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# PRIVACY AND CONFIDENTIALITY ISSUES IN HISTORICAL HEALTH SCIENCES COLLECTIONS

*Anne T. Gilliland\* and Judith A. Wiener\*\**

## I. INTRODUCTION

Historical health sciences collections are rare and unique materials containing large amounts of information subject to confidentiality and privacy laws and concerns. Formerly, the custodians of these collections handled these issues in relative obscurity, but technological changes and changing laws and norms around health care privacy have made these issues more acute and public. The intent of this Article is to describe the nature of these collections and the qualifications of the people who administer them, and to analyze some of the privacy and confidentiality issues that arise in the course of that work. The aim is to acquaint privacy officers, in-house legal counsel, and other members of the legal profession with the privacy and confidentiality challenges that these collections present, with the needs of researchers who use these collections, and with the reasons why historical health sciences collections are important.

Part II will discuss the nature of historical health sciences materials and of the people who work with these collections.<sup>1</sup> In Part III the authors identify privacy and confidentiality laws and circumstances that affect these collections with a special emphasis on the Health Insurance Portability and Accountability Act (HIPAA).<sup>2</sup> Part IV discusses strategies and solutions for complying with these laws and circumstances while still providing access to researchers and protecting the integrity of the historical record.<sup>3</sup>

## II. HISTORICAL HEALTH SCIENCES SPECIAL COLLECTIONS

Health sciences libraries of every scope and size, from modest community hospitals to academic medical centers, often have historical or special collections of some quantity within their holdings. These materials come into a library through a variety of methods and can be comprised of a multitude of formats. The assorted provenance of the materials combined with the wide variety of

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\* Anne T. Gilliland, J.D., M.S.L.I.S., is the Scholarly Communications Officer for the Libraries at the University of North Carolina, Chapel Hill.

\*\* Judith A. Wiener, M.A., M.L.I.S., is Assistant Professor and Assistant Director for Special Collections and Outreach at the Health Sciences Library at the Ohio State University.

1. See discussion *infra* Part II.
2. See discussion *infra* Part III.
3. See discussion *infra* Part IV.

formats often makes these collections susceptible to privacy concerns and subject to privacy and confidentiality laws.<sup>4</sup>

Historical health sciences collections materials differ from general patient records within a medical environment because they are believed to have enduring historical or other value that can differ from the purpose for which they were created.<sup>5</sup> In a chapter in the book, *Capturing Nursing History*, Keith C. Mages and Julia A. Fairman give the example of the ward diary of Mary Clymer, a student nurse in the 1880s, and the “vivid glimpse into the past” that this sort of primary source in a historical health sciences collection can offer.<sup>6</sup> Accounting books that doctors created at the beginning of the 20<sup>th</sup> century to document patient accounts can be used by historians to study the economics of health care during the time period. Likewise, films created to instruct nurses in best care practices can be studied to trace the history and evolution of women’s professional roles by gender study researchers.

#### A. General Role and Scope

##### 1. Types of Collections

According to the Association of Research Libraries, the term “special collections’ has been used in North American libraries in many different ways.”<sup>7</sup> Most commonly it refers to rare books, manuscripts, archival collections of mixed formats and printed materials, such as newspapers and pamphlets not held in book form.<sup>8</sup> As technology develops and information delivery methods evolve, so does the nature of these collections, such that it is now common to find that materials such as audio visual and digital material have been added to the umbrella of special collections departments.<sup>9</sup> A common thread in the variety of materials within such departments is that they are rare or unique. In addition, they often fall within a particular collection scope, such as a regional or subject specialization.

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4. See generally Anne T. Gilliland & Judith A. Wiener, *Digitizing and Providing Access to Privacy-Sensitive Historical Medical Resources: A Legal and Ethical Overview*, 8 J. ELEC. RES. MED. LIBR. 382, 384 (2011).

5. FREDRIC M. MILLER, ARRANGING AND DESCRIBING ARCHIVES AND MANUSCRIPTS 3-4 (Society of American Archivists 1990).

6. Keith C. Mages & Julie A. Fairman, *Working With Primary Sources: An Overview*, in CAPTURING NURSING HISTORY: A GUIDE TO HISTORICAL METHODS IN RESEARCH 129, 129-30 (Sandra B. Lewenson & Eleanor Krohn Herrmann eds., Springer Publishing Company 2008).

7. Alice Prochaska, *Preface* to ARL WORKING GROUP ON SPECIAL COLLECTIONS, SPECIAL COLLECTIONS IN ARL LIBRARIES 5 (2009), <http://www.arl.org/bm~doc/scwg-report.pdf>.

8. *Id.* at 5-6.

9. *Id.* at 6.

## 2. Types of Materials

Special collections repositories in the health sciences often contain the same types of textual and non-textual materials listed above.<sup>10</sup> Depending on the type and breadth of the collections, the materials may contain privacy-sensitive materials. Historically, the protection of sensitive health care information was entrusted to the care and custody of one's physician. Professional physician codes of ethics focusing on the patient's privacy right were established early and can be found within the Hippocratic Oath.<sup>11</sup> In general, patients entrusted their physicians to act on behalf of their best interest in regards to privacy, and physicians were expected to uphold this expectation in their interactions with their patients. Absent the establishment of privacy legislation, the amount and type of information that could be documented, shared or saved was left to the physician's or health organization's best discretion.<sup>12</sup>

Physicians and medical organizations often turned records from their daily practices over to special collections or archival areas of libraries as the materials aged and were not needed on a daily basis.<sup>13</sup> Commonly, donors recognized the records' historical or documentary value. As a result, the degree of privacy-sensitive information contained within medical archives can vary widely within any given institution. This information can include detailed information about patient health contained in a physician's journal, correspondence between a patient and health care provider, detailed logbooks kept by hospitals, or detailed photographs of patients or research subjects. In many cases in the past, custodians may not have paid careful attention as to whether or not privacy-sensitive material was located within their collections because privacy laws were less stringent and because of the sheer volume of material that they collected.

## 3. Common Institutional Affiliations and Staffing

Staffing patterns vary among special collections units within health care organizations. Large academic medical centers commonly have professionally-trained curators or archivists who staff special collections departments within hospitals or health sciences libraries, while smaller hospitals may have a less formal department, such as a storage room supervised by an administrative professional or volunteers.<sup>14</sup>

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10. See generally Gilliland *supra* note 4.

11. *Greek Medicine: The Hippocratic Oath*, NATIONAL LIBRARY OF MEDICINE (Michael North trans., June 24, 2010), [http://www.nlm.nih.gov/hmd/greek/greek\\_oath.html](http://www.nlm.nih.gov/hmd/greek/greek_oath.html).

12. Barbara L. Craig, *Confidences in Medical and Health Care Records from an Archives Perspective*, in *PRIVACY AND CONFIDENTIALITY PERSPECTIVES: ARCHIVISTS & ARCHIVAL RECORDS*, 246, 246-47 (Menzi L. Behrnd-Klodt & Peter Wosh, eds., Society of American Archivists 2005).

