



The Practice of Privacy

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Abstract

Drawing on our experiences managing CLIR-funded processing initiatives for public health collections containing protected health information as part of the grant “Private Practices, Public Health: Privacy-Aware Processing to Maximize Access to Health Collections,” we offer insight into how we developed “Recommended Practices for Enabling Access to Manuscript and Archival Collections Containing Health Information About Individuals,” which appears at the end of this report, and we make recommendations for enabling access.

Whether privacy is legally mandated, as with HIPAA (the Health Insurance Portability and Accountability Act) and FERPA (the Family Educational Rights and Privacy Act); governed by institutional, state, or federal records schedules; or applied per local practice, the result is that many repositories maintain records that pose significant challenges to access. Yet as researchers continue to focus their attention on histories of medicine, public health, science and technology, disability studies, and patient care—and, increasingly, investigate explanations for more recent developments—they seek out these very collections. How can archivists promote the use of records that inform social and medical histories through the lens of patient care and help researchers decide if an archival collection is useful and worth their time?

By putting these questions up for discussion, and suggesting new answers, we encourage partnerships between archivists and researchers in the area of health collections, advocating for these collections’ importance despite access anxiety and the very real challenges of preserving,

screening, and making available records of a potentially sensitive nature. Drawing on our experiences managing CLIR-funded processing initiatives for public health collections containing protected health information as part of the grant “Private Practices, Public Health: Privacy-Aware Processing to Maximize Access to Health Collections,” we review best practices developed during the project and make recommendations for enabling access.

The project “Private Practices, Public Health: Privacy-Aware Processing to Maximize Access to Health Collections” was proposed by the Center for the History of Medicine of the Francis A. Countway Library on behalf of the Medical Heritage Library (MHL). It received funding from The Andrew W. Mellon Foundation as administered by the Council on Library and Information Resources (CLIR) in 2012; project work began in April 2013. The grant enabled the Center for the History of Medicine and its partner, the Alan Mason Chesney Medical Archives of the Johns Hopkins Medical Institutions—both MHL principal contributors—to open currently inaccessible public health collections to researchers.



The collections opened as a product of this grant include the [Oliver Cope papers, 1891-1992](#) (Countway); the [William George Hardy and Miriam Pauls Hardy Collection, 1875, 1930-2008](#) (Hopkins); the [Harvard School of Public Health's Department of Biostatistics records, 1981-2009](#) (Countway); the [Stephen W. Lagakos papers, 1979-2009](#) (Countway); the [Erich Lindemann papers, 1885-1991](#) (Countway); the [Elmer V. McCollum and Harry G. Day Collection, 1881-2003](#) (Hopkins); the [B. Frank Polk Collection, 1972-1990](#) (Hopkins); the [Arnold S. Relman papers, 1953-2011](#) (Countway); and the [Barbara Starfield Collection, 1948-2011](#) (Hopkins).

What is HIPAA? What Does it Mean to be a Covered Versus Non-covered Entity?

The adoption of the Privacy Rule under HIPAA, which went into effect on April 14, 2003, has had a major impact on archivists responsible for collections documenting the health sciences and on the researchers who want to use these collections. HIPAA was the first comprehensive federal law on access to and use of health information; the first general federal medical privacy law to extend rights of privacy beyond the file unit of the medical record to individually identifiable health information in all types of file systems, documents, formats, and media; and the first federal law to extend rights of privacy beyond health information of living individuals to health information of the deceased. The Privacy Rule applies only to archives designated as part of HIPAA-covered entities and their business associates, and does not apply to archives not part of covered entities that also hold medical records and other related health information. Archival repositories subject to HIPAA are subject to serious penalties for breaches.

