1) (2013) (allowing covered entities to use and disclose PHI for treatment purposes without prior written authorization); Standards for Privacy of Individually Identifiable Health Information, 64 Fed. Reg. at 59,940 ("We therefore propose that covered entities be permitted to use and disclose protected health information without individual authorization for treatment and payment purposes, and for related purposes that we have defined as health care operations. For example, health care providers could maintain and refer to a medical record, disclose information to other providers or persons as necessary for consultation about diagnosis or treatment, and disclose information as part of referrals to other providers. Health care providers also could use a patient's protected health information for payment purposes such as submitting a claim to a payer. In addition, they could use a patient's protected health information for health care operations, such as use for an internal quality oversight review.").

199. *See supra* notes 197–98; *see also* 45 C.F.R. § 164.506(c)(1) (allowing covered entities to disclose PHI for payment purposes without prior written authorization); Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. at 82,614 ("Activities we include in the definition of payment reflect core functions through which health care and health insurance services are funded. It would not be appropriate for a rule about health information privacy to hinder mechanisms by which health care is delivered and financed. . . . Rather, we allow these activities to occur, subject to and consistent with the requirements of this rule.").

The question becomes whether patients expect that their health care providers will internally use their PHI and disclose their PHI to development officers, major gifts officers, institutionally-related foundations, and BAs for fundraising purposes. Although it would be helpful, research revealed no empirical research assessing patients' expectations with respect to the use and disclosure of their PHI for fundraising purposes. The question thus becomes whether we think that patients would expect that their PHI will be used and disclosed for fundraising purposes without their prior written authorization in exchange for their request for and receipt of treatment.

I do not believe that patients expect that, as a result of requesting and receiving treatment at a hospital or other health care institution, their physicians and other hospital representatives will use and disclose their PHI for fundraising purposes. That is, I do not believe that patients have any idea that development officers search demographic information to identify patients who live in zip codes associated with expensive neighborhoods. I do not believe that patients know that major gift officers use cash payment and Cadillac insurance status<sup>200</sup> in an attempt to identify patients who have the resources to make philanthropic donations. I do not believe that patients know, or want, vice presidents of philanthropy at their hospitals' institutionally related foundations—folks who are very well known, well connected, and social in their communities—to be accessing their treating physician's name and their department of service, which can suggest diagnosis or health condition as well as the class of health care services requested or received. In summary, I believe that fundraising fails the patient expectation test and that a more express prior notification and authorization requirement would serve the ethical principle of respect for persons, including the obligation to provide information necessary for autonomous persons to make decisions about what happens to them and their health information.<sup>201</sup>

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200. See generally Jenny Gold, 'Cadillac' Insurance Plans Explained, KAISER HEALTH NEWS (Mar. 18, 2010), <http://www.kaiserhealthnews.org/stories/2009/september/22/cadillac-health-explainer-npr.aspx> (describing a "Cadillac" insurance plan as a relatively expensive plan that has excellent benefits and covers even the most expensive treatments).

201. See generally NAT'L COMM'N FOR THE PROT. OF HUMAN SUBJECTS OF BIOMEDICAL & BEHAVIORAL RESEARCH, U.S. DEPT' HEALTH, EDUC. & WELFARE, ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH (Apr. 18, 1979) [hereinafter BELMONT REPORT], available at <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html#erespect>.

My beliefs are supported by analogy to other positions HHS has maintained regarding patient expectations. For example, as discussed above, it is HHS's view that patients do expect that their PHI will be used and disclosed for treatment and insurance reimbursement purposes, but that they do not expect that their PHI will be used and disclosed for research purposes.<sup>202</sup> Thus, with a few exceptions, HHS generally requires authorization before a covered entity can use or disclose PHI for research purposes.<sup>203</sup> I certainly agree with HHS's decision to require authorization in the research context, and I also think that fundraising, like research, is sufficiently unexpected not to allow waiver of patient authorization. My beliefs are also supported by the American Medical Association's ("AMA") Code of Medical Ethics and many state health information confidentiality laws, which do not contain exceptions to the general duty of confidentiality for fundraising and related data collection activities.<sup>204</sup> Indeed, I associate

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202. See *supra* note 197; Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. at 82,625 ("A large number of commenters, however, indicated that they did not expect that individually identifiable health information about themselves would be used for research purposes without their authorization. Therefore, we retain more stringent protections for research disclosures without patient authorization.").

203. See 45 C.F.R. § 164.512(i).

204. *Privacy Policy*, MARTIN & SUHEY ORTHOPEDICS, <http://martinsuhey.com/privacy-policy-21> (last visited Apr. 14, 2014) ("In return for the patient's honesty, the physician generally should not reveal confidential communications or information without the patient's express consent unless required to disclose the information by law. There are exceptions to the rule, such as where a patient threatens bodily harm to himself or herself or to another person."); *Opinion 5.05-Confidentiality*, in CODE OF MEDICAL ETHICS, AM. MED. ASS'N, available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion505.page>? (last updated June 2007) ("The physician should not reveal confidential information without the express consent of the patient, subject to certain exceptions which are ethically justified because of overriding considerations. When a patient threatens to inflict serious physical harm to another person or to him or herself and there is a reasonable probability that the patient may carry out the threat, the physician should take reasonable precautions for the protection of the intended victim, which may include notification of law enforcement authorities. When the disclosure of confidential information is required by law or court order, physicians generally should notify the patient. Physicians should disclose the minimal information required by law, advocate for the protection of confidential information and, if appropriate, seek a change in the law."); *Opinion 5.075-Confidentiality: Disclosure of Records to Data Collection Companies*, in CODE OF MEDICAL ETHICS, AM. MED. ASS'N available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion5075.page>? (last updated June 1998) (stating, with respect to the disclosure of confidential health information to data collection companies: "Data collection from computerized or other patient records for marketing purposes raises serious ethical concerns. . . . These arrangements may violate principles of informed consent and patient confidentiality. Patients divulge information to their physicians only for purposes of diagnosis and treatment. If other uses are to be made of the information, patients must give their permission after being fully informed about the purpose of such disclosures. If permission is not obtained, physicians violate patient

biomedical and behavioral research more closely with treatment; indeed, between research and fundraising, I would expect my PHI to be used by my health care providers for research before it would be used for fundraising.

In order to give patients notice of how they should expect their PHI to be used and disclosed, the Privacy Rule does require patients to be given a document called a “notice of privacy practices.”<sup>205</sup> The purpose of the notice of privacy practices is to give individuals “adequate notice of the uses and disclosures of protected health information that may be made by the covered entity, and of the individual’s rights and the covered entity’s legal duties with respect to protected health information.”<sup>206</sup> Covered entities must give the notice of privacy practices to patients at their date of first service delivery,<sup>207</sup> post the notice in a clear and prominent location where it is reasonable to expect individuals seeking services from the health care provider will be able to read the notice,<sup>208</sup> and make the notice available to any individual upon request,<sup>209</sup> including when the notice is revised.<sup>210</sup> The Privacy Rule does not require patients to read or understand the notice, and it does not require the covered entity to explain the notice to patients.<sup>211</sup> The empirical literature assessing the use and readability of the notice of privacy practices suggests that many notices are difficult to read and are written at a much higher reading

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confidentiality by sharing specific and intimate information from patients’ records with commercial interests. . . . Finally, these arrangements may harm the integrity of the patient-physician relationship. The trust that is fundamental to this relationship is based on the principle that the physicians are the agents first and foremost of their patients.”), available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion5075.page>? (last visited Apr. 14, 2014); NEV. REV. STAT. § 449.720(2) (2012) (“Except as otherwise provided in NRS 108.640, 239.0115, 439.538, 442.300 to 442.330, inclusive, and 449.705 and chapter 629 of NRS [none of which relate to fundraising], discussions of the care of a patient, consultation with other persons concerning the patient, examinations or treatments, and all communications and records concerning the patient are confidential.”).

