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This research reports on the findings of a study of archival processing in medical center archives, health sciences collections, and history of medicine collections. This exploratory study examined how archivists in these settings process collections and, in so doing, how they balance the potentially conflicting needs of protecting privacy and providing timely access. Four practicing archivists were interviewed, the interviews were transcribed, and data were coded inductively. Participants addressed how they identified sensitive information scattered throughout collections, the impact this sensitive information had on processing decisions, how they communicated access restrictions, and ways in which they managed access. The findings suggest that sensitive information is best protected when it becomes a shared commitment and a shared responsibility between all groups involved.

Headings:

Archives

Archival processing

Medical archives

Privacy

PROCESSING TO PROTECT PRIVACY AND PROMOTE ACCESS: A STUDY OF
ARCHIVAL PROCESSING IN MEDICAL ARCHIVES, HEALTH SCIENCES
COLLECTIONS, AND HISTORY OF MEDICINE COLLECTIONS

by
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CONTENTS

Introduction.....	2
Literature Review.....	5
Methodology	26
Findings.....	33
Discussion	53
Conclusions and Future Research	62
Bibliography	64
Appendix A.....	66
Appendix B	68

INTRODUCTION

With the passage the Health Information Portability and Accountability Act (HIPAA) law in 1996 and its subsequent later revisions such as the Privacy Rule, which went into effect in 2003 and was most recently changed in 2013, archivists in medical archives, health sciences collections, and history of medicine collections faced a legal mandate to protect personal health information. Whereas previously this issue had been a matter of professional ethics in the medical and archival communities, HIPAA instituted national standards to protect personal medical information and carried steep penalties for institutions designated as “covered entities” under HIPAA’s Privacy Rule who failed to protect this information from access.¹ Navigating access and identifying and restricting any protected health information (PHI) identifiers thus became a legal as well as an ethical responsibility for archivists who collected medically-related materials.

Around the same time that archivists in medical archives and other health sciences settings were still grappling with HIPAA compliance and what this meant for balancing access and privacy, the archives field underwent a turn in processing theory. In 2005, Mark Greene and Dennis Meissner published an influential and controversial article in *The American Archivist* entitled “More Product, Less Process: Revamping Traditional Archival Processing.” Bringing attention to the issue of backlogs and the failings of

¹ Beverlee Warren, “The Role of the Privacy Officer: A Portrait in the Gallery of Possibilities for Health Sciences Librarians,” *Journal of Hospital Librarianship* 2, no. 2 (June 2002): 26–27; Emily Novak Gustainis and Phoebe Evans Letocha, “The Practice of Privacy,” *Proceedings of the CLIR Cataloging Hidden Special Collections and Archives Symposium, March 2015*, 2015, 164.

traditional archival processing procedures, Greene and Meissner's article advocated essentially a "good enough" approach to archival processing.² Although it was not universally embraced by the whole archives field, Greene and Meissner's More Product Less Process (MPLP) approach to archival processing sparked conversation and helped give rise to the widespread trend of MPLP or minimal processing in the archives field. Archivists began to critically examine their processing workflows and assumptions about the process of arranging and describing archival collections. Many repositories adopted this MPLP or minimal processing approach outlined by Greene and Meissner in order to tackle growing backlogs and provide patrons with access to more collections previously unprocessed and thus inaccessible. Advocates refer to minimal processing as a user-centric approach; they contend that an archive's primary responsibility is to provide patrons with quick access to archival materials. As such, they argue that an archivist's time is best spent devoted to doing only the minimum that matters in order to make a collection available. With MPLP or minimal processing, the archivist makes a trade-off between more detailed description and arrangement, including the identification of potentially sensitive information, and making more collections accessible.³

While this approach may be well suited for large manuscript repositories with substantial backlogs of twentieth-century collections, it begs the question as to whether and how institutions that regularly handle sensitive information spread throughout collections can make a similar trade off. In addition to providing patrons with access to archival materials, repositories such as medical archives, health sciences collections, and

² Mark A. Greene and Dennis Meissner, "More Product, Less Process: Revamping Traditional Archival Processing," *The American Archivist* 68, no. 2 (2005): 208–63.

³ *Ibid.*, 240–52.

history of medicine collections have another duty to protect confidential material, especially when it involves third-party privacy concerns and an individual's medical information. Not only do these institutions have to consider the ethical aspects associated with privacy, but certain medical repositories are also designated as covered entities under HIPAA legislation, meaning they are legally required to restrict access to any material containing Protected Health Information (PHI).

This research project will examine the realities of processing archival collections in institutions such as medical archives that regularly encounter and must account for sensitive health information spread throughout collections. More specifically, this project asks the following questions: 1) How do practicing archivists approach processing collections that contain large amounts of hidden sensitive information? 2) In so doing, how do they balance the potentially conflicting needs of protecting privacy and providing timely access? Through an exploratory study involving interviews with practicing archivists, this research will shed light on how archivists process collections that involve sensitive information – their workflows, processing procedures, activities, and methods for identifying and dealing with sensitive information.

LITERATURE REVIEW

The subjects of privacy and access concerns, HIPAA and medical archives, and archival processing have been explored by many in the archives field. Literature on the subject of privacy and access has established the ethical and legal imperative for archivists to protect private information in certain cases.⁴ While such essays have presented strategies for determining the sensitivity of personal information, they do not primarily address how processing decisions might fit into the challenge of balancing privacy and access. Nor do many of these approach the issue from an empirical standpoint. Literature on HIPAA and medical archives has likewise provided useful theories, strategies, and recommendations for HIPAA compliance, but few report on research studies designed to gather data regarding how practicing archivists are actually processing collections and potentially making use of the theories and strategies presented in the literature. Finally, while archivists have written extensively on archival processing, especially in the wake of Meissner and Greene's influential More Product Less Process (MPLP) model of archival processing, medical archives and other repositories containing medically-sensitive materials in their collections have not received much representation in this literature.

⁴ See for example: Elena S. Danielson, *The Ethical Archivist* (Chicago: Society of American Archivists, 2010); Karen Benedict, *Ethics and the Archival Profession: Introduction and Case Studies* (Chicago: Society of American Archivists, 2003); Steven Bingo, "Of Provenance and Privacy: Using Contextual Integrity to Define Third-Party Privacy," *The American Archivist* 74, no. 2 (2011): 506–21; Randall C. Jimerson, "Ethical Concerns for Archivists," *Public Historian* 28, no. 1 (2006): 87–92; Eric Ketelaar, "The Right to Know, the Right to Forget? Personal Information in Public Archives," *Archives and Manuscripts* 23, no. 1 (May 1995): 8–17.

ARCHIVES & PRIVACY

A body of literature exists within the archives field that specifically addresses concerns related to privacy and access. Both legal and ethical considerations come into play when archivists are faced with decisions regarding access and privacy protection. These two dimensions – law and ethics – define much of the discussion surrounding privacy and access in archives.⁵ In *The Ethical Archivist*, Elena Danielson devotes a whole chapter toward the subject of archives and privacy. In it, she notes that archivists in the United States have a legal mandate to comply with privacy laws such as FOIA (Freedom of Information Act, 1996), FERPA (Family Educational Rights and Privacy Act, 1974), and HIPAA (Health Insurance Portability and Accountability Act, 1996).⁶ While FOIA allows for citizens to gain access to government information, both FERPA and HIPAA restrict specific types of information from access. Archivists also face questions regarding what to do with personal and potentially private data such as Social Security Numbers and personal financial information that finds its way into the archives. With the exception of material covered by laws like FERPA and HIPAA, Danielson discusses that the risk of lawsuit for breaches of privacy in archival institutions is actually quite low.⁷ Meissner and Greene concur, claiming that historically, few lawsuits have been litigated successfully against archives for invasion of privacy offenses.⁸ So, why do archivists care about protecting privacy if there exists little risk for legal repercussions?

⁵ Bingo, “Of Provenance and Privacy”; Danielson, *The Ethical Archivist*.

⁶ For more information on each of these pieces of legislation and their impact on the archives field, see Danielson, *The Ethical Archivist*, 198–99.

⁷ *Ibid.*, 200.

⁸ Dennis Meissner and Mark A. Greene, “More Application While Less Appreciation: The Adopters and Antagonists of MPLP,” *Journal of Archival Organization* 8, no. 3/4 (July 2010): 204; Danielson, *The Ethical Archivist*, 200.

The ethical duty of archivists to protect personal data is well established in the professional literature and forms the other component of the privacy discussion in the United States. Danielson emphasizes this ethical component, claiming “no truly professional archivist wants to be responsible for causing pain and distress.”⁹ In an article addressing archival ethics and potential cultural and political ramifications for access, Jimerson echoes this sentiment. He points to the ethical duty archivists have to balance the needs of donors, researchers, record creators, and “third parties” listed in archival records.¹⁰

Benedict examines international code of ethics for archivists and lists ten globally-accepted ethical principles. Among Benedict’s principles, one encounters the statement that “archivists should discourage restricting access to records except for essential reasons of legality, privacy, or confidentiality...”¹¹ While archivists ethically should strive to promote broad access for archival records, Benedict’s ethical principles also call for archivists to protect privacy in certain circumstances and comply with legislation that restricts access. Likewise, Bingo’s examination of the tension between privacy and access brings up both the legal and ethical dimensions to the subject. Bingo calls for access as a default state for archival materials, but advocates for archivists to be especially attuned to privacy concerns relating to third-party privacy.¹²

The protection of third-party privacy forms an important moral or ethical rationale for restricting access to certain materials in archives. On the subject of third party privacy in archives, Ketelaar claims the following: “Their professional code [requires] archivists

⁹ Danielson, *The Ethical Archivist*, 200.

¹⁰ Jimerson, “Ethical Concerns for Archivists,” 89.

¹¹ Benedict, *Ethics and the Archival Profession*, 5.

¹² Bingo, “Of Provenance and Privacy,” 508.

to respect the privacy especially of persons who have no say in the use or destiny of archival materials.”¹³ According to Danielson, the issue of third-party privacy is tied to the secondary nature of archival materials. As Danielson explains, materials move from a private zone to the public zone when a donor transfers his or her collection to the archives. There, the materials can be accessed by “unknown persons for unpredictable uses.”¹⁴ Third party materials are often included within this transfer. For example, when an individual donates his or her correspondence as part of a collection, letters written to the donor by other individuals are usually included. These individuals, the third parties who may not even know that their letters have been transferred to the public arena of the archives, lose control over their private thoughts, which are now transferred to often unrestricted collections. Danielson argues that there exists an important distinction between secrecy and privacy, illustrated by the example of third-party materials contained in correspondence. Privacy is essentially about the ability to control what happens to one’s personal data.¹⁵

Bingo also brings attention to the issue of third-party privacy and introduces the concept of contextual integrity as a tool to help archivists make decisions regarding access and privacy. He argues that archivists can better identify what might constitute sensitive information by examining the changing contexts that information undergoes as it is transferred to the archives. Approaching the issue of privacy using contextual integrity involves paying careful attention to the “context in which information is supplied, gathered, and used.”¹⁶

¹³ Ketelaar, “The Right to Know, the Right to Forget?,” 16.