13. Gilliland, *supra* note 4, at 384-85.

14. See generally *ARCHIVISTS AND LIBRARIANS IN THE HISTORY OF THE HEALTH SCIENCES*, <http://www.alhhs.org/> (last visited Jan. 12, 2012); see generally GREGOR TRINKAUS-RANDALL,

Professionally trained curators or archivists are likely to possess master's degrees granted by history or library science programs. These individuals usually employ a standard archival arrangement and description theory that emphasizes the higher organizational level of collections, rather than detailing materials at an individual level.<sup>15</sup> Normally, archives are arranged at a collection level to preserve the organization given to it by the creator, in order to preserve the original documentary relationships and as a way to organize the mass volume of modern records efficiently.<sup>16</sup> For example, letters are often described in an archival inventory, or finding aid, as a group under the subject of "correspondence," rather than listed or described by their content individually. Archival theory emphasizes that materials should be kept in the same original order that their creator maintained them, so in many cases, when collections come into an archival facility in reasonable order, archival staff keep documents in that same order without item-level examination.<sup>17</sup> Therefore, a great deal of private information may be present within collections without the knowledge or intellectual control of anyone at the institution.

### *B. Traditional Confidentiality and Privacy Concerns and Methods for Resolving Them*

#### 1. Privacy and Confidentiality through Obscurity

Prior to the development of the Internet and of technology for digitization, the risk for widespread exposure of privacy sensitive archival materials was more limited.<sup>18</sup> The rare and unique nature of the material contained within special collections means that they are often not physically circulated or available for checkout by library patrons. Often a researcher would have to travel to the archives and go through archival materials on-site in order to physically view them. Today, although researchers still visit reading rooms, more and more materials are available online or provided in digitized form. Online publication of finding aids has facilitated discovery of materials in historical health sciences collections and increased demand for digitized content.

#### 2. Access Control in the Reading Room

When researchers visit a reading room, often they must provide identification, sign release and use forms that document they understand the

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PROTECTING YOUR COLLECTIONS: A MANUAL ON ARCHIVAL SECURITY (Society of American Archivists 1995).

15. Miller, *supra* note 5, at 19, 28-30.

16. Miller, *supra* note 5, at 27-29.

17. Miller, *supra* note 5, at 20, 31, 37-41.

18. *See generally* TRINKAUS-RANDALL, *supra* note 14; *see also* Gilliland, *supra* note 4, at 391-92.

rules and policies of the particular archival institution, and leave their belongings, except for pencils, and some paper or perhaps a laptop (if permitted), outside the reading room area. Typically, custodians pull material and artifacts from closed stacks for researchers to consult, usually a box at a time. Materials may not leave the secure reading room environment of the library, and copying of materials is limited because of security, theft, handling, and preservation concerns.<sup>19</sup> In addition to providing for the protection and preservation of rare and sometimes fragile materials, indirectly, these policies also protect privacy and confidentiality through obscurity and barriers to access on-site.<sup>20</sup> Although on-site researchers have access to privacy-sensitive records and materials, the risk of widespread breach of any confidence or privacy issues is limited because the records are not shared widely beyond the confines of the reading room.

### C. Contemporary Confidentiality and Privacy Issues

#### 1. Role of the Internet and Digitization

The advent and increased use of technological means to promote and increase access to special collections materials has exponentially increased the threat of widespread confidentiality and privacy breaches to users.<sup>21</sup> In the past, only one researcher at a time could access a limited amount of material in an archival reading room, but today, archival digitization and discovery projects have created an environment where anyone can access special collections materials anywhere, at any time, and for any purpose. Digitization is a great tool for increasing access to rare or unique materials and promoting the use of archival materials. At the same time, this widespread access has serious implications for the protection of privacy of those individuals whose lives and medical information may be reflected within the collections.<sup>22</sup> This, in turn, places an organization at greater risk for HIPAA and other privacy legislation violations, especially if these digitized holdings are made available through widespread Internet discovery means, such as search engines or digital libraries.<sup>23</sup>

#### 2. Changing Norms for Donor Agreements and Expectations

The ability of technology to make records available for widespread distribution and access may also pose risks to donation agreements and donor

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19. See TRINKAUS-RANDALL, *supra* note 14.

20. Gilliland, *supra* note 4, at 382, 384. See generally TRINKAUS-RANDALL, *supra* note 14.

21. Gilliland, *supra* note 4, at 392.

22. Gilliland, *supra* note 4, at 392.

23. Gilliland, *supra* note 4, at 386-87. See generally Aprille C. McKay, *Third Party Privacy and Large Scale Digitization of Manuscript Collections: Legal and Ethical Obligations*, <http://www.lib.unc.edu/mss/archivalmassdigitization/download/mckay.pdf>.

expectations. Donors who felt comfortable with the mission and archival access policies of a special collections unit may have given material with few or no restrictions.<sup>24</sup> These same donors might have felt quite differently about their entrustment if they had known, or could have imagined, that the materials given to document or preserve the historical record in one setting would one day be made openly accessible to a wide audience without restriction of use or purpose.<sup>25</sup> Compounding this issue is the fact that older donor agreements and contracts may not have addressed digital distribution methods, even when they were possible, or that the donors of such materials may not have had the rights or permission to provide such access.<sup>26</sup> When feasible, some donor agreements may need to be revised or revisited.

### 3. Beyond Privacy and Confidentiality Law—Ethical Concerns in Historical Health Sciences Collections

The archival professional is bound by a set of ethical standards that encourages him or her to maintain a careful balance between providing wide access to materials while protecting the privacy of those who are documented within the materials.<sup>27</sup> The major professional organizations that maintain the local and global standards and expectations of their members all include language within their codes of ethics that speak to these seemingly contradictory responsibilities and dictate that the privacy of the individuals reflected within archival materials should be protected and weighed against the professional duty to provide access to materials.<sup>28</sup> Thus, the use restrictions and access structure solutions provided by HIPAA may provide archivists with the opportunity to develop a structure and solution to the problem of balancing access against privacy in accordance with the law and their own professional ethical standards.<sup>29</sup>

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24. Gilliland, *supra* note 4, at 392.

25. Gilliland, *supra* note 4, at 392.

26. *Securing Permission to Digitize and Display Collections Online*, DIGITAL LIBRARY OF GEORGIA, <http://dlg.galileo.usg.edu/AboutDLG/DisplayPermission.html?Welcome> (last visited January 12, 2012); *see also* Gilliland, *supra* note 4, at 392.

27. *See Code of Ethics for Archivists*, SOCIETY OF AMERICAN ARCHIVISTS (Feb. 2005), [http://www.archivists.org/governance/handbook/app\\_ethics.asp](http://www.archivists.org/governance/handbook/app_ethics.asp); *see also Code of Ethics*, ASSOCIATION OF CANADIAN ARCHIVISTS (June 1999), <http://www.archivists.ca/content/code-ethics>; *see also ICA Code of Ethics*, INTERNATIONAL COUNCIL ON ARCHIVES (Sept. 1996), <http://www.ica.org/5555/reference-documents/ica-code-of-ethics.html>.

28. Society of American Archivists, *supra* note 27; Association of Canadian Archivists, *supra* note 27; International Council on Archives, *supra* note 27.

29. William G. Carpenter, Charlene Nichols, Sarah A. Polirer, and Judith A. Wiener, *Exploring the Evolution of Access: Classified, Privacy, and Proprietary Restrictions*, 74 THE AMERICAN ARCHIVIST ONLINE SUPPLEMENT, session 602, (2012), <http://www2.archivists.org/sites/all/files/AOSv074-Session602.pdf>.