Archives work with their legal counsel to determine whether they are subject to HIPAA. The extension of the HIPAA privacy and security requirements to business associates (as a result of the 2013 changes to the Privacy Rule brought about by the HITECH Act) may bring many more archival repositories under HIPAA regulation. These repositories have turned for guidance to the policies and procedures of archival repositories that have been operating under HIPAA since its inception. There is no list of archival repositories that identifies each of their status under HIPAA. The Chesney Medical Archives is part of the Johns Hopkins HIPAA-covered entity. As the official archival repository for the Johns Hopkins Hospital, its holdings include medical records from the hospital. The Center for the History of Medicine, Francis A. Countway Library of Medicine, is not part of a HIPAA-covered entity because Harvard Medical School does not own the teaching hospitals. The History of Medicine Division of the National Library of Medicine is not a covered entity, although it adopted some HIPAA-like policies for access to some collections such as hospital records. Some repositories may close collections based on the assumption that they are covered by HIPAA when they may not be.

Repositories within HIPAA-covered and non-covered entities must also comply with state laws applying to medical records and health information in holdings, comply with the Federal Common Rule for Protection of Human Subjects (for institutions that accept federal research funds), adhere to institutional requirements for protection of health information, and observe donor agreements for protecting health privacy.

One area of possible confusion may be the differences between the state definition of medical record and the HIPAA definition of protected health information. HIPAA defines protected



health information as “individually identifiable health information transmitted or maintained in any form or medium (electronic, oral, or paper) by a covered entity or its business associates, excluding certain educational and employment records and excluding information on those individuals who have been deceased for longer than 50 years.” The definition of what is considered a medical record may vary by context and purpose of creation, as well as state law. HIPAA does not define the term *medical record*. It is a term defined more by state law. State medical records laws vary by state, and institutions may interpret and apply the state definition according to local circumstances and systems. State laws may not all have caught up with the definition of protected health information under HIPAA. Records and information related to individuals who have been deceased for more than 50 years may still be protected by state medical records statutes and other state privacy laws.

The variations in whether and how repositories are covered by HIPAA and differences in state laws result in much confusion for researchers wanting to access and use collections containing health information. They may encounter a different set of access policies at each repository they want to use. Not all archives have the resources to support access, such as privacy boards, institutional review boards, or informed legal counsel.

As archivists at two of the country’s leading medical archives, we developed a set of recommended best practices in an effort to enable access to manuscript and archival collections containing protected health information and other types of access-protected records containing health information about individuals. We intend this document to inform our colleagues at other medical archives as well as archivists who encounter these collections at archives that do not have a medical focus. We also want historians of medicine and

other researchers to familiarize themselves with the issues we raise so they, too, can advocate for the preservation of these materials.

How Did We Engage Researchers, Historians, and Archivists?

For Countway and Hopkins to develop best practices for archivists facing confusion and challenges in making available health-related records about individuals in their collections, it was essential that we understand the informational needs of researchers seeking to use restricted records. We needed to hear their in-the-trenches experiences trying to access such records, and we needed to elicit information about the descriptive content they considered most valuable to discovery. Such an exploration meant evaluating how language used in finding aids and catalog records correlated with the perceived potential of a collection to satisfy a research need. It also meant seeking feedback on the process for applying for access to collections containing protected records.

To do so, we led discussion sessions, launched an online survey, presented at professional conferences, and then distributed our “Recommended Practices for Enabling Access to Manuscript and Archival Collections Containing Health Information about Individuals” to research and professional communities for feedback. Our first action was to distribute an online survey on access to health records to the Medical Heritage Library governance committee and to a number of professional and discipline-directed listservs. In total, 63 people responded. It was this data that helped spur our conversations between archivists and historians.¹

As part of the survey, we asked respondents to indicate the types of records they were interested

1 Data are available at http://www.medicalheritage.org/wp-content/uploads/2010/06/Data_All_140424_nocontacts.pdf.



in using for their research that required permission from an access or privacy board. Overwhelmingly, these were medical records and indices (patient, diagnostic, or other) created or maintained by a health care provider such as a hospital or medical practice. The second most cited records desired were psychiatric or other mental health-related records such as psychotherapy notes. When asked whether or not they could apply to a review board to obtain access to sought-after records, only 56 percent (32) of the respondents reported having access to a review board. Of the 32 respondents who did have access, only 56 percent (18) actually went through the process of applying. Why was this last number so low?

