The Practice of Privacy

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Abstract: Drawing upon the experiences of two archivists who managed CLIR-funded processing initiatives for public health collections containing protected health information as part of the "Private Practices, Public Health: Privacy-Aware Processing to Maximize Access to Health Collections" grant, paper will offer insight into how their "Best Practices for Enabling Access to Manuscript and Archival Collections Containing Health Information About Individuals" was developed during the project and make recommendations for enabling access.

INTRODUCTION

Whether privacy is legally mandated (as with HIPAA and FERPA), governed by institutional, State, or Federal records schedules, or applied per local practice, 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 aid researchers deciding if an archival collection is useful and worth their time?

By putting these questions up for discussion, and suggesting new answers, this paper will encourage partnerships between archivists and scholars/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 upon the experiences of two archivists who managed CLIR-funded processing initiatives for public health collections containing protected health information as part of

the "Private Practices, Public Health: Privacy-Aware Processing to Maximize Access to Health Collections" grant, it will review best practices developed during the project and make recommendations for enabling access.

"Private Practices, Public Health: Privacy-Aware Processing to Maximize Access to Health Collections," was proposed on behalf of the Medical Heritage Library (MHL), receiving funding from The Andrew W. Mellon Foundation as administered by the Council on Library Resources (CLIR) in 2012; project work commenced in April 2013. The grant enabled the Center for the History of Medicine, Francis A. Countway Library, 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 (inclusive), http://nrs.harvard.edu/urn-3:HMS.Count:med00189 (Countway); William George Hardy and Miriam Pauls Hardy Collection, 1875, 1930-2008 (inclusive), http://www.medicalarchives.jhmi.edu/finding_aids/william_hardy/william_hardyd.html (Hopkins); Harvard School of Public Health, Department of Biostatistics records, 1981-2009 (inclusive), http://nrs.harvard.edu/urn-3:HMS.Count:med00187 (Countway); the Stephen W. Lagakos papers, 1979-2009 (inclusive), http://nrs.harvard.edu/urn-3:HMS.Count:med00185 (Countway); Erich Lindemann papers, 1885-1991 (inclusive), http://nrs.harvard.edu/urn-3:HMS.Count:med00191 (Countway); Elmer V. McCollum and Harry G. Day Collection, 1881-2003 (inclusive), http://www.medicalarchives.jhmi.edu/finding_aids/elmer_mccollum/elmer_mccollumd.html (Hopkins); B. Frank Polk Collection, 1972-1990,

http://www.medicalarchives.jhmi.edu/finding_aids/frank_polk/frank_polkd.html (Hopkins); Arnold S. Relman papers, 1953-2011 (inclusive), http://nrs.harvard.edu/urn-3:HMS.Count:med00188 (Countway); and Barbara Starfield Collection, 1948-2011, http://www.medicalarchives.jhmi.edu/finding_aids/barbara_starfield/barbara_starfieldd.html (Hopkins).

What is HIPAA? What does it mean to be a covered vs. a non-covered entity?

The adoption of the Privacy Rule under HIPAA, which went into effect on April 14, 2003, has had a major impact upon archivists who are responsible for collections documenting the health sciences, as well as the researchers who want to use these collections. It was the first comprehensive federal law on access and use of health information, the first general federal medical privacy law to extend rights of privacy beyond 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 decedents. 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 the regulation of HIPAA. These repositories have turned for guidance

to the policies and procedures of archival repositories who have been operating under HIPAA since it went into effect in 2003. 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 is not part of a HIPAA covered entity because Harvard Medical School does not own the teaching hospitals. The History of Medicine Division at NLM is not a covered entity, although they have 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 have all caught up with the definition of Protected Health Information under HIPAA. Records and information related to individuals who have been deceased for over 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 results 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 access to Privacy Boards, IRBs, or informed legal counsel. As archivists at two of the leading medical archives, we developed a set of recommended best practices to 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. We intended this document not only to inform our colleagues at other medical archives, but also archivists who encounter these collections at archives that don't 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 you engage researchers and historians? Archivists?

In order for the Countway and Hopkins to develop best practices for archivists facing challenges and confusions over making health-related records about individuals in their collections available, it was essential that we understood the informational needs of researchers seeking to

use restricted records; that is, hear their "in the trenches" experiences of trying to access records containing health information about individuals and elicit information about the descriptive content they considered most valuable to discovery. Such an exploration meant evaluating how language employed in finding aids and catalog records correlated with the perceived potential of a collection to satisfy a research need and seeking feedback on the process for applying for access to collections with protected records.

