

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 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)

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)

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)

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!

Johns Hopkins University

3910 Keswick Road Baltimore MD 21211

Harvard University

90053862

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

PI: Phoebe Evans Letocha

Reporting Period: March 1, 2013 - February 28, 2014

Project Period: March 1, 2013 - June 30, 2014

Financial Status Report

REVENUE SUMMARY			
Year	Award Amount	Cash Collected	Due From Sponsor
Year 1	91,375.00	68,964.45	22,410.55
Total	\$ 91,375.00	\$ 68,964.45	\$ 22,410.55

EXPENDITURE SUMMARY					
Expense Categories	Budget	Previously Reported	Current Activity	Cumulative Total	Variance to Budget
Salary	69,665.00	-	78,309.27	78,309.27	(8,644.27)
Fringe Benefits	18,274.00	-	-	-	18,274.00
Consultant Costs	-	-	2,226.70	2,226.70	(2,226.70)
Repairs and Maintenance	-	-	1,200.00	1,200.00	(1,200.00)
Supplies	3,436.00	-	-	-	3,436.00
Total	\$ 91,375.00	\$ -	\$ 81,735.97	\$ 81,735.97	\$ 9,639.03


 Tracy Wayman, Manager, Sponsored Projects Shared Services

3/27/14
 Date

Grant Number: 114719

Should you have questions regarding this report, please contact Erika Chance at echance5@jhmi.edu.

****No Cost Extension Pending**