

## The Opportunities of Engagement: Working with Scholars to Improve Description and Access at the Center for the History of Medicine

*Emily R. Novak Gustainis, Head, Collections Services, Center for the History of Medicine, Francis A. Countway Library of Medicine*

### Abstract


The Center for the History of Medicine has used its two CLIR-funded grant initiatives to engage researchers at all stages of their professional careers in an effort to understand how archival description can be improved or modified to the benefit of scholars while remaining attentive to workflows that speed processing. This paper considers findings from the Center's "Foundations of Public Health Policy" (2008) and "Private Practices, Public Health: Privacy-Aware Processing to Maximize Access to Health Collections" (2012) initiatives.

As the Center for the History of Medicine's (the Center) head of collections services, my day-to-day work focuses on the mechanisms of discovery: systems, standards, and practice. While I occasionally staff the reference desk, it requires planning on my part to meaningfully interact with our researchers and find out if what we are doing on the back end is meeting their needs. Researchers are our prime movers, the reason we kick the gears into action and then examine the cogs, so it is no wonder user assessment is instrumental to trying out new ways to do our work. Over the past seven years and through two CLIR grants, the Center has posed a number of questions to its constituents: How do you prefer to learn about collections? What makes a finding aid useful? What is the minimum amount of information you need to determine if a collection is worth your time? And, most recently, how can we help improve access to records containing health information about individuals? These opportunities to engage fuel our data collection, both on our processes and our products.

I will say up front that there are only two ideas to take away from this paper, and I expect they

are not revolutionary. One, repositories should increase the depth of description for collections that have limited access; and two, approaches to description should better recognize the needs of different disciplines. In my experience, our inclination as archivists is to provide much more description for open collections because they can be used right now, rather than to expend energy helping our users make tough choices about whether or not to go through the process—when it is even possible—of appealing for access to unprocessed collections. Similarly, our urge to suppress catalog records for unprocessed holdings can drastically reduce opportunities for our researchers to discover collections, resulting in missed opportunities to gauge what is of user interest.

With the Center's 2008 grant, "Foundations of Public Health Policy" and 2012 grant, "Private Practices, Public Health: Privacy-Aware Processing to Maximize Access to Health Collections," which was proposed under the auspices of the Medical Heritage Library and conducted in partnership with the Alan Mason Chesney Medical Archives of the Johns Hopkins Medical Institutions, the Center had the opportunity to explore, respectively, the



descriptive needs of a wide variety of researchers and those of medical and social historians needing access to records containing health information about individuals held by both HIPAA (Health Insurance Portability and Accountability Act) and non-HIPAA covered repositories. The results were polar opposites of one another.

### Foundations of Public Health Policy Grant

For “Foundations of Public Health Policy,” the Center committed to building a community of interested public health practitioners, scholars, and students to support the acquisition and use of public health collections and to advise us on collections description and outreach. For descriptive assessment, this included recruiting 52 public health and information professionals, students, and historical researchers to evaluate the use of box and folder lists for the collections we were processing, those of public health and public health administration leaders Leona Baumgartner (1902-1991), Allan Macy Butler (1894-1986), Howard Hiatt (1925-), and David Rutstein (1909-1986). The box and folder lists were grouped by series and delivered online as spreadsheets through a take-home exercise and a post-exercise interview. Our objectives were to:

- Assess how useful researchers found box and folder lists containing select metadata independent of any top-level descriptive information associated with a finding aid (such as biographical notes, subject access point, or series descriptions)
- Ascertain whether or not researchers could perform routine information-seeking tasks associated with identifying materials of interest for research use with just a spreadsheet

- Determine whether a spreadsheet provided enough descriptive information to engender “trust” in the resource researchers were using; that is, to find out whether researchers were comfortable with this resource alone as a determining factor to schedule a research visit

Additionally, the scholarly engagement exercise and interviews were helpful to observe the potential challenges MPLP (or at the Center, what we would consider “appropriate level” processing) and other innovations may present to users. Participants, who were divided across the four collections processed for the project, were asked to complete an exercise (Appendix A) consisting of both general and quantitative multiple choice questions and collection-specific, qualitative questions about how they used two versions of an Excel spreadsheet to answer a number of questions. This included an “A” version spreadsheet with nine elements (box number, folder number, series, subseries, sub-subseries, folder title, begin date, end date, and in the case of Hiatt alone, access restrictions) and a “B” version with additional descriptive information provided in a notes field, such as to indicate the presence of photographs. The average completion time of the exercise was one hour, with the post-assignment interview averaging 30 minutes. In retrospect, it was impressive we had 52 respondents, though we did need to eliminate some of the non-U.S. participant data because of differing interpretations of survey terminology.