Respondents said the application process took too much time, especially in cases where they did not find out about the restrictions until they were already on site. Respondents also said they were not convinced they would actually get access if they went through the process, or they lacked the support or guidance to do so. When asked what the most significant barrier was to using records containing confidential and/or protected health information held by special collections, archives, and museums, the top answers were, "I see records that look interesting in catalogs or collection guides, but I can't tell if they will be useful," and "The process takes too long." What can archivists do to combat these challenges? We found that making the process more transparent, enhancing descriptions for these types of records, educating researchers about the process, and advocacy could help combat frustration.

After the survey closed, we sought opportunities to interact with researchers and members of our profession. We held a workshop for Harvard University's History of Medicine Working Group, comprising graduate students and faculty from

the History of Science Department. This gathering helped inform us of the needs of emerging scholars. We also held a lunch workshop at the 2014 annual meeting of the American Association of the History of Medicine, called "Negotiating Access to Patient-Related Materials: A Conversation between Archivists and Historians." At this meeting Evans Letocha explained HIPAA and helped eliminate some of the misconceptions about it. She also illustrated how the law affects those trying to use HIPAA-covered records, while Novak Gustainis presented our initial survey findings and discussed the potential impact of findings on processing practices. As part of the session, we were extremely fortunate to have historians Janet Golden of Rutgers University and Cynthia Connolly of the University of Pennsylvania share with attendees their successes and challenges using patient records to inform their own work. This helped attendees learn more about the difficulties and determine whether it is worth applying for access to an internal review or access board to use a collection. One priority that emerged from the discussion was to improve the user experience, particularly through potential partnerships between professional organizations of historians and those of archivists.²

Our capstone presentation was made at the 2014 annual meeting of the Society of American Archivists in Washington, D.C. (Gustainis 2014, Evans Letocha 2014). The session, "Partners in Practice: Archivists and Researchers Collaboratively Improving Access to Health Collections," offered the perspectives of both historians-researchers and archivists on the importance of making discoverable a wide variety of records that contain health information about individuals. The session, moderated by Susan Lawrence of The Ohio State

² Slides are available at <http://www.medicalheritage.org/announcements-and-articles/> under "Presentations."



University, included a talk by John Harley Warner of Yale University on why patient records matter to historians. Lawrence works at the intersection of history and research ethics.³ Warner focuses on the transnational history of medicine and science and is currently working on a study of the transformation of the hospital patient chart from 1801 to the present.⁴

What We Learned about Processing and Description Practices

One of the things we wanted to accomplish with the grant was to understand what, if any, differences existed between processing collections in HIPAA-covered versus non-HIPAA-covered environments. At Countway, we used a time- and labor-tracking database (called MD) that we developed as part of our first CLIR grant (Foundations of Public Health Policy). With this database, we tracked time spent performing activities specific to a collection. These activities include processing tasks such as rehousing, box and folder listing, and encoding and descriptive work related to creating finding aids. In advance of the grant's project start date, we customized a copy of MD for Hopkins, collaboratively determining how discrete processing activities relative to applying restrictions should be recorded and mapped so that we could compare time spent on specific processing actions, including restrictions reviews.

As a result of creating timing analyses for processing all grant-funded collections, we drew six broad conclusions.

- **It is paramount that archivists and collections managers educate researchers about the different types of restrictions in place at repositories.** After looking

at the portion of our collections that are access-protected, we discovered that a far greater percentage processed for the Private Practices grant contained records that were closed because they were created by Harvard University and the Johns Hopkins Medical Institutions as a product of operations. It is the variety of records restrictions (including those for students and personnel) in place at our repositories—not just the presence of health information about individuals—that has resulted in large portions of closed collections. As archivists, we assumed that most of the records that had to be access-protected were patient-related. If we were under this impression, then our researchers must be, too.