To do so, we led discussion sessions, launched an online survey, presented at professional conferences, and ultimately distributed our "Recommended Practices for Enabling Access to Manuscript and Archival Collections Containing Health Information about Individuals" to the research and professional communities for feedback. Our first action item was to distribute an online survey on access to health records ("Research Access to Protected Records Containing Health Information about Individuals"), which was distributed to the Medical Heritage Library governance committee and circulated to a number of professional and discipline-directed listservs. In total, sixty-three people responded. It was this data (available online) that helped spur our conversations between archivists and historians (http://www.medicalheritage.org/wpcontent/uploads/2010/06/Data_All_140424_nocontacts.pdf).

As part of the survey, respondents were asked to indicate the types of records containing health information about individuals that they had been interested in using for their own research that had required permission from an access/privacy board to use; overwhelmingly, they were medical records and indices (whether patient, diagnostic, or other) created or maintained by a healthcare provider, such as a hospital or medical practice, followed by 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 records they were interested in using, only 56.14% (32) had access to a review board, and of the 32 individuals who did have access, only 56.25 (18) actually went through the process of applying.

Why would only just over half of the individuals who could apply for access actually go through with applying? Respondents said it was took too much time – especially when they found out about the restrictions when they were already on-site, weren't convinced they'd actually get access if they went through the process, or that they lacked support or guidance. When asked what the most significant barrier to using records containing confidential/protected health information held by special collections, archives, and museums, the number one 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 odds? We found that process transparency, combined with enhanced description for these types of records and researcher education could help combat frustration. And, as Evans Letocha describes in a later section, advocacy.

After the survey was closed, we sought a number of opportunities to interact with researchers and members of our profession. This included a workshop for Harvard University's History of Medicine Working Group, comprised of graduate students and faculty from the History of Science Department, which helped inform us of the needs of emerging scholars, and a lunch workshop at the 2014 annual meeting of the American Association of the History of Medicine ("Negotiating Access to Patient Related Materials: A Conversation between Archivists and Historians"). This meeting offered Evans Letocha an opportunity to explain what HIPAA was and help eliminate some of the misconceptions related to the Act, as well as illustrate how it

affects those trying to use HIPAA-covered records, and enabled Novak Gustainis to present on initial survey findings and consider the potential impact of findings on processing practices. As part of the session, we were extremely fortunate to have historians Janet Golden (Rutgers University) and Cynthia Connolly (University of Pennsylvania) share with attendees both their successes with, and challenges to, using patient records to inform their own work and learn more about how difficult it can be to determine whether or not it is worth applying to an Internal Review Board (IRB)/Access Board to use a collection. Improving the user experience, particularly through potential partnerships between the professional organizations of historians and those of archivists emerged as a priority. (For slides, see: http://www.medicalheritage.org/announcements-and-articles/ under "Presentations.")

Our capstone presentation was at the 2014 Annual Meeting of the Society of American Archivists in Washington, D.C. 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 a wide variety of records that contain health information about individuals discoverable. The session was moderated by Susan Lawrence (Ohio State University) and included a presentation by John Harley Warner of Yale University ("Why Patient Records Matter to the Historian"). Lawrence works on the intersections of history and research ethics (most recently with her 2007 article, "Access Anxiety: HIPAA and Historical Research," in the *Journal of the History of Medicine and Allied Sciences*); Warner, an educator and historian, 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. (For slides, see: http://www.medicalheritage.org/announcements-and-articles/ under "Presentations.")

What did you learn 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 have employed the use of a time and labor tracking database ("MD") we developed as part of our first CLIR-funded initiative, *Foundations of Public Health Policy*. Using the database, we track how much time we spend performing activities specific to a collection, including processing activities such as rehousing, box and folder listing, and encoding and descriptive work related to created finding aids. In advance of the grant's project start date, Novak Gustainis worked with Evans Letocha to customize a copy of MD specific to Hopkins, collaboratively determining how discreet processing activities relative to applying restrictions should be recorded/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, Countway and Hopkins drew six overarching conclusions:

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

As a result of looking at the actual percentages of our collections that are access-protected, we discovered that a far greater percentage of the collections 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 product of operations. It is the variety of records restrictions – including those for students and personnel -- in place at our repositories and not just the presence of health information about individuals -- that has resulted in large percentages

of our collections being closed. We, as archivists, assumed that most of the records that had to be access-protected were patient-related. If we are under this impression, then our researchers must, too.