From our interviews, we gleaned the following:

- By overwhelming consensus, participants agreed that a spreadsheet was a good enough tool to make preliminary selections about what to look at during a research visit, particularly in conjunction with a collection-level record available through HOLLIS, the online catalog of the Harvard University Library.




- Folder lists without contextual groupings (such as series or subseries) would have been less helpful to discovery. Comments from participants confirmed that folder titles can be “deceptive” on their own. Knowing that a folder named “Meetings with Jane, 1990” is part of a series of teaching records or a series of patient files substantially changes a researcher’s interpretation of a folder title.
- Inexperienced researchers tended to want more descriptive information and preferred spending less time at a repository. Experienced researchers cared only about access. Moreover, experienced researchers stated that regardless of how an archivist handled a collection, they wanted to conduct their own records review. In other words, they were not going to take anyone’s word on what was in a collection or if it was relevant to their work.
- No one was concerned about subject access and only a handful of people mentioned an interest in having more contextual information (beyond groupings) or content-related information.
- Participants cared about record formats. Most liked the “B” version of the spreadsheet with the notes field because the occasional notes provided by processors indicated the presence of photographs or other non-textual items.
- Participants liked the idea of applying a minimal controlled vocabulary to a folder title (“qualifiers”) to help disambiguate folder transcriptions, such as “Writings” or “Correspondence.” However, multiple qualifiers would have to be employed; if you qualify a folder with “writings,” the implication is that the whole thing will be writings, not writings intermixed with correspondence and reference material to support said writings. One individual thought indicating whether

or not a preceding or succeeding folder that had a more descriptive title (such as activities) contained the same type of records as a vaguely titled folder.

- Unless archivists are going to provide a substantial number of folder-level scope and content notes, it does not seem worth providing them at all. Most people did not think folders with notes were “more important,” and very few people assumed Center archivists were making judgment calls on content.
- While most researchers assumed the spreadsheet could be manipulated, such as to sort by date or add columns, they did not do so. They scrolled and keyword-searched the spreadsheets. For two collections, we provided one massive spreadsheet, and for two collections we provided folder lists tabbed out in Excel by series. The tabbed versions of spreadsheets ended up confusing a few participants, particularly those uncomfortable with Excel. Spending time on novel ways to use the spreadsheet was not of much interest.
- Thoughtful accessioning practices can facilitate access in advance of a full finding aid. Public health processors roughly sorted the records into series and subseries in advance of box and folder listing. The more astute we are about doing this at the point of acquisition or accessioning, the faster we can enable meaningful access in lieu of full finding aids.

As a result of the grant, our then acquisitions archivist—and what is now our acquisitions team—spends much more time grouping and packing records up front and on-site with the donor when feasible. Because all acquisitions are listed before being sent to off-site storage, the result is a higher-quality collection inventory that is easier for public services staff to navigate and a resource that speeds processing planning. We are also far



more comfortable allowing researcher access to unprocessed collections.

### Private Practices, Public Health Grant

In 2012, the Center partnered with the Alan Mason Chesney Medical Archives of the Johns Hopkins Medical Institutions to process the papers of seven leaders in public health research and advocacy. The grant, “Private Practices, Public Health: Privacy-Aware Processing to Maximize Access to Health Collections,” addressed issues of access in both HIPAA and non-HIPAA covered entities, seeking best practices for archivists facing challenges and confusion over making health-related records in their collections available. Specifically, the project sought to: a) understand the informational needs of scholars seeking to use restricted records and what they consider most valuable to research; b) evaluate how language used by the Center and Hopkins to communicate restrictions in finding aids correlates with the perceived utility of the finding aid and the potential of the collection to satisfy a research need; and c) get feedback on the process for applying for access to collections with restricted records.