205. See 45 C.F.R. § 164.520.

206. See *id.* § 164.520(a)(1).

207. *Id.* § 164.520(c)(2)(i)(A).

208. *Id.* § 164.520(c)(2)(iii)(B).

209. *Id.* § 164.520(c).

210. *Id.* § 164.520(c)(2)(iv).

211. See, e.g., Rachele S. Stewart, *Protective Measures for Private Health Information*, 4 PERSP. HEALTH INFO. MGMT. 1, 5 (2007), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2047293/pdf/phim0004-0005.pdf> (“Some facilities simply ask patients to sign the Privacy Practice form, but do not take the time to explain its provisions.”).

level than plain language.<sup>212</sup> In addition, the medical and privacy literatures suggest that most patients do not even read HIPAA-required notices of privacy practices or other privacy policies.<sup>213</sup>

Assuming for the moment that a patient actually reads the notice of privacy practices either at the time of first service delivery or in posted form, the required fundraising language can be short and non-descriptive and may not actually describe the ambitious nature of the fundraising activities undertaken by many covered entities. Indeed, on September 16, 2013, HHS released its Model Notice designed to comply with the Privacy Rule. The only fundraising language contained in the Model Notice provides: “In the case of fundraising: We may contact you for fundraising efforts, but you can tell us not to contact you again.”<sup>214</sup> This concise statement does nothing to inform patients (or raise patient expectations) regarding the classes of PHI that may be used without prior patient authorization or the types of individuals and organizations, including employed major gifts officers, institutionally-related foundations, and contracted business associates, who may receive PHI from covered entities for fundraising purposes.

A review of covered entities’ actual notices suggests that they are not much better than HHS’s Model Notice. The Cleveland Clinic Health System (“CCHS”) in Cleveland, Ohio, has a four-page notice of privacy practices that states, in relevant part: “Philanthropic Support. We may use general demographic information about you to contact you in an effort to raise funds to sup-

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212. See, e.g., Anh T. Ha & Stuart A. Gansky, *HIPAA Notice of Privacy Practices Used in U.S. Dental Schools: Factors Related to Readability or Lack Thereof*, 71 J. DENTAL EDUC. 419, 424 (2007) (“Not surprisingly, most U.S. dental schools’ NPPs [notices of privacy practices] are quite difficult to read and at a much higher reading level than plain language.”); Steven Walfish & Keely M. Watkins, *Readability Level of Health Insurance Portability and Accountability Act Notices of Privacy Practices Utilized by Academic Medical Centers*, 28 EVALUATION & HEALTH PROFS. 479, 479 (2005) (“The majority (65%) of [notices analyzed] were written beyond the 12th-grade reading level, and almost the entire sample (90%) fell in the difficult range of reading ease.”).

213. See, e.g., Memorandum from Paul M. Schwartz & Daniel Solove, Notice and Choice: Implications for Digital Marketing to Youth, to The Second NPLAN/BSMG Meeting on Digital Media and Marketing to Children 2 (June 29-30, 2009), available at [http://changelabsolutions.org/sites/default/files/documents/Notice\\_and\\_choice.pdf](http://changelabsolutions.org/sites/default/files/documents/Notice_and_choice.pdf) (“An additional major problem with notice and choice is that notice is illusory in practice. Privacy policies are long, cumbersome, and hard to read. Moreover, most people do not read privacy policies.”); *Observership Program Guidelines and Evaluation Forms*, AM. MED. ASS’N, available at <http://www.ama-assn.org/ama/pub/about-ama/our-people/member-groups-sections/international-medical-graduates/observership-guidelines.page> (last visited Apr. 14, 2014) (“[M]ost patients do not read the Notice of Privacy Practices”).

214. MODEL NOTICE, *supra* note 5, at 4.

port CCHS and its operations. We also will tell you how to cancel these communications.”<sup>215</sup> The language is so brief that even if noticed and read, it may not trigger any patient expectations regarding the philanthropic activities described in Part III of this article. In addition, the language does not appear to have been updated in light of the Final Regulations because there is no mention of using or disclosing treating physician information, department of service information, or health outcome information.

Similarly, New York City’s Memorial Sloan-Kettering Cancer Center (“Sloan-Kettering”) has an eight-page notice of privacy practices. On page three, Sloan-Kettering states:

Fundraising. To support our business operations, we may use demographic and other information about you, including your name, where you live or work, your health insurance status, your age and gender, [and] the dates that you received treatment . . . in order to contact you to raise money to help us operate. We may also share this information with [a] . . . charitable foundation . . . who may contact you to raise money on our behalf.<sup>216</sup>

Slightly more descriptive than CCHS’s language, this language may trigger some patient expectations regarding the philanthropic activities described in Part III of this article. However, the fact that the fundraising paragraph is located on page three of an eight-page notice certainly raises the question of whether the language would be noticed and read. In addition, the notice does not provide individuals with clear notice that they have the right to opt out of fundraising activities.<sup>217</sup> Like CCHS’s language, Sloan-Kettering’s language also does not appear to have been updated in light of the Final Regulations because there is no mention of using or disclosing treating physician information, department of service information, or health outcome information.

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215. *Notice of Privacy Practices*, CLEVELAND CLINIC HEALTH SYS., <http://my.clevelandclinic.org/Documents/Legal/npp.pdf> (last visited Apr. 14, 2014).

216. *Notice of Privacy Practices*, MEMORIAL SLOAN-KETTERING CANCER CENTER (Sept. 23, 2013), available at <http://www.mskcc.org/sites/files/node/2008/documents/revise-privacy-practices-eng-201309v1.pdf>.

217. If the general consent references fundraising activities and allows patients to opt out of them, then the Privacy Rule’s requirements may technically be satisfied. Because the general consent is not internally referenced, linked, or otherwise attached, however, I am unable to determine whether the general consent references fundraising and the extent to which a patient can opt out of fundraising activities. *Id.*

By final example, Sanford Health in Bismark, North Dakota, has a nine-page notice of privacy practices. On page four, the notice states:

Fundraising communications[.] We may contact you to request a tax-deductible contribution to support important activities of [Sanford Health]. In connection with any fundraising, we may disclose to our fundraising staff demographic information about you (e.g., your name, address and phone number) and dates on which we provided healthcare to you.<sup>218</sup>

Although Sanford Health's language is very clear and concise, the question, again, is whether patients will find the language on the fourth page of the notice and, if so, whether the language will trigger patient expectations regarding the philanthropic activities described in Part III of this article. Since the language does not appear to inform patients that they have the right to opt out of receiving fundraising communications, the notice may technically not comply with the Privacy Rule.<sup>219</sup> Like CCHS's and Sloan-Kettering's language, Sanford Health's language also does not appear to have been updated in light of the Final Regulations because it contains no mention of treating physician information, department of service information, or health outcome information.