2. ***Processing workflows that are systems-dependent require further evaluation.***

Both Countway and Hopkins have very similar processing approaches (similar series/records groupings, listing and transcribing practices at the folder level, a staff member in place to audit description, etc.), though Countway's workflows are less sequenced than those of Hopkins due to the collection management system used by Hopkins. It will be important for Countway to monitor adjustments in workflow, timing data, and outputs when it moves to ArchivesSpace. Most processing analyses (including analyses authored by Novak Gustainis) have focused on activities independent of systems; activities articulated in conjunction with the use of more widely used Open Source systems merits evaluation.

3. ***The average processing costs per box for a HIPAA-covered and non-HIPAA covered entity are virtually the same.***

Excluding project oversight costs (that is, costs for Novak Gustainis and Evans Letocha), Countway expended $659.83/cubic foot by start volume and $800.90/cubic foot by end volume and Hopkins expended $661.24/cubic foot by start volume start volume and $786.50/cubic foot by end volume. Averaging the two institution's averages, a reasonable figure for planning purposes would be $660.55-$794.00 per cubic foot if a) employing staffing models (described in point five of this section), rate of compensation, and workflows that are similar to those of either Countway or Hopkins, b) are predominantly analog in format, and c) originate in the 20th century.

4. ***Screening for restrictions definitely takes longer in a HIPAA-covered environment.*** Countway applies restrictions at the folder level, and does so through sampling. To account for sampling, Center for the History of Medicine researchers are required to sign a waiver requiring them, as a condition of use, not to reveal any personally identifying information should something that was missed be encountered. Hopkins, however, 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 closed. Researchers at Hopkins can only use what is absolutely confirmed to not contain PHI, unless they have a waiver of authorization from its Privacy Board or other HIPAA authorization for access to PHI. For collections roughly comparable in volume, hourly rates for restrictions between the two institutions were very different for a similar volume of records (9.76-10.61 hours per cubic foot for Countway and 44.21-46.71 hours per cubic foot for Hopkins). Item level screening (which requires, at a minimum, two passes, one by the processor and one by the Collections Services Archivist) is only one part of the higher rate. It is the number of people involved with processing that affects outputs (see next point).

5. ***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 due to staffing models employed. The Center used a dedicated project or staff archivist, generally with one processing assistant working 17 hours a week per collection. Hopkins employed a project archivist and between five and six student employees per collection, which required multiple trainings, more project oversight, and greater efforts to standardize descriptive outputs. More skilled and experienced processors are more efficient but

have higher labor costs. Due to the time restraints of the grant, Hopkins had its project archivist manage students on collections concurrently (the normal pattern is to have a project archivist do one collection at a time with minimal time working on multiple collections, usually at beginning and end of projects). When Hopkins doesn't have a project archivist, outputs are further reduced; students gets assigned one project at a time, often over multiple semesters with numerous breaks in between. Opening hidden collections and making dents in backlog requires stable, professional staffing.

6. Researchers whose work is supported by the use of records containing health information about individuals need more robust descriptive information to support their decision-making processes.

One of things we can do as archivists is introduce more of the variables researchers are looking for in our description. As part of the online survey we conducted, we provided a list of things archivists could incorporate in to our collection descriptions and ranked them as either "Not Very Useful," "Somewhat Useful," "Very Useful," or "Does not Apply." Fifty-one respondents answered the question, with some surprising results. For example, providing the date span of records came up as the most useful thing. Given that the national descriptive standard for the profession (*Describing Archives: A Content Standard*) requires a date statement for minimum-level description, we are already providing the most useful information or a surprising number of record descriptions do not include dates. Date span was followed by: patient diagnosis or condition; geographic region; sex of patients; race of patients; duration of treatment; the names of procedures and prescribed medication; names of medical devices employed; average age of patients when treated; the names of treating physicians/surgeons; and the 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 in the middle, and insurance (and by extension billing/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 our researchers.