To do so, the Medical Heritage Library, represented by the Center’s Kathryn Hammond Baker, Scott Podolsky, and Emily Novak Gustainis, and Hopkins’s Phoebe Evans Letocha, led discussion sessions, launched an online survey, presented at professional conferences, and ultimately distributed Novak Gustainis and Evans Letocha’s jointly authored [“Recommended Practices for Enabling Access to Manuscript and Archival Collections Containing Health Information about Individuals”](#) to the research and professional communities for feedback. While this engagement work was under way, Center and Hopkins staff were simultaneously processing collections, including the Center’s collections of the papers

of Oliver Cope (1902-1994), Stephen W. Lagakos (1946-2009), Erich Lindemann (1900-1974), and Arnold S. Relman (1923-2014), as well as the records of the Harvard School of Public Health’s Department of Biostatistics, 1981-2009.

Efforts included:

- A SurveyMonkey survey (Appendix B) on access to health records, “Research Access to Protected Records Containing Health Information about Individuals,” was distributed to the Medical Heritage Library governance committee and circulated to professional and discipline-directed listservs. In total, 63 people responded. Data obtained as a result of the survey were analyzed for engendering discussions between archivists and historians and informing the creation of the Recommended Practices document.
- A workshop for Harvard University’s History of Medicine Working Group, comprising graduate students and faculty from the History of Science Department, which included an interactive review of finding aids for collections containing restricted records and a discussion of the type of descriptive content researchers might need to evaluate the usefulness of the records for research.
- A lunch workshop at the 2014 annual meeting of the American Association for the History of Medicine (AAHM) to elicit the information historians need to determine whether or not it is worth applying to an Internal Review Board (IRB), what information is most useful to them, and what they think is missing from finding aids. As part of the session, historians Janet Golden, Rutgers University, and Cynthia Connolly, University of Pennsylvania, shared with the audience their research experiences and difficulties using patient records to inform




their research and launched a discussion of how to improve the user experience.

- A presentation at the 2014 Annual Meeting of the Society of American Archivists in Washington, DC. The session, “Partners in Practice: Archivists and Researchers Collaboratively Improving Access to Health Collections,” offered 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 of The Ohio State University and included a presentation by John Harley Warner of Yale University, “Why Patient Records Matter to the Historian.”

As a result of these efforts, it became clear that because of the complexities related to applying for access to records containing health information about individuals—whether closed to comply with HIPAA, state law, or institutional policy—different kinds of descriptors were necessary. When survey participants were asked whether or not they could apply to a review board to obtain access, only 56.14 percent (32) had access to a review board, and of the 32 individuals who did have access, only 56.25 percent (18) actually went through the process. Respondents said it took too much time—especially when they learned about the restrictions only when they were already on-site, were not convinced they would actually get access if they went through the process, or believed that they lacked support or guidance. Respondents stated that the most significant barrier to using records containing confidential/protected health information held by special collections, archives, and museums was lack of information about the records themselves and access procedures, stating, “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.”

Researchers simply needed more information to help them make decisions. As professionals, we cannot control what the Internal Review Board or Access Board applications require or how frequently they meet, but we can provide more description. Offering samples of variables found in the records, such as patient diagnosis or condition; the age, gender, and race of patients; and the types of medications or procedures, can make a difference. Better indicating the kinds of records in a collection (patient histories vs. case files vs. medical records, rather than just “patient records”) and providing more explicit statements at the folder level indicating why the folder is restricted, and for how long, can also help. For example, all of the Center’s finding aids authored for the grant include descriptive information about the type of restrictions found in the collections, why they were imposed, and how to obtain access. At the folder level, the Center provided a transcription of the full folder title (redacting patient names), the year the records will open to the public, and a qualifying description in the form of a folder-level scope note to convey the intellectual contents of the folder without revealing protected information. Because the Center is a non-HIPAA covered entity, access restrictions were determined by sampling the content of records in each folder. Hopkins, a HIPAA-covered entity, has a similar descriptive approach, except Hopkins staff must screen documents at the item level for protected health information. Readers are encouraged to review the paper “The Practice of Privacy” by Emily Novak Gustainis and Phoebe Evans Letocha, in this volume, for more detailed information about the descriptive process.