I do not believe that most patients expect that their PHI will be used and disclosed for fundraising. Moreover, I do not believe that the Privacy Rule's notice of privacy practices requirement provides patients with such an expectation because: (1) many patients simply do not read notices of privacy practices; and, for those patients who do read them; (2) the fundraising language in HHS's Model Notice and in covered entities' actual notices is too brief and insufficiently descriptive to trigger any expectations regarding the philanthropic activities described in Part III of this article; (3) the fundraising language, even if descriptive, may be located deep within a long notice and may not have been specifi-

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218. *About Sanford Health*, SANFORD HEALTH, <http://www.sanfordhealth.org/about> (last visited Apr. 14, 2014); *What Is HIPAA?*, SANFORD HEALTH, <http://www.bismarck.sanfordhealth.org/information/HIPAAbrochure.pdf> (last visited Apr. 14, 2014). Sanford Health merged with Medcenter One in 2012.

219. *See* Privacy of Individually Identifiable Health Information, 45 C.F.R. § 164.520(b)(1)(iii)(A) (2013) (stating that the notice of privacy practices must include "a separate statement informing the individual . . . [i]n accordance with § 164.514(f)(1), the covered entity may contact the individual to raise funds for the covered entity and the individual has a right to opt out of receiving such communications").

cally noticed; (4) some notices do not provide clear statements notifying patients that they have the right to opt out of receiving fundraising communications; and (5) most covered entities do not appear to have updated their notices of privacy practices in light of the Final Regulations. For these reasons, I argue that the use of the notice of privacy practices to trigger patient expectations regarding fundraising and to provide notice of a patient's right to opt out of receiving fundraising communications is illusory in practice.<sup>220</sup>

The second reason I believe fundraising activities that involve PHI other than basic demographic information and dates of health care should require prior patient authorization is that fundraising is neither a core function of covered entities nor necessary to support the core functions of treatment and payment. As background, the Privacy Rule permits covered entities to use and disclose PHI without patient authorization when the purpose of the use or disclosure is a core function of the covered entity or an activity that is necessary to support a core function.<sup>221</sup> The core functions of covered entities include treatment and payment.<sup>222</sup> That is, the main reason patients seek care from a health care provider is for diagnosis and treatment.<sup>223</sup> The core function of health plans is to pay health care providers for the treatment they have provided and to reimburse insured patients for health care for which they have already paid.<sup>224</sup> And, the core function of health care clearinghouses is to transmit and translate information between and among health care providers, billing companies, and health care payers with the end goal of ensuring that providers get paid for treating patients.<sup>225</sup> Confidentiality gives way to these important, core health care functions.

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220. Schwartz & Solove, *supra* note at 213, at 1–2.

221. See *Marketing*, U.S. DEP'T HEALTH & HUMAN SERVS. (Apr. 3, 2003), <http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/marketing.html> [hereinafter HHS on Marketing] (distinguishing marketing activities from the core functions of treatment and payment).

222. U.S. DEP'T HEALTH & HUMAN SERVS., PROTECTED HEALTH INFORMATION 16 (2003) available at <http://www.hhs.gov/ocr/privacy/hipaa/understanding/training/udmn.pdf> (listing treatment and payment as core functions).

223. *Id.*

224. *Id.* at 15.

225. *Id.*; see also Privacy of Individually Identifiable Health Information, 45 C.F.R. § 160.103 (2013) (defining health care clearinghouse).

The Privacy Rule does allow covered entities to use and disclose PHI without prior patient authorization for certain administrative, financial, and legal purposes that are *necessary* to support the core functions of treatment.<sup>226</sup> For example, federal and state laws require hospitals to assess the quality of health care they provide,<sup>227</sup> obtain a license to do business from the relevant state agency,<sup>228</sup> and obtain certification from the Centers for Medicare and Medicaid Services if they wish to obtain reimbursement for providing health care services to Medicare and Medicaid beneficiaries.<sup>229</sup> For these reasons, quality assurance, licensing, and certification activities are considered necessary to support the core functions of treatment and payment and prior patient authorization is not required.<sup>230</sup>

Even if they are helpful or beneficial or important, activities that are *not* necessary to support the core functions of treatment and payment do require prior patient authorization.<sup>231</sup> For example, the act of selling patients' PHI could be helpful to a covered entity because it could generate income for the covered entity. Because selling PHI is not necessary to treat patients or to support other core functions, the Privacy Rule generally prohibits

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226. See PROTECTED HEALTH INFORMATION, *supra* note 222, at 39 (emphasis added).

227. See Conditions of Participation: Quality Assessment and Performance Improvement Program, 42 C.F.R. § 482.21 (2013) (noting that a federal Medicare condition requires participating hospitals to “develop, implement and maintain an effective, ongoing, hospital-wide, data-driven quality assessment and performance improvement program”).

228. See, e.g., Illinois Hospital Licensing Act, 210 ILL. COMP. STAT. 85/4 (West 2008) (“No person shall establish a hospital without first obtaining a permit from the Department [of Public Health].”).

229. See, e.g., Ctrs. for Medicare & Medicaid Servs., *The Certification Process*, in STATE OPERATIONS MANUAL (1991), available at <http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/S0M107c02.pdf> (providing information about how health care providers and suppliers can become Medicare certified).

230. See PROTECTED HEALTH INFORMATION, *supra* note 222, at 16; *Uses and Disclosures for Treatment, Payment, and Health Care Operations*, U.S. DEP'T OF HEALTH & HUMAN SERVS., at 2 (2003) available at <http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/usesanddisclosuresfortpo.html> (explaining that “health care operations” include the “administrative, financial, legal, and quality improvement activities of a covered entity that are necessary to run its business and to support the core functions of treatment and payment,” and further explaining that health care operations include quality assurance, licensing, and certification); see also Standards for Privacy of Individually Identifiable Health Information, 67 Fed. Reg. 53,182, 53,208 (Aug. 14, 2002) (to be codified at 45 C.F.R. pts. 160, 164) (discussing core functions).

231. See HHS on Marketing, *supra* note 221, at 1 (“With limited exceptions, the Rule requires an individual’s written authorization before a use or disclosure of his or her protected health information can be made for marketing. So as not to interfere with core health care functions, the Rule distinguishes marketing communications from those communications about goods and services that are essential for quality health care.”).

it.<sup>232</sup> By further example, the act of marketing products and services to patients could be helpful to a covered entity because it could generate additional income for the covered entity. Because marketing is not necessary to treat patients or to support other core functions, the Privacy Rule generally prohibits it without prior patient authorization.<sup>233</sup>

In response to HHS's 2010 Proposed Rule,<sup>234</sup> several health care providers submitted comments to HHS explaining that philanthropy is helpful, beneficial, and important. For example, Yale University told HHS that "[i]t would be *helpful* if [HHS] were to allow use of certain broad information, such as the name of the clinical department or service that provided care, to assist covered entities in customizing their fundraising appeals."<sup>235</sup> Similarly, Indiana University explained to HHS that "[s]ome types of covered entities, such as large, multi-disciplinary health care providers or hospitals, may *benefit* from being able to use additional information to help identify appropriate recipients of fundraising communications."<sup>236</sup> Likewise, Beth Israel Deaconess Medical Center told HHS, "This is particularly *important* to large academic medical centers like ours, and would allow us to use our very limited resources to better target our fundraising efforts at the Medical Center."<sup>237</sup> I agree with Yale, Indiana, and Beth Israel that philanthropy is helpful, beneficial, and important; however, I do not believe philanthropy is a necessary, core function of covered entities in the same way that treatment, payment, and health care operations are.<sup>238</sup>

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232. See Privacy of Individually Identifiable Health Information, 45 C.F.R. § 164.502 (a)(5)(ii)(A) (2013) ("[Except as permitted] . . . a covered entity or business associate may not sell protected health information.").

