Thank You

Thank you for submitting your annual report. We look forward to reading it and will contact you should we have any questions. A record of the responses you have provided is displayed below for your convenience. You should also receive a copy of your report, including all uploaded files, at the email address you've provided. If you do not receive this email, check your institution's spam filter; if it is neither in your inbox nor quarantined, please write to hiddencollections@clir.org to confirm receipt.

If there are ways CLIR could improve this form to make reporting easier for you, we would appreciate receiving your feedback and/or suggestions at hiddencollections@clir.org.

Award reference number

41200614

Project title

Private Practices, Public Health: Privacy-Aware Processing to Maximize Access to Health Collections

Lead institution/organization

Harvard University

Project P.I.(s)

Kathryn Hammond Baker, Deputy Director, Center for the History of Medicine, Harvard Medical School and Phoebe Evans Letocha, Collections Services Archivist, Alan Mason Chesney Medical Archives of The Johns Hopkins Medical Institutions

Contact name and title

Kathryn Hammond Baker, Deputy Director, Center for the History of Medicine, Harvard Medical School

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Goals and objectives

1. Participant information exchange and implementation of project time and labor tracking. Both Evans Letocha and Novak Gustainis trained and oriented project staffs at their home institutions, as well as conducted cross-training/information sessions via conference call throughout the project. Because the Hopkins online-HIPAA module and Harvard Medical School's training modules turned out to be identical, access to the Hopkins module was deemed unnecessary. In lieu of actual legal counsel training sessions, Evans Letocha shared Hopkins policy documents with Center staff; additional information was gathered from U.S. government websites.

In advance of the March 1, 2013 project start date, Gustainis worked with Evans Letocha to customize a copy of MD specific to Hopkins and they collaboratively determined how discreet processing activities relative to applying restrictions should be recorded. Both institutions were prepared for Day 1 collection of data to support workflow analysis. (Specifically, how the different institutional approaches to applying restrictions affect length of processing time as a whole, as well as for discreet processing activities.) Preliminary analyses for the types of restrictions found in Countway-processed collections were compiled by Amber LaFountain and Bryan Sutherland under the direction of Novak Gustainis and are attached as Appendix C. Timing data for the collection will be generated in the coming months to use in conjunction with, and to contextualize, our investment in this process.

2) Creation of "privacy aware" finding aids and collocation of practices. Both Countway and Hopkins created (or are in the process of creating) DACS-compliant description, MARC (or MARC compliant) collection-level records, and EAD2002-compliant encoded finding aids. All Countway finding aids include descriptive information about the type of restrictions found in the collections, why those restrictions have been imposed, and how access to records may be obtained. For each folder, Countway has provided a transcription of the full folder title (redacting patient names), provided the year the records in the folder will be open to the public, and applied a qualifying description in the form of a folder-level scope note to convey the intellectual contents of the folder without revealing protected information. Links to finding aids may be found in the "Presentations and Publications" section.

Hopkins, which is in the process of authoring its finding aids, will also provide a transcription of the full folder title, however, it is identifying documents at the item level that include protected health information (PHI) and redacting PHI from the description.

3) Dissemination, evaluation, and promotion of privacy aware descriptive products. Countway and Hopkins are in the process of examining the benefits and disadvantages of each of our workflows and will continue to seek feedback throughout the remaining grant period specific to: a) how the language used 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; b) the informational needs of scholars seeking to use restricted records and what they consider most valuable to research; and c) feedback on the process for applying for access to collections with restricted records. To this end, in January, Countway and Hopkins launched an online survey to engage the community's opinions and perspectives on access to collections containing protected health information (see Appendix D for survey instrument or visit https://www.surveymonkey.com/s/M25BFXF). Both institutions presented the survey to the Medical Heritage Library governance committee (of which both are members) and the survey was circulated on professional and discipline-directed listservs. At this time, 61 people have responded. The data will be analyzed in April and will be presented as part of an American Association of the History of Medicine (AAHM) lunch workshop in Chicago this May. The workshop, "Negotiating Access to Patient Related Materials: A Conversation between Archivists and Historians," will serve as an opportunity to engage researchers on what they need to know to determine whether or not it is worth applying to an IRB to use restricted records and what information is most useful to them or missing from finding aids.