So how do we balance the needs of users who are seemingly satisfied with a structured box and folder list on one side of the continuum and those that want the kind of information that can only be gleaned by labor-intensive sampling? Perhaps for public health and other to-be-determined collections with little or no patient records, we should scale back on descriptive processes, letting the collections do the talking while we ramp up efforts to describe records that do not easily present. Archivists can also become more comfortable describing boxes of access-protected records only at the container or series level, focusing on the records that comprise a series more holistically. Flexible and appropriately applied approaches to processing can be built only through concerted efforts to understand the needs of our multiple constituencies. The Center is now testing the best

practices developed for the description of collections containing health information about individuals on the Dwight E. Harken papers, 1930s-1990s, and should be completed concurrent to the symposium. We look forward to sharing the finding aid with members of the community for feedback.

## References

Gustainis, Emily. 2015. Now Available! Recommended Practices for Enabling Access to Manuscript and Archival Collections Containing Health Information About Individuals (Feb. 12). Available at <http://www.medicalheritage.org/2015/02/now-available-recommended-practices-for-enabling-access-to-manuscript-and-archival-collections-containing-health-information-about-individuals/>.



## APPENDIX A: Example User Study: “Foundations of Public Health Policy” (2008)

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*Center for the History of Medicine, User Study,  
2009–2010*

**A**s part of its Foundations in Public Health Policy grant work, the Center for the History of Medicine, Countway Library, is conducting a study to document and analyze how researchers use and respond to different access tools developed for delivering information about its collections to the public. This grant, as funded by the Andrew W. Mellon Foundation and administered by the Council on Library and Information Resources (CLIR), has enabled the Center to experiment with ways to make collections available to researchers over shorter periods of time. Your participation in this study will help us determine the efficacy and utility of these tools.

The study consists of two parts:

1. An exercise consisting of both multiple choice survey questions and detailed questions designed to assess how participants use two different versions of a spreadsheet to answer questions about a collection. *We estimate that it will take about one hour to complete the study exercise.*
2. An interview (either at the Center or via conference call) that will focus on content and usability issues related to how you used the spreadsheets to complete the exercise. *We estimate the interview to take between thirty minutes and one hour.*

We sincerely appreciate your taking the time to participate and provide feedback. We are happy to answer any questions you might have about the project. Please contact Michael Dello Iacono, Project Archivist, [MPD13@hms.harvard.edu](mailto:MPD13@hms.harvard.edu), and Emily R. Novak Gustainis, Collections Services Archivist, [ERN6@hms.harvard.edu](mailto:ERN6@hms.harvard.edu).



## A. Introductory Questions

### 1. How would you identify yourself?

- \_\_\_\_\_ A new/inexperienced researcher who has not used many archival or manuscript collections
- \_\_\_\_\_ An experienced researcher who has visited a number of archives and used a number of archival or manuscript collections
- \_\_\_\_\_ A person in the Public Health Field new to archival research
- \_\_\_\_\_ A person in the Public Health Field who is an experienced researcher
- \_\_\_\_\_ An information professional (librarian, archivist, metadata specialist, etc.)

### 2. How comfortable are you conducting research online and using electronic resources?

1	2	3	4	5
Very comfortable			Very uncomfortable	

### 3. How many archives have you visited in the last three years to conduct primary research?

- a) 0 repositories                      b) 1–5 repositories
- c) 6–10 repositories                  d) More than 10

### 4. Have you been unable to use a collection at a repository because it was unavailable for research use (or was “unprocessed”)? (Please circle)

Yes      No

### 5. If so, how many times during the last three years? \_\_\_\_\_

### 6. Which statement best reflects how you feel about the amount of time an archives or special library takes to provide public access to a new collection you are interested in using?

- a) I would rather have a repository provide access to a collection (or part of a collection) that has been minimally reviewed for research use (for example, only has a box list) so long as the collection is made available to the public as soon as possible.
- b) I would rather wait until a collection has been well organized and thoroughly documented for optimal research use, even though it may take longer for the repository to make it available to the public.





### 7. Which is more important to you?

- a) Being able to spend less time at a repository because I have very detailed information about a collection and know exactly what to have pulled for me, even if it means I might not be able to access a collection in the immediate future while this type of information is being collected.
- b) Having access to a collection, even if it means I may need to spend a lot of time at a repository searching for the information I want.

### 8A. If you could only have ONE of the following discovery tools, which would you rather have available to you online and in ADVANCE of your visiting the Center for the History of Medicine?