¹⁴ Danielson, *The Ethical Archivist*, 183.

¹⁵ *Ibid.*, 183–84.

¹⁶ Bingo, “Of Provenance and Privacy,” 507.

Other strategies have also been proposed for addressing the ethical side of the privacy question. Paul Sillitoe, writing in reaction to the UK's data protection laws, claims that archivists can use the 'harm test' as a general baseline for evaluating how sensitive personal information found in publically accessible records might be.¹⁷ The 'harm test' requires the archivist to consider "what *would* occasion substantial distress in a reasonable person."¹⁸ However, Sillitoe also notes the limitations of the 'harm test.' Since terms such as "substantial distress" and "reasonable person" are not defined, it requires some judgement from the archivist as to what constitutes harm for the reasonable person. Thus, the 'harm test' would not impose a consistent application of privacy practices across repositories.¹⁹ Ketelaar refers to the "human dignity factor," which operates much like the "harm test." Essentially, the archivist might allow access to personal information if human dignity is not threatened by this access. As a subset of this guiding framework, the personal information retained by the archive should be that which is useful for the good of society through research.²⁰ Thus, Ketelaar's human dignity factor serves to guide archivists when making appraisal and access decisions regarding personal sensitive information. Like Sillitoe, Ketelaar acknowledges that this more abstract aspect of privacy falls to professional ethics and is "not formally or legally defined."²¹

¹⁷ Paul J. Sillitoe, "Privacy in a Public Place: Managing Public Access to Personal Information Controlled by Archives Services," *Journal of the Society of Archivists* 19, no. 1 (April 1998): 9–10.

¹⁸ *Ibid.*, 10.

¹⁹ *Ibid.*, 9–10.

²⁰ Ketelaar, "The Right to Know, the Right to Forget?," 13. It is important to note that Ketelaar speaks of privacy from a European perspective, which considers privacy a basic human right. Although the United States may not share the same perspective on privacy as a human right, Ketelaar's strategies for determining the sensitivity of personal information can still guide archivists in making access decisions.

²¹ *Ibid.*, 11.

Danielson has identified four general approaches that archivists take in order to balance access and privacy considerations. These four models consist of shifting responsibility to donors and researchers, actively screening collections by archives staff members before allowing access, requiring researchers to submit requests to Institutional Review Boards for peer review, and responding to privacy complaints on a case by case basis.²²

Danielson claims that the most popular approach in the United States is to shift the responsibility for identifying sensitive, restricted materials to donors and researchers.²³ Such an approach is reminiscent of Meissner and Greene's and Weideman's defenses of MPLP against criticisms that minimal processing may result in more personal, sensitive information accessible in collections.²⁴ Although this model seems practical and convenient for the archivist who must process voluminous collections, Danielson cautions that archivists still must bear some responsibility if personal information is made accessible that causes reputational damage or harm to individuals and their families. Donors may lose trust in the institution's ability to effectively steward archival materials and may publicly denounce the institution in extreme cases. Conversely, it may be impractical and resource-intensive for institutions to effectively screen every box.²⁵ Danielson notes that the prescreening approach to addressing privacy concerns is most effective with well-funded collections and situations in which donors are hesitant to donate materials because of privacy and reputational

²² Danielson, *The Ethical Archivist*, 209–14.

²³ *Ibid.*, 210.

²⁴ Meissner and Greene, "More Application While Less Appreciation," 206–9; Christine Weideman, "Accessioning as Processing," *The American Archivist* 69, no. 2 (2006): 277, 282–83.

²⁵ Danielson, *The Ethical Archivist*, 210–11.

concerns.²⁶ Many archives, however, frequently end up dealing with privacy complaints on a case by case basis due to the large volume of materials in modern archives. Some archives are even beginning to offer access to unprocessed or partially processed collections following Greene and Meissner's 2005 MPLP article, but have taken "calibrated approaches" in order to evaluate the likelihood of certain series containing sensitive or private materials.²⁷ Regarding the adoption of these four models, Danielson ultimately concludes that archivists need to evaluate which approach best fits their collections and the level of risk that is acceptable for the institution.²⁸

PRIVACY AND MEDICAL ARCHIVES

Medical archives and repositories that collect history of medicine and health sciences materials operate in an environment where ethics and law intersect. Many archivists who work in these institutions have to consider legal responsibilities in addition to ethical arguments when balancing access and privacy.²⁹ With the passage of the Health Information Portability and Accountability Act (HIPAA) in 1996, restricting access to personal medical information became an issue of legal compliance.³⁰ As Warren explains, HIPAA instituted national standards to protect personal medical information,

²⁶ *Ibid.*, 211.

²⁷ *Ibid.*, 212.

²⁸ *Ibid.*

²⁹ Judith A. Wiener and 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.," *Journal of the Medical Library Association* 99, no. 1 (January 2011): 15–22; Anne T. Gilliland and Judith A. Wiener, "A Hidden Obligation: Stewarding Privacy Concerns in Archival Collections Using a Privacy Audit.," *Journal for the Society of North Carolina Archivists* 11, no. 1 (2014): 19–35; Melanie Meyers, "HIPAA-Cratic Oath? Processing and Access under the Health Insurance Portability and Accountability Act," *Archival Outlook*, December 2011, 12–13; Danielson, *The Ethical Archivist*.

³⁰ Wiener and Gilliland, "Balancing Between Two Goods"; Meyers, "HIPAA-Cratic Oath?"

whereas previously it had been a matter of professional ethics in the medical and archival communities.³¹ Prompted by the changing technological landscape, Congress passed HIPAA to protect both the confidentiality and privacy of health information. According to Wiener and Gilliland, the law had two intentions: “to facilitate the electronic exchange of health information by quieting concerns over privacy and confidentiality” and to “provide more security for health information when workers changed jobs and faced the possibility of being denied health insurance coverage in the new workplace because of preexisting conditions.”³² As Wiener and Gilliland and others in the profession note, HIPAA was not designed specifically with archives and health sciences libraries in mind. This piece of legislation, however, greatly affects access and processing decisions for these institutions.³³

HIPAA’s privacy rule is the portion of HIPAA that exerts the most direct influence upon archives and libraries. Revised in 2013, the privacy rule mandates the protection of 18 different personal identifiers associated with health information, which it terms as “protected health information” (PHI). These include names, telephone numbers, Social Security Numbers, medical record numbers, even full-face photographic images.³⁴ Essentially, it covers identifiable information that could be used to link health information to individuals. Importantly, it protects information, not specific formats. What this means for archives is that any documents and records containing PHI must be either protected from access or stripped of the protected information to allow free access. Archives and libraries fall into one of three designations according to HIPAA: covered

³¹ Warren, “The Role of the Privacy Officer,” 26–27.

³² Wiener and Gilliland, “Balancing Between Two Goods,” 16.

³³ Meyers, “HIPAA-Cratic Oath?,” 13; Wiener and Gilliland, “Balancing Between Two Goods,” 16–18.

³⁴ For a full list of PHI, see Wiener and Gilliland, “Balancing Between Two Goods,” 17.

entities, non-covered entities, and hybrid entities. It can sometimes be difficult to understand the exact designation of an institution and what that designation means for the institution's responsibilities under HIPAA. Gustainis and Letocha and Wiener and Gilliland recommend getting legal consultation to determine an institution's status and legal responsibilities.³⁵ Only institutions that are designated by HIPAA as "covered entities" are required to comply with this privacy rule.³⁶ However, Meyers has argued that "HIPAA sets the standard for what is acceptable to reveal and what is to remain protected and confidential."³⁷ As such, many archives that are not covered entities have set access policies that generally follow HIPAA standards with a recognition that legislation is moving in the direction of HIPAA's privacy protection guidelines. Wiener and Gilliland, as well as Gustainis and Letocha, observe that even if an archive is not a covered entity, it may still be subject to additional federal or state privacy and confidentiality laws, such as the Federal Common Rule for Protection of Human Subjects, which also regulate access to personal information.³⁸

Archivists have commented on the multiple impacts HIPAA has had on processing and access in medical archives and health sciences collections. Meyers, Wiener and Gilliland, and Gustainis and Letocha observe that HIPAA puts a strain on processing resources since archivists in covered entities must devote large amounts of time toward identifying and redacting or restricting material containing PHI.³⁹ Meyers

³⁵ Gustainis and Letocha, "The Practice of Privacy"; Wiener and Gilliland, "Balancing Between Two Goods."

³⁶ Gustainis and Letocha, "The Practice of Privacy," 164–65; Wiener and Gilliland, "Balancing Between Two Goods," 17.

³⁷ Meyers, "HIPAA-Cratic Oath?," 12.

³⁸ Wiener and Gilliland, "Balancing Between Two Goods," 17; Gustainis and Letocha, "The Practice of Privacy," 164.

³⁹ Meyers, "HIPAA-Cratic Oath?," 12; Wiener and Gilliland, "Balancing Between Two Goods," 19; Gustainis and Letocha, "The Practice of Privacy," 167–68.

contends that some collections contain so much PHI that they are virtually rendered unusable, while other collections require the archivist to meticulously process down to the item level.⁴⁰ While redacting PHI to provide access is an option, it can also be very time consuming. Gustainis and Letocha conducted a timing analysis in which they tracked time and labor to investigate “what, if any differences existed between processing collections in HIPAA-covered entities versus non-HIPAA-covered environments.”⁴¹ They found that the average processing costs per box were roughly equivalent between the two; however, the screening for sensitive information at the covered entity took much longer. For about the same volume of materials, it took archivists at the non-covered entity 9.76 to 10.61 hours per cubic foot to screen for restrictions, whereas archivists at the covered entity spent 21.4 to 46.21 hours per cubic foot.⁴²

Archivists have also raised fears that medical information is less likely to be preserved and accessed by legitimate scholars since complicated, time consuming policies surround providing access to this type of material.⁴³ Those who have made the case for preserving materials containing PHI call for archivists to take a long term view with regards to the records’ eventual value.⁴⁴ Dong argues that medical records “have the potential to be cultural heritage documents,” but archivists must consider their enduring value in terms of future rather than present use.⁴⁵ Danielson also identifies the importance

⁴⁰ Meyers, “HIPAA-Cratic Oath?,” 12.

⁴¹ Gustainis and Letocha, “The Practice of Privacy,” 167.

⁴² *Ibid.*

⁴³ Meyers, “HIPAA-Cratic Oath?,” 12–13; Lorraine Dong, “Taking the Long View of Medical Records Preservation and Archives,” *Journal of Documentation* 71, no. 2 (February 18, 2015): 387–400; Gustainis and Letocha, “The Practice of Privacy,” 170.

⁴⁴ Meyers, “HIPAA-Cratic Oath?”; Dong, “Taking the Long View of Medical Records Preservation and Archives”; Daniel Sokolow, “You Want Me to Do What? Medical Librarians and the Management of Archival Collections,” *Journal of Hospital Librarianship* 4, no. 4 (December 2004): 31–50.