### III. CONTEMPORARY PRIVACY AND CONFIDENTIALITY LAWS AND CIRCUMSTANCES THAT AFFECT HISTORICAL HEALTH SCIENCES SPECIAL COLLECTIONS

Although historical health sciences special collections custodians have long been concerned about privacy and confidentiality issues with regard to their collections, several laws and trends have made these issues more urgent.<sup>30</sup> The foremost concern is the Health Insurance Portability and Accountability Act (HIPAA).<sup>31</sup> Other Federal statutes, as well as state privacy and confidentiality laws, also may apply to certain collections or parts of collections.<sup>32</sup> In addition, there are changing expectations around privacy from the donors or potential donors, from the subjects of the historical health sciences special collections (when they are living or from their heirs), from the scholars who do research in these collections, and from the institutional boards that regulate and oversee this research.<sup>33</sup>

#### A. *Health Insurance Portability and Accountability Act*

HIPAA has preempted many state laws for breach of privacy and breach of confidence.<sup>34</sup> Although HIPAA was not aimed specifically at the historical health sciences special collections community, its effect on these collections has been substantial.<sup>35</sup> Traditionally, archival professionals relied on their own best professional judgment, tied to their system of professional ethics to provide access to sensitive materials. This approach was a careful balance of providing access while maintaining privacy. HIPAA, however, overrode this long-established professional judgment system as organizations became concerned about how to apply the law to collections that fell under HIPAA but were not the focus of the law.<sup>36</sup> Confusion ensued as archival leaders sought direction from their internal counsel and even Congress and were provided with uneven responses to their request for resources. In many cases, responses to researchers and to collections custodians have been contradictory or incomplete.<sup>37</sup>

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30. See, e.g., Health Insurance Portability and Accountability Act of 1996 (HIPAA), Public L. No. 104-191, 110 Stat. 1936 (codified as amended in scattered sections of 42 U.S.C. and 29 U.S.C.).

31. *Id.*

32. Gilliland, *supra* note 4, at 387-91; Judith A. Wiener & Anne T. Gilliland, *Balancing Between Two Goods: Health Insurance Portability and Accountability Act and Ethical Compliance Considerations for Privacy-Sensitive Materials in Health Sciences Archival and Historical Special Collections*, 99(1) J. MED. LIBR. ASS'N, 15, 15-16 (Jan. 2011).

33. See generally Gilliland, *supra* note 4. See also Wiener, *supra* note 32, at 16-18.

34. 45 C.F.R. § 160.202-203 (2011).

35. See generally Susan C. Lawrence, *Access Anxiety: HIPAA and Historical Research*, 62 J. HIST. MED. ALLIED SCI. 422, (2007), and Society of American Archivists Science, *HIPAA Resource Page*, ARCHIVISTS AND LIBRARIANS IN THE HISTORY OF THE HEALTH SCIENCES, (Feb. 7, 2011), <http://www.library.vcu.edu/tml/speccoll/hipaa.html>.

36. See generally Lawrence, *supra* note 35.

37. Lawrence, *supra* note 35, at 423.



## 1. Purpose of HIPAA

Congress passed HIPAA in 1996 which forced the federal government to address issues of privacy and confidentiality in an age where technology made the exchange of health information easier.<sup>38</sup> The two primary concerns were to enable electronic exchange of health information by providing sufficient security constraints and to secure health information that might come to light as preexisting conditions when workers changed jobs.<sup>39</sup> Consequently, HIPAA applies to certain types of health care organizations that transmit information electronically.<sup>40</sup>

Although the purpose of HIPAA was not directly related to historical health sciences special collections, legislators were aware that its provisions would have an impact on these collections early on.<sup>41</sup> As regulations were being promulgated, archivists and historians testified at Congressional hearings about the impact that the act would have on historical research.<sup>42</sup>

## 2. Overview of HIPAA's Provisions

HIPAA's privacy standards are promulgated and administered through the Department of Health and Human Services and its regulations in the Privacy Rule.<sup>43</sup> The Privacy Rule applies to health plans, health care clearinghouses, and certain health care providers.<sup>44</sup> In many cases, historical health sciences special collections are a unit of a college or university that has a medical school or other health sciences departments. In other cases, the historical health sciences special collections are a unit of a hospital or other health care institution. These are institutions to which HIPAA will usually apply, either to the entire organization or to part of it.<sup>45</sup> Within that context, the first point of decision for a special collections custodian is to determine whether the collection is considered to be part of a covered, non-covered, or a hybrid entity.<sup>46</sup> The Privacy Rule applies only to covered entities and to the covered portions of hybrid entities.<sup>47</sup> In many cases, the parent organization will have already made this determination, and the

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38. HIPAA, *supra* note 30; *see also* Lawrence, *supra* note 35, at 426.

39. Lawrence, *supra* note 35, at 426.

40. 45 C.F.R. § 160.102 (2011).

41. *See Decedent Health Information: Hearing before the Subcomm. on Privacy and Confidentiality, Nat'l Comm. on Vital and Health Statistics* (Jan. 11, 2005) (testimony of Nancy McCall, The Johns Hopkins Medical Institutions [hereinafter McCall], and Stephen E. Novak, Columbia University [hereinafter Novak]), <http://www.ncvhs.hhs.gov/050111tr.htm>.

42. *See id.*

43. U.S. DEP'T HEALTH HUM. SERVS., SUMMARY OF THE HIPAA PRIVACY RULE 1 (2003), <http://www.hhs.gov/ocr/privacy/hipaa/understanding/summary/privacysummary.pdf> [hereinafter SUMMARY OF HIPAA].

44. 45 C.F.R. § 160.102-103 (2011).

45. Lawrence, *supra* note 35, at 431-32.

46. Wiener, *supra* note 32, at 17.

47. 45 C.F.R. § 164.103, 160.102, 160.103 (2011); SUMMARY OF HIPAA, *supra* note 43, at 15.

special collections custodian may look to a privacy officer for help in determining this status and whether, in the case of a hybrid entity, the special collections are covered or not.<sup>48</sup>

Once an organization has been designated as a covered or a hybrid entity, the Privacy Rule applies to “protected health information” (PHI), a subset of individually identifiable health information that includes specific address identifiers like, telephone, numbers, email addresses, and other similar identifiers, various sorts of health record numbers, Social Security numbers, license numbers, vehicle identifiers, biometric identifiers, and identifiable photographic images.<sup>49</sup> PHI must be redacted before information can be freely shared.<sup>50</sup> Because the Privacy Rule applies to information held by covered entities on April 14, 2003, it covers information in many documents that were created many years prior to that date, even if the subjects are deceased.<sup>51</sup> For example, the provisions of the Privacy Rule would govern the use of PHI in nineteenth-century records if held by a hospital that is a covered entity today.<sup>52</sup>

The Privacy Rule has many provisions for situations where an entity may disclose PHI, and one of these is disclosure for research purposes.<sup>53</sup> In most cases, the entity must confine the disclosure to the minimum amount necessary.<sup>54</sup> Beyond that, the Privacy Rule imposes a number of additional conditions on disclosure of PHI for research purposes.<sup>55</sup> One situation where the Privacy Rule allows disclosure is when the subjects have given an authorization.<sup>56</sup> Such an authorization must be specific to the research at hand, not for future, undefined research projects.<sup>57</sup> Without authorizations from the subjects, an entity may disclose PHI under the following conditions: (1) when an institutional review board (IRB) or privacy board has issued a waiver; (2) when the researcher, in certain situations, can show that the PHI will be used for a research protocol only or for some similar purpose; or (3) when the PHI is only from decedents.<sup>58</sup> In the last instance, the researcher must be able to document the death of the subjects if necessary.<sup>59</sup>

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48. Wiener, *supra* note 32, at 17.