- a) A detailed summary of a collection's content, biographical/institutional information about the creator(s) of the collection, and information about what kinds of documents are in the collection, including date spans for all materials.
- b) A spreadsheet containing a list of every folder "title" in every box of the collection as it was originally labeled by the person who created or assembled the collection.

### 8B: Why did you pick A or B?

### 9. Which is more important to you?

- a) Being able to simultaneously search for subjects or people across many finding aids in order to discover which collections at a particular repository may help me with my research.
- b) Being able to print an inventory for, or guide to, a collection for personal reference use from a list of collections posted on a repository's website.

## B. Spreadsheet-Specific Questions

### Part B-I


To complete Part B-I, please copy and paste the following location into your web browser: <http://repository.countway.harvard.edu/xmlui/handle/10473/3600>

Under "Sample Submissions," select the file: CLIR\_baumgartner\_boxlist\_A.xls

Under "Associated Files," click on "View/Open" for the file: CLIR\_baumgartner\_boxlist\_A.xls

*Please take a few minutes to look at the spreadsheet and then answer the following questions. Please feel free to cut and paste answers from the spreadsheet into this Word document.*

1. What are the five major groups of records found in the collection?

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2. Pick two of the groups you identified in question 1. What kinds of information would you expect to be in these groups of records?
  3. What types of materials would you expect to find in the collection?
  4. Why?
  5. In what year did Baumgartner travel to Russia?
  6. Please name two of Baumgartner's published articles from the 1950s.
  7. What steps did you take to answer to questions 5 and 6?
  8. How much material is there in the collection related to speeches given by Baumgartner?
  9. What steps did you take to answer question 8?
  10. If you were looking for letters between Baumgartner and her family members, where would you expect to find them?
  11. Please list three individuals Baumgartner corresponded with.
  12. From 1954-1962, Leona Baumgartner served as Commissioner of Public Health for the city of New York. Where would you look for records in the collection that relate to Baumgartner's public appearances as Commissioner?
  13. You are researching the activities of the American Public Health Association (APHA) in the 1950s and 1960s. Which boxes would you ask to see?
  14. How would you find out if there were items from the 1970s?
  15. How would you determine how much material from the 1970s is in Series 4?
  16. Did you need to print the spreadsheet in order to answer the above questions?
  17. Did you save the spreadsheet to your desktop or local drive before working on the questions?

### **Part B-II**

To complete Part B-II, please copy and paste the following location into your web browser:

<http://repository.countway.harvard.edu/xmlui/handle/10473/3600>

Under "Sample Submissions," select the file: CLIR\_baumgartner\_boxlist\_B.xls

Under "Associated Files," click on "View/Open" for the file CLIR\_baumgartner\_boxlist\_B.xls



*Please take a few minutes to look at the spreadsheet and then answer the following questions. Please feel free to cut and paste answers from the spreadsheet into this Word document*

1. Summarize the kind of information provided in the “Notes” column.
2. What types of materials would you expect to find in the collection?
3. Baumgartner delivered many speeches and lectures throughout her career. Please name two people who delivered a talk along with Dr. Baumgartner.
4. Please explain how you found the above answer.
5. Do folders with notes in the “Notes” column contain more important documents?
6. Please list the question numbers in section B-I that you would now answer differently having seen the “Notes” column.

## APPENDIX B: Private Practices, Public Health Survey (2012)

### Survey on Research Access to Protected Records Containing Health

#### About the survey

This survey is being conducted by the Center for the History of Medicine, Francis A. Countway Library of Medicine, and the Alan Mason Chesney Medical Archives of the Johns Hopkins Medical Institutions as part of a joint effort to develop best practices for enabling access to special collections containing protected health information (PHI) and other types of access-protected ("restricted") records. For the purposes of this survey, health information (protected or otherwise) is defined according to the HIPAA Privacy Rule (1996) as:

"Information, including demographic information, which relates to: 1) an individual's past, present, or future physical or mental health or condition, 2) the provision of health care to the individual, OR 3) the past, present, or future payment for the provision of health care to the individual, AND that identifies the individual or for which there is a reasonable basis to believe can be used to identify the individual. Protected health information includes many common identifiers (e.g., name, address, birth date, Social Security Number) when they can be associated with the health information listed above."