⁴⁵ Dong, “Taking the Long View of Medical Records Preservation and Archives,” 387.

of taking a long-term view for the value of private, personal information. She argues that it is important for archivists to provide a safe repository for these materials to turn into cultural artifacts. The general recognition within the archives community is that the sensitivity of personal information declines over time.⁴⁶ Wiener and Gilliland respond to concerns that archivists are taking a more conservative approach toward collecting medical materials by pointing to the archivist's ethical duty to preserve the integrity of the historical record.⁴⁷ Gustainis and Letocha note that "access anxiety" has led many repositories to refuse "to deliberately collect patient-related materials because they do not have the capacity to manage access."⁴⁸ Gustainis and Letocha call for archivists to enact access policies so that researchers can gain access to medical-related collections and for researchers to advocate for access so that together both groups can justify the retention of medical materials in archival repositories.⁴⁹

Baur *et al.* identify specific groups who have a stake in the preservation and access of medical information. Reporting on a case study of archiving patients' mental health records from 1945 to 1970 in the United Kingdom, Baur *et al.* observe that health professionals, medical researchers, and medical historians are three groups that have real needs for accessing preserved medical information. The health professionals can use the data "to assess the efficacy of treatment and historical outcomes of treatment," while medical researchers may require the information in medical files when researching

⁴⁶ Danielson, *The Ethical Archivist*; Bingo, "Of Provenance and Privacy."

⁴⁷ Wiener and Gilliland do note that further studies are needed to see if archivists' concerns over such medical material not being collected as much due to HIPAA are actually founded: Wiener and Gilliland, "Balancing Between Two Goods."

⁴⁸ Gustainis and Letocha, "The Practice of Privacy," 170.

⁴⁹ *Ibid.*, 170–72.

diseases and treatments.⁵⁰ Finally, the historians can draw upon the preserved records for secondary purposes to write histories of medical treatments or social histories.

Much of the literature advises archivists to seek appropriate legal counsel when questions arise in determining access requirements and necessary restrictions, especially for institutions designated as covered entities.⁵¹ HIPAA's privacy rule covers information but not specific document formats. It can sometimes be difficult to determine exactly what falls under HIPAA's protection. Wiener and Gilliland point to some grey areas regarding HIPAA regulation, such as old letters written pre-HIPPA that contain sensitive health information.⁵² In an article addressing medical librarians who must also manage archival collections, Sokolow also emphasizes the importance of consulting the appropriate legal specialist to determine proper access conditions.⁵³ In their "Recommended Practices for Enabling Access to Manuscript and Archival Collections Containing Health Information About Individuals," Gustainis and Letocha also suggest that archivists turn to both their administration and legal counsel when determining their HIPAA status and their responsibilities under other federal and state privacy legislation such as state medical record laws and the Federal Common Rule for the Protection of Human Subjects.⁵⁴

As Wiener and Gilliland state, archivists "balance on a legal and ethical tightrope of preserving and providing access to the historical record, while at the same time

⁵⁰ Nicole Baur, John Draisey, and Joseph Melling, "Public Policy and Patient Privacy: Archiving Patients' Mental Health Records from the Age of the Great Hospital, c.1948-1970," *Archives (London)* 36, no. 123–124 (October 2011): 36.

⁵¹ Wiener and Gilliland, "Balancing Between Two Goods"; Gilliland and Wiener, "A Hidden Obligation"; Warren, "The Role of the Privacy Officer"; Sokolow, "You Want Me to Do What?"; Gustainis and Letocha, "The Practice of Privacy."

⁵² Wiener and Gilliland, "Balancing Between Two Goods," 18.

⁵³ Sokolow, "You Want Me to Do What?," 40–41.

⁵⁴ Gustainis and Letocha, "The Practice of Privacy," 173–74.

respecting the confidences of those whose lives are reflected in the records.”⁵⁵ This is not an easy task, and many works provide guidance on how archivists can approach issues of privacy and access in medical archives. Sokolow mentions three methods for providing legal and ethical access to records containing PHI. The archivist can 1) redact the PHI identifiers, but Sokolow notes that sometime the researcher may need this information depending on the nature of the research. In order to access the full record, the researcher must either 2) gain a consent form for the subject identified in the records or 3) submit the research proposal to an IRB or privacy board.⁵⁶ Wiener and Gilliland emphasize the importance of planning, such as the establishment of clear institutional privacy and access policies, in helping archivists achieve balanced access and privacy compliance.⁵⁷

Gustainis and Letocha also provide guidance on this issue of balancing privacy and access in their “Recommended Practices for Enabling Access to Manuscript and Archival Collections Containing Health Information About Individuals,” created as part of the CLIR-funded project “Private Practices, Public Health: Privacy-Aware Processing to Maximize Access to Health Collections.”⁵⁸ Gustainis and Letocha, however, approach the issue from the researcher’s perspective and needs. They investigated the information-seeking needs of researchers when attempting to access restricted medical materials. Based on their study, Gustainis and Letocha found that to facilitate access it is important for archives to not only have institutional access policies in place, but also make these access policies clear to researchers. They note that many researchers experience

⁵⁵ Wiener and Gilliland, “Balancing between Two Goods,” 15.

⁵⁶ Sokolow, “You Want Me to Do What? Medical Librarians and the Management of Archival Collections,” 36–37.

⁵⁷ Wiener and Gilliland, “Balancing between Two Goods,” 21–22.

⁵⁸ Gustainis and Letocha, “The Practice of Privacy.”

frustration since access policies can differ from repository to repository. As part of their recommended best practices, Gustainis and Letocha call for better transparency overall. They suggest that repositories develop access review processes, apply them consistently, post them online, communicate selection and appraisal decisions as they relate to sensitive information, and provide non-identifying information about the restricted material such as record formats in the archival description so that potential researchers can better gauge if the material might be useful.⁵⁹

Gilliland and Wiener address specifically the issues of protecting sensitive information in an age where minimal processing and MPLP have become standard approaches for processing archival collections. Gilliland and Wiener propose a “sensitivity audit” that archivists would ideally perform as part of the accessioning process. They explain that this would fit into established appraisal workflows in which the archivist evaluates preservation and other potential access issues. For the first step, archivists would determine if sensitive information is likely to be included in the collection based on material types and subjects identified during the initial survey of the collection. Once the “amount and integration of sensitive material” has been roughly established by the archivist, processing plans can be devised based on results from this initial sensitivity audit.⁶⁰ According to Gilliland and Wiener, the sensitivity audit can help an archivist determine if an item level approach is necessary.⁶¹

⁵⁹ *Ibid.*

⁶⁰ Gilliland and Wiener, “A Hidden Obligation,” 27–29.

⁶¹ *Ibid.*, 30.

ARCHIVAL PROCESSING

In an article entitled “More Product, Less Process: Revamping Traditional Archival Processing,” published in the widely-read *American Archivist* journal in 2005, Greene and Meissner challenged traditional assumptions about necessary tasks associated with processing archival collections.⁶² To combat growing backlogs of unprocessed collections that they felt were made all the more unmanageable by overly laborious processing workflows and activities, Greene and Meissner introduced a new model of archival processing. Archivists refer to this as the MPLP (More Product Less Process) model. Greene and Meissner argue that archivists should adopt what is essentially a “good enough” or “golden minimum” approach to archival processing.⁶³ Essentially, archivists should do only that which is necessary to make the collection accessible for patron use. While Greene and Meissner note in passing that some extraordinary collections may be deserving of more “meticulous” processing, overall they exhort archivists to seriously examine current processing workflows and aim for the bare minimum needed to make collections open to the public. Essentially, MPLP endeavored to provide to the archives community a framework for managing and allocating processing resources.⁶⁴

Within the MPLP framework, the need to move through backlogs and make more collections accessible supersedes the call to provide detailed description and arrangement or extensive preservation actions. Meticulous description, as well as intensive preservation tasks such as removing metal fasteners or refolding, should become the

⁶² Greene and Meissner, “More Product, Less Process.”

⁶³ *Ibid.*, 254–56.

⁶⁴ Greene and Meissner, “More Product, Less Process”; Meissner and Greene, “More Application While Less Appreciation.”

exception rather than the rule for archival processing. These time consuming tasks should be undertaken only when necessary. Thus, the MPLP framework creates a trade-off between more detailed description and arrangement – as well as preservation activities – and making more collections accessible.⁶⁵

Greene and Meissner's MPLP model was not universally accepted within the archives community, but it sparked important conversation and numerous subsequent publications on the subject of archival processing and resource management.⁶⁶ Donna McCrea at the University of Montana published the results of a project aimed at reducing backlogs by adopting minimal processing standards.⁶⁷ Inspired by Greene and Meissner's call to do only that which is necessary to make a collection available for research, McCrea reports that archivists at the University of Montana were able to reach processing rates of two hours per linear foot.⁶⁸ Among the many time saving approaches to processing adopted as part of this minimal processing framework, McCrea reveals that archivists at the University of Montana began to move away from physically arranging folders and looking inside folders for contents and date ranges. With this less thorough approach, McCrea admits that it is entirely possible that sensitive materials may be overlooked since archivists do not look in every folder. However, this appears not to be

⁶⁵ Greene and Meissner, "More Product, Less Process," 240–52; Matt Gorzalski, "Minimal Processing: Its Context and Influence in the Archival Community," *Journal of Archival Organization* 6, no. 3 (October 31, 2008): 186–200, doi:10.1080/15332740802421915.

⁶⁶ Weideman, "Accessioning as Processing"; Donna E. McCrea, "Getting More for Less: Testing a New Processing Model at the University of Montana," *The American Archivist* 69, no. 2 (2006): 284–90; Gorzalski, "Minimal Processing"; Adrienne R. S. Harling, "MPLP as Intentional, Not Necessarily Minimal, Processing: The Rudolf W. Becking Collection at Humboldt State University.," *American Archivist* 77, no. 2 (Fall/Winter 2014): 489–98; Emily R. Novak Gustainis, "Processing Workflow Analysis for Special Collections: The Center for the History of Medicine, Francis A. Countway Library of Medicine as Case Study," *RBM: A Journal of Rare Books, Manuscripts, and Cultural Heritage* 13, no. 2 (October 2012): 113–28.

⁶⁷ McCrea, "Getting More for Less."

⁶⁸ *Ibid.*, 288.

an issue for the archives because it also allows researchers access to unprocessed collections.⁶⁹ Not all institutions, however, may be willing or able to make such concessions.

Similarly, Christine Weideman, director of Manuscripts and Archives at the Yale University Library, instituted what she refers to as a “minimum standards” approach to processing in order to deal with backlog issues. Influenced by Greene and Meissner’s MPLP recommendations, Weideman undertook and published a case study detailing the application of MPLP principles at the Yale University Manuscripts and Archives.⁷⁰ Weideman and archivists at the Yale Manuscripts and Archives concluded it was neither practical nor possible to process down to the item-level. In addition to adopting a “good enough,” “minimum standards” approach, Weideman discusses that archivists at the Yale Manuscripts and Archives strive to make “accessioning as processing” the goal.⁷¹ That is, as part of the accession process, collections are arranged and described following minimal processing standards in which only treatments necessary to make a collection available are applied to the collection. Thus, collections ideally never even enter the backlog, and archivists spend only an average of 25 minutes per linear foot.⁷² Weideman admits, however, that less time spent in arrangement and description shifts more of the discovery burden onto researchers, who may have to spend more time sifting through folders to find relevant materials.⁷³ This trade-off, though, succeeds in making more collections overall available for researchers to use. In implementing this approach,

⁶⁹ *Ibid.*, 287.