In addition to the AAHM lunch session, Countway and Hopkins also successfully submitted a session proposal for the August 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," will take place on Thursday, August 14. The session offers perspectives from both the historian/researcher perspective and the archivist; speakers include John Harley Warner (Yale), Evans Letocha, and Novak Gustainis, and will be moderated by Susan Lawrence (Ohio State University). 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, 1801-present, tentatively titled Bedside Stories: Clinical Narrative and the Grounding of Modern Medicine. Lawrence, also a historian, works on the intersections of history and research ethics, most recently with her article, "Access Anxiety: HIPAA and Historical Research," in the Journal of the History of Medicine and Allied Sciences.

4) Creation of privacy processing guidelines for public consumption. Evans Letocha and Novak Gustainis have started to compile project documentation and draft an approach to authoring guidelines/best practices relevant to enabling access to health collections for mass distribution, as well as how a processed collection in which protected information is identified and/or segregated can best be digitized. Our commitment to scholarly engagement, described in our proposal as discussions with fifteen researchers, has already been met via Countway's access workshop and interviews with active researchers. Sessions at AAHM and SAA sessions will open up further discussions with many more scholars.

Outcomes and deliverables

In addition to the accomplishments discussed in the Goals and Objectives section, the project has yielded:

• Preliminary restrictions analyses for Countway CLIR-processed collections [see Appendix C]. Restrictions data and time and labor data for all grant collections will be analyzed, interpreted, and compared by August 1 for reporting at SAA.

• Outreach: Countway and Hopkins have utilized their websites, the project wiki, the MHL website, Twitter, and listservs to inform professional and research communities about processed collections and project progress.

The timing data and outreach activities, as well as the processing deliverables and best practices document, will cumulatively produce the following outcomes:

• Awareness of new collections open to research that builds on the rich public health resources already available at collaborator institutions, including the public health collections opened at the Countway as a direct result of its 2008 CLIR initiative

• Strengthened communications between archivists and their user communities and improved professional discourse of the subject of access restrictions

• Changes in the ways both collaborator institutions describe health-related records and present access restrictions in their finding aids that are responsive to researcher needs

• Increased awareness in the special collections arena about the relevancy of HIPAA and how to provide access to collections with protected content

• A wiki and best practices resource for the archival community to utilize and which it can contribute

Please see attached compilation of supporting Appendices:

A. Detailed processing status report for Hopkins collections

B. Countway/History of Medicine Working Group Preliminary Recommendations

C. Analysis for restrictions found in Center for the History of Medicine project collections

D. Instrument: Survey on Research Access to Protected Records Containing Health Information About Individuals

E. Johns Hopkins CLIR Financial Report, March 2013 - February 2014

Other accomplishments or promising developments

Emily Novak Gustainis (Countway) conducted an interview with Edmund Ramsden, a Wellcome Trust Fellow, on his use of the Erich Lindemann papers. Ramsden is the first scholar to use the Lindemann papers, accessing the collection only months after processing was completed. Feedback on the application of folder-level restrictions information and its presentation in the finding aid was extremely positive – Dr. Ramsden reported, "It is the best finding aid I have ever used."

Challenges

Due to administrative obstacles, we started six weeks late (April 15, 2013). However, the extension received will allow us to complete the deliverables as proposed: processing, analysis of the researcher survey, and draft guidelines and recommendations. It will further encompass work not originally conceived as part of the grant proposal: presentations to scholars and archivists at the annual meetings of ALHHS, AAHM, and SAA via panel sessions, analysis of their feedback, final guidelines, and plans for post-grant work.

While not a setback or a challenge per se, Hopkins utilizes student workers to do much of the physical processing of collections. Because they are students, Hopkins invests a significant amount of time training new students each semester. Time and labor tracking was not initially proposed for either institutions' implementation of MD; however it was added at a later date and time estimates were approximated by the Hopkins project archivist.

Hopkins also employs a processing methodology that is premised on a wider distribution of processing labor, and processed grant collections concurrently, rather than serially. For this reason, the project archivist manages collections that are at various stages of completion at any given time. This makes it difficult to gather preliminary timing data from Hopkins until all processing is complete.