233. HHS on Marketing, *supra* note 221, at 1.

234. Modifications to the HIPAA Privacy, Security, and Enforcement Rules Under the Health Information Technology for Economic and Clinical Health Act, 75 Fed. Reg. 40,868 (proposed July 14, 2010) (to be codified at 45 C.F.R. pts. 160, 164).

235. Letter from Dorothy K. Robinson, Vice President & Gen. Counsel, Yale Univ., to Dep't of Health & Human Servs., Office of Civil Rights 4 (Sept. 13, 2010) (on file with author) (emphasis added).

236. Letter from Marcia N. Gonzales, Exec. Dir. of Research Compliance, Indiana Univ., to Dep't of Health & Human Servs., Office of the Sec'y (Sept. 13, 2010) (on file with author) (emphasis added).

237. Letter from Kristine C. Laping, Senior Vice President of Dev., Beth Israel Deaconess Med. Ctr., to Kathleen Sebelius, Sec'y, U.S. Dep't of Health & Human Servs., Office for Civil Rights (Sept. 13, 2010) (on file with author) (emphasis added).

238. *But see* Letter from David S. Guzick, Senior Vice President, Health Affairs, Univ. of Fla., to Kathleen Sebelius, Sec'y, U.S. Dep't of Health & Human Servs. Office for Civil

The third reason I believe fundraising activities that involve non-demographic PHI should require prior patient authorization is that fundraisers who prepare and third parties who read targeted fundraising communications that reference patients' treating physicians or departments of service could easily determine a patient's diagnosis or the type of health care services requested or received. For example, a quick Internet search on my smart phone revealed that New York City's Dr. Nadege M. Coupet specializes in treating patients infected with the HIV virus,<sup>239</sup> Las Vegas's Dr. Sheldon Freedman specializes in treating patients with sexual dysfunction,<sup>240</sup> and Phoenix's Dr. Robert Cohen specializes in plastic surgery.<sup>241</sup> A fundraiser who accesses the name of a patient's treating physician to prepare a targeted fundraising communication as well as a third party who inadvertently reads or receives the targeted communication could easily determine (in the time it takes the fundraiser or third party to Google the name of the physician on a smart phone) the patient's general health condition or the type of health care services requested or received by the patient. Indeed, several individuals who commented on HHS's 1999 Proposed Rule stated that "disease or condition-specific letters requesting contributions, if opened by the wrong person, could reveal personal [health] information about the intended recipient."<sup>242</sup>

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Rights 4 (Sept. 13, 2010) (on file with author) ("Many [covered entities] are non-profits and it is *essential* to their existence that they raise funds from the public . . .") (emphasis added); Letter from Susan Waltman, Exec. Vice President & Gen. Counsel, Greater N.Y. Hosp. Assoc., to U.S. Dep't of Health & Human Servs., Office for Civil Rights (Sept. 13, 2010) (on file with author) ("Fundraising efforts are *crucial* to a hospital's ability to provide care and treatment to all patients.") (emphasis added).

239. *About Dr. Coupet*, NADEGE M. COUPET, <http://www.drcoupet.com/internal-medicine-physician/> (last visited Apr. 14, 2014) ("I am a Board Certified African American physician specializing in Internal Medicine and HIV Medicine."); *Health Services*, NADEGE COUPET, <http://www.drcoupet.com/internist-doctor-health-services/hiv-sepcialist-nyc-hiv-infection> (last visited Apr. 14, 2014) ("I am an AAHIVM certified HIV specialist with more than 14 years experience in treating patients infected with the HIV virus.").

240. *Dr. Sheldon J. Freedman*, SHELDON J. FREEDMAN, MD LTD., <http://www.urologychannel.com/freedman/physicians.shtml> (last visited Apr. 14, 2014) ("His medical practice deals with urologic problems in men and women with special emphasis on sexual dysfunction, urologic oncology, pelvic floor reconstruction, stress incontinence, and stone disease.").

241. *Dr. Robert Cohen*, DR. ROBERT COHEN, <http://www.robertcohenmd.com/> (last visited Apr. 14, 2014) (describing Dr. Cohen as a board-certified plastic surgeon who practices in Scottsdale, Arizona).

242. See Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82,462, 82,718 (Dec. 28, 2000) (to be codified at 45 C.F.R. pts. 160, 164).

In addition to the identity of the patient's physician, the patient's department of service also could reveal the patient's health condition or type of health care services requested or received by the patient. For example, a patient who received services in a hospital's oncology department likely has cancer, had cancer, or suspects that he or she has cancer. A patient who received services in a hospital's chemical-dependency unit likely has a substance use disorder, is in recovery from a substance use disorder, or suspects that he or she has a substance use disorder. A patient who received services in a hospital's behavioral health unit likely has a mental illness, has a history of mental illness, or suspects that he or she has a mental illness. With the exception of patients who receive negative diagnostic test results, patients do not generally request or receive services from a particular department or unit unless they require such services. In addition, patients who suspect that they have certain illnesses, including mental illnesses, sexually transmitted diseases, and other sensitive conditions, are as deserving of confidentiality as individuals who are diagnosed with such illnesses.

In summary, fundraisers who have access to the identity of the patient's treating physician and the patient's department of service may be able to determine the patient's diagnosis or type of health care services requested or received. In addition, a targeted fundraising letter sent to a patient's home that is specific as to the identity of the patient's treating physician or department of service can suggest the diagnosis of the patient or the type of health care services requested or received to any third party who intentionally or inadvertently happens to read or see the letter. For these reasons, I argue that the patient's prior written authorization should be obtained before a covered entity uses or discloses the name of the patient's treating physician or the patient's department of service for fundraising purposes.<sup>243</sup>

The fourth reason I argue fundraising activities that use a patient's non-demographic PHI should require prior authorization is that a close examination of the comments received by HHS in response to its 2010 Proposed Rule do not indicate a shift in public

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243. See AM. MED. ASS'N, COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, PHYSICIAN PARTICIPATION IN SOLICITING CONTRIBUTIONS FROM PATIENTS CEJA REP. 7-A-04, at 3 (2004) (stating that a physician who sends "personalized solicitation letters to patients' homes where others may notice them, or [a physician who communicates] patient information to third parties," including fundraisers, may undermine confidentiality).

attitudes regarding the proper balance of confidentiality and philanthropy. Rather, the comments indicate that covered entities continue to want to gather, use, and disclose as much PHI as possible for fundraising purposes while patients' rights advocates and privacy coalitions continue to want to prioritize health information confidentiality. The fact that covered entities continue to want to gather, use, and disclose expanded classes of PHI for fundraising does not mean that philanthropy should, on a normative level, outweigh basic patients' rights. Rather, as discussed in more detail in Part V, I propose that health information confidentiality and health care philanthropy be balanced through a more express notification of fundraising activities and a prior written authorization requirement.