49. 45 C.F.R. § 164.514(e)(2) (2011); *see also* Wiener, *supra* note 32, at 17.

50. 45 C.F.R. § 164.514(e)(2) (2011).

51. 45 C.F.R. § 164.502(f) (2011); *see* Wiener, *supra* note 32, at 17-18; *see also* Lawrence, *supra* note 35, at 436.

52. *See* Wiener, *supra* note 32, at 17-18.

53. U.S. DEP'T HEALTH HUM. SERVS., PROTECTING PERSONAL HEALTH INFORMATION IN RESEARCH: UNDERSTANDING THE HIPAA PRIVACY RULE 11-13 (2003), [http://privacyruleandresearch.nih.gov/pdf/HIPAA\\_Booklet\\_4-14-2003.pdf](http://privacyruleandresearch.nih.gov/pdf/HIPAA_Booklet_4-14-2003.pdf) [hereinafter PROTECTING PERSONAL HEALTH INFORMATION].

54. *See generally id.*

55. PROTECTING PERSONAL HEALTH INFORMATION, *supra* note 53, at 11-13.

56. PROTECTING PERSONAL HEALTH INFORMATION, *supra* note 53, at 11-13.

57. PROTECTING PERSONAL HEALTH INFORMATION, *supra* note 53, at 11-12.

58. PROTECTING PERSONAL HEALTH INFORMATION, *supra* note 53, at 13-17..

59. PROTECTING PERSONAL HEALTH INFORMATION, *supra* note 53, at 17.

As an alternative, a researcher may use a limited data set with PHI redacted without restrictions.<sup>60</sup> The covered entity that supplies the data must have “no actual knowledge that the remaining information could be used alone or in combination with other information to identify the individual who is the subject of the information.”<sup>61</sup>

### 3. HIPAA’s Conflict with the Purposes of the Historical Researcher and Historical Collections Custodian

From its inception, custodians of historical special collections and archives have seen the HIPAA Privacy Rule as problematic because of its lack of a “grandfather” date and because of its rules around use of health information are geared toward the needs of scientific, not historical researchers.<sup>62</sup> Despite the testimony of prominent archivists and special collections curators at the time it was adopted, the Privacy Rule reaches forever into the past.<sup>63</sup> The rationale for this long reach was a concern that health information about genetic problems and inherited conditions from the past would be used to discriminate in the present.<sup>64</sup> Because IRBs were already overburdened with dealing with approving research with human subjects under the Common Rule, many institutions set up privacy boards to deal with HIPAA authorizations and waivers.<sup>65</sup> In many cases, there have been reports that, from the historians’ point of view, researchers were incorrectly denied waivers or were given inaccurate information.<sup>66</sup>

Increasingly, there is a belief that HIPAA will become the “floor” for correct handling of privacy and confidentiality issues in historical health sciences research, even if its requirements are not tailored to this kind of research.<sup>67</sup> This trend is seen in a recent proposal to strengthen privacy and confidentiality requirements under the Common Rule for research with human subjects even when HIPAA does not apply.<sup>68</sup>

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60. PROTECTING PERSONAL HEALTH INFORMATION, *supra* note 53, at at 15-16.

61. PROTECTING PERSONAL HEALTH INFORMATION, *supra* note 53, at 10. *But see* Paul M. Schwartz & Daniel J. Solove, *The PII Problem: Privacy and a New Concept of Personally Identifiable Information*, 86 N.Y.U. L. REV. 1814, 1845-47 (2011) (discussing the ease of identifying individuals even after many pieces of personally identifiable information are redacted). *See also* Mages, *supra* note 6, at 129-148 (example of analyzing HIPAA requirements for a primary research document from the 1880’s).

62. *See* McCall, *supra* note 421, and Novak, *supra* note 41.

63. *See* Novak, *supra* note 421. (At the time of the publication of this article there have been discussions about modifying HIPAA’s reach into the past, but they are not law. Modification to the HIPAA Privacy, Security and Enforcement 75 Fed. Reg. 40868 (proposed July 14, 2010). The Society of American Archivists supports these changes.) Letter from Helen Tibbo, Society of American Archivists President to Dept. of Health and Human Servs. Office for Civil Rights (Sep. 13, 2010) (available at [http://www2.archivists.org/sites/all/files/SAA\\_HIPAA\\_091310.pdf](http://www2.archivists.org/sites/all/files/SAA_HIPAA_091310.pdf)).

64. Lawrence, *supra* note 35, at 438.

65. Lawrence, *supra* note 35, at 451-52.

66. Lawrence, *supra* note 35, at 423.

67. Lawrence, *supra* note 35, at 423, 451.

68. Human Subject Research Protections, 76 Fed. Reg. 44512 (July 26, 2011).

Similarly, institutional privacy officers may not start with a clear sense of what special collections contain or when the Privacy Rule may apply.<sup>69</sup> Among many custodians, there is great concern that the legitimacy of the historical record may be affected because of this lack of knowledge, because collections may be fragmented or de-accessioned, or custodians will be forced to stop collecting certain types of materials.<sup>70</sup> Collection custodians must be prepared to educate legal counsel and privacy professionals about the scope and mission of their collections.<sup>71</sup>

Many historical health sciences collections custodians are keenly interested in digitizing their collections in order to facilitate access for researchers that cannot physically travel and to reduce wear and tear on fragile materials. The trend in many special collections projects is mass digitization, where material is converted to digital form as quickly as possible without extensive analysis of the content. This may be impossible or unwise when dealing with historical health science collections because of the need to examine material closely to look for privacy and confidentiality breaches and issues.<sup>72</sup>

#### *B. Other Privacy and Confidentiality Laws*

Although HIPAA causes the most concern among custodians of historical health sciences special collections, other privacy and confidentiality laws are also relevant and may have requirements to which custodians must adhere.<sup>73</sup> These include other federal laws, most notably the Federal Educational Rights and Privacy Act (FERPA)<sup>74</sup> in educational settings, and state privacy and confidentiality laws.<sup>75</sup>

FERPA is foremost among federal statutes, other than HIPAA, that may have a bearing on the historical health sciences special collections.<sup>76</sup> These collections often include records from medical schools and nursing schools that are heavily used and consulted.<sup>77</sup> FERPA applies when the Department of Education provides funding to an educational institution.<sup>78</sup> FERPA gives control of records to each student and provides limits on the situations under which an institution can release these records.<sup>79</sup> In addition, many institutions have their own policies with regard to student records, and there may be requirements to

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69. Gilliland, *supra* note 4, at 400.