Project personnel

Maura Marx, formerly of the Open Knowledge Commons (OKC) and originally a principal investigator on the grant left OKC prior to the grant start-up date in early 2013. As a result, Harvard

University was designated to administer the grant project and manage financial disbursements. However, all other project personnel and their roles are as proposed:

• Kathryn Hammond Baker, P.I., and chair of the Medical Heritage Governance Committee, has managed the disbursement of project funds, participated in interviews with scholars relevant to the utility of grant-produced finding aids, participated in project survey design, and, with Novak Gustainis, relayed project progress and concerns to the Medical Heritage Library Governance Committee

• Phoebe Evans Letocha, P.I., manages local staff. She serves on the Medical Heritage Library's Governance Committee and provides regular updates on the status of the project. She contributes toward the local development, testing, evaluation, and documentation of the workflow. She supervises and trains staff in the identification of restricted information within project collections. She collaborated with colleagues at Countway in the design, distribution and preliminary review of survey sent out to scholarly community on access restrictions in archival collections. She submitted session proposal for American Association for the History of Medicine annual meeting.

• Emily R. Novak Gustainis, Project Manager (Countway), manages local staff, processing workflows, and the project implementation of MD. Gustainis participates in the Medical Heritage Library's Governance Committee meetings and with Baker and Evans Letocha, designed, distributed, and promoted the project's survey on access restrictions in archival collections. Gustainis submitted the proposal for the 2014 Society of American Archivists Annual Meeting.

• Amber LaFountain, Project Archivist (Countway), processed, described, and created the publicly accessible finding aid for the Erich Lindemann papers, and is currently processing the Oliver Cope papers. LaFountain collaboratively developed collection processing plans, managed one processing assistant, and has generated publicity for the project through blog posts and a conference presentation.

• Katherine Mika, processing assistant to LaFountain (Countway), rehoused, box and folder listed, and performed preservation photocopying as necessary for grant collections. Mika is also helping prepare descriptive information for the Oliver Cope papers.

• Linda Klouzal, Project Archivist for Hopkins, developed arrangement and processing plans for Hopkins collections and plans and tracks project workflow. Klouzal directly trains and supervises student employees assigned to the project. Along with students, she sorts, rehouses, and catalogs collection

materials. She creates higher level descriptive records. She reviews and edits collection catalog entries created by students. She authored and edited blog posts on project for Medical Heritage Library.

• 8 undergraduate and 2 graduate student assistants (Hopkins). Sorting, rehousing, and cataloging collection materials.

Presentations and publications

Finding Aids

Two new findings aid and four new or revised bibliographic catalog records were published by the Center for the History of Medicine in OASIS, the online portal to guides to special collections held by the Harvard University Library, and the OPAC of Harvard University, respectively, prior to the submission of this interim report:

• Stephen W. Lagakos papers, 1979-2009 (inclusive), 1995-2009 (bulk): http://nrs.harvard.edu/urn-3:HMS.Count:med00185 (finding aid);
http://discovery.lib.harvard.edu/?itemid=|library/m/aleph|013759100 (catalog record)

• Erich Lindemann papers, 1885-1991 (inclusive), 1950-1974 (bulk): http://nrs.harvard.edu/urn-3:HMS.Count:med00191(finding aid); (catalog record)

• Harvard School of Public Health, Department of Biostatistics records, 1981-2009 (inclusive), 1999-2003 (bulk): (catalog record)

• Arnold S. Relman papers, 1953-2011 (inclusive), 1974-2011 (bulk):
http://discovery.lib.harvard.edu/?itemid=|library/m/aleph|012678021 (catalog record)

Please note that the Department of Biostatistics records were formerly part of the Lagakos collection, but separated from his professional papers due to differing provenance.

Presentations/Workshops

• Kathryn Hammond Baker and Emily R. Novak Gustainis held a workshop on March 10, 2014 for faculty and students of Harvard University's History of Science department on accessing historical patient records. The workshop included an interactive review of finding aids that describe restricted

records, a discussion of the type of descriptive elements and content that researchers might need to evaluate the usefulness of the records for research. Recommendations stemming from this workshop may be found in Appendix B. Presentation slides may be found on the wiki: https://wiki.med.harvard.edu/pub/Countway/ArchivalCollaboratives/EXTRELATEDRESOURCES/HMWG2014March10_slides.pdf

• Using the Erich Lindemann papers as the predominant example, Project Archivist Amber LaFountain presented on processing collections containing restricted records as part of the Spring 2014 New England Archivists meeting session, "Perfecting the Process: Working with digital records, access restrictions, retention decisions, and evolving policies while processing manuscript and corporate archival collections" (see program for Friday, March 21, 2014 at: http://newenglandarchivists.wildapricot.org/2014_SpringMeetingSchedule; slides are available here: https://cms.www.countway.harvard.edu/wp/wp-content/uploads/2014/03/LaFountain_NEA_March2014_Final.pptx).