- **Processing workflows that are systems-dependent requires further evaluation.** Both Countway and Hopkins have very similar processing approaches (e.g., similar series/records groupings, listing and transcribing practices at the folder level, staffing in place to audit description), though Countway's workflows are less sequenced than those of Hopkins because of the collection management system Hopkins uses. It will be important for Countway, when it moves to ArchivesSpace, to monitor adjustments in workflow, timing data, and outputs. Most processing analyses (including those authored by Novak Gustainis) focus on activities independent of systems. Activities articulated in conjunction with more widely used open source systems merit evaluation.
- **Average processing costs per box for a HIPAA-covered and non-HIPAA-covered entity are virtually the same.** Excluding project oversight costs (costs for Novak Gustainis and Evans Letocha), Countway spent \$659.83/cubic foot by start volume and

3 See Lawrence 2007.

4 The session description is available at <http://archives2014.sched.org/event/4513e77709f236c8a7721c45787e612d#.VgAx-W9NVhBd>.



\$800.90/cubic foot by end volume. Hopkins spent \$661.24/cubic foot by start volume and \$786.50/cubic foot by end volume. Averaging the two institutions' costs, a reasonable figure for planning purposes would be \$660 to \$794 per cubic foot under the following conditions: staffing models, compensation rates, and workflows are similar to those of Countway or Hopkins; collections are predominantly analog in format; and they originate in the twentieth century.

- **Screening for restrictions takes longer in a HIPAA-covered environment.** Countway applies restrictions at the folder level through sampling. To account for sampling, Center for the History of Medicine researchers are required to sign a waiver requiring them not to reveal any personally identifying information should they encounter something missed. Hopkins conducts item-level reviews for restrictions and then does a second-pass audit on restricted folders, unless it is obvious that an entire series or subseries will need to be restricted. Researchers at Hopkins can use only what is absolutely confirmed not to contain protected health information, unless they have a waiver of authorization from its Privacy Board or complete an [application form](#) for another route of access allowed under HIPAA.⁵ The two institutions' hourly rates for restrictions differed greatly despite a similar volume of records—9.76 to 10.61 hours per cubic foot for Countway, and 21.4 to 46.21 hours per cubic foot for Hopkins. Item-level screening, which requires a minimum of two passes—one by the processor and one by the collections services archivist—only partly accounts for Hopkins's higher rate. The

⁵ Application forms for access to individually identifiable health information are available on the [Chesney Medical Archives website](#).

number of people involved with processing greatly affects outputs.

- **As the number of people involved with processing goes up, processing outputs go down.** While cost per cubic foot does not vary much between institutions, the speed at which collections were processed was very different because of staffing models used. Countway used a dedicated project or staff archivist, generally with one processing assistant working 17 hours a week per collection. Hopkins used a project archivist and five or six student employees per collection, which required multiple trainings, more project oversight, and greater efforts to standardize descriptive outputs. Having more skilled and experienced processors is more efficient but costs more. Because of the grant's time restraints, Hopkins had its project archivist manage students on collections concurrently. Normally a project archivist handles one collection at a time, working on multiple collections mainly at the beginning and end of projects. When Hopkins does not have a project archivist, outputs are further reduced. Students get assigned one project at a time, often over multiple semesters, with numerous breaks in between. Opening hidden collections and making dents in backlog require stable, professional staffing.
- **Researchers whose work is supported by using records containing health information about individuals need more robust descriptive information to inform their decision making.** One approach we can take as archivists is to introduce in our description more of the variables researchers are looking for. In our online survey, we provided a list of elements archivists could incorporate into collection descriptions, asking respondents



to rank them not very useful, somewhat useful, very useful, or does not apply. Fifty-one respondents answered, with some surprising results. For example, respondents ranked providing the date span of records most useful. Given that *Describing Archives: A Content Standard* requires a date statement for minimum-level description, we, as archivists, already provide what respondents rank as the most useful information, or perhaps a surprising number of record descriptions still do not include dates. Other descriptions respondents ranked as useful (after date span) were: patient diagnosis or condition, geographic region, patient gender, patient race, duration of treatment, names of procedures and prescribed medication, names of medical devices used, average age of patients when treated, names of treating physicians or surgeons, and presence of genetic information.

Similarly, we asked what kinds of records researchers would be most interested in knowing were in a collection. Patient histories and case files ranked the highest, with informed consent and autopsy records next, and insurance (and by extension billing and coverage records) ranking last. As archivists, familiarizing ourselves with these kinds of records so that we can better identify them in our finding aids would benefit researchers.