70. Novak, *supra* note 42.

71. Gilliland, *supra* note 4, at 400.

72. Gilliland, *supra* note 4, at 397.

73. Gilliland, *supra* note 4, at 387-90.

74. Family Educational Rights and Privacy Act 20 U.S.C. § 1232g (2010) [hereinafter FERPA].

75. Gilliland, *supra* note 4, at 387-90.

76. *See* FERPA, *supra* note 74.

77. Gilliland, *supra* note 4, at 387-88.

78. *Id.* at 387; *see also* FERPA, *supra* note 74.

79. Gilliland, *supra* note 4, at 387-88.

comply with state open records laws and other statutes.<sup>80</sup> FERPA has no provision for a private remedy, and penalties and enforcement are handled on an institutional basis through the Family Policy Compliance Office.<sup>81</sup> When they apply, FERPA regulations add another layer of compliance and concern for the custodian of historical health sciences collections.<sup>82</sup>

State privacy and confidentiality laws may provide a cause of action when HIPAA does not apply (such as when a special collection is not a covered entity), when these laws provide greater protection than HIPAA provides, or when a subject pursues a private remedy.<sup>83</sup> Most actions will be subject to relevant statutes of limitations and, in many jurisdictions, require that the breach of privacy or confidentiality involve living people.<sup>84</sup>

Traditionally, “the common law tort of breach of confidentiality” and the physician’s code of ethics governed the confidence and privacy of the communications between patient and doctor.<sup>85</sup> While there was no common law privilege that governed the admissibility of communications to a physician in court, the privilege was instituted by statute during the 19<sup>th</sup> century.<sup>86</sup> Outside the realm of the courtroom, if a patient felt that a physician had breached that duty and sought redress through the courts, the action was predicated on the law of confidence, not privacy.<sup>87</sup> Under this legal theory, a plaintiff suffers injury when a trusted relationship is damaged by a betrayal of a confidence.<sup>88</sup> As Neil M. Richards and Daniel J. Solove point out, “the focus of the tort of breach of confidentiality is on the nature of the relationship” and the “norms of trust within relationships.”<sup>89</sup>

Although the law of confidence continued to develop robustly in the United Kingdom, in the United States the notion of privacy supplanted it to a large extent when Brandeis and Warren published their famous article, “The Right to Privacy,” in 1890.<sup>90</sup> One of their arguments was that the technological innovations<sup>91</sup> of the day made it necessary for the law to protect not only confidential relationships between people, but also to protect the disclosure of

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80. Gilliland, *supra* note 4, at 388.

81. *Gonzaga Univ. v. Doe*, 536 U.S. 273 (2002).

82. Gilliland, *supra* note 4, at 388.

83. Gilliland, *supra* note 4, at 390-91.

84. *See generally* DANIEL J. SOLOVE & PAUL M. SCHWARTZ, *PRIVACY LAW FUNDAMENTALS* (2011) [hereinafter *PRIVACY LAW FUNDAMENTALS*]; and Gilliland, *supra* note 4, at 390-91.

85. Peter A. Winn, *Confidentiality in Cyberspace: The HIPAA Privacy Rules and the Common Law*, 33 *RUTGERS L.J.* 617, 622 n. 11 (2002).

86. Neil M. Richards and Daniel J. Solove, *Privacy’s Other Path: Recovering the Law of Confidentiality* 96 *GEO. L.J.* 123, 135 (2007).

87. *Id.* at 134-138, 156-58.

88. *Id.* at 126.

89. *Id.* at 174.

90. Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 *HARV. L. REV.* 193 (1890); *see also* Richards, *supra* note 86.

91. Richards, *supra* note 86, at 128.

information outside of these relationships. Newspapers were growing and proliferating rapidly, spreading celebrity gossip and human-interest stories.<sup>92</sup> Eastman Kodak had recently invented a small camera that could take un-posed snapshots without the subjects' knowledge or consent.<sup>93</sup> Consequently, Warren and Brandeis argued that "the doctrines of contract and of trust [were] inadequate to support the required protection."<sup>94</sup> A right of privacy was needed to protect people "against the world."<sup>95</sup>

In *Roberson v. Rochester Folding Box Co.* in 1902,<sup>96</sup> a New York court held that a woman could not recover damages for an invasion of privacy,<sup>97</sup> and, as a result, that state provided for a right of privacy by statute.<sup>98</sup> Other states followed suit and also began to recognize the right of privacy through the courts or by statute, using some version of the reasoning that Warren and Brandeis had advanced.<sup>99</sup> By 1960, privacy law had developed to the point where William Prosser defined four privacy torts: (1) public exposure of private facts of an embarrassing nature; (2) placing one in "false light in the public eye;" (3) appropriation of plaintiff's "name and likeness" for the defendant's advantage; and (4) intrusion into the plaintiff's "seclusion or solitude."<sup>100</sup>

Within the context of health care, the public disclosure of private facts is the privacy tort most likely to provide a cause of action if medical confidences or embarrassing information comes to light.<sup>101</sup> This tort is defined as a public disclosure, usually through wide dissemination, of private information that is "highly offensive to a reasonable person" and not of legitimate public concern.<sup>102</sup> Within a special collection of historical medical information, subjects of records might have a cause of action if embarrassing information, such as information about venereal disease, illegitimacy, or mental disorders, is disseminated as a result of digitizing collections. In addition, digitization and dissemination of personal information that is not highly offensive, such as Social Security numbers, also may cause harm to subjects.<sup>103</sup>

The tort of false light occurs when private facts are exposed in a way that leads to true but highly inaccurate impressions, such as the stories peddled by sensational tabloids.<sup>104</sup> It is unlikely that this tort would form the basis of a

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92. Richards, *supra* note 86, at 128.

93. Richards, *supra* note 86, at 128-29.

94. Warren, *supra* note 90, at 211; Richards, *supra* note 86, at 128-29.

95. Warren, *supra* note 90, at 213.

96. *Roberson v. Rochester Folding Box Co.*, 64 N.E. 442 (N.Y. 1902).

97. *Id.* at 447-48.

98. Richards, *supra* note 86, at 147.

99. Richards, *supra* note 86, at 146-48.

100. William L. Prosser, *Privacy*, 48 CAL. L. REV. 383, 389 (1960).

101. PRIVACY LAW FUNDAMENTALS, *supra* note 84, at 72-74.

102. RESTATEMENT (SECOND) OF TORTS § 652D (1977).

103. Gilliland, *supra* note 4, at 389.

104. Gilliland, *supra* note 4, at 389-90; *see also* RESTATEMENT (SECOND) OF TORTS, *supra* note 102.

cause of action for the subject of historical medical special collections material, particularly because the entity disclosing the information must have acted with “actual malice or a reckless disregard for the truth.”<sup>105</sup> However, occasionally the subjects of digitized historical information have sued on the basis of defamation, false light’s close cousin.<sup>106</sup> At first blush, it appears unlikely that the tort of misappropriation of a name or likeness could form a cause of action in the context of historical health sciences special collections. However, some archives choose to sell images from their collections for the purpose of generating profit, and so this might be a cause for concern where this is a source of revenue for an institution.<sup>107</sup>

In contrast, the law of confidence has developed more slowly in the United States.<sup>108</sup> Nevertheless, most states recognize the tort of breach of confidence between physician and patient, with many also recognizing tort liability for a third party who induces such a breach.<sup>109</sup> There is a sense that the law of confidence may form the basis of a cause of action in more situations in the future. Unlike the privacy torts, there is no requirement that information exposed be offensive and there are fewer issues of free speech and public concern.<sup>110</sup> In the context of historical health sciences special collections, a breach of confidence is most likely to be a concern when the subject or subjects are still living, when information is relatively recent, and where the donor or original owner of the information had a “duty of confidence toward the subjects.”<sup>111</sup>

### C. *Changing Expectations of Privacy and Confidentiality*

As previously discussed, medical records have historically contained sensitive patient information and patients expected that their physicians would safeguard medical privacy and confidences.<sup>112</sup> Patients generally trusted that their medical information would be kept private and physicians were entrusted to uphold this expectation. As some records moved from files in current use to those deemed historically significant, archivists held to the same privacy protection expectations.<sup>113</sup> However, record sharing through the advancements

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105. Gilliland, *supra* note 420, at 389.