In response to its 2010 Proposed Rule, HHS received 306 comments totaling 2030 pages.<sup>244</sup> Sixty-one of these comments contained the word "fundraising,"<sup>245</sup> although not all of these sixty-one comments discussed the Privacy Rule's fundraising requirements in detail. Fifty-five of these sixty-one comments were authored by health care providers, institutionally related foundations, other fundraising organizations, medical societies, health plans, and health care attorneys, while six of these comments were authored by patients' rights advocates, privacy coalitions, health information management organizations, and a professor and his students in an ethics class at a graduate business school.<sup>246</sup>

In its 2010 Proposed Rule, HHS did not ask the public to carefully balance a patient's right to confidentiality with a health care provider's desire to engage in grateful patient fundraising. The only question HHS asked the public to consider was the narrow question of whether the Privacy Rule's fundraising provisions should be loosened to allow covered entities to access a broader

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244. *Health Information Technology for Economic and Clinical Health Act: Modifications to the HIPAA Privacy, Security, and Enforcement Rules*, REGULATIONS.GOV (Sept. 13, 2010), <http://www.regulations.gov/#!docketDetail;D=HHS-OCR-2010-0016> (downloaded individually and combined into one consecutively paginated document).

245. A search within the 306 comments for the word "fundraising" revealed sixty-four comments. *Id.* Three of these comments, including those from the College of Healthcare Information Management Executives, the California Hospital Association, and the World Privacy Forum, appear to be duplicative, leaving sixty-one non-duplicative comments that contain the word "fundraising." *See id.*

246. *Id.*

class of PHI, including a patient's department of service, without the patient's prior authorization.<sup>247</sup>

The majority of the very small number of health care providers and related organizations who responded supported the ability to access treating physician, department of service, and health outcome information without prior patient authorization. The Greater New York Hospital Association ("GNYHA"), for example, supported HHS's proposal to allow department of service information to be used and disclosed without prior authorization.<sup>248</sup> According to GNYHA, "This approach would allow hospitals to narrow their target audience, [and] provide a clear fundraising message . . . ."<sup>249</sup> The Council for Advancement and Support of Education ("CASE"), a leader in educational fundraising, also stated that access to additional categories of PHI would "strengthen grateful patient fundraising and reduce costly and ineffective fundraising communications."<sup>250</sup> CASE further explained that "[t]he current restrictions limit the ability of college, university and foundation fundraisers to effectively target their fundraising communications and provide patients a meaningful opportunity to support their areas of care."<sup>251</sup>

Other health care providers also expressed their desire for access to treating physician and department of service information without prior patient authorization. Providence Health & Services stated that "health care fundraising efforts could be strengthened and streamlined with access to department of service or generic areas of treatment information."<sup>252</sup> The Johns

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247. HHS specifically stated: "In particular, we solicit comment on: (1) Whether the Privacy Rule should allow additional categories of protected health information to be used or disclosed for fundraising, such as department of service or similar information, and if so, what those categories should be." Modifications to the HIPAA Privacy, Security, and Enforcement Rules Under the Health Information Technology for Economic and Clinical Health Act, 75 Fed. Reg. 40,868, 40,897 (proposed July 14, 2010) (to be codified at 45 C.F.R. pts. 160, 164).

248. Letter from Susan Waltman, Exec. Vice President & General Counsel, Greater N.Y. Hosp. Ass'n, to U.S. Dep't of Health & Human Servs., Office for Civil Rights 3 (Sept. 13, 2010) (on file with author).

249. *Id.*

250. Letter from John Lippincott, President, Council for Advancement & Support of Education, to Office of the Sec'y, U.S. Dep't of Health & Human Servs. 3 (Sept. 10, 2010) (on file with author).

251. *Id.* at 3-4.

252. Letter from John Koster, President & Chief Exec. Officer, Providence Health & Services, to U.S. Dep't of Health & Human Servs., Office for Civil Rights 2 (Sept. 13, 2010) (on file with author).

Hopkins Health System agreed: “[I]n addition to the patient’s department of service, fund-raising efforts [should] be allowed to use the name of the treating physician by the development office or foundation without the necessity of an authorization.”<sup>253</sup> The Federation of American Hospitals shared Johns Hopkins’ view that fundraising “is an important function, particularly for non-profit institutions, and we believe that liberalization of the rules in this area would not compromise the interests of individuals.”<sup>254</sup>

The problem is that these comments did not advance the real question at hand of how to properly balance the need to protect patient confidentiality with providers’ desire to use and disclose PHI for philanthropic purposes. The bulk of the comments submitted simply reinforce the viewpoint of health care providers and fundraisers that access to a larger subset of PHI could ease their fundraising efforts.

It is not surprising that comments authored by patients’ rights advocates and privacy coalitions expressed the opposing viewpoint. The World Privacy Forum firmly told HHS that “[s]haring *any* health information with a fundraiser is a gross violation of privacy.”<sup>255</sup> The World Privacy Forum explained: “Telling a fundraiser that the patient was treated by a particular department can be tantamount to disclosing the diagnosis. Sharing outcomes information is just as bad.”<sup>256</sup> Less upset, but still firm, was the State of California Office of Health Information Integrity: “The State of California is not in favor of allowing additional categories of PHI to be used or disclosed for fundraising.”<sup>257</sup>

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253. Letter from Donald L. Bradfield, Senior Counsel, the Johns Hopkins Health Sys., to U.S. Dep’t of Health & Human Servs., Office for Civil Rights 2 (Sept. 13, 2010) (on file with author).

254. Letter from Fed’n of Am. Hosps., to the Honorable Kathleen Sebelius, Sec’y, U.S. Dep’t of Health & Human Servs. 5 (Sept. 13, 2010) (on file with author).

255. Letter from Pam Dixon, Exec. Dir., World Privacy Forum, to the U.S. Dep’t of Health & Human Servs., Office for Civil Rights 14 (Sept. 13, 2010) (on file with author) (emphasis added).

256. *Id.* World Privacy Forum further stated: “Consider a person who had told no friend or family of her cancer treatment who subsequently receives a call from a stranger who knows about that treatment. How can any such use be justified under any circumstances? . . . Imagine that a hospital hired a business associate to do fundraising and that you received a call from a neighbor, cousin, or colleague working for that fundraiser who knew that you were treated by the oncology department?” *Id.*

257. STATE OF CAL., COMMENTS TO THE HIPAA PRIVACY, SECURITY & ENFORCEMENT NPRM 14 (Sept. 13, 2010) (on file with author).

The bipartisan Coalition for Patient Privacy agreed that confidentiality should trump philanthropy, and argued that patients should have to affirmatively opt in to the receipt of fundraising communications, citing the need to preserve the confidentiality of sensitive health information.<sup>258</sup> The Center for Democracy and Technology (“CDT”) agreed with the Coalition for Patient Privacy; that is, CDT wanted HHS to “[e]stablish an opt in standard for fundraising communications to patients that use PHI beyond demographics and dates of service.”<sup>259</sup>

The College of Healthcare Information Management Executives similarly urged HHS to retain its current policy and “not attempt to enhance fundraising opportunities,” citing the operational difficulty of distinguishing between broad designations, such as department of service, and narrow designations, such as diagnosis, because the department of service (e.g., oncology) could suggest the patient’s diagnosis (i.e., cancer).<sup>260</sup>

Finally, a professor and several of his students in an Ethics for the Law Office Class at the Minnesota School of Business would require prior patient authorization for fundraising. The class stated, “We recognize the need for . . . funding for new medical equipment and technology . . . but in achieving that goal, we should not compromise private health information . . . .”<sup>261</sup>

Given that HHS only solicited public comment on the narrow question of “[w]hether the Privacy Rule should allow additional categories of protected health information to be used or disclosed for fundraising, such as department of service or similar information,” the polarized comments referenced above are not surprising.<sup>262</sup> Health care providers want access to treating physician

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258. Letter from Coal. for Patient Privacy, to the Honorable Kathleen Sebelius, Sec’y, U.S. Dep’t of Health & Human Servs., Office of Civil Rights 18 (Sept. 13, 2010) (on file with author).