⁷⁰ Weideman, “Accessioning as Processing.”

⁷¹ *Ibid.*, 276.

⁷² *Ibid.*, 276–79.

⁷³ *Ibid.*, 282–83.

Weideman briefly addresses privacy issues related to sensitive materials in collections. Donors are asked to identify any sensitive materials in the collections and to define what they mean by “sensitive.”⁷⁴ Essentially, the burden of identifying sensitive materials is shifted to the donor.

Adrienne Harling claims that the broader applicability of MPLP lies in its use as a “decision-making framework” for allocating processing resources, rather than a prescriptive set of processing workflow rules.⁷⁵ She also suggests that the minimal processing examples provided in Greene and Meissner’s original MPLP article, which led many in the archives field to equate MPLP with minimal processing, were targeted at a very specific type of institution such as Yale and the University of Montana.⁷⁶ Harling notes the following:

“Greene and Meissner’s message was targeted at large, formal archives with climate-controlled storage, an unwieldy backlog of unprocessed collections, and a permanent staff of multiple archival specialists. Their description implied that those processing collections in this setting would be doing meticulous work including item-level arrangement, comprehensive preservation tasks, and well-researched and carefully written finding aids. Meanwhile, new collections would be acquired at a steady rate (adding to the already unmanageable backlog), donors would regularly inquire about why their collections were not yet available, and researchers would be unaware that the collections in the backlog existed.”⁷⁷

Not all archival institutions fit this mold. For example, reporting on a case study at the Humboldt State University (HSU) Special Collections, Harling explains that they used MPLP as a conceptual model by tailoring its guidelines to fit the specific

⁷⁴ *Ibid.*, 277.

⁷⁵ Harling, “MPLP as Intentional, Not Necessarily Minimal, Processing,” 490.

⁷⁶ For a discussion on the differences between MPLP and minimal processing and how the two became conflated, see Harling, “MPLP as Intentional, Not Necessarily Minimal, Processing,” 490–92.

⁷⁷ *Ibid.*, 490.

circumstances of the HSU Special Collections. Backlog management did not form a significant issue for archivists at HSU Special Collections. However, the lack of climate controlled storage was an important consideration, and archivists at HSU Special Collections needed to devote more resources toward preservation during processing. In Harling's case study, processing decisions were closely tied to the situational realities at HSU Special Collections. Therefore, MPLP came into play not as an inspiration for the adoption of minimal processing standards, but as a conceptual framework that kept HSU Special Collections archivists focused on their end-user needs.⁷⁸

Harling rightly identifies that Greene and Meissner left open the question of how MPLP and its message regarding resource allocation management might be adopted or adapted at other archival institutions that do not fit Greene and Meissner's textbook scenario.⁷⁹ She begins to fill in this gap by presenting a case study for HSU, which does not fit the mold of large archives with climate-controlled storage and unmanageable backlogs. However, studies are still needed to better understand how other types of repositories approach processing, especially in a post-MPLP age where archivists are critically examining their processing activities, workflows, and resource management in order to provide optimal service to their users.

In particular, studies of processing in medical archives and other institutions that regularly balance timely access with privacy concerns due to large amounts of sensitive materials are underrepresented in the literature.⁸⁰ The few notable exceptions are Gilliland and Weiner's suggestion of inserting a "sensitivity audit" to the survey phase of

⁷⁸ Harling, "MPLP as Intentional, Not Necessarily Minimal, Processing."

⁷⁹ *Ibid.*, 490.

⁸⁰ In a survey of responses to MPLP in 2008, Gorzalski concluded that studies relating to privacy in an age of MPLP and minimal processing were still needed: Gorzalski, "Minimal Processing."

processing in “A Hidden Obligation,” and Gustainis and Letocha’s suggestions in their recent article, “The Practice of Privacy.”⁸¹ In addition to investigating researchers’ information-seeking needs, Gustainis and Letocha also conducted a timing analysis to compare the time and costs for processing medically-related collections at a covered versus a non-covered entity. While Gustainis and Letocha do not specifically mention MPLP, they do, however, note the increased time it took to screen materials at the covered entity because item-level screening was employed.⁸²

Another article that specifically addresses MPLP and privacy is Meissner and Greene’s follow up to their original 2005 article. In “More Application While Less Appreciation: The Adopters and Antagonists of MPLP,” they approach privacy from a legal and ethical standpoint and ultimately conclude that the risk for archival institutions being sued due to breaches of privacy is quite low. In this assessment no mention is made of medical archives and university archives who must protect patient health information and student records, respectively, according to federal laws. Regarding the archivist’s ethical duties, Meissner and Greene further argue that archivists’ “greater ethical vulnerability may come from withholding access” to materials.⁸³ They contend that archivists have historically shouldered the unhappy burden of taking responsibility for restricting a donor’s sensitive material from researchers. Meissner and Greene advocate that archivists begin educating donors and researchers so that responsibilities relating to privacy may be shared across all three groups.⁸⁴

⁸¹ Gilliland and Wiener, “A Hidden Obligation”; Gustainis and Letocha, “The Practice of Privacy.”

⁸² Gustainis and Letocha, “The Practice of Privacy,” 168.

⁸³ Meissner and Greene, “More Application While Less Appreciation,” 204.

⁸⁴ *Ibid.*, 206–9. This approach is reminiscent of Weideman’s strategy of asking donors to identify material they deem sensitive: Weideman, “Accessioning as Processing,” 277.

This argument, however, does not seem to include archival repositories in which archivists face strong legal and ethical mandates to protect sensitive information found in their collections. Meissner and Greene do not cite studies from medical archives, university archives, or other institutions that regularly handle sensitive information that warrants protection by either legal mandate or compelling ethical codes. Can archivists in medical archives and other institutions that regularly handle collections containing sensitive, personal health information make a similar trade-off? This has not been fully explored in the flurry of responses to MPLP from the archival community. Thus, how archivists approach processing collections containing sensitive information remains an under-examined topic in the archival processing literature, especially from an empirical research standpoint.

This research study fills helps fill in this gap, contributing empirical data to better understand how practicing archivists are currently approaching processing collections containing sensitive information in order to protect privacy while also facilitating access, particularly in medical archives, health sciences collections, and history of medicine collections settings. It builds upon and takes cues from Gustainis and Letocha's recent study by turning the focus from user experiences to the experiences of the archival processors and also using Gustainis and Letocha's suggested best practices as a launching point when investigating how archivists actually go about processing to protect privacy and promote access.⁸⁵

⁸⁵ Gustainis and Letocha, "The Practice of Privacy."

METHODOLOGY

This research took the form of an exploratory study since few research studies exist in the archives field that have drawn together processing, access, and privacy, especially in medical archives, history of medicine, or health sciences settings.⁸⁶ This study examined the processing of archival collections in relation to the responsibilities held by archivists to both protect sensitive information and provide timely access. This topic was examined in-depth through qualitative methods in order to better understand the multiple facets of the issues in archivists' own words. Practicing archivists from medical center archives, health sciences collections, and history of medicine collections – all institutions that regularly deal with health information scattered throughout collections – were interviewed. The interviews focused on analog processing and did not address the processing of digital materials. Data gathered from the interviews were analyzed through a qualitative analysis of content using inductive coding.

Although much has been written on theory related to archival description and arrangement in general, this study narrowed the focus to arrangement and description in institutions that regularly face privacy and access concerns related to medical information spread throughout collections. Further, it aimed to get at the processing realities as experienced by practitioners in the field who work in institutions like medical archives that collect materials involving personal and protected health information. Since this

⁸⁶ One notable exception is Gustainis and Letocha, "The Practice of Privacy," 2015. This study builds upon their findings.

subject has been understudied, it was important to understand the multiple facets of the issues first rather than seek to generalize through quantitative methods. As such, qualitative data were sought for this study. Further, the need to tie the data to its specific context was another important consideration that led to the choice of qualitative data; medical archives and other institutions with sensitive health information found throughout their archival holdings might face different pressures and choose to adopt different practices than repositories that do not regularly deal with such sensitive information scattered amidst the collections.

RECRUITMENT

To get at processing realities, data were gathered from four practicing archivists who have had to grapple with issues related to protecting privacy while ensuring access to collections in medical archives, health sciences collections, and history of medicine collections. Purposeful rather than probabilistic sampling strategies were employed because it was important that archivists be recruited based on their ability to speak about the phenomenon under study.

Personal recruitment emails were sent out to archivists at major university medical archives, health sciences collections, and history of medicine collections (Appendix A). Participants were required to have over three years processing experience in order to ensure they would have sufficient experience to draw upon for the interviews. These recruitment emails included both institutions that were covered entities under the HIPAA law and also institutions that were not covered entities. Email addresses and contact information were taken from institution web pages and used to initially contact

three archivists who met the study criteria. Snowball sampling was also employed for recruitment in this study. All three archivists who were contacted provided the names of a total of four additional colleagues whom they felt would meet the study criteria and have useful information to contribute.

A total of seven archivists were contacted for participation in this study. Four archivists responded favorably within the time frame and received follow-up emails to set up a time to meet for the interview. This low response rate does unfortunately place some limitation on the strength of the study results. However, patterns did emerge from the four interviews conducted and some degree of saturation did occur as similar answers were given by multiple participants.

Participating archivists averaged roughly eight years of experience, with 5.5 years as the minimum and 10 years as the maximum amount of experience.⁸⁷ While the sample size is small, the average of eight years of experience held by participants is far greater than the three years stipulated in the study criteria. One archivist represented a covered entity, and three archivists worked for institutions that were not covered entities. A total of three different organizations were represented by the four archivists interviewed for this study.

Two archivists, participant 2 and participant 4, represented the same institution but held different roles within the processing workflow: one as curator (participant 2) and one as a processor supervisor (participant 4). Participant 2, the curator, was responsible for acquiring collections, meeting with donors, and communicating potential restrictions and the desired level of processing to the processing supervisor. Participant 4, the

⁸⁷ One of the participants held the role of curator rather than processing archivist, but was very active in dialogs with technical services regarding the processing of collections containing medical information.

processing supervisor, held responsibility for the actual processing of the collections, but frequently engaged in dialogs with the curator regarding the processing implications of the presence of sensitive information and curator's desired level of processing. When this processing supervisor encountered potentially sensitive information not previously discussed by the curator, they met with the curator to discuss it and, if any further questions arose regarding the sensitivity of the information, the curator had the responsibility for following up with their resources to address the sensitive information.

Participant 1 served as a special collections librarian and had duties related to reference, acquisition, and processing of rare books and manuscripts in the collection.