106. Gilliland, *supra* note 4, at 389-90; *see also* PETER B. HIRTLE, EMILY HUDSON, & ANDREW T. KENYON, *COPYRIGHT AND CULTURAL INSTITUTIONS: GUIDELINES FOR DIGITIZATION FOR U.S. LIBRARIES, ARCHIVES, AND MUSEUMS 181-185* (Cornell University Library 2009).

107. Gilliland, *supra* note 4, at 390.

108. Gilliland, *supra* note 4, at 390; Winn, *supra* note 85, at 652-58.

109. *PRIVACY LAW FUNDAMENTALS*, *supra* note 84, at 72; *see* *Hammonds v. Aetna Cas. & Surety Co.* 243 F. Supp. (N.D. Ohio, E.D. 1965), and *Biddle v. Warren Gen. Hosp.* 715 N.E. 2d 518 (Ohio, 1999) (demonstrating recognition of the tort of breach of physician-patient confidence and the tort of inducing such a breach).

110. *PRIVACY LAW FUNDAMENTALS*, *supra* note 84, at 72-73.

111. Gilliland, *supra* note 4, at 390.

112. *See supra* Part II A.

113. Craig, *supra* note 12, at 246-47.

in technology has meant that patient records can be shared with a larger audience and possibilities for widespread privacy breaches have become a reality. Therefore, it was not the nature of the medical or archival profession, patient expectations, or even the records themselves, but the development of technological means of sharing the records that led to much of the legislation that now governs the use and transfer of privacy-sensitive medical information.<sup>114</sup>

Custodians of historical health sciences special collections must contend with conflicting expectations of privacy from a variety of sources. Some of these conflicts arise from the fact that the collections deal with material that was created and collected at a variety of different times in history, including times when different situations were considered offensive and the role between health care provider and patient was more paternalistic than it is at present. Donor expectations, especially when those donors were physicians or other health care providers, have also changed over time.<sup>115</sup> Although there is greater sensitivity to health care privacy in general, today many custodians face considerable pressure to digitize collections, often without a chance to perform a complete inventory in order to determine if those collections contain private information.

#### 1. Expectations of More Privacy

Undoubtedly, the expectations of privacy that have had the greatest impact on historical health sciences special collections come from HIPAA.<sup>116</sup> Even as they were being promulgated, the provisions of HIPAA's Privacy Rule generated concern among custodians of these collections.<sup>117</sup> When HIPAA does not apply, such as when PHI has not been generated by covered entities, the Privacy Rule's requirements have caused custodians to assess health-related privacy and confidentiality issues more stringently. For example, it is not unusual for historical health sciences collections to contain many images.<sup>118</sup> In the past, the historical health sciences special collections' parent institutions probably collected photographs of patients and published them widely without permission from their subjects.<sup>119</sup> Today, such photographs would only be taken with express permission.<sup>120</sup>

The rise of the Internet is also responsible for these greater expectations of privacy in two ways. First, the average person has a greater awareness of privacy and the ability to lose his or her privacy than in the past because of the intrusions of social media and the ability to broadcast information more broadly

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114. Carpenter, *supra* note 29.

115. *See supra* Part III.

116. *See generally* Lawrence, *supra* note 35.

117. *See generally* Novak and McCall, *supra* note 41. *See also* Lawrence, *supra* note 35, at 436.

118. Gilliland, *supra* note 4, at 390.

119. Gilliland, *supra* note 20, at 385.

120. Gilliland, *supra* note 4, at 385.



through electronic channels.<sup>121</sup> This is seen explicitly in HIPAA's concern with ongoing issues with regard to genetic disease and insurance coverage and with its emphasis on information transmitted electronically.<sup>122</sup>

Second, the ability to digitize historical records carries with it the possibility of exposing them to wider view.<sup>123</sup> When it is feasible, most custodians will find it desirable to digitize material in order to preserve fragile formats and allow off-site researchers to use material. It is highly likely that extensive archival holdings have not been inventoried at a detailed level.<sup>124</sup> However, if material is placed on the open Internet without assessment, it is possible that it will contain PHI that should not be disseminated widely. It is possible to digitize material and still limit access, but there must be a detailed audit and inventory of what information is present before a custodian can make those decisions.<sup>125</sup>

## 2. Desire & Expectations for Less Privacy

Ironically, the use of the Internet and electronic communication also leads to a desire for less privacy and, in many situations, a false sense of security online.<sup>126</sup> This is true even in the arena of health information. For example a number of social media sites encourage people with medical conditions to share information about their symptoms and medications online. Sites such as CaringBridge.org<sup>127</sup> and patientslikeme.com,<sup>128</sup> encourage the use of access controls or the use of pseudonyms in order to maintain some measure of privacy online. In most cases, the patient himself or herself, or a close family member, posts the information, not a third party or a health care provider. Nevertheless, some sites encourage the posting of extensive information, such as the results of medical tests, medication dosages, side effects, surgeries, and so on.<sup>129</sup>

Often the impulse toward revealing health information online may come from a false sense of anonymity.<sup>130</sup> Someone who reveals health information may believe that a pseudonym is sufficient enough to protect his or her privacy, not realizing how it may be possible to narrow down that person's identity.<sup>131</sup> A person with a health condition may not realize how data mining, tracing IP addresses, or facial recognition software can be used to identify people even

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121. Daniel J. Solove, *UNDERSTANDING PRIVACY* 2-8 (Harvard University Press 2008).

122. Lawrence, *supra* note 35, at 436-438

123. Gilliland, *supra* note 4, at 393.

124. *See supra* Part III.

125. Gilliland, *supra* note 4, at 396-97.

126. Daniel J. Solove, *THE FUTURE OF REPUTATION: GOSSIP, RUMOR, AND PRIVACY ON THE INTERNET* 146-47 (Yale University Press 2007) [hereinafter *FUTURE OF REPUTATION*].

127. CARINGBRIDGE.ORG: A NONPROFIT CONNECTING FAMILY AND FRIENDS WHEN HEALTH MATTERS MOST, <http://www.caringbridge.org> (last visited Apr. 1, 2012).

128. PATIENTSLIKEME, <https://www.patientslikeme.com/> (last visited Apr. 1, 2012).

129. *Id.*

130. *See FUTURE OF REPUTATION, supra* note 126, at 146-48.