Finally, the use of folder level scope notes to indicate the types of restrictions that applied to a particular folder were revealed to be of high utility. Prior to the grant, at Countway, series level restrictions statements explained why folders were access-protected, with dates provided for when the folder would open. However, owing to the multiple types of restrictions that could be encountered in a series, for *Private Practices*-processed collections, Countway included a "why" statement in a folder-level scope note for each restricted folder. This resulted in more transparency as to why a specific folder was access-protected. Researchers specifically interested in health information could therefore better target folders of research interest. Not only is this useful to researchers, but it has proven useful to Public Services, who no longer need to recall folders to figure out which restrictions apply. As a result, Countway has adopted this practice for all collections processing. As a HIPAA-covered entity, Hopkins's approach was, and had to be, more granular. Staff screened documents at the item level for protected health information (PHI) and other confidential information (CI) such as student and personnel information. Staff then redacted PHI and CI from descriptions, and identified documents that contain PHI and CI in the finding aid.

As a result of this work, Countway is testing the best practices for the description of collections containing health information about individuals on the Dwight E. Harken papers, 1930s-1990s.

Processing of the Harken papers is underway, and should be completed by the end of March 2015. Countway will share the finding aid with members of the Medical Heritage Library and other constituents who provided feedback on the recommendations for comment. At Hopkins, the project highlighted the inefficiencies of using undergraduate student assistants, including student turnover, schedule changes, limited hours during the spring and fall semesters, and the more labor intensive training and supervision that more senior staff must provide for student employees. Hopkins is reviewing its staffing model and will compare processing metrics on future processing projects that utilize different staffing models using undergraduate students for more limited tasks.

What are the next steps that archivist and researchers wishing to use these collections need to take to enable access?

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

Collections containing health information are endangered. Due to access anxiety on the part of archivist and their repositories, these collections remain hidden and at risk of destruction. Many repositories refuse to deliberately collect patient-related materials because they don't 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 be an unacceptable risk for repositories to take. 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 in size, 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 of these records in order to justify the cost of preserving them. Scholars need to also overcome their access anxiety and push to gain access to these collections in order to justify the need to collect these materials. Both archivists and scholars will need to make a commitment to advocate for the preservation and use of collections documenting the health of our populace.

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

Archivist should be advocates for both the collections and the researchers who produce valuable scholarly work utilizing the health collections in our care. 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 don't know to refer interested researchers to them. Rather than branding these collections as restricted and off limits or remaining ignorant to their existence, archivists need to discover these materials and then have a commitment to facilitating access to patient related materials. Archivists need to become better aware 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 PHI is necessary for research and the researcher has a plan to protect PHI. Archivists need to better familiarize themselves with the research provisions of HIPAA and state medical records laws. They then should insist that they become part of the review process by serving as members of Privacy Boards and IRBs 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 the preservation of the most significant collections in order to enable new knowledge creation utilizing historic medical records as primary source materials. Before researchers can produce scholarly works utilizing health information, they need to have the awareness that these collections exist. Our best practices document offers guidelines to help archivists describe these holdings in a privacy aware manner that provides researchers with the qualitative information that they want and need to make decisions about whether they can pursue research activities utilizing these records. More repositories need to overcome their access anxiety and describe these holdings. Protecting privacy is a shared responsibility between archivists and researchers.

In parallel to the CLIR project, Hopkins has been conducting a citation study of the scholarly output of the 243 researchers between April 2003 and July 2014 who have applied for Privacy Board waivers to use the Hopkins holdings that have been protected by HIPAA. We hope that these findings can 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 adopted a HIPAA issue brief that outlines advocacy efforts that SAA endorses at the federal, state, and institutional levels. 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 SAA Council. http://www2.archivists.org/statements/issue-brief-health-information-portability-and-accountability-act.

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 due to the passage of the HITECH Act include a change in the definition of PHI to exclude information about individuals who have been deceased for more than 50 years. Archivists Nancy McCall and Steve Novak testified in 2005 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. While this was a welcome advocacy accomplishment, 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 PHI 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 have appeared in publications or other public venues are not considered PHI under the Privacy Rule. At the state level, state medical record statutes to need to be brought in line with federal regulations to allow for standardization. Archivists and historians need to also 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 (ALHHS), and the American Association for the History of Medicine (AAHM), 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 between repositories such as this one between Hopkins and Countway through the Medical Heritage Library (MHL) sponsored CLIR Hidden Collections project, enable the creation and promotion of best practices for processing description, and research use of these collections.

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

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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 hopes 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, as 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); United States 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 twenty boxes transferred to the archives as a representative sample from an original 100 boxes of records, indicate that the remaining eighty 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 in to 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, the names of 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.