259. Letter from Ctr. for Democracy & Tech. to Georgina Verdugo, Dir., Office for Civil Rights, U.S. Dep’t of Health & Human Servs. 26 (Sept. 13, 2010) (on file with author).

260. Letter from Richard A. Correll, President & CEO, Coll. of Healthcare Info. Mgmt. Execs., to Georgina Verdugo, Dir., Office for Civil Rights, U.S. Dep’t of Health & Human Servs. 5 (Sept. 13, 2010) (on file with author).

261. Letter from Maria Greilinger, Tamara Daugherty, Marie Thorp, Roberta Kurth, & Alan Witz, Ethics for the Law Office Class, Minnesota Sch. of Bus., to U.S. Dep’t of Health & Human Servs., Office for Civil Rights 3 (on file with author).

262. Modifications to the HIPAA Privacy, Security, and Enforcement Rules Under the Health Information Technology for Economic and Clinical Health Act, 75 Fed. Reg. 40,868, 40,897 (proposed July 14, 2010) (to be codified at 45 C.F.R. pts. 160, 164).

and department of service information to ease their fundraising efforts whereas patients' rights advocates and privacy coalitions do not want PHI, other than basic demographic information, to be used or disclosed for fundraising. Each comment submitted reflected one of these two opposing positions. Perhaps if HHS had asked for ideas regarding how to "better balance health information confidentiality with health care philanthropy," or "how to best preserve patient confidentiality while supporting health care philanthropy," the comments might have been more nuanced. Not one health care provider who submitted a comment could even articulate one reason why philanthropy should trump confidentiality other than easing covered entities' fundraising efforts. Not one health care provider who submitted a comment seriously analyzed the confidentiality concerns raised by grateful patient fundraising and other health care philanthropy initiatives.

Again, HHS's solicitation of comments on the narrow question of whether access to additional PHI would make grateful patient fundraising easier is partly to blame. Also blameworthy is administrative law's notice-and-comment rulemaking process.<sup>263</sup> Although a rich discussion of all of the problems associated with the notice-and-comment rulemaking process is beyond the scope of this article, a quick discussion of two illustrative problems might help put the content of the Final Regulations in context.

First, although proposed rules are supposed to be vehicles for policymaking, many policy decisions are made well before the relevant agency ever issues a proposed rule.<sup>264</sup> Indeed, when HHS in its 2010 Proposed Rule quietly solicited public comment on whether to expand the classes of PHI that could be used and disclosed for fundraising without prior patient authorization,<sup>265</sup> HHS did not appear to be introducing a potential new policy the merits of which could be considered by the public for the first time. Instead, HHS appeared to be adopting the September 2004 policy recommendation of the National Committee on Vital and Health Statistics ("NCVHS") that a patient's department of service could

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263. *The Regular Rulemaking Process*, OFF. OF ADMIN. L., [http://www.oal.ca.gov/regular\\_Rulemaking\\_Process.htm](http://www.oal.ca.gov/regular_Rulemaking_Process.htm) (last visited April 14, 2014).

264. See Richard Murphy, *Enhancing the Role of Public Interest Organizations in Rulemaking via Pre-Notice Transparency*, 47 WAKE FOREST L. REV. 681, 682 (2012).

265. See Modifications to the HIPPA Privacy, Security, and Enforcement Rules Under the Health Information Technology for Economic and Clinical Health Act, 75 Fed. Reg. at 40,897.

be used and disclosed for fundraising purposes without prior authorization.<sup>266</sup> The NCVHS recommendations were based in part on a July 2004 hearing where the NCVHS heard testimony from representatives of AHP, an academic medical center, and a privacy institute.<sup>267</sup> Not surprisingly, AHP and the academic medical center were in favor of expanding the classes of PHI that could be used and disclosed for fundraising purposes without prior patient authorization whereas the privacy institute favored requiring prior patient authorization.<sup>268</sup> Without any attempt to balance these two positions, the NCVHS (in a letter authored by its physician chair) simply decided to adopt the pro-philanthropy perspective articulated by AHP and the academic medical center.<sup>269</sup> Six years later, HHS in its 2010 Proposed Rule referenced the NCVHS recommendations en route to proposing the loosening of confidentiality in the context of health care philanthropy.<sup>270</sup>

In summary, the 2010 Proposed Rule should have been the initial vehicle for new policymaking relating to patient confidentiality in the context of fundraising. However, I suggest that HHS made its policy decision back in 2004, after receiving the NCVHS recommendations, and simply used the 2010 Proposed Rule (including the Rule's very narrow request for comments) and the

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266. Letter from John R. Lumpkin, Chairman, Nat'l Comm. on Vital & Health Statistics, to the Honorable Tommy G. Thompson, Sec'y, U.S. Dep't of Health & Human Servs. (Sept. 2, 2004), *available at* <http://www.ncvhs.hhs.gov/020425lt.htm>.

267. *Id.*

268. *Id.*

269. *Id.*

270. *See* Modifications to the HIPPA Privacy, Security, and Enforcement Rules Under the Health Information Technology for Economic and Clinical Health Act, 75 Fed. Reg. at 40,897 ("NCVHS also held a hearing and heard public testimony on this issue in July 2004. After considering the testimony provided, the NCVHS recommended to the Secretary that the Privacy Rule should allow covered entities to use or disclose information related to the patient's department of service (broad designations, such as surgery or oncology, but not narrower designations or information relating to diagnosis or treating physician) for fundraising activities without patient authorization. NCVHS also recommended that a covered entity's notice of privacy practices inform patients that their department of service information may be used in fundraising, and that patients should be afforded the opportunity to opt out of the use of their department of service information for fundraising or all fundraising contacts altogether. . . . In light of these concerns and the prior recommendation of the NCVHS, the Department takes this opportunity to solicit public comment on whether and how the current restriction on what information may be used and disclosed should be modified to allow covered entities to more effectively target fundraising and avoid inappropriate solicitations to individuals, as well as to reduce the need to send solicitations to all patients.").

2013 Final Regulations to establish a formal administrative record should the Final Regulations become the subject of later judicial review.

A second problem with notice-and-comment rulemaking is that its process can favor well-resourced industry participants. When a particular regulatory action threatens the interests of an entire industry, the participants in that industry can collectively invest in attorneys, consultants, lobbyists, and politicians to protect their interests. In the health care industry, heavily regulated health care providers, health plans, and their professional associations frequently join forces to create professional, legal responses to proposed rules that can be signed and submitted by all of the members of the industry or that can be copied and personalized by industry members and individually submitted. The result is that HHS receives dozens of comments that support the same position whenever it attempts to regulate the health care industry. In response to the 2010 Proposed Rule, for example, the AMA joined forces with thirty-six other major medical societies, associations, and academies to submit a powerful, joint comment to HHS.<sup>271</sup> By further example, the AHP submitted its own thirteen-page, single-spaced comment to HHS<sup>272</sup> that AHP's members, including the Mary Bird Perkins Cancer Center and the Beth Israel Deaconess Medical Center, then re-submitted and referenced,<sup>273</sup> respectively.