Finally, respondents found folder-level scope notes indicating the types of restrictions that applied to a particular folder to be highly useful. Prior to the grant, Countway used series-level restriction statements to explain why folders were access-protected, and provided opening dates. However, because of the multiple types of restrictions that can be encountered in a series, for the collections processed

for the Private Practices project, Countway included a statement explaining the reason for the restriction in a folder-level scope note for each restricted folder. Researchers specifically interested in health information can then better target folders of research interest. Not only is this useful to researchers, it has proved useful to the Center's Public Services staff, who no longer need to recall folders to figure out which restrictions apply. Subsequently, Countway adopted this practice for all collections processing. As a HIPAA-covered entity, Hopkins's approach had to be more granular. Staff screened documents at the item level for protected health information and other confidential material such as student and personnel information. They then redacted such information from descriptions, and identified documents that contain such information in the finding aid.

As a result of this work, Countway is testing the best practices for describing collections containing health information about individuals on the Dwight E. Harken papers, 1911–1993.⁶ Countway will share the finding aid with members of the Medical Heritage Library and other constituents who provided comments on the recommendations. At Hopkins, the project highlighted the inefficiencies of using undergraduate student assistants. These included student turnover, schedule changes, limited hours during the spring and fall semesters, and the labor-intensive training and supervision that more senior staff must provide for student employees. Hopkins is reviewing its staffing model and will compare metrics on future processing projects that use different staffing models such as relying on undergraduate students for more limited tasks.

6 The finding aid for the Dwight E. Harken papers, 1911–1993 (inclusive), 1940–1975 (bulk), B MS c118, is now available online at http://oasis.lib.harvard.edu/oasis/deliver/deepLink?_collection=oasis&uniqueId=med00207.



Next Steps to Enable Access

We conclude that three steps are needed to enable access to the collections in question.

1. We need to raise awareness among both archivists and researchers that collections documenting health are hidden and endangered.

Because of access anxiety on the part of archivists and their repositories, these collections remain hidden and at risk of destruction. Many repositories refuse to deliberately collect patient-related materials because they do not have the capacity to manage access. Local libraries and historical societies are reluctant to accession collections that may be subject to privacy concerns. They may not have adequate staffing or training to handle requests for access to restricted records. The penalties for HIPAA breaches may pose an unacceptable risk for repositories. It is easier to say no than to invest the resources necessary to make these collections accessible to researchers. Even repositories at large academic health centers whose mandate is to document the history of medicine may not have the resources to accept large runs of medical records after they are no longer required for active patient care activities. Medical records generated by centralized hospital medical records divisions are massive. They constitute millions of records, with significant storage costs. We cannot expect that every medical record can be preserved. Repositories need to have access policies in place that enable research use to justify preservation costs. Scholars need to overcome their access anxiety, and push to gain access to these collections to justify the need to collect these materials. Both archivists and scholars will need to make a commitment to advocate for preserving and using collections documenting the health of our populace.

2. Archivists need to make descriptions available so that researchers can request and use these collections.

Archivists should be advocates for both the collections and the researchers who produce valuable scholarly work using them. Archivists may not even be aware of all the patient-related records they may already have in their own repository, if these materials are unprocessed and hidden. Hidden patient records may not show up in catalog searches, so public services archivists do not know to refer interested researchers to them. Rather than branding these collections restricted and off limits or remaining ignorant to their existence, archivists need to discover these materials and then commit to facilitating access to them. Archivists must increase their awareness of what HIPAA and state medical records laws do and do not allow. HIPAA includes provisions for access to protected health information for research purposes when it is necessary for research and the researcher has a plan to protect it. Archivists need to better familiarize themselves with the research provisions of HIPAA and state medical records laws. They should then insist on becoming part of the review process by serving as members of privacy boards and institutional review boards that can offer waivers of authorization to allow researchers regulated access to protected records in compliance with HIPAA, state laws, and institutional policies.