Participant 3 worked as the head of technical services at a covered entity. This individual was in charge of acquiring collections from donors, creating and reviewing processing plans, and processing the collection.

THE INTERVIEW PROCESS

Before conducting the interviews, permission to record the interviews was requested of the participants. It was emphasized that the audio recording of the interview was completely voluntary and that the archivists could still participate without consenting to the recording; notes would be taken if any participant declined the recording. All four participants gave permission for the interviews to be recorded. Additionally, participants were given a consent form to sign before the interview began. This form outlined the study's purpose and reiterated the voluntary nature of participation in the study.

Semi-structured interviews were conducted at the participants' home institutions. Semi-structured interviews provided flexibility to follow up on leads or questions that

might arise through the course of the interview, but also ensured enough structure to create thematic consistency across the different interviews. Additionally, since this project examines a topic that has not been extensively addressed in archival literature, there was concern that a structured interview might narrow the participants' range of potential responses, leading to an incomplete understanding of the lived experiences of archivists processing in repositories with medical-related collections. Thus, it was important to build enough flexibility into the data gathering tool so that archivists could share their particular perspectives on the issue, some of which might have been unexpected; a semi-structured interview allowed for probing questions or the reordering of questions if necessary.

A research guide was prepared with a list of general questions and topics to be covered through the course of the interviews (Appendix B). All interviews were based on this research guide. Additional follow-up and clarification questions were posed during the interviews. Participants focused their discussion on the processing of analog rather than digital materials. Based on themes brought up during the course of the interview, an additional question regarding potential access to restricted material was introduced. All interviews were recorded using a ZoomH4n recorder.

DATA ANALYSIS

A qualitative analysis of content using inductive coding was employed to analyze the data gathered from the interviews. All participants consented to having the interview recorded, so the interviews were able to be transcribed in full. The transcripts were then coded inductively, since not enough had been written on the subject to generate a set of

codes prior to data analysis. Moreover, to do so without a good understanding of the phenomenon of interest may have introduced bias to the data and potentially led to some unexpected concepts or themes becoming overlooked. After the data in the research transcripts were coded inductively, the researcher grouped the codes into four thematic categories: 1) Identifying Sensitive Information, 2) Impact on Processing Decisions, 3) Communicating Access Restrictions, and 4) Managing Access.

LIMITATIONS

Since this study involves qualitative data, the researcher ultimately serves as the research instrument. As such, there is the potential for some bias; however, all research involves a human element which can introduce bias. To increase the trustworthiness and dependability of the study, this project endeavored to employ thick description and details, as well as transparency in data collection and analysis.

Self-reporting forms another limitation associated with gathering data through interviews. Thus, this project has included data from multiple individuals, and the analysis has triangulated themes across the interviews. The small sample size and response rate also caution against generalization. As an exploratory study, this project only begins to uncover the issues of balancing privacy and timely access in medical archives, history of medicine collections, and health sciences collections. This project attempts to set a framework for better understanding this phenomenon through consulting experts in the field who daily encounter this issue. As this issue is very closely tied to the context of medical archives and other institutions that deal with ample amounts of health information or other sensitive information in their collections, the specific results from

this study should not be generalized. Rather, the findings are intended to aid archivists in transferable contexts, as well as spark discussion regarding best practices for processing and privacy.

FINDINGS

IDENTIFYING SENSITIVE INFORMATION

Participants revealed two main ways they identify sensitive information in collections: 1) conversations with donors or the archivist responsible for acquisition, and 2) manual screening by looking at the materials. In order to identify sensitive information, however, multiple archivists stressed the importance of familiarizing oneself with HIPAA identifiers, the status of the institution (*i.e.*, covered or non-covered entity), and information covered under state privacy laws. Participants also noted that once the archivist knows what types of information and identifiers could be considered potentially sensitive, medical information becomes just one of many things they look for while surveying and processing collections. As a second stage to identifying sensitive information, archivists also sometimes had to apply ethical consideration or seek expert consultation if the distinction between sensitive information and non-sensitive information was not clear-cut. However, participants revealed that, generally, figuring out whether information required access restrictions was a matter of taking the time to dig a little deeper into the material and/or engage in conversations with donors or experts. Many participants noted, in fact, that taking the time to identify and address sensitive information emerged as more of an issue than encountering grey areas regarding the sensitivity of information.

Archivists relied on conversations with either donors or the curators to give them a “heads-up” (participant 4) to the presence of potential sensitive information in a

collection. All four participants stressed the important role that conversations with donors can play in helping them identify sensitive information. One archivist explained that ongoing conversations between the donors and acquisitions archivist can play an important first step in ensuring sensitive medical information is identified and protected, especially in situations where the donor is part of a covered entity: “We also rely a lot on the donors to warn us. And, I think [if] they’re HIPAA entities and so, some of the materials that we get, they are legally obligated to remove those materials or in some way work with the curator to make sure that nothing is transferred that shouldn’t be” (participant 4). Participant 2 echoed this theme of communication with donors when collections are being acquired: “I think that [it] is on the curator to talk with the donor or person who’s giving that material to discuss.” Even when dealing with institutional and departmental records, the same participant noted that “you’re still talking to a person and getting that material and that’s the time to discuss.” Another archivist explained that “if you can work with the donors and they’re willing to take the time, then that is definitely better because they know the papers better than me” (participant 3).

Participants, however, did not solely rely on conversations with donors. They also identified sensitive information in collections through “confirmation in person” (participant 4) by looking through the collection materials during an initial survey or during the processing itself. All four participants discussed manually identifying and screening for sensitive information during processing activities. Participant 2 explained that identifying sensitive material comes down to “either working with the donor to find out which portions are restricted or have PHI or when it comes down to actually doing the processing.” When asked how they determined if a collection contained PHI or other

types of sensitive information, one archivist replied: “By looking through it, the painfully slow process of processing a collection” (participant 3). Working for a covered entity, this participant stressed the importance of taking the time for manual screening and not cutting corners to speed up the process. This archivist cautioned, “When people ask how long it takes to process, my answer is usually, ‘as long as it takes.’ And, I really don’t think it’s a good idea to cut corners with MPLP when dealing with a collection at a covered entity. You really have to set aside the time to look through the materials and identify anything that could potentially be considered PHI” (participant 3). Another archivist, this one from a non-covered entity, also mentioned the necessity of taking time to look closer at materials that set off red flags. The archivist explained the following: “Sometimes I’ve found things, and I’m like, ‘ooh, this kind of has red flags on it.’ And then when we look at it closer... it’s not really a problem. But if you start seeing things that – names, identifiers that look like they could be patient numbers or patient record numbers – those are things to take a closer look at” (participant 1).

Knowledge of HIPAA identifiers and other types of sensitive information emerged as another important component of identifying sensitive information. In order to identify sensitive information in collections, archivists need to have the background knowledge that will enable them to pick it out in a collection. When questioned regarding what advice they would give to someone who is new or starting a position processing medical or health sciences collections, all four participants mentioned in their responses some variation on the theme of the importance of knowing what is considered sensitive and what laws hold sway over materials in their collections. Regarding background knowledge that aids in identifying sensitive information, participant 1 advised, “Know if

you're part of a covered entity. Know how to identify sensitive information, whether something falls under HIPAA or not." This archivist also pointed out that HIPAA is not the only privacy law that governs what sort of information needs to be restricted. They noted that "even if you're not covered by HIPAA, which is a federal law, knowing [sic] what you need to look for as far as state laws are concerned." Participant 3 provided a similar response: "Make sure that you're very clear on HIPAA... Find the law, read it, keep it close. Revisit it if you need to. Spend some time learning what PHI is and the different forms of PHI identifiers." Another participant noted that "being aware of what sensitive information needs to be segregated and restricted" (participant 2) is also necessary so that processing archivists can clearly restrict and communicate these restrictions with researchers and reference archivists. Even participants from non-covered entities communicated a commitment to identify and protect sensitive medical information. One participant explained that "being familiar with HIPAA and the types of information that we need to at least be aware of has been really useful to me" and that this is something they make sure to cover with new staff (participant 4). Even though this participant did not work at a covered entity, the archivist explained that ethically they felt "responsible for the privacy and stewardship of these records."

Two of the participants reported that screening for medically sensitive materials or PHI identifiers forms part of a broader survey. Once the archivist knows what to look for, medically sensitive information becomes just one of a number of other red flags they seek alongside financially sensitive materials, preservation concerns, Social Security Numbers, bugs, mold, etc. According to one participant, medically sensitive information "is one of many things that we're looking for" (participant 4). Participant 4 explained that

in the initial survey “we are always looking for not just medically sensitive materials but financially sensitive materials, preservation concerns, mold, bugs, and like all that kind of red flag sort of materials.” The archivist from the covered entity described a similar approach to the survey: “In that survey I would look for possible restrictions, as well as types of formats and size and how I’ll house them, as well as just the content and the context of the records” (participant 3). A third participant mentioned medically sensitive information as one of many things to look for within the context of processing, explaining that Social Security Numbers and information covered under state privacy laws also need to be considered when identifying sensitive information; it is not just medical information covered under HIPAA that archivists need to watch out for when processing (participant 1).

Archivists in this study were able to determine what was sensitive from a legal standpoint through consulting with subject matter experts if they were uncertain whether the information identified was actually of a sensitive nature. All four participants reported that they sought expert consultation of some form when they came across information that fell into a grey area. Two of the participants from non-covered entities mentioned consulting with their institution’s scholarly communications officer. One of them noted that they consult with the scholarly communications officer both when acquiring collections that may contain sensitive information and also when they are unsure if certain materials may be considered sensitive. This participant explained, “we have a scholarly communications officer here in [institution’s name], and we’ve consulted with that person as we move forward in determining whether a collection is a good fit and, if it is, some of the challenges that are posed” (participant 2). Regarding any cases where the

archivist is unsure about the sensitivity of materials, this same participant replied, “in those instances we meet with our scholarly communications officer just to make sure that we aren’t putting individuals, donors, or people in the collection in any type of precarious position, but also to make sure that we are not getting [institution’s name] into any type of potential legal situation” (participant 2). Participant 1 also echoed the importance of the scholarly communications librarian as a resource, claiming that when they notice potentially sensitive information, “I will typically consult with our scholarly communications librarian... We’ll talk about what’s the potential problem, and how should we potentially deal with it.” One of the archivists, also from a non-covered entity, reported that they rely on expert consultation in the form of dialogs with the curator: “I tend to just work with the curator... and if [they are] concerned, [they] typically work it out with [their] resources before [they] bring the materials to me” (participant 4). This curator was also interviewed for this study and was one of the two participants who cited the scholarly communications officer/librarian as a resource. Additionally, participant 2 also cited the university council – essentially another legal team – as another resource. The last participant, who represented a covered entity, turned to a subject matter expert on HIPAA for guidance: “I can email [name] and ask [them] how to handle it, and [they are] very good about getting back to us quickly” (participant 3). This same archivist emphasized the importance of having “a specialist, a subject matter expert” when later questioned regarding advice for new processors.