Blog Posts

The following blog posts were issued by Countway and Hopkins between March 1, 2013 and March 31, 2014:

• https://cms.www.countway.harvard.edu/wp/?p=7402 (Countway/Project announcement, 5/15/2013)

• http://www.medicalheritage.org/2013/05/countway-and-hopkins-receive-mellon-foundation-grant/ (Center/Hopkins Project announcement, 5/15/2013)

• http://www.medicalheritage.org/2013/10/update-on-clir-project-at-chesney-medical-archives/ (Hopkins/Project update, 10/2/2013)

• http://www.medicalheritage.org/2013/10/processing-of-the-erich-lindemann-papers-nearing-completion/ (Center/Lindemann update, 10/23/2013)

• http://www.medicalheritage.org/2013/10/have-you-heard-about-the-hardys/ (Hopkins/Hardy post, 10/30/2013)

• https://cms.www.countway.harvard.edu/wp/?p=8347 (Countway/Relman processing announcement, 12/2/2013)

• https://cms.www.countway.harvard.edu/wp/?p=8404 (Countway/Survey announcement, 1/17/2014

• https://cms.www.countway.harvard.edu/wp/?p=8749 (Countway/Lindemann papers opened to public)

• https://cms.www.countway.harvard.edu/wp/?p=8760 (Countway/NEA Perfecting the Process Panel session, 3/28/2014)

• https://cms.www.countway.harvard.edu/wp/?p=7899 (Countway/Lagakos papers and Biostatistics Dept. records open)

Future plans

Processing

The Center for the History of Medicine will finish processing the Oliver Cope papers in April 2014; Hopkins will finish processing the Barbara Starfield collection by April 30, 2014 and commence processing the E.V. McCollum collection at the end of April; processing will be completed by June 30.

By August 30, seven new finding aids will be published (Cope, Dept. of Biostatistics, Relman, Starfield, Polk, Hardy, McCollum).

Presentations

Project collaborators will have held two sessions by the conclusion of the project, the luncheon session at AAHM and the SAA session, as detailed in the narrative.

Publications

By September 30, Countway and Hopkins will have finalized a guidance and best practices document, published it on the wiki, and disseminated information about the document via professional listservs and print publications.

Research

Additional research will include a survey of finding aids with health information for descriptive comparison to those generated by the project.

APPENDIX A: Annual/Interim Report CLIR
March 31, 2014

Johns Hopkins Medical Institutions, Alan Mason Chesney Medical Archives

Collections:

Barbara Starfield Collection

Format: Text, Image, Book, Manuscript, Data Set, Artifact

Collection Size: 84 boxes (98.5 cubic feet) and 8.18 GB of digital files.

Status: Collection boxes are completely inventoried, and partial collection description drafted. Work has just started on linking folder records to the series records according to arrangement plan (17 cubic feet completed). This work is progressing quickly and should be complete by the end of April. Work that remains: screening of series and folders. Description of restrictions on the series and folder records as appropriate. Physically process and catalog 1.2 cubic feet of photographs. Complete the collection description. Editing and publication of finding aid.

B. Frank Polk Collection

Format: Text, Image, Book, Manuscript, Data Set

Collection Size: 31 boxes (37.6 cubic feet) at start of processing; 25 boxes (28.6 cubic feet) at end of processing

Status: Collection has been physically processed and described. 14.9 cubic feet of the collection folders have been screened for restrictions and have screening notes in the catalog records, and 13.7 cubic feet remain to be screened. Description of restrictions on the remaining series and folder records will be added as appropriate. Once screening is complete, staff will edit and publish the finding aid.

