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

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ABOUT

The following recommendations were developed by the Alan Mason Chesney Medical Archives of the Johns Hopkins Medical Institutions and the Center for the History of Medicine at the Francis A. Countway Library of Medicine in an effort to enable access to manuscript and archival collections containing protected health information (PHI) and other types of access-protected records containing health information about individuals. This work was made possible through the generous funding of the Council for Library and Information Resources' *Cataloging Hidden Special Collections and Archives* program (2012: *Private Practices, Public Health: Privacy-Aware Processing to Maximize Access to Health Collections*).

DETERMINING AN INSTITUTION'S STATUS AND POLICY NEEDS

- Repositories should train staff to recognize individually identifiable health information, regardless of whether or not they are entities covered by the Health Insurance Portability and Accountability Act (HIPAA). Repositories that are HIPAA-covered should provide training to familiarize staff with legal requirements. Repositories should survey their holdings to determine the extent to which they include individually identifiable health information that may be protected by federal or state laws.
- Repositories should consult with their administration and legal counsel to determine their status under HIPPA, the Federal Common Rule for the Protection of Human Subjects, and their state's medical records laws. Repositories should document that status and determine their institution's risk tolerance, as 1) laws such as HIPAA allow institutions to be more restrictive than the law requires, and 2) some donor agreements may require restrictions beyond that which is covered by HIPAA.
- Repositories should create inter-organizational partnerships to align policies, for example, other special collections repositories at the same institution, medical records/health information management departments in hospitals, and institutional records management offices. Repositories holding records of outside institutions that contain individually identifiable health information should consult with the depositing

institution to determine if the records are subject to HIPAA business associate agreements.

- Repositories should review the types of requests that they receive for access to individually identifiable health information and develop access review processes relevant to the type of use requested, such as medical genealogy, biography, and research as defined by HIPAA and the Common Rule.
- Repositories, to the extent possible, may want to create an impartial Access Board or Privacy Board or consult with an IRB to review applications for access to protected health information and medical records in their holdings. An archivist with knowledge of the holdings should be designated to be part of the review process, either as an advisor to or as a member of the review board. If no Access Board is possible, repositories should be prepared to explain why access can be granted to some users and not others.
- Repositories should document their decision-making processes and policies and apply them consistently. Decision trees may be helpful tools to review access decisions (see Johns Hopkins examples).

ARTICULATING POLICY AND FOSTERING PROCESS TRANSPARENCY

- Repositories should publish their access and use policies on their websites and should provide copies of any application forms online.
- Repositories should clearly articulate the steps a researcher or other user would need to take to apply for access and the application workflow, so that users know how far in advance they will need to make an application before they may be granted access.
- Repositories may wish to provide model applications or a process by which applicants can ask questions or seek guidance on the application process so that they can successfully complete the application.
- For non-HIPAA covered entities, repositories should create use agreements that communicate personal liability for the misuse or distribution of health information about individuals.

COMMUNICATING THE NATURE OF RESTRICTIONS

- Repositories should provide non-technical information on their websites about the kinds of access restrictions their users will encounter when considering the use of records, regardless of whether restrictions are imposed by: Federal law (HIPAA, FERPA); United States government records laws; state law; gift agreement; deposit agreement; or institutional policy.
- Repositories should provide at least one example of each of the restrictions found in their collections using a published or otherwise publicly available finding aid or catalog record to illustrate the restriction.

- Repositories should explain where users can find information about access restrictions, such as publicly accessible catalog records, online finding aids, or published inventories.
- Repositories should provide information about the gaps in systems where information is generally provided (such as restrictions only being noted in catalog records for collections that have been processed), as well as overtly state when information about access restrictions is only available through consultation with Public Services staff.
- Repositories should embed information regarding the presence of access restrictions at all levels of hierarchical description. Collection-level access descriptions may alert users to the presence of restrictions, but it is series, subseries, and folder-level notices regarding access status that enable users to understand which restrictions apply to records of interest.
- Repositories should clearly articulate their policies regarding citation. Access Board and IRB applications should clearly indicate if citation is permitted, and if so, repositories should have specific examples for citing records in collections that are not accessible without access approval and, if the collection is unprocessed, whose physical organization may change in the future.
- Repositories may want to allow and encourage users to deposit a code key to medical records and other protected records that cannot be cited by identifiers, such as patient name or medical record number, without authorization. Repositories should clearly state in finding aids when records have been redacted or removed from the collection.

DESCRIBING RECORDS TO BEST ENABLE DISCOVERY AND ACCESS

- When describing collections containing health information, communicate the specific record formats in which health information is found. A list of different kinds of records containing health information and their scope may be found here. Examples include: admission records; autopsy records; case files; diagnostic indices; doctor-patient correspondence; medical records; patient histories; prescription logs; surgical logbooks; and specimens. If you are not sure of the kind of record you have, try to create a redacted copy of the record (or a page or two from a volume) and consult an archivist or librarian who more routinely encounters these types of records.
- When describing records, incorporate examples of the pharmaceuticals, medical instrumentation and devices, diseases or illnesses, and procedures and treatments described in the records, as well as the names of frequently mentioned doctors, surgeons, midwives, mental health professionals, and dentists encountered as a product of sampling. Processors should also record types of commonly collected information about patients in the records, such as diagnosis, names, dates of birth, age at time of

treatment, weight, marital status, number of children, place of residence, occupation, and employer. A complete list of variables may be found here.

- Descriptions should overtly state if a collection is a part of a much larger, original group of records, as well as inform users as to what happened to the rest of the records or where they may be found. (For example, a collection consisting of twenty boxes transferred to the archives as a representative sample from an original 100 boxes of records, and that the remaining eighty boxes were destroyed per institutional policy.) Specimens related to a collection, but housed elsewhere, should be indicated, regardless of whether or not they can be accessed.
- Because processing methodologies vary from repository to repository, processing information in finding aids should include how record descriptions were created, such as through a percentage of records sampled per container or per alphabetical or numeric run.
- Repositories should enable opportunities for user enhancement of collection descriptions, particularly for unprocessed or infrequently used collections. A survey instrument or quick conversation with a researcher may help contextualize records, add to lists of procedures or treatments employed, or enrich collection-level descriptions of holdings. Users may also provide examples of "the patient's own words" that can be included anonymously in finding aids to help characterize records.
- Repositories should consider digitally imaging redacted versions of records and embedding them in finding aids in order to visually communicate how information is organized in the records. Repositories can also consider embedding blank versions of survey instruments, commonly found forms in medical records, pages from codebooks, and protocols.