The archivists interviewed in this study also applied ethical considerations to guide their decision-making when they encountered information did not fall under privacy legislation, but still could potentially be identified as sensitive. Even the

participant from the covered entity acknowledged the ethical reason for wanting to protect an individual's medical information: "Obviously, I don't want to do something illegal, and I also don't want to be responsible for letting someone's personal information be made public because that's not what I would want to happen with my information and I want to ethically treat everyone the same way" (participant 3). This theme of ethical considerations was also repeated by the three participants from the non-covered entities. Although they were not legally required to protect this information to the same extent and were not subject to the same legal penalties as the archivist at the covered entity, they still discussed protecting medical information as an ethical duty. As participant 2 explained, "since we are not a covered entity, we are not legally bound by HIPAA, but ethically we want to make sure that we follow the ethical guidelines and do not present sensitive information or share information that falls under HIPAA guidelines." One explained it as a sense of stewardship, claiming that they felt "responsible for the privacy and the stewardship of these records" even though they did not have the same legal obligation as covered entities did (participant 4). Another archivist discussed the questions they consider when trying to balance privacy and the greater good: "You just have to weigh, you know, what is this? What's the greater good here? What's in the gift agreement from the donor? Do you think this is something that the donor gave to you and didn't realize it was in there, and they wouldn't have given it to you had they realized it was there?"

When speaking about nineteenth century collections that contained medically sensitive information, one archivist emphasized still an awareness and sensitivity to issues of third party privacy even if the material is not of the nature to be restricted. This participant also cited an awareness of privacy concerns with twentieth century materials like the records

of abortion providers: “We just have so many collections for groups like abortion providers and physicians where it’s not HIPAA covered but we’re just very thoughtful about people’s privacy. It’s not necessarily even medically sensitive, but the idea that somebody could eventually dig into these and cause harm to somebody in this collection is really in the forefront of our minds” (participant 4). This same participant also revealed that considering the reasons behind HIPAA and other privacy laws helps them make “thoughtful decisions” about information to worry about in collections.

Respondents communicated that it was sometimes also a matter of taking time to investigate farther to determine whether information was of a sensitive nature. Three of the participants discussed this in terms of delving deeper into the material itself and handling the restrictions during processing. Participant 1 explained, “you start looking through and then if something catches a red flag, then you delve deeper down to make sure.” Working at a covered entity, another archivist emphasized that “you really have to set aside the time to look through the materials and identify anything that could potentially be considered PHI” (participant 3). This was the same archivist who revealed that they were hesitant to use MPLP methods to “cut corners” at a covered entity. The fourth participant mentioned taking the time for dialogs between processors, curators, and experts like the scholarly communications officer or university council. This participant also cited that they take time to “delve into the collection control file” to see more about the nature of restrictions, often when dealing with legacy collections (participant 2).

Interestingly, some archivists revealed that taking the time to identify and deal with restrictions can form more of a challenge or issue than the act of determining the sensitivity of materials. This was explicitly stated by the participant from the covered

entity: “I’d say for the most part, I know what needs to be restricted or not restricted. It’s the time, the going through and having the time to identify all the restrictions” (participant 3). This participant claimed that correspondence formed an especially time consuming problem because at their institution a lot of HIPAA-related information tended to be buried in correspondence. What emerged as an issue was putting in the resources (time and material costs) to deal with the restrictions not necessarily the act of trying to determine if information needed to be restricted or not. Reflecting this notion, when questioned about thought processes they go through when determining if information is sensitive, one archivist replied: “I can’t think of a specific scenario because we really rely on the expert, the lawyer, to advise” (participant 2). Although this participant acknowledged that sometimes there were cases in which they were unsure if materials were considered sensitive, they noted that they sought expert advice in these situations. Another archivist revealed that determining the sensitivity of materials fell more under the curator’s job duties. Their job was to bring it to the curator’s attention and discuss the processing implications of handling the potentially sensitive materials: “I see it as my role to alert the curator that this is here and to inform [them] that here are the workflow implications if we decided to retain these things because there can be an immense time challenge and materials costs to actively restricting and redacting things” (participant 4).

Two archivists emphasized that the real issue was striking a balance between devoting enough time to locate sensitive material and not spending so much time that one becomes paralyzed. They acknowledged the need to spend extra time, but, in the words of one participant, new staff “can become paralyzed in looking at every sheet of paper to

see if it has Social Security Numbers, student records, [institution's name] university restrictions, medical restrictions," etc. (participant 4). Another participant reiterated this notion: "It's not possible to read every document when you're processing. Well, it is, but then you never finish" (participant 3). Participant 4 claimed that approaching processing "at a higher level and thinking about: well, where are these things most likely to be?" helps them when processing large collections that may contain sensitive information. Both archivists stated that this ability to balance the two extremes comes with experience gained through processing.

IMPACT ON PROCESSING DECISIONS

Participants reported a variety of ways in which the appearance of sensitive information made an impact on processing decisions. While the identification of sensitive information did not fundamentally change archivists' general processing workflows, it impacted the description, processing time, processing activities, and even appraisal considerations.

Two of the archivists noted the extra time and resource commitment that accompanies sensitive information found in collections. The participant from the covered entity stated that "I have to go ahead and allot more time to processing the collection than I would if I was working just in an academic library because... there's monetary penalties that are much higher" (participant 3).⁸⁸ The other participant discussed this time commitment in terms of appraisal considerations, explaining that "part of the process is to identify it [sensitive information] in the collection and then think about what it is adding

⁸⁸ This participant also cited ethical reasons as a factor for this extra allotted time.

to the collection and is it worth retaining” (participant 4). This archivist noted that there are material costs and time costs to redacting and restricting sensitive information in collections and “if we’re going to take those steps, then we want to make sure that it’s for a good reason.”

Another archivist responded that sensitive information impacts processing activities because they have to think about strategies for handling the restrictions and managing access: “we just think of strategies for how can we make this accessible?” (participant 1). For this archivist, these activities also included restricting folders or series and meeting with the scholarly communications officer to discuss access and determine the sensitivity of the information.

Interestingly, one archivist explained that sensitive information affected finding aid description. While all four participants reported using the finding aid to communicate access restrictions, this participant explained: “We have a lot of nineteenth century collections that are full of people’s names and how they died and what they were treated for... Anyone can come and use these materials, but the description that we create for those files might be different than they would be for somebody’s schooling or their writings or something else... If it’s anything pre-twentieth century, I would say it’s open for business but the description might vary depending on what kind of material it is because we’re trying to be thoughtful” (participant 4). This archivist also reported that they will not list patient names or that kind of information in the description on the internet, even if the materials are open for research.

COMMUNICATING ACCESS RESTRICTIONS

Participants cited the importance of communicating access restrictions both internally within the institution and externally to potential researchers. Participants revealed a number of methods for conveying access restrictions internally, but all stated that the finding aid was the primary way of communicating access restrictions externally to researchers. Archivists strove to communicate this information consistently and clearly.

When processing, archivists communicated access restrictions internally in a variety of ways. One archivist discussed physically identifying the information during the course of processing through inserted paper tabs that served as “a kind of visual note to me that says, ‘This material is restricted’” (participant 3). In addition to visually marking restrictions, this archivist typed up restrictions into an excel sheet to keep track of them. They also segregated the restricted materials into a separate series or they followed whatever convention had been used prior for restrictions if the materials were additions to an existing collection.

In fact, three archivists in this study reported that physically segregating the restricted materials was the ideal. As another participant noted, this communicated the restrictions more clearly and provided the institution with better holdings management. This archivist explained: “I would say we’ve done it every possible way that you can think of, but what we’re trying to do consistently now is to physically remove files that are restricted not necessarily intellectually, so they might still be listed in whatever series or wherever they might fall. But to make it easier to flag them, we are trying to have at least a section of a box or a whole box that is those restricted materials and so that way

we can have better holdings management of the files that are restricted” (participant 4). The archivist from the covered entity also discussed physically separating material but keeping it intellectually together. This archivist ideally tended to “identify the restricted material and put it in a restricted folder” (participant 3) which would then be placed in a restricted series. The files were intellectually linked by this archivist “giving them the same names so that somebody can easily trace back where it came from” (participant 3). The word “restricted” was also written on the folder.

Two archivists mentioned striving for better consistency in processing. One discussed this in terms of moving towards physically segregating restricted materials, as mentioned earlier. The other talked about consistency in terms of handling restrictions for additions. While this archivist preferred to physically segregate restricted material into its own folders and series, they reported that if it were additions to a collection that had previously been processed, they “would attempt to follow that model to make it coherent” (participant 3). By that model, the participant mainly referred to the previously used local practice of using a red dot on a folder to indicate the presence of restricted the materials. This red dot would alert the reference archivist to the presence of sensitive material, and the reference archivist would then screen the folder before providing a researcher with access to its contents.

Another participant noted that they used ArchivesSpace, a content management system, to communicate any potential restrictions to the archivists in technical services. Using ArchivesSpace, this participant emphasized that they had “a role of communicating what should be restricted, for how long, what type of sensitive information it is, and how/at what level the collection should be processed” (participant 2). Once the collection

is processed by technical services, information about the restrictions and the length of time for the restrictions is communicated to others by the finding aid and the collection control file.

Participant 1 mentioned only that restrictions are communicated through folders or series marked as restricted and that this information is primarily communicated to the public and others through the finding aid at either the folder or series level. This archivist was not from a covered entity and noted that they were also the one in charge of providing access.

To communicate access restrictions with the public, all four participants mainly relied on description and access restriction notes in the published finding aids. In the finding aid, one archivist discussed that they “try and have the restriction fall at every level where it belongs. So if it’s one file that’s restricted, it would be listed at the file but then also at the series and at the collection level so that wherever you land, hopefully you will know that there is a portion of this collection that’s restricted and how to find those things” (participant 4). This aids users who may come across the finding aid via the internet and access the finding aid at levels below the initial collection level description. Participant 2 stressed the desire to include the date for the restriction to be lifted in the finding aid.

In processing collections containing sensitive information, archivists strove to clearly communicate restrictions for the reference archivist, patrons, or others who might view the collection down the road. Without clear communication and segregation of restrictions, one archivist noted that the onus for identifying sensitive information would fall to the reference archivist and could be like “finding a needle in a haystack”

(participant 3). This archivist emphasized the importance of clear communication, claiming “I think the best way to handle restrictions is to deal with it on the front end, so that someone down the road like the reference archivist doesn’t have to deal with it at kind of an ad hoc basis” (participant 3). Another participant noted that at their institution they were striving for more consistency and transparency in communication: “A lot of our older collections will just say, “Access restricted,” and you’re going to have to find out for what reason and for how long... But we’re definitely moving towards having more transparency about what the restriction actually is and when it is lifted” (participant 4). Another participant from this same institution echoed this need to clearly communicate restrictions and their length, claiming, “we in the [institution’s name] feel that it’s important to have a date when the restriction is lifted for future researchers and future staff, and that that is communicated in the finding aid as well as the collection control file so that it’s very clear about what is restricted and when that restriction could be lifted” (participant 2).