131. Nicolas P. Terry, *Physicians and Patients Who "Friend" or "Tweet,"* 43 *IND. L. REV.*, 285, 325-326 (2010).

when names and addresses are redacted or suppressed.<sup>132</sup> The custodian of a historical health sciences collection should be aware of these trends and possibilities in the protection of personal health information.

### 3. Privacy in Context

One way to think about privacy is to think of it less as a series of absolutes and more as norms that appear within a context and can vary in relationship to that context. Helen Nissenbaum refers to this concept as “contextual integrity,” which she defines as “compatibility with presiding norms of information appropriateness and distribution.”<sup>133</sup> Determining a privacy violation involves analysis of “several variables, including the nature of the situation...the nature of the information...the roles of agents receiving information; their relationships to information subjects; on what terms the information is shared by the subject; and the terms of further dissemination.”<sup>134</sup>

Although this contextual analysis makes for more variable and relativistic judgments about what constitutes a privacy breach, Nissenbaum argues that this approach is a strength that makes privacy analyses more flexible.<sup>135</sup> In her view, there are two reasons this flexibility is needed.<sup>136</sup> The first is because the “norms of privacy in fact vary considerably from place to place, culture to culture, period to period; this theory not only incorporates this reality but systematically pinpoints the sources of variation.”<sup>137</sup> In addition, restrictions on dissemination of information (which Nissenbaum calls “flow”) “will be a messy task, requiring a grasp of concepts and social institutions as well as knowledge of facts of the matter.”<sup>138</sup>

This approach avoids the pitfalls of basing privacy on a set of protected elements, an approach that may fail in certain situations, or when new tools and technologies are introduced.<sup>139</sup> Ironically, it prefigures a return to the common sense rules and the professional best judgment that historical health sciences collections custodians employed before privacy laws were strengthened.

## IV. SOLUTIONS AND STRATEGIES

When the absolute strictures of HIPAA do not apply, it makes sense for the custodian of a historical health sciences collection to use the contextual approach in assessing privacy issues with regard to their collections because these

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132. FUTURE OF REPUTATION, *supra* note 126; *see also In the Face of Danger: Facial Recognition and the Limits of Privacy Law*, 120 HARV. L. REV. 1870 (2007).

133. Helen Nissenbaum, *Privacy as Contextual Integrity*, 79 WASH. L. REV. 119, 155 (2004).

134. *Id.*

135. *See generally* Nissenbaum, *supra* note 133

136. Nissenbaum, *supra* note 133, at 155-56.

137. Nissenbaum, *supra* note 133, at 156.

138. Nissenbaum, *supra* note 133, at 156.

139. Schwartz, *supra* note 61, at 1847-48.

collections are excellent examples of the variability in assessing privacy norms “from place to place, culture to culture, period to period.”<sup>140</sup> Material may have been created and collected in a very different milieu from the one in which it exists today. The custodian of historical health sciences collections thinks in terms, not only of contemporary norms and needs, but also on what the collection says about past attitudes and on what materials will be useful to researchers in the future.<sup>141</sup> This sensitivity to context makes the custodian an ideal person to make the assessment of contextual integrity that Nissenbaum posits.<sup>142</sup> Factors in a custodian’s assessment that correspond to Nissenbaum’s list include: the age of the material; the kind of symptoms or situations represented; the subjects’ awareness that the material exists and was collected; the likely audience for the material; the donor and his or her situation; and the probability of wide dissemination of the information.<sup>143</sup> The institutional position on privacy and confidentiality matters and the institutional appetite for risk is also a part of that calculation.

It is essential that custodians of historical health sciences special collections be aware of the institutional climate in which they work and communicate with legal counsel about privacy and confidentiality concerns.<sup>144</sup> Because of the Privacy Rule’s breadth and complexity, it has not been well understood within the community of historians, archivists, and historical health sciences collections custodians. Conversely, it is unlikely that the average institutional privacy officer or institutional in-house legal counsel is aware of the needs and norms of historical research.<sup>145</sup> In many situations, these individuals may not be aware that historical health sciences exist, have a good idea of what they include, or completely understand their importance.<sup>146</sup>

#### *A. HIPAA Compliance for Historical Health Sciences Special Collections*

The first question to answer in determining HIPAA compliance for historical health sciences special collections is whether the institution to which the collection belongs is a covered, non-covered, or hybrid entity.<sup>147</sup> If the institution is a hybrid entity, the next assessment is whether the collection is part of the covered or non-covered portion.<sup>148</sup> If the collection is considered part of a covered entity, either because the entire institution is covered by HIPAA or because the collection is in the covered part of a hybrid institution, then the

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140. Nissenbaum, *supra* note 133, at 156.

141. *See supra* Part I.

142. *See generally* Nissenbaum, *supra* note 133.

143. Nissenbaum, *supra* note 133.

144. *See* Gilliland, *supra* note 4, at 400.

145. *See* Gilliland, *supra* note 20, at 400.

146. Wiener, *supra* note 32, at 19-20.

147. Wiener, *supra* note 32, at 17.

148. Wiener, *supra* note 32, at 17.

custodian must abide by the Privacy Rule in handling the material.<sup>149</sup> Collections must be presented with PHI redactions unless researchers have proper authorization from subjects, subjects are deceased and the research is necessary, or the researcher has obtained a waiver from an Institutional Review Board or Privacy Board.<sup>150</sup>

Custodians of historical health sciences collections must be prepared to explain the HIPAA regulations to historical researchers who may not be familiar with these legal matters within the health sciences. At the same time, members of Institutional Review Boards, which normally handle ethical treatment of human subjects under the Common Rule, may not have a good understanding of the norms and necessity of historical research.<sup>151</sup> Consequently, custodians of historical health sciences collections may prefer to institute special Privacy Boards to deal with HIPAA waivers for historical research.<sup>152</sup>

#### *B. Compliance with other Privacy and Confidentiality Laws*

If the institution is not covered, HIPAA does not apply, but resources may still contain personal health information or other privacy-sensitive material. In this situation, a custodian will still need to assess material and consult with institutional legal counsel or other appropriate authorities in order to make an assessment on whether and when to restrict access.<sup>153</sup>

Liability is one question of interest in analyzing privacy and confidentiality breaches in conjunction with historical health sciences collections. If a donor has violated a confidential relationship or the privacy of subjects, technically the donor should be the first at fault.<sup>154</sup> Ideally, donor restrictions and agreements at the time that gifts are made will be predicated on the risk of such a breach, but this is not always the case.<sup>155</sup> In other cases, the provenance of material may be obscure or unknown. Some have posited that the custodian of the collection must have knowledge of the confidential or private material or have acted willfully, and that this may cut off liability.<sup>156</sup>

There is little case law in this area, which probably indicates that most disputes are handled through donor agreements, careful vetting at the time collections are acquired, or by private settlements when controversies arise.<sup>157</sup> One of the few cases that dealt with some of these issues involved the Brown

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149. SUMMARY OF HIPAA, *supra* note 43, at 15.

150. PROTECTING PERSONAL HEALTH INFORMATION, *supra* note 57, at 11-17; *see* Gilliland, *supra* note 4, at 395 (showing a flowchart of this decision process).

151. *See* Lawrence, *supra* note 35, at 451-52.

152. Wiener, *supra* note 32, at 20; Lawrence, *supra* note 35, at 451-52.

153. *See* Gilliland, *supra* note 4, at 395 (showing a flowchart of this decision process).