For example, per HIPAA, a medical record, laboratory report, or hospital bill would be PHI because each document would contain a patient's name and/or other identifying information associated with the health data content.

By responding to this survey, you are helping libraries and archives improve how they describe records and make hidden collections available to researchers in more useful ways.

Thank you!

#### Finding aids and access

##### 1. Have you used manuscript collections or archival records as part of your research?

- Yes  
 No

##### 2. If yes, have you used a collection guide ("finding aid") that included information about whether or not patient or other health-related records in the collection had access restrictions?

- Yes  
 No

##### 3. How have you learned about the presence of restricted records for the majority of the collections you have used (or were interested) in using?

- A librarian or archivist  
 Online using a finding aid  
 Online using a library catalog record

Other (please specify)



## Survey on Research Access to Protected Records Containing Health

### 4. What are the kinds of records you were interested in using, but were restricted? Check all that most often apply:

- Medical records and indices (whether patient, diagnostic, or other) maintained by a healthcare provider, such as a hospital or medical practice
- Medical imaging records, such as x-rays
- Photographs of patients
- Psychiatric or other mental health-related records, such as psychotherapy notes
- Research records (such as datasets, human subject research information, etc.) that contain personally identifiable information ("personal identifiers"), such as names, addresses, phone numbers, medical records numbers, etc.
- Other (please specify)

### Use of IRB

### 5. Was submitting a request to an Internal Review Board (IRB) to use the records a possibility?

- Yes
- No

### 6. If yes, did you end up submitting an IRB to access the records you were interested in using?

- Yes
- No

### 7. If no, why not?

### Barriers to use



## Survey on Research Access to Protected Records Containing Health

### 8. What do you think is the most significant barrier to your use of records containing confidential/protected health information held by special collections, archives, and museums?

- The IRB process takes too long
- Too much paperwork is required to get access to restricted records
- I see records that look interesting in catalogs or collection guides, but I can't tell if they will be useful
- Nothing is digitized
- Repositories aren't open when I have time to do my research
- I don't think I'll be able to quote, reference, or use the records in publications
- No one will tell me if I can use the records or not
- This does not apply to me. There are no barriers to my use of records

Other (please specify)

### 9. What descriptive information do you think is missing from library catalog records or collection guides (such as those for a manuscript collection)? What information would be most useful to you in deciding whether or not a collection has information relevant to your research?

### Ways to Maximize Access



## Survey on Research Access to Protected Records Containing Health

**10. How useful would having the following descriptive information be in determining whether or not you would submit an IRB to use restricted records containing protected health information?**

	Not very useful	Somewhat useful	Very useful	Does not apply to my research
Average age of patients at time of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Date span of records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diagnosis/condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Duration of treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Geographic region covered	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Names of medical devices used	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prescribed medications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Race of patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sex of patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Surgical procedures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treating physician/surgeon	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>			



## Survey on Research Access to Protected Records Containing Health

### 11. How useful would knowing that the following record formats were in a group of restricted records be to your determining whether or not to submit an IRB?

	Not very useful	Somewhat useful	Very useful	Does not apply to my research
Admission/registration records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Autopsy records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Billing information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Case files	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Consultation files	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Correspondence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diagnostic indices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family medical histories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic testing records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Graphs and charts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hospital policies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Immunization records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insurance claims	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Informed consent records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lab notebooks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Microscope slides/specimens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Photographs/medical imaging	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient histories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient questionnaires	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient summaries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prescription books/logs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research protocols	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Surgical logbooks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify)	<input type="text"/>			

### Comments and Demographics

#### 12. Do you have comments regarding access to special collections containing health records?





## Survey on Research Access to Protected Records Containing Health

### \* 13. How do you identify yourself?

- A student (any field)
- A professor/instructor of history, the history of medicine, or the history of science
- A professor/instructor of another Humanities sub-discipline or a different discipline
- A researcher (no academic affiliation)
- A physician or healthcare provider with an interest in the history of medicine or science
- A librarian or archivist

### 14. How long have you identified as the above?

- 1-5 years
- 6-10 year
- 11-15 years
- Over 15 years

### 15. If we have questions about your responses to the survey, can we contact you to follow-up?

- Yes
- No

### 16. If so, please provide your name, affiliation, and email address:

THANK YOU FOR YOUR PARTICIPATION!