Multiple archivists also iterated the importance of different positions within the archive all working together to achieve clear, consistent communication regarding sensitive materials and access restrictions. Two mentioned the importance of reference archivists communicating to the researchers, either orally or through a written form, their responsibilities to protect and not publish sensitive information. A third archivist mentioned that sometimes they have had researchers come to staff in the reading room and “bring material to our attention questioning, ‘should this material be restricted or not?’” (participant 2). This same participant emphasized the importance of all positions working together to protect privacy and effectively communicate access restrictions,

describing it as having in place “a workflow on both ends about how to handle materials with sensitive information.” When asked to elaborate on what they meant by “both ends,” the archivist replied: “If you’re bringing in collections, that’s sort of the first step in determining what could potentially be sensitive... and being aware of what sensitive information needs to be segregated and restricted, but with a time limit so that that is very well communicated at the time the collection is received and that can be communicated to the processing folks and that that can be communicated to research services, so it’s sort of all working together” (participant 2). These archivists thus cited reference archivists and the archivists involved in acquisition as important components in identifying and effectively communicating access restrictions on sensitive materials.

MANAGING ACCESS

Participants revealed a wide range of users who sought access to their collections. Participants 1, 2, and 4 listed students and faculty as their main users. These same three participants also mentioned various types of academic scholars including historians in medicine, social history historians, faculty researchers, women’s history researchers, public health researchers, and others investigating trends in public health. Participant 3 categorized users only as either outside researchers or individuals connected with the institution.

Academic scholars and students, however, were not the only types of researchers whom participants reported as users of their collections. One archivist mentioned that their users included genealogists and “private people coming because they are interested in collections” (participant 4). This archivist revealed that “it’s not just the historians”

who use their materials. The participant from the covered entity remarked that although they do get outside researchers, “the vast majority are somehow affiliated with [their institution’s name]” (participant 3). Reflecting the wide range of users, one participant explained the following: “We aren’t necessarily processing our collections with one researcher in mind. We want to describe them in the way that best portrays the content of the collection, and then hopefully whoever comes in to use them can get to them in that way” (participant 4).⁸⁹

When researchers did come in to use the collections, two archivists discussed having the reference archivist inform researchers of their responsibility to protect privacy in case they come across anything sensitive in the collections that may have escaped the notice of the processing archivist. As multiple archivists revealed, there is the possibility that the processing archivist may not be able to catch everything, especially with large collections. According to participant 3, this communication took the form of having the reference archivist verbally speak with patrons about this responsibility when they are going over the copyright notice if material may potentially be published: “If it’s a collection with 70 boxes, chances are you might miss some PHI. And so, I think it’s really good that then when the reference archivist talks to the researcher, if a researcher is going to come and use the collection, that the reference archivist also explains to them... ‘if you come across any of this information, this is not to be made public. Let us know’” (participant 3). Another archivist provided researchers with an extra form to sign. When researchers requested any collections that potentially contained sensitive information, they were required to sign an extra statement about sensitive materials, which was created

⁸⁹ The other three participants did not discuss finding aid description in connection with their users.

in consultation with the scholarly communications librarian, as part of the user agreement. In it, “researchers are advised that the disclosure of certain information pertaining to identifiable individuals without the consent of those individuals may have legal ramifications... if facts concerning an individual’s private life are published that would be deemed highly offensive to a reasonable person” (participant 1).

Two archivists also mentioned an access review process to enable researchers to gain access to sensitive materials. One archivist lamented the fact that their institution did not have an “official avenue for people [to] use sensitive information” (participant 1) the way that some other institutions did. This archivist noted that other institutions have an IRB board or a privacy board that can grant approval to researchers, but their institution lacked this sort of official mechanism. Another participant discussed ongoing efforts to set up a more consistent, formalized access review process. The archivist explained that a task force had been formed “to discuss sensitive issues so that there would be a formal process for people to be able to request restricted material on a case by case basis” (participant 2). The goal was to be more consistent and “have a policy in place that mirrors IRB but is not as intense or rigorous for a person to go through, since we are not a covered entity.” Although the access review process is still in development, the participant revealed that the goal is to have a form that researchers could access and then have a committee that would review the applications or forms.

All four participants revealed that they allowed researchers to access unprocessed collections, but it was very much a case by case decision. Archivists cited a variety of factors that played into these decisions. One archivist noted that the decision depended on the nature of the restrictions added to the collection. Another archivist stated that if the

collection is “pretty small” and if they are “working with someone closely,” then they “don’t have a problem going through it with them” (participant 1). Another participant discussed that they do have unprocessed collections that are open for research, but the “description should be upfront about the fact that some parts of the collection might then be closed... there’s sometimes sensitive things that we haven’t been able to remove or we’re just going to restrict in bulk” (participant 4). Two of the archivists also listed situations in which access to unprocessed collections would not be granted. Participant 2 cited large collections that were newly acquired, but also mentioned that such collections would not necessarily be locatable through the finding aid. Another listed collections that had been sent to storage to be scheduled, usually because “their condition is pretty bad and we can’t guarantee that there isn’t sensitive material in there” (participant 4).

In discussing access to unprocessed collections, the archivist from the covered entity reiterated the theme of everyone working together to protect sensitive information. This archivist strove to clearly designate sensitive materials even during basic accession activities so that the burden did not fall solely on the reference archivist: “it requires more work, then, for the reference archivist when we do that [allow access to unprocessed collections] because then more of the onus is on [the reference archivist] to identify the materials that need to be restricted, which is why since I’ve started here I’ve tried really hard, when we get an accession, to do a baseline accession level processing where if we do notice anything is restricted, I try to segregate that or at least make it very clear what’s restricted when the accession comes in” (participant 3).

When considering unprocessed versus processed collections, multiple participants noted that this can be “a tricky distinction” (participant 4). Two participants mentioned

that collections are processed to the level they need to be, and processed versus unprocessed can mean different things to different people. Indeed, in noting that they try to identify sensitive materials to help out the reference archivist during the initial accession, participant 3 claimed that for some collections, the accession is “as much work that’s going to happen to the collection.” Still another participant also noted that some legacy collections are considered “closed” due to being unprocessed, but it turns out that they are more under-processed than actually unprocessed.

DISCUSSION

The findings from this study better illustrate how practicing archivists out in the field approach processing analog materials at institutions with collections containing sensitive medical information spread amidst the materials. The four archivists interviewed from medical center archives, history of medicine, or health sciences collections employed primarily a two-pronged approach to identifying sensitive information. They consulted with donors, but also manually looked through the collection when surveying and processing. These two methods for identifying sensitive information reflect two of the four models identified by Danielson for how archivists balance privacy and access concerns: shifting the burden to donors and researchers, and active screening by archives staff members.⁹⁰ Archivists in this study tended to blend these approaches rather than relying solely on one method to identify restrictions.

When archivists actively screened for sensitive information, medically-sensitive information emerged as just one of many things that the archivists sought in their initial survey or during processing. Archivists kept an eye out for PHI alongside other types of sensitive information like financial information or Social Security Numbers, as well as oversized materials, materials with preservation issues, etc. This screening for sensitive material during the survey, especially if the archivist had been forewarned by donors about its potential presence, reassembles a less formalized version of Gilliland and

⁹⁰ Danielson, *The Ethical Archivist*, 209–14.

Weiner's sensitivity audit.⁹¹ The participants discussed that sensitive information identified during this initial survey would be taken into account when developing processing plans and the level of processing needed. The archivist from the covered entity especially noted that the presence of sensitive information required them to allot more processing time.

The findings thus support Gustainis and Letocha's observation that while processing costs were the same for covered and non-covered entities, identifying sensitive information in a covered entity carried a greater time cost.⁹² While another archivist in this study did discuss the time and resource commitment for redacting or restricting sensitive information, it was the archivist from the covered entity who was the most vocal about the time commitment required to identify and address sensitive information. This archivist noted that they allot more time for processing collections at the covered entity than they did when working in just an academic library. This was both because of the legal penalties and the ethical awareness that they were dealing with people's sensitive medical information. Like the item level screening performed at Hopkins that greatly contributed to processing time in Gustainis and Letocha's time analysis, the archivist from the covered entity discussed the need to "really set aside the time to look through the materials and identify anything that could be considered PHI" (participant 3). Other archivists cited an awareness and commitment to identifying and protecting sensitive information, but not quite to the same degree as the archivist interviewed from the covered entity who cautioned against "cut[ting] corners with MPLP when dealing with a collection at a covered entity." Instead, this participant emphasized

⁹¹ Gilliland and Wiener, "A Hidden Obligation," 27–29.

⁹² Gustainis and Letocha, "The Practice of Privacy," 167–68.

the need to “allot more time” and really go through the materials to identify potential PHI. Based on these findings and the observations by Gustainis and Letocha in their time analysis, the necessity of taking the extra time to screen, identify, and address restrictions at covered entities suggests that a strict interpretation of MPLP is likely not compatible with processing demands at a covered entity.⁹³

Thus, time costs emerged as a real issue related to processing collections containing sensitive information. It was not that archivists struggled to understand the applicable laws – they had resources they could consult. Rather, participants discussed that it was more the time it takes to screen for, identify, and either redact or restrict the material that caused a problem. This theme was especially prominent in the interview from the archivist at the covered entity.

The responses from participants also suggest that it can be a matter of finding balance when processing collections containing sensitive information. Archivists cautioned against spending so little time (i.e., cutting corners with MPLP according to one archivist) that you miss lots of hidden materials, but at the same time they warned against working at a such slow rate that one becomes paralyzed looking through every sheet of paper, thus preventing material from actually getting processed. Finding this balance and learning to process at a higher level, considering “where are these things likely to be” (participant 4) rather than looking at every sheet of paper, are skills that participants noted came with experience processing.

⁹³ *Ibid.*

The findings also reinforce arguments that protecting privacy is both the archivist's legal and ethical responsibility.⁹⁴ The archivists sought expert consultation for clarity on their legal responsibilities and stressed the importance of knowing one's resources when starting a new processing position at an institution that collects medical materials. This supports claims regarding the importance of legal consultation.⁹⁵ The participants did not speak about privacy purely from a legal perspective, however. They also readily acknowledged their ethical duty to protect privacy, especially in cases involving the concept of third party privacy.⁹⁶ Some archivists also discussed their ethical responsibilities in terms of Sillitoe's harm test.⁹⁷ The archivist from the covered entity also emphasized that in addition to legal concerns, they did not want to be responsible for "letting someone's personal information be made public because that's not what I would want to happen with my information" (participant 3). Overall, the participants conveyed a commitment and awareness of respecting privacy in situations where information might be particularly sensitive. For example, one archivist mentioned being very thoughtful about description for nineteenth century collections that contained information on individuals and how they died. Although the collection was open for research, this archivist was thoughtful in how this personal information was presented in the finding aid description and what information was available for viewing on the internet.

⁹⁴ Bingo, "Of Provenance and Privacy"; Benedict, *Ethics and the Archival Profession*; Danielson, *The Ethical Archivist*; Ketelaar, "The Right to Know, the Right to Forget?"; Sillitoe, "Privacy in a Public Place."