Notwithstanding the intellect and energy of patients' rights advocates and privacy coalitions such as the Coalition for Patient Privacy<sup>274</sup> and the World Privacy Forum,<sup>275</sup> their legal, financial,

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271. See Letter from Mari Savickis, Am. Med. Ass'n, to the Honorable Kathleen Sebelius, Sec'y, U.S. Dep't of Health & Human Servs., Office for Civil Rights (Sept. 13, 2010), available at <http://www.regulations.gov/#!documentDetail;D=HHS-OCR-2010-0016-0173>.

272. See Letter from William C. McGinly, President & CEO, Ass'n for Healthcare Philanthropy, to Dep't of Health & Human Servs., Office of the Sec'y (Sept. 13, 2010), available at <http://www.regulations.gov/#!documentDetail;D=HHS-OCR-2010-0016-0137>.

273. See Comment from Amy Benton, Mary Bird Perkins Cancer Ctr., to U.S. Dep't of Health & Human Servs. (Sept. 13, 2010), available at <http://www.regulations.gov/#!documentDetail;D=HHS-OCR-2010-0016-0122> (attaching the AHP's comment and stating, "Mary Bird Perkins Cancer Center and Mary Bird Perkins Cancer Center Foundation fully support the Association for Healthcare Philanthropy's (AHP) position . . . . We have attached AHP's comments"); see Letter from Kristine C. Laping, *supra* note 237, at 2 ("We share the concerns expressed by the Association for Healthcare Philanthropy . . .").

274. *Coalition for Patient Privacy*, PATIENT PRIVACY RIGHTS, <http://patientprivacyrights.org/coalition-patient-privacy/> (last visited Apr. 14, 2014).

275. *About Us*, WORLD PRIVACY FORUM, <http://www.worldprivacyforum.org/about-us.html> (last visited April 14, 2014).

and other resources pale in comparison to the resources of the likes of Yale University,<sup>276</sup> Stanford University,<sup>277</sup> and Beth Israel Deaconess Medical Center,<sup>278</sup> as well as the nation's other outstanding academic medical centers and medical institutions. Patients' rights advocates and privacy coalitions simply lack the resources to launch a comparable fight, including the resources to submit high numbers of professional, persuasive comments.

One result is that agencies such as HHS usually receive more comments from industry participants than from the non-regulated public. Again, in response to its 2010 Proposed Rule, HHS received approximately fifty-five comments from the health care industry that contained the word "fundraising." In comparison, HHS received only six comments from patients' rights organizations, privacy coalitions, health information management organizations, and an ethics class at a graduate business school. In its Final Regulations, HHS explained that these numbers were persuasive: "[T]he vast majority of commenters supported allowing the use or disclosure of additional protected health information for fundraising" and "a small minority of commenters opposed allowing the use of additional protected health information to target fundraising efforts, citing privacy concerns with doing so."<sup>279</sup> Given that the notice-and-comment rulemaking process can favor industry, I argue that simply counting the (relatively small number of) comments submitted on behalf of the nation's hundreds of thousands of health care providers that make up the \$2.7 trillion health care industry<sup>280</sup> and comparing that number to the number of comments submitted by patients' rights and privacy coalitions is not a reason to favor philanthropy over confidentiali-

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276. See Letter from Dorothy K. Robinson, *supra* note 235.

277. See Letter from Privacy Officer, Dir. of Research Compliance, & Privacy & Sec. Officers, Stanford Univ., to U.S. Dep't of Health & Human Servs., Office for Civil Rights (Sept. 13, 2010), available at <http://www.regulations.gov/#!documentDetail;D=HHS-OCR-2010-0016-0263>.

278. See Letter from Kristine C. Laping, *supra* note 237, at 1.

279. Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules under the Health Information Technology for Economic and Clinical Health Act and the Genetic Information Nondiscrimination Act, 78 Fed. Reg. 5566, 5620 (Jan. 25, 2013) (to be codified at 45 C.F.R. pts. 160, 164). According to HHS, "These commenters stated that the use of additional protected health information would streamline their fundraising efforts and ensure that individuals were sent communications about campaigns that would be meaningful to their experiences." *Id.*

280. Elisabeth Rosenthal, *The \$2.7 Trillion Medical Bill: Colonoscopies Explain Why U.S. Leads the World in Health Expenditures*, N.Y. TIMES, June 2, 2013, at A1 (referencing the nation's \$2.7 trillion annual health care bill).

ty. Instead, I suggest that the notice-and-comment rulemaking process favors well-resourced industry participants.<sup>281</sup> To me, the comments simply indicate that covered entities continue to want to gather, use, and disclose PHI about patients for fundraising purposes while patients' rights advocates and privacy coalitions continue to want to prioritize confidentiality. The fact that covered entities continue to want to gather, use, and disclose PHI for fundraising does not mean that philanthropy should, on a normative level, outweigh basic patients' rights. Rather, and as discussed in more detail in the final Part of this article, I propose that health information confidentiality and health care philanthropy be balanced through a more express notification of fundraising and authorization requirement.

## V. A PROPOSAL

In this final Part, I examine three options for the future regulation of the use and disclosure of PHI for fundraising and select the option that I believe creates the best balance between health care philanthropy and health information confidentiality.

One option is to revise the Final Regulations to prohibit all grateful patient fundraising. If grateful patient fundraising risks breach of confidentiality (and a range of other ethical issues including conflicted decision making, health care resource allocation injustices, financial exploitation, and breach of privacy),<sup>282</sup> then one approach is to eliminate grateful patient fundraising in its entirety. This option could be implemented by deleting the language currently codified at 45 C.F.R. § 164.514(f)(1)–(2) or by deleting such language and replacing it with:

(f) *Fundraising communications.* A covered entity may not use, or disclose to a business associate or to an institutionally related foundation, any protected health information for fundraising or philanthropic purposes.

I disagree with this approach. As discussed in detail in Part III, philanthropy supports a wide variety of important health care initiatives and related educational missions. Academic medical cen-

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281. See Murphy, *supra* note 264, at 683 (“Thus, it is possible that changes made to the rulemaking process that were intended, in part, to enable strong public interest group participation may often disfavor such groups.”).

282. See generally Tovino, *Giving Thanks*, *supra* note 9 (discussing the ethical issues raised by physician involvement in grateful patient fundraising).

ters rely on philanthropy to satisfy educational needs, research programs, clinical initiatives, and building and infrastructure support. Non-profit health care organizations engage in fundraising to provide resources to their community-based hospitals and clinics and to improve access to health care and other services for the uninsured and under-insured. Private health care foundations use philanthropy to serve the economically poor and underserved, including women, children, and seniors who live in the community served by the foundation. Health care philanthropy, which totaled \$28.12 billion in 2012,<sup>283</sup> cannot be eliminated in its entirety.

A second option is to maintain the status quo. That is, a second option is to: (1) keep the language in the Final Regulations allowing covered entities to use and disclose treating physician and department of service information without prior patient authorization; and (2) support our current approach to health care philanthropy which relies on significant physician involvement in grateful patient fundraising. As discussed in significant detail elsewhere, I dislike this option because it provides insufficient protection of the physician-patient relationship and risks conflicted decision making, health care resource allocation injustices, financial exploitation, breach of privacy, and breach of confidentiality.<sup>284</sup>

A third option is to allow grateful patient fundraising to proceed with some limitations that are designed to protect health information confidentiality and other basic patients' rights. This option, which I support, would require: (1) the revision of the Final Regulations to better protect health information confidentiality; and (2) the adoption of a complementary set of ethical guidelines governing physician involvement in grateful patient fundraising.<sup>285</sup>

In terms of revising the Final Regulations, I first propose that covered entities not be allowed to use or disclose treating physician and department of service information without prior patient authorization. Thus, I propose that 45 C.F.R. § 164.514(f)(1) be revised to read:

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283. *Charitable Giving Rose 3.5 Percent in 2012*, GIVING USA (June 20, 2013), <http://www.givingusareports.org/news-and-events/news.aspx?NewsTypeId=3&NewsId=182>.