William George Hardy and Miriam Pauls Hardy Collection

Format: Text, Image, Audio, Book, Manuscript, Artifact

Collection Size: 25 boxes (27.6 cubic feet) at start of processing; 23 boxes (24 cubic feet) at end of processing

Status: Collection has been physically processed with the exception of the photograph series (2 cubic feet). Collection folders representing 5 cubic feet have been screened for restrictions and have screening notes in the catalog records, and 19 cubic feet remain to be screened. Description of restrictions on the remaining series and folder records will be added as appropriate. Once screening is complete, staff will edit and publish the finding aid.

E.V. McCollum Collection

Format: Text, Image, Audio, Book, Manuscript, Artifact

Collection Size: 14 boxes (16 cubic feet)

Status: unprocessed. Processing will begin in April.

APPENDIX B

List of researcher recommendations re: finding aids and patient records
History of Medicine Working Group meeting, 10 March 2014

1. Provide information on the types of restrictions and outline the steps a researcher needs to take to apply for access.

2. Provide a sample/model completed Access Board application. Something to help guide researchers on how to fill out the application.

3. Clearly state Public Services is available to advise them on 1) making a case for access and 2) how redaction can be accomplished so that the researcher can include that information in an Access Board application.

[For 1 -3, I see there being a need to add a new page in the "Research and Access" section on the website related to restrictions with a downloadable version of the Access Board Application, a model application, and a statement to the effect of "unprocessed collections may be accessible if there is a demonstrated need."]

4. If an Access Board request is approved, researchers want explicit information about whether or not they can quote/cite the records. Jess mentioned that the Board often returns applications with the "other" box checked, which can also be confusing.

5. Provide links to sample records, such as surveys, protocols, codebooks, etc. [Samples would need to characterize a group of records, not be a random selection. Could put in Omeka or in the DRS.]

6. It is more helpful if groups of records (such as correspondence) include some indication as to the content, especially if there are clearly articulated topics/threads or named correspondents. It was indicated that this can be difficult to do because processors can't look at everything and that processors do not want to emphasize one subject over another as it may be considered interpretive on the part of the archivist. [The compromise would be to sample and overtly state that the topics of the correspondence are the product of sampling.]

7. More information about the processing practices employed. Talk about sampling/what we do. [While this has improved, we can always do more]

8. A way for researchers to leave feedback/notes about a collection that the next user of the collection could access

9. Reconsider how we present our holdings information. Bibliographic records with the "Unprocessed. Closed to research" notice in the Holdings/852 display can scare away new researchers from putting in a request to use an unprocessed collection, while the "severity" of

the note is intended to discourage anyone and everyone from trying to get at unprocessed records before they can be properly cited, etc. Most often, inexperienced researchers won't contact us, so we don't know how many people would actually like to use that collection. Is there a happy medium? Requests for unprocessed collections inform processing planning and we do permit access to unprocessed collections when possible.

APPENDIX C1: Lindemann papers restrictions analysis

	# Folders	Harvard University Records - 80 years	Harvard University Records - 50 years	Medical / patient / health records	Psychiatric / mental health records	Student Records	Density of personally identifying information	Total Restricted
Collection Totals:	**4451**	**792**	**286**	**8**	**437**	**28**	**1**	**1552**
Percentage of total collection:	**100%**	**17.794%**	**6.426%**	**0.180%**	**9.818%**	**0.629%**	**0.022%**	**34.869%**
Percentage of Restricted Folders:	n/a	**51.031%**	**18.428%**	**0.515%**	**28.157%**	**1.804%**	**0.064%**	**100%**
Series I. Professional Appointments Files, 1915-1978, undated								
Series I Totals	2485	729	202	6	67	25	1	1030
Percentage of Total Series	100%	29.336%	8.129%	0.241%	2.696%	1.006%	0.040%	41.449%
Percentage of Restricted Folders:	n/a	70.777%	19.612%	0.583%	6.505%	2.427%	0.097%	100%
Series II. West End Research Project, 1949-1975, undated								
Series II Totals	295	4	3	0	214	0	0	221
Percentage of Total Series	100%	1.356%	1.017%	n/a	72.542%	n/a	n/a	74.915%
Percentage of Restricted Folders:	n/a	1.810%	1.357%	n/a	96.833%	n/a	n/a	100%
Series III. Professional Activities Files, 1929-1974, undated								
Series III Totals	321	3	6	0	1	0	0	10
Percentage of Total Series	100%	0.935%	1.870%	n/a	0.312%	n/a	n/a	3.115%
Percentage of Restricted Folders:	n/a	30%	60%	n/a	10%	n/a	n/a	100%
Series IV. Correspondence, 1925-1974, undated								
Series IV Totals	115	23	0	0	5	0	0	28
Percentage of Total Series	100%	20%	n/a	n/a	4.348%	n/a	n/a	24.348%
Percentage of Restricted Folders:	n/a	82.143%	n/a	n/a	17.857%	n/a	n/a	100%
Series V. Writings and Publications, 1922-1976, undated								
Series V Totals	160	0	0	2	1	0	0	3