Once they become aware of the existence of health collections, archivists need to work with historians and other researchers to appraise the research value of these records and advocate for preserving the most significant collections. This will enable the creation of new knowledge, using historic medical records as primary source materials. Before researchers can produce scholarly



works using health information, they need to know these collections exist. Our best practices document (Appendix A) offers guidelines to help archivists describe these holdings in a privacy-aware manner that provides researchers with the qualitative information they need to make decisions about pursuing research activities with these records. More repositories need to overcome their access anxiety and describe these holdings. Protecting privacy is a responsibility shared by archivists and researchers.

Parallel to the CLIR project, Hopkins conducted a citation study of the scholarly output of the 243 researchers who, between April 2003 and July 2014, applied for Privacy Board waivers to use HIPAA-protected Hopkins holdings. We hope this study's findings demonstrate measurable data on what scholarship can be produced if repositories develop the infrastructure to enable access to restricted records in a privacy-aware and HIPAA-compliant environment.

3. Archivists and researchers need to work together to advocate for changes in federal and state law that balance individual privacy protections with the need for scholarly access to create new knowledge in the history of medicine.

In August 2014, the Society of American Archivists (SAA) adopted a HIPAA issue brief that outlines advocacy efforts that the society endorses at the federal, state, and institutional levels. Phoebe Evans Letocha and Lisa Mix worked with SAA's Committee on Advocacy and Public Policy and the Science, Technology and Healthcare Roundtable to present this [issue brief](#) to the SAA Council (SAA 2014).

The issue brief outlines a series of recommended changes in HIPAA at the federal level, in state

medical record laws, and in practices at the institutional and professional level. The 2013 changes in the HIPAA Privacy Rule enacted because of the passage of the HITECH Act include a change in the definition of protected health information to exclude information about individuals deceased for more than 50 years. In 2005, archivists Nancy McCall and Steve Novak testified in favor of this change before the National Committee on Vital and Health Statistics, and SAA endorsed this new definition during the 2010 comment period to change the Privacy Rule.

This was a welcome advocacy accomplishment, but more changes are needed: a) to provide a date from record creation at which records would no longer be protected in cases where the death date of an individual is unknown; b) to allow easier access to protected health information for family members conducting medical genealogy research; c) to clarify the extent to which archival repositories that are not part of covered entities and that have health-care-related holdings are subject to business associate agreements; and d) to make it clear that individually identifiable information and photographs that appeared in publications or other public venues are not considered protected under the Privacy Rule.

At the state level, medical record statutes need to be aligned with federal regulations to allow for standardization. Archivists and historians also need to turn their attention to advocacy efforts to propose changes in state laws that would enable research using medical records. At the institutional level, through our professional organizations including SAA, Archivists and Librarians in the History of the Health Sciences, and the American Association for the History of Medicine, archivists and researchers should communicate and collaborate to develop best practices and promote a common research agenda that



makes these collections available for scholarly use. Collaborations such as this one, between Hopkins and Countway through the Medical Heritage Library-sponsored CLIR project, enable the creation and promotion of best practices for processing description, and research use of these collections.

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B. Frank Polk Collection, 1972-1990: http://www.medicalarchives.jhmi.edu/finding_aids/frank_polk/frank_polkd.html.

Elmer V. McCollum and Harry G. Day Collection, 1881-2003: http://www.medicalarchives.jhmi.edu/finding_aids/elmer_mccollum/elmer_mccollumd.html.

Erich Lindemann papers, 1885-1991: http://oasis.lib.harvard.edu/oasis/deliver/deepLink?_collection=oasis&uniqueId=med00191.

Harvard School of Public Health's Department of Biostatistics records, 1981-2009: http://oasis.lib.harvard.edu/oasis/deliver/deepLink?_collection=oasis&uniqueId=med00187.

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Stephen W. Lagakos papers, 1979-2009: http://oasis.lib.harvard.edu/oasis/deliver/deepLink?_collection=oasis&uniqueId=med00185.

William George Hardy and Miriam Pauls Hardy Collection, 1875, 1930-2008: http://www.medicalarchives.jhmi.edu/finding_aids/william_hardy/william_hardyd.html.