154. *See* McKay, *supra* note 23.

155. *See* Gilliland, *supra* note 4, at 398.

156. *See* McKay, *supra* note 23.

157. McKay, *supra* note 23.

and Williamson Tobacco Papers and the Tobacco Archives at the University of California, San Francisco (UCSF).<sup>158</sup>

The controversy began in 1994 when Stanton Glantz, an anti-smoking activist and professor at UCSF, received a large number of papers from an anonymous donor calling himself “Mr. Butts.”<sup>159</sup> The papers were copies of documents from Brown and Williamson’s research, policy, and marketing that included increasing evidence that the company knew that nicotine was addictive.<sup>160</sup> Some documents were from medical and health-related studies.<sup>161</sup> “Mr. Butts” also sent copies of the documents to the New York Times and Congressman Henry Waxman.<sup>162</sup>

“Mr. Butts” was actually a paralegal named Merrell Williams who had worked for one of Brown and Williamson’s law firms.<sup>163</sup> A former smoker with health problems, Williams had become increasingly troubled by the contents of the documents he was handling and convinced that Brown and Williamson was sending incriminating documents to its attorney to protect them as attorney work products and by attorney-client privilege.<sup>164</sup> He embarked on a concentrated campaign to find and copy problematic documents during the course of his work.<sup>165</sup> Both Brown and Williamson and Williams alleged fraud—Brown and Williamson because Williams violated a confidentiality agreement when he copied the documents and Williams because the tobacco company had falsely claimed that the documents were privileged.<sup>166</sup>

Glantz gave the papers to the UCSF library and archives.<sup>167</sup> As word spread that the documents were available at UCSF, traffic became unmanageable for the librarians, so they digitized the documents, first as a CD-ROM, the medium of choice at that time, and then on the Internet.<sup>168</sup> Initially, the librarians were concerned about the uncertain provenance of the papers and the precedent they were setting in accepting the documents and making them available. Were the documents legitimate? Those concerns came to an end in the winter of 1995,

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158. See generally, McKay, *supra* note 23; Karen Butter, Robin Chandler, & John Kunze, *The Cigarette Papers: Issues in Publishing Materials in Multiple Formats*, D-LIB MAG. (Nov. 1996), <http://www.dlib.org/dlib/november96/11butter.html>; Sally Lehrman, *University Blocks Efforts to Reveal Researchers’ Identity*, 374 NATURE 109 (March 1995); Jon Wiener, *The Cigarette Papers*, THE NATION (January 1, 1996) [hereinafter *Cigarette Papers*]; Clay Calvert, *Smoking Out Big Tobacco: Some Lessons About Academic Freedom, The World Wide Web, Media Conglomeration, and Public Service Pedagogy from the Battle over the Brown & Williamson Documents*, 24 PEPP. L. REV. 391 (1996-97).

159. *Cigarette Papers*, *supra* note 158, at 12.

160. Calvert, *supra* note 158, at 400-03.

161. Calvert, *supra* note 158, at 400-02.

162. *Cigarette Papers*, *supra* note 158, at 18.

163. See generally *Cigarette Papers*, *supra* note 158.

164. See *Cigarette Papers*, *supra* note 158, at 18; see also Calvert, *supra* note 158.

165. Calvert, *supra* note 158, at 401.

166. *Cigarette Papers*, *supra* note 158, at 17-18.

167. *Cigarette Papers*, *supra* note 158, at 12.

168. *Cigarette Papers*, *supra* note 158, at 12.

when Brown and Williamson realized that UCSF had copies of the documents and requested for the library to turn them over.<sup>169</sup> When UCSF refused, the tobacco company sued.<sup>170</sup> Brown and Williamson lost at trial and on appeal, despite Merrell Williams's violation of his confidentiality agreement, in part because UCSF had made the documents available to researchers and started digitization plans.<sup>171</sup> To cut off access to the documents after those actions would have been a constitutionally unacceptable prior restraint on free speech. In addition, as the judge pointed out, other copies of the documents existed, and parts had been published or publicized by others as well.<sup>172</sup> Furthermore, UCSF had not been involved in any wrongdoing: "If the University had in fact been a wrongdoer in obtaining the information, then we would have a very different situation."<sup>173</sup>

Although the outcome of this one case does not necessarily predict the course of any other litigation, it is an encouraging precedent for custodians of historical health sciences collections.<sup>174</sup> Today, all of the documents Glantz received are kept online by UCSF, with a fully developed procedure for handling privileged and confidential documents.<sup>175</sup>

### C. Digitization and Access Control

Digitization provides many benefits for historical health sciences collections because of the ability to preserve fragile materials and to provide access to remote researchers. However, if material contains large amounts of PHI that must be redacted before material can be posted online, its usefulness can be limited. One option for digitized material is to still control access to authorized personnel and researchers, thus complying with HIPAA or other privacy and confidentiality laws and norms. If material is to be freely available on the Internet, the custodian should select material where few redactions will be necessary.<sup>176</sup> The same analyses of "contextual integrity" that are used for general access can also be applied to digitization.<sup>177</sup>

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169. Calvert, *supra* note 158, at 403.

170. Calvert, *supra* note 158, at 394, 403; *Cigarette Papers*, *supra* note 158, at 12.

171. *Brown & Williamson Tobacco Corp. v. Regents of Univ. of Cal.*, No. 967298 (Super. Ct. Cal S.F. County 1995); *see generally* Calvert, *supra* note 158; *see also* Legacy Tobacco Documents Library, available at [http://legacy.library.ucsf.edu/about/about\\_collections.jsp#ucbw](http://legacy.library.ucsf.edu/about/about_collections.jsp#ucbw) (brief discussion of case at University Of California, San Francisco).

172. *See Brown & Williamson Tobacco Corp. v. Regents of Univ. of Cal.*, No. 967298, at 59 (Super. Ct. Cal S.F. County 1995).

173. *Id.* at 56.

174. Calvert, *supra* note 158, at 452-53.

175. U.C. San Francisco, *Library Documents Designated as Privileged or Confidential*, LEGACY TOBACCO DOCUMENTS LIBRARY (2007), <http://legacy.library.ucsf.edu/help/docdesignation.jsp>.

176. Gilliland, *supra* note 4, at 396-98.

177. *See supra* Part III; *see generally* Nissenbaum, *supra* note 133.

## V. CONCLUSION

Historical health sciences collections play an important role in research, both in the field of the history of medicine and also in a variety of other areas in the sciences and social sciences. These collections exist in a variety of institutions, from large academic medical centers to small hospitals. The requirements of HIPAA, along with other concerns over privacy and confidentiality in the digital age, have made the task of providing access to these collections more complex and onerous. Custodians of historical health sciences collections are likely to consult privacy officers and attorneys for assistance in determining the status of materials under HIPAA and other privacy and confidentiality laws in order to make material available to researchers.

It may take considerable time to determine the HIPAA status of a historical health sciences special collections unit and set up procedures to aid researchers. There may be considerable effort expended in analyzing other privacy and confidentiality issues that these collections represent. Nevertheless, the time and effort it takes to make these analyses is well spent. The social and historical value of these materials is immense. Most materials are irreplaceable and have a unique role in documenting and informing us about our social and cultural heritage.