	# Folders	Harvard University Records - 80 years	Harvard University Records - 50 years	Medical / patient / health records	Psychiatric / mental health records	Student Records	Density of personally identifying information	Total Restricted
Percentage of Total Series	100%	n/a	n/a	1.250%	0.625%	n/a	n/a	1.875%
Percentage of Restricted Folders:	n/a	n/a	n/a	66.667%	33.333%	n/a	n/a	100%
Series VI. Subject Files, 1885-1973, undated								
Series VI Totals	274	29	49	0	32	2	0	112
Percentage of Total Series	100%	10.584%	17.883%	n/a	11.679%	0.730%	n/a	40.876%
Percentage of Restricted Folders:	n/a	25.893%	43.750%	n/a	28.571%	1.786%	n/a	100%
Series VII. Audio-Visual Records, 1950-1973, undated								
Series VII Totals	431	0	25	0	87	1	0	113
Percentage of Total Series	100%	n/a	5.800%	n/a	20.186%	0.232%	n/a	41.449%
Percentage of Restricted Folders:	n/a	n/a	22.124%	n/a	76.991%	0.885%	n/a	100%
Series VIII. Biographical Files, 1922-1978, undated								
Series I Totals	33	4	0	0	0	0	0	4
Percentage of Total Series	100%	12.121%	n/a	n/a	n/a	n/a	n/a	12.121%
Percentage of Restricted Folders:	n/a	100%	n/a	n/a	n/a	n/a	n/a	100%
Series IX. Collected Publications, 1891-1991, undated								
Series IX Totals	337	0	1	0	0	0	0	1
Percentage of Total Series	100%	n/a	0.297%	n/a	n/a	n/a	n/a	0.297%
Percentage of Restricted Folders:	n/a	n/a	100%	n/a	n/a	n/a	n/a	100%

APPENDIX C2: Lagakos papers restrictions analysis

	# Folders	Harvard University Records - 80 years	Harvard University Records - 50 years	Medical / patient / health records	Psychiatric / mental health records	Student Records	Density of personally identifying information	Total Restricted
Collection Totals:	**417**	**0**	**0**	**65**	**0**	**1**	**0**	**66**
Percentage of total collection:	**100.000%**	**0.000%**	**0.000%**	**15.588%**	**0.000%**	**0.240%**	**0.000%**	**15.827%**
Percentage of Restricted Folders:	n/a	**0.000%**	**100.000%**	**98.485%**	**0.000%**	**1.515%**	**0.000%**	**100.000%**
Series I. Research Records								
Series I Totals	315	0	0	63	0	0	0	63
Percentage of Total Series	100%	0.000%	0.000%	20.000%	0.000%	0.000%	0.000%	20.000%
Percentage of Restricted Folders:	n/a	0.000%	0.000%	100.000%	0.000%	0.000%	0.000%	100.000%
Series II. Writings								
Series II Totals	85	0	0	2	0	0	0	2
Percentage of Total Series	100%	0.000%	0.000%	2.353%	0.000%	0.000%	0.000%	2.353%
Percentage of Restricted Folders:	n/a	0.000%	0.000%	100.000%	0.000%	0.000%	0.000%	100.000%
Series III. Teaching Records								
Series III Totals	5	0	0	0	0	1	0	1
Percentage of Total Series	100%	0.000%	0.000%	0.000%	0.000%	20.000%	0.000%	20.000%
Percentage of Restricted Folders:	n/a	0.000%	0.000%	0.000%	0.000%	100.000%	0.000%	100.000%
Series IV. Professional Organizations Records								
Series IV Totals	6	0	0	0	0	0	0	0
Percentage of Total Series	100%	0.000%	0.000%	0.000%	0.000%	0.000%	0.000%	0.000%
Percentage of Restricted Folders:	n/a	0.000%	0.000%	0.000%	0.000%	0.000%	0.000%	0.000%
Series V. Personal Records								
Series V Totals	6	0	0	0	0	0	0	0
Percentage of Total Series	100%	0.000%	0.000%	0.000%	0.000%	0.000%	0.000%	0.000%
Percentage of Restricted Folders:	n/a	0.000%	0.000%	0.000%	0.000%	0.000%	0.000%	0.000%