APPENDIX A: RECOMMENDED PRACTICES FOR ENABLING ACCESS TO MANUSCRIPT AND ARCHIVAL COLLECTIONS CONTAINING HEALTH INFORMATION ABOUT INDIVIDUALS

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1 February 2015

About

The following recommendations were developed by the [Alan Mason Chesney Medical Archives of the Johns Hopkins Medical Institutions](#) and the [Center for the History of Medicine at the Francis A. Countway Library of Medicine](#) in an effort to enable access to manuscript and archival collections containing protected health information (PHI) and other types of access-protected records containing health information about individuals. The recommendations serve to underscore the importance of making available primary sources for health information about individuals to historians and other researchers to inform the history of American medicine and serve as a foundation for evidence for policy-shaping works. When these collections remain hidden and inadequately described, they are at greater risk for destruction, thus impeding future archival research that furthers our collective understanding of health and disease. Facilitating access involves striking a balance between the privacy concerns of living individuals and the greater public good that can be accomplished by scholarship.

This work was made possible through the generous funding of the [Council for Library and Information Resources' Cataloging Hidden Special Collections and Archives](#) program (2012: *Private Practices, Public Health: Privacy-Aware Processing to Maximize Access to Health Collections*).

The recommendations need not be pursued in sequential order. Repositories are encouraged to pursue some policy recommendations concurrently or to test one of the many descriptive enhancements. It is the hope of the authors that these recommendations will help alleviate many of the concerns repositories have related to collecting and preserving health services records, especially those that are not affiliated with hospitals or medical schools.

Determining an Institution's Status and Policy Needs

- Repositories should train staff to recognize [individually identifiable health information](#), regardless of whether or not they are entities covered by the Health Insurance Portability and Accountability Act ([HIPAA](#)). Repositories that are HIPAA-covered should provide training to familiarize staff with legal

requirements.

- Repositories should survey their holdings to determine the extent to which they include individually identifiable health information that may be protected by federal or state laws.
- Repositories should consult with their administration and legal counsel to determine their status under [HIPAA](#); the [Federal](#)



Common Rule for the Protection of Human Subjects; and their state's medical records laws.

- Repositories should document their status under such rules and statutes and determine their institution's risk tolerance, since (1) laws such as HIPAA allow institutions to be more restrictive than the law requires, and (2) some donor agreements may require restrictions beyond that which is covered by HIPAA.
- Repositories should create intra-organizational partnerships to align policies, for example, among special collections repositories at the same institution, medical records/health information management departments in hospitals, and/or institutional records management offices.
- Repositories holding records of outside institutions that contain individually identifiable health information should consult with the depositing institution and with their own legal counsel to determine whether housing the records would make the repository subject to HIPAA business associate agreements.
- Repositories should review the types of requests that they receive for access to individually identifiable health information and develop access review processes relevant to the type of use requested, such as medical genealogy, biography, and research as defined by HIPAA and the Common Rule.

Implementing Policy and Fostering Process Transparency

- Repositories, to the extent possible, may want to create an impartial Access Board or Privacy Board or consult with an Institutional Review Board (IRB) to review applications for access to protected health information and

medical records in their holdings. An archivist with knowledge of the holdings should be designated to be part of the review process, either as an advisor to or as a member of the review board. If no Access Board is possible, repositories should be prepared to explain why access can be granted to some users and not others.

- Repositories should document their decision-making processes and policies and apply them consistently. Decision trees may be helpful tools to review access decisions (see Johns Hopkins [examples](#)).
- Repositories should publish their access and use policies on their websites and should provide copies of any application forms online; researchers should be reminded that publishers may also have their own privacy requirements as a condition of accepting a manuscript for publication.
- Repositories should clearly articulate the steps a researcher or other user would need to take to apply for access and the application workflow, so that users know how far in advance they will need to make an application before they may be granted access.
- Repositories may wish to provide model applications or a process by which applicants can ask questions or seek guidance on the application process so that they can successfully complete the application.
- Repositories should create a user agreement for patrons to sign that communicates personal liability for the misuse or distribution of health information about individuals.