⁹⁵ Wiener and Gilliland, "Balancing Between Two Goods"; Gilliland and Wiener, "A Hidden Obligation"; Sokolow, "You Want Me to Do What?"; Gustainis and Letocha, "The Practice of Privacy."

⁹⁶ Bingo, "Of Provenance and Privacy"; Danielson, *The Ethical Archivist*; Benedict, *Ethics and the Archival Profession*; Ketelaar, "The Right to Know, the Right to Forget?"

⁹⁷ Sillitoe, "Privacy in a Public Place," 9–10.

The theme of clear documentation to facilitate communication of access restrictions both internally and externally also emerged from the interviews. Participants revealed multiple ways for communicating access restrictions during processing, but they shared the theme of striving to achieve greater consistency and clarity in communication. Once sensitive information was located, most participants ideally tried to physically separate it but intellectually keep it linked with its associated materials. Finding aid description also played an important role in externally communicating access restrictions to researchers. One archivist specifically mentioned listing the access restriction at each level of the hierarchical description that it falls. This reflects one of the suggestions offered by Gustainis and Letocha in their recommended best practices to facilitate access. They argue that researchers can experience confusion and frustration regarding restrictions due to unclear description and access policies that differ from institution to institution. As one way to combat this, Gustainis and Letocha therefore recommend that archivists clearly indicate to researchers if the folders or series that may be of interest contains restrictions.⁹⁸

The interviews revealed that the archivists were actually engaging in several of the best practices put forth by Gustainis and Letocha in their “Recommended Practices for Enabling Access to Manuscript and Archival Collections Containing Health Information about Individuals.”⁹⁹ Participants sought legal counsel in the form of HIPAA experts or scholarly communications officers in order to address their legal responsibilities in protecting privacy. They also acknowledged that other laws such as state medical records and other privacy legislation also governed access policies.

⁹⁸ Gustainis and Letocha, “The Practice of Privacy,” 175.

⁹⁹ *Ibid.*, 173.

Additionally, two researchers mentioned the importance of IRB or privacy boards to facilitate consistent, clear access to sensitive materials that could be communicated to researchers. Another recommended best practice that emerged from the interviews is that even archivists from non-covered entities felt it was important for staff to be able to recognize the types of sensitive information covered under HIPAA. One archivist even stated that knowledge of this information helped them to make more thoughtful decisions: “Even if you are not working for an institution that is a covered entity, that recognizing the reasoning behind those laws can be really useful and helps me make, I hope, thoughtful decisions about what kinds of records I need to worry about” (participant 4). Archivists need to know how and what to identify as sensitive information in order to protect it, a fact most participants stressed when sharing advice that they would give to new processors.

Participants also shed light on the users of collections that contain medical information. Some groups listed by the participants such as the academic researchers, social scientists interested in trends in public health, and historians – social historians and researchers on history of medicine topics – are the same as those already identified by Baur et al. and Guistainis and Letocha.¹⁰⁰ The interviewed archivists, however, also brought attention to non-academic users of their collections, namely genealogists and private individuals interested in the collections. These form other groups for archivists to keep in mind when designing access review processes.

¹⁰⁰ Baur, Draisey, and Melling, “Public Policy and Patient Privacy”; Guistainis and Letocha, “The Practice of Privacy.”

Three of the four models presented by Danielson for how archivists manage privacy and access concerns were represented in some form by participants' responses.¹⁰¹ These four approaches consist of 1) archivists actively screening collections, 2) shifting the responsibility of identifying sensitive information to others, 3) controlling the information use by an access review board, generally an IRB, and 4) "responding to complaints on a case-by-case basis... shifting responsibility to the data subject."¹⁰² Participants' responses reflected the first three of Danielson's models. None discussed Danielson's fourth approach in which responsibility is transferred to the data subject, perhaps because much of the sensitive medical information also involved issues of third party privacy.

Archivists actively screened for sensitive information, they shifted some responsibility onto donors and researchers, and also discussed access to sensitive materials mediated through some sort of access review board. Although Danielson specifically mentions an IRB board when discussing access review approaches, the two archivists in this study who mentioned the benefits of an access review board were not covered entities. They discussed the subject more in terms of an access review committee or board to facilitate access to sensitive information and create greater consistency in access. One archivist explained that their access review committee was intended to mirror an IRB, but with a less "intense or rigorous" process for researchers to undertake to gain access (participant 2). This access review committee would thus function similarly to the IRB board mentioned by Danielson. The three approaches used by participants in this

¹⁰¹ Danielson, *The Ethical Archivist*, 209–14.

¹⁰² The fourth approach in which archivists deal with privacy complaints on a case-by-case basis is noted by Danielson as an "emerging default mode" employed by archivists: *Ibid.*

study did not necessarily emerge as exclusive categories. Most archivists reported that they not only actively kept on the lookout for sensitive materials during processing but also consulted with donors and informed researchers of their responsibilities, in effect shifting some of the responsibility to these groups.

Rather than fully shifting responsibility, however, this study's findings suggest that privacy is best protected when it becomes a shared commitment and a shared responsibility between all groups involved. Greene and Meissner advocate placing more of the burden on donors and researchers with their MPLP model.¹⁰³ While these findings do support the involvement of researchers and donors in protecting privacy, effective protection of sensitive information emerges more as a shared responsibility through clear communication between all groups rather than something to be passed on from one group to another.¹⁰⁴ As one archivist explained it, "if you're bringing in collections, that's sort of the first step in determining what could potentially be sensitive...and at the same time being aware of what sensitive information needs to be segregated and restricted, but with a time limit so that that is very *well communicated* at the time the collection is received and that can be *communicated* to the processing folks and that that can be *communicated* to research services, so it's sort of *all working together*" [emphasis added] (participant 2).

Talking with donors about sensitive materials found in collections is an important first step, but communication doesn't stop there. Processors do their best to physically segregate material that needs to be restricted and to clearly communicate this information to outside researchers and internal research services archivists. Yet, as participants

¹⁰³ Meissner and Greene, "More Application While Less Appreciation," 204–9.

¹⁰⁴ At a covered entity, the archivists are ultimately responsible for ensuring that PHI is not made available. However, efforts between donors, archivists, and researchers to protect sensitive information can help ensure that sensitive material is not inadvertently disclosed.

revealed, it can be difficult to catch every bit of PHI or sensitive information, especially if it is hidden in correspondence or if the archivist is processing a large collection.

Informing researchers of their responsibilities regarding privacy can help in case something slips through the cracks. Researchers also have a responsibility to ensure they do not publish or disclose sensitive information they may inadvertently come across in collections. The findings from this study suggest that ultimately the processor stands as just one component of a wider system in which access restrictions and responsibilities are clearly communicated among all groups involved.

CONCLUSIONS AND FUTURE RESEARCH

Multiple archivists contacted for this study were unable to participate within the time confines of the study. This research therefore contains a small sample size. Based on the small sample size and exploratory nature of this study, the research findings should not be generalized. Additionally, since only one respondent from a covered entity agreed to participate in this study, one cannot assume that this individual's responses represent the experiences for all institutions that are covered entities. Instead, this study has begun to explore the processing issues recently brought up in Gustainis and Letocha's 2015 study. The institutions examined in this study were different than those compared in Gustainis and Letocha's processing labor and time analysis.¹⁰⁵ The results thus better illuminate how archivists out in the field are addressing privacy and access concerns in their processing; however, the results should be considered more in terms of their transferability to similar situations rather than their generalizability.

Future research could seek more quantitative data regarding how practicing archivists process collections in institutions with collections containing medically-sensitive materials and information. Using the findings from this study and Gustainis and Letocha's suggested best practices, institutions could be surveyed to produce more generalizable data regarding processing practices to protect privacy. Further research could also be conducted examining trends, patterns, and/or differences between processing at covered entities versus non-covered entities. Additionally, as this study

¹⁰⁵ Gustainis and Letocha, "The Practice of Privacy."

only investigated the processing of analog materials, future studies could examine the digital component of processing collections containing potential sensitive medical information. Finally, the scope of the study could also be expanded to consider how repositories address privacy concerns in general, not just those related to medical collections. It would be interesting to see how the responsibility for protecting sensitive information is divided at other institutions that do not house medically-sensitive information. Is there still this shared commitment and awareness that the participants from the medical, health sciences, and history of medicine collections discussed?

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APPENDIX A

PERSONALIZED E-MAIL CONTACT TEMPLATE (SNOWBALL SAMPLING)

Dear [individual's name and title],

My name is Alexandra Dowrey, and I am a master's student in UNC at Chapel Hill's Library and Information Science program. For my master's paper, I am doing a research study on archival processing in medical archives and health sciences collections. Specifically, I am examining how archivists in these institutions process collections that may contain sensitive information.

I spoke with [individual's name] regarding my topic, and he/she mentioned that you would be a good person to speak with regarding my research. I am conducting an exploratory study and am seeking to interview archivists with over three years of experience who work with processing collections in either medical archives or with health sciences/history of medicine collections.

If you would be interested in participating in my study, I would greatly appreciate the chance to interview you and hear your insight regarding this subject.

My study has been approved by the IRB, and I am happy to answer any questions you might have regarding my research project. If you are willing to participate in my study or have questions, I can be reached at [email address]

Thank you very much for your time.

PERSONALIZED E-MAIL CONTACT TEMPLATE (Without snowball sampling)

Dear [individual's name and title],

My name is Alexandra Dowrey, and I am a master's student in UNC at Chapel Hill's Library and Information Science program. For my master's paper, I am doing a research study on archival processing in medical archives and health sciences collections. Specifically, I am examining how archivists in these institutions process collections that may contain sensitive information.

I came across your name while perusing the [archive name] website and saw that your institution collects materials related to [specific medical center/history of medicine/health sciences collection]. I am conducting an exploratory study and am seeking to interview archivists with over three years of experience who work with processing collections in either medical archives or with health sciences/history of medicine collections. If you feel

that you would be able to speak about this topic, I would greatly appreciate the chance to interview you and hear your insight regarding this subject.

My study has been approved by the IRB, and I am happy to answer any questions you might have regarding my research project. If you are willing to participate in my study or have questions, I can be reached at [email address]

Thank you very much for your time.

APPENDIX B

INTERVIEW GUIDE

1. Could you walk me through the general process/workflow of how you approach processing collections at your institution?
2. How do you determine if a collection contains PHI or other sensitive information?
3. How does the appearance of PHI or other sensitive information impact your processing decisions, if it does at all?
 - a. How so?
 - b. OR, how does your usual approach to processing account for dealing with PHI and other sensitive information?
4. Who are your users?
5. Do you allow access to unprocessed collections? Why or why not?
6. How do you communicate or indicate access restrictions? (For example, I have seen places mark a folder with a red dot, remove restricted materials into a separate restricted file, etc.)
7. Are there ever cases where you are not sure if materials are sensitive or considered PHI under HIPAA?
 - a. In these situations, what considerations factor into your decision to either restrict or allow access?
 - b. Are there any resources or individuals you consult if you have questions regarding compliance with HIPAA or other privacy legislation?
8. What advice would you give to someone new who is starting a processing position involving medical or health sciences collections?