APPENDIX C3: Department of Biostatistics restrictions analysis

Biostatistics	# Folders	Harvard University Records - 80 years	Harvard University Records - 50 years	Medical / patient / health records	Psychiatric / mental health records	Student Records	Density of personally identifying information	Total Restricted
Collection Totals:	**169**	**36**	**169**	**0**	**0**	**3**	**0**	**169**
Percentage of total collection:	**100%**	**21.302%**	**100.000%**	**0.000%**	**0.000%**	**1.775%**	**0.000%**	**100.000%**
Percentage of Restricted Folders:	n/a	**21.302%**	**100.000%**	**0.000%**	**0.000%**	**1.775%**	**0.000%**	**100%**
Series 00489: I. Administrative Records								
Series I Totals	63	4	59	0	0	0	0	63
Percentage of Total Series	100.000%	6.349%	93.651%	0.000%	0.000%	0.000%	0.000%	100.000%
Percentage of Restricted Folders:	n/a	6.349%	93.651%	0.000%	0.000%	0.000%	0.000%	100.000%
Series 00493: II. Faculty Search and Appointment Records								
Series II Totals	43	30	13	0	0	0	0	43
Percentage of Total Series	100.000%	69.767%	30.233%	0.000%	0.000%	0.000%	0.000%	100.000%
Percentage of Restricted Folders:	n/a	69.767%	30.233%	0.000%	0.000%	0.000%	0.000%	100%
Series 00490: III. Departmental Meetings Records								
Series III Totals	21	2	19	0	0	0	0	21
Percentage of Total Series	100.000%	9.524%	90.476%	0.000%	0.000%	0.000%	0.000%	100.000%
Percentage of Restricted Folders:	n/a	9.524%	90.476%	0.000%	0.000%	0.000%	0.000%	100.000%
Series 00491: IV. Committee Records Student Records								
Series IV Totals	14	0	14	0	0	1	0	14

Biostatistics	# Folders	Harvard University Records - 80 years	Harvard University Records - 50 years	Medical / patient / health records	Psychiatric / mental health records	Student Records	Density of personally identifying information	Total Restricted
Percentage of Total Series	100.000%	0.000%	100.000%	0.000%	0.000%	6.667%	0.000%	100.000%
Percentage of Restricted Folders:	n/a	0.000%	100.000%	0.000%	0.000%	6.667%	0.000%	100.000%
Series 00492: V. Course Records Student Records								
Series V Totals	28	0	28	0	0	2	0	28
Percentage of Total Series	100.000%	0.000%	100.000%	0.000%	0.000%	7.143%	0.000%	100.000%
Percentage of Restricted Folders:	n/a	0.000%	100.000%	0.000%	0.000%	7.143%	0.000%	100.000%