Communicating the Nature of Restrictions

- Repositories should provide non-technical information on their websites about the kinds of access restrictions their users will encounter when considering the use of records, regardless of whether restrictions are imposed by: Federal law (HIPAA, FERPA); U.S. government records laws; state law; gift agreement; deposit agreement; or institutional policy.
- Repositories should provide at least one example of each of the restrictions found in their collections using a published or otherwise publicly available finding aid or catalog record to illustrate the restrictions.
- Repositories should explain where users can find information about access restrictions, such as publicly accessible catalog records, online finding aids, or published inventories. Repositories should provide information about the gaps in systems where information is generally provided (such as restrictions only being noted in catalog records for collections that have been processed), as well as overtly state when information about access restrictions is only available through consultation with Public Services staff.
- Repositories should embed information regarding the presence of access restrictions at all levels of hierarchical description. Collection-level access descriptions may alert users to the presence of restrictions, but it is series, subseries, and folder-level notices regarding access status that enable users to understand which restrictions apply to records of interest.
- Repositories should clearly articulate their policies regarding citation. Access Board and

IRB applications should clearly indicate if citation is permitted, and if so, repositories should have specific examples for citing records in collections that are not accessible without access approval and, if the collection is unprocessed, whose physical organization may change in the future.

- Repositories may want to allow and encourage users to deposit a code key to medical records and other protected records that cannot be cited by identifiers, such as patient name or medical record number, without authorization. Repositories should clearly state in finding aids when records have been redacted or removed from the collection.

Describing Records to Best Enable Discovery and Access

The following recommendations are intended to illustrate the rich descriptive information that archivists can offer without revealing patient names or other identifiers. When selecting descriptive approaches, processors should balance the needs of their research communities with local processing practices to determine which of the following descriptive enhancements could improve discoverability and use of their collections.

- When describing collections containing health information, communicate the specific record formats in which health information is found. A developing list of different kinds of records containing health information and their scope may be found [here](#). Examples include: admission records; autopsy records; case files; diagnostic indices; doctor-patient correspondence; medical records; patient histories; prescription logs; surgical logbooks; and specimens. If you are not sure of the kind of record you have, try to create a redacted copy of the record (or a page or two from a



volume) and consult an archivist or librarian who more routinely encounters these types of records.

- Descriptions should overtly state if a collection is a part of a much larger, original group of records, as well as inform users as to what happened to the rest of the records or where they may be found. (For example, when a collection consists of 20 boxes transferred to the archives as a representative sample from an original 100 boxes of records, indicate that the remaining 80 boxes were destroyed per institutional policy.) Specimens related to a collection that are housed elsewhere should be indicated, regardless of whether or not they can be accessed.
- Processors should identify when records were created for a specific research study or when doctors assembled sets of patient records as source material for specific publications.
- Processors should record types of commonly collected information about patients in the records, such as diagnoses, names, dates of birth/death, and ages at time of treatment. As time or expertise permits, processors should sample the records and incorporate into the description patient-related information, such as marital status, number of children, race, ethnicity, occupation, and place of residence or employment; and treatment-related information, such as the names of frequently mentioned doctors, surgeons, midwives, mental health professionals, and/or dentists encountered, pharmaceuticals, types of medical treatments and procedures, and instrumentation and devices used. A developing list of variables may be found [here](#).

- Because processing methodologies vary from repository to repository, processing information in finding aids should include how record descriptions were created, such as through a percentage of records sampled per container or per alphabetical or numeric run.
- Repositories should enable opportunities for user enhancement of collection descriptions, particularly for unprocessed or infrequently used collections. A survey instrument or quick conversation with a researcher may help contextualize records, add to lists of procedures or treatments employed, or enrich collection-level descriptions of holdings. Users may also provide examples of “the patient’s own words” that can be included anonymously in finding aids to help characterize records. Similarly, health care providers familiar with the creation of specific categories of patient record types can help contextualize records based on their clinical experience of how records are used. Health care providers may also be able to decipher medical shorthand or abbreviation unfamiliar to archivists who don’t have specialized medical training or familiarity with local institutional terms.
- Repositories should consider digitally imaging redacted versions of records and embedding them in finding aids in order to visually communicate how information is organized in the records. Repositories can also consider embedding blank versions of survey instruments, commonly found forms in medical records, pages from codebooks, and protocols.