284. *See generally* Tovino, *Giving Thanks*, *supra* note 9.

285. *See id.* (adopting a complementary set of ethical guidelines).

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(f) *Fundraising communications.* (1) *Standard: Uses and disclosures for fundraising.* Subject to the conditions of paragraph (f)(2) of this section, a covered entity may use, or disclose to a business associate or to an institutionally related foundation, the following protected health information for the purpose of raising funds for its own benefit, without an authorization as defined in paragraph (f)(3):

- (i) Demographic information relating to an individual, including name, address, other contact information, age, gender, and date of birth;
- (ii) Dates of health care provided to an individual; and
- (iii) Health insurance status.

Second, and in conjunction with the ethical proposals made in the companion article, I propose that 45 C.F.R. § 164.514(f)(2)(i) be revised to require patients be notified regarding whether the covered entity will be conducting wealth screenings and other information searches using publicly or commercially available information:

(f)(2) Implementation specifications: Fundraising requirements.

- (i) A covered entity may not use or disclose protected health information for fundraising purposes as otherwise permitted by paragraph (f)(1) of this section unless: (a) a statement required by 164.520(b)(1)(iii)(A) is included in the covered entity's notice of privacy practices; and (b) a statement indicating whether the covered entity will conduct patient wealth screenings and other information searches using publicly or commercially available information is included in the covered entity's notice of privacy practices.

In turn, 45 C.F.R. § 164.520(b)(1)(iii)(A), which describes the way in which patients should be alerted to uses and disclosures of their PHI for fundraising through the notice of privacy practices, should be amended to provide:

(b)(1)(iii) Separate statements for certain uses or disclosures. If the covered entity intends to engage in any of the following activities, the description required by paragraph (b)(1)(ii)(A) of this section must include a separate statement informing the individual of such activities, as applicable:

- (A) In accordance with § 164.514(f)(1), the covered entity may, *without prior written authorization*, use and disclose to institutionally-related foundations and associates the information listed at paragraph (f)(1)(i)–(iii), as long as the covered entity provides information regarding how the individual may opt out of these information uses and disclosures. In accordance with § 164.514(f)(3), the covered entity may, *but only with prior written authorization*, use and disclose to institutionally-related

foundations and business associates protected health information other than the information listed at paragraph (f)(1)(i), together with information regarding how the individual may authorize such uses and disclosures.

Third, I propose adding a new 45 C.F.R. § 164.514(f)(3) to the end of the fundraising regulation. This new subsection would establish standard fundraising notification and authorization language that covered entities would use to notify patients regarding their philanthropy activities and obtain their patients' prior written authorization. The new subsection would provide:

(f)(3) *Fundraising notification and authorization.* A covered entity may use or disclose protected health information in addition to the information listed at paragraph (f)(1)(i)–(iii) for fundraising purposes only if the covered entity provides express written notification to the patient regarding the means the covered entity uses to obtain philanthropic donations and obtains the individual's prior written authorization to such means. A valid fundraising notification and authorization must include at least the following elements:

- (A) The name and address of the covered entity;
- (B) A statement that the covered entity uses patient fundraising to support clinical initiatives, educational missions, or other health care or educational goals, as appropriate;
- (C) A description of the means the covered entity uses to obtain philanthropic donations, including a description of any physician involvement in grateful patient fundraising, development office involvement in grateful patient fundraising, institutionally-affiliated foundation involvement in fundraising, independent contractor or business associate involvement in fundraising, the conduct of wealth screenings, and similar measures;
- (D) A description of the specific classes of protected health information, such as treating physician and department of service information, that the patient is authorizing the covered entity to use and disclose for fundraising purposes;
- (E) The name(s) of any employed, affiliated, or contracted fundraisers with whom these classes of protected health information will be shared or to whom these classes of protected health information will be disclosed;
- (F) A statement that employed, affiliated, and contracted fundraisers may not further use or disclose protected health information other than for fundraising purposes;
- (G) A statement that employed, affiliated, and contracted fundraisers are subject to regulation by the federal HIPAA Privacy Rule and are subject to civil and criminal penalties for unauthorized uses and disclosures of protected health information;

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(H) A statement that the covered entity's primary relationship with the patient is a treatment relationship, not a philanthropic relationship;

(I) A general statement that the covered entity may not condition treatment, payment, or health care operations on a fundraising authorization or philanthropic donation;

(J) A specific statement that the covered entity may not vary the provision, timing, quality, or quantity of treatment on a fundraising authorization or philanthropic donation;

(K) A statement regarding how the individual may contact the covered entity's Privacy Official to discuss concerns regarding fundraising. This statement shall include the postal address, telephone number, and email address of the covered entity's Privacy Official;

(L) A statement regarding how the individual may contact the federal Department of Health and Human Services ("HHS") to complain and report a breach of confidentiality by either the covered entity or a contracted fundraiser. This statement shall include a link to HHS's "How to File a Complaint" Web page, available at <http://www.hhs.gov/ocr/privacy/hipaa/complaints/>; and

(M) Signature of the individual and date. If the authorization is signed by a personal representative of the individual, a description of such representative's authority to act for the individual must also be provided.

Fourth, I propose that HHS revise its Model Notice, which currently contains the following superficial statement: "In the case of fundraising: We may contact you for fundraising efforts, but you can tell us not to contact you again."<sup>286</sup> The Model Notice should be revised to provide:

In the case of fundraising:

*Without your prior written authorization*, we may internally use and disclose to institutionally-related foundations and business associates certain demographic information (including name, address, other contact information, age, gender, and date of birth), dates of health care provided to you, and information regarding your health insurance status. You may opt out of these unauthorized information uses and disclosures by contacting the Privacy Official at the following [email address], [physical mailing address], or [telephone number].

*Only with your prior written authorization*, we may internally use and disclose to institutionally-related foundations and business associates protected health information other than demographic information, dates of health care, and health in-

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286. MODEL NOTICE, *supra* note 5, at 4.

urance status. You may authorize such uses and disclosures by contacting the [Name of Covered Entity] Privacy Official at the following [email address], [physical mailing address], or [telephone number].

### CONCLUSION

Philanthropy plays an important role in the American health care system. Due to high uncompensated health care costs, inadequate Medicare and Medicaid reimbursement, rising health care compliance costs associated with health care reform, and expensive medical equipment, many health care institutions depend on philanthropic donations. For these reasons, health care philanthropy should be encouraged.

One concern with health care philanthropy is its reliance on the use and disclosure of patient identifiable information and the associated risk of breach of confidentiality. This concern can be lessened through the proper regulation of the use and disclosure of protected health information for fundraising. To this end, this article critiques and proposes corrections to Privacy Rule and Model Notice provisions that govern the permissible scope of uses and disclosures of protected health information for fundraising purposes. These regulatory proposals are designed to support health care philanthropy while protecting a patient's right to health information confidentiality.