APPENDIX C4: Relman papers restrictions analysis

RELMAN	# Folders	Harvard University Records - 80 years	Harvard University Records - 50 years	Medical / patient / health records	Psychiatric / mental health records	Student Records	Density of personally identifying information	Total Restricted
Collection Totals:	**417**	**52**	**12**	**33**	**1**	**0**	**9**	**107**
Percentage of total collection:	**100%**	**12.470%**	**0.959%**	**7.910%**	**0.239%**	**0.000%**	**2.158%**	**23.741%**
Percentage of Restricted Folders:	n/a	**52.525%**	**4.040%**	**33.333%**	**1.010%**	**0.000%**	**9.090%**	**100%**
Series I. Professional Correspondence								
Series I Totals	177	23	0	19	0	0	5	47
Percentage of Total Series	100%	12.994%	0.000%	10.734%	0.000%	0.000%	2.824%	26.553%
Percentage of Restricted Folders:	n/a	48.936%	0.000%	40.425%	0.000%	0.000%	10.638%	100%
Series II. Subject Files								
Series II Totals	302	2	1	4	0	0	2	9
Percentage of Total Series	100%	0.662%	0.331%	1.324%	0.000%	0.000%	0.662%	2.980%
Percentage of Restricted Folders:	n/a	22.222%	11.111%	44.444%	0.000%	0.000%	22.222%	100%
Series III. Committee Records								
Series III Totals	37	23	8	0	1	0	1	33
Percentage of Total Series	100%	62.162%	21.622%	0.000%	2.703%	0.000%	2.703%	89.189%
Percentage of Restricted Folders:	n/a	69.697%	24.242%	0.000%	3.030%	0.000%	3.000%	100.000%
Series IV. Writings								
Series IV Totals	300	1	0	2	0	0	1	4
Percentage of Total Series	100%	0.333%	0.000%	0.667%	0.000%	0.000%	0.333%	1.333%

RELMAN	# Folders	Harvard University Records - 80 years	Harvard University Records - 50 years	Medical / patient / health records	Psychiatric / mental health records	Student Records	Density of personally identifying information	Total Restricted
Percentage of Restricted Folders:	n/a	25.000%	0.000%	50.000%	0.000%	0.000%	25.000%	100.000%
Series V. Events								
Series V Totals	67	2	0	0	0	0	0	2
Percentage of Total Series	100%	2.985%	0.000%	0.000%	0.000%	0.000%	0.000%	2.985%
Percentage of Restricted Folders:	n/a	100.000%	0.000%	0.000%	0.000%	0.000%	0.000%	100.000%
Series VI. Personal Records								
Series VI Totals	19	1	3	0	0	0	0	4
Percentage of Total Series	100%	5.263%	15.789%	0.000%	0.000%	0.000%	0.000%	0.211%
Percentage of Restricted Folders:	n/a	25.000%	75.000%	0.000%	0.000%	0.000%	0.000%	100.000%
Series VII. Slides								
Series VII Totals	47	0	0	8	0	0	0	8
Percentage of Total Series	100%	0.000%	0.000%	17.021%	0.000%	0.000%	0.000%	17.021%
Percentage of Restricted Folders:	n/a	0.000%	0.000%	100.000%	0.000%	0.000%	0.000%	100.000%

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)

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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

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	◯	◯	◯	◯
Date span of records	◯	◯	◯	◯
Diagnosis/condition	◯	◯	◯	◯
Duration of treatments	◯	◯	◯	◯
Genetic information	◯	◯	◯	◯
Geographic region covered	◯	◯	◯	◯
Names of medical devices used	◯	◯	◯	◯
Prescribed medications	◯	◯	◯	◯
Race of patients	◯	◯	◯	◯
Sex of patients	◯	◯	◯	◯
Surgical procedures	◯	◯	◯	◯
Treating physician/surgeon	◯	◯	◯	◯

Other (please specify)

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	◯	◯	◯	◯
Autopsy records	◯	◯	◯	◯
Billing information	◯	◯	◯	◯
Case files	◯	◯	◯	◯
Consultation files	◯	◯	◯	◯
Correspondence	◯	◯	◯	◯
Diagnostic indices	◯	◯	◯	◯
Family medical histories	◯	◯	◯	◯
Genetic testing records	◯	◯	◯	◯
Graphs and charts	◯	◯	◯	◯
Hospital policies	◯	◯	◯	◯
Immunization records	◯	◯	◯	◯
Insurance claims	◯	◯	◯	◯
Informed consent records	◯	◯	◯	◯
Lab notebooks	◯	◯	◯	◯
Microscope slides/specimens	◯	◯	◯	◯
Photographs/medical imaging	◯	◯	◯	◯
Patient histories	◯	◯	◯	◯
Patient questionnaires	◯	◯	◯	◯
Patient summaries	◯	◯	◯	◯
Prescription books/logs	◯	◯	◯	◯
Research protocols	◯	◯	◯	◯
Surgical logbooks	◯	◯	◯	◯

Other (please specify)

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 adresss:

THANK YOU FOR YOUR PARTICIPATION!