Privacy in the Past: A Study of the Use of Unrestricted Health Information in Digitized Medical Archival Collections

Sarah E. Almond
salmond@hsc.edu
• Community Histories Workshop was contracted by the Dix Park Conservancy and the city of Raleigh to investigate history of Dorothea Dix Hospital, a recently-closed asylum

• Discovered archival medical records at the NC State Archives for patients dating back to 1856

• Previously restricted, these records were newly available based on a change in state records laws.

• Proposed CHW Project: to photograph and transcribe all available records for historical and medical research, data visualization
After transcribing and cleaning the data, though...

- It became clear that there were hereditary implications for certain diagnoses.

- Research in Ancestry.com proved that most patients (and their descendents) were relatively easy to locate.
Further research revealed...

- 19th century asylums kept thorough records to
  - Justify their existence
  - Better define and understand the emerging science of psychiatry

- Which then led to
  - Eugenic experiments
  - The assumption that mental illness was hereditary, and the subsequent stigma attached
HIPAA
The Health Insurance Portability and Accountability Act of 1996
<table>
<thead>
<tr>
<th>IL number</th>
<th>IL name</th>
<th>IL occupation</th>
<th>IL admission date</th>
<th>IL gender</th>
<th>IL age</th>
<th>IL marital status</th>
<th>IL admission cause</th>
<th>IL length of stay</th>
<th>IL nature</th>
<th>IL intake condition</th>
<th>IL mortality</th>
<th>IL residence</th>
<th>IL discharge or death</th>
<th>IL residence in hospital</th>
<th>IL final condition</th>
<th>IL remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Miss Jones</td>
<td>teacher</td>
<td>2 months</td>
<td>M</td>
<td>28</td>
<td>Single</td>
<td>epilepsy to dian</td>
<td>4 months</td>
<td>mania</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1898-5-6</td>
<td>cured</td>
</tr>
<tr>
<td>2</td>
<td>Farmer</td>
<td>M</td>
<td>19</td>
<td>M</td>
<td>19</td>
<td>Single</td>
<td>epilepsy</td>
<td>3</td>
<td>epilepsy</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1856-6-14</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Laborer</td>
<td>M</td>
<td>30</td>
<td>M</td>
<td>30</td>
<td>Single</td>
<td>epilepsy</td>
<td>5 years</td>
<td>epilepsy</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1880-6-26</td>
<td>died</td>
</tr>
<tr>
<td>4</td>
<td>Laborer</td>
<td>F</td>
<td>37</td>
<td>F</td>
<td>37</td>
<td>Widowed</td>
<td>domestic troubles</td>
<td>10 years</td>
<td>mania</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1899-2-9</td>
<td>died</td>
</tr>
<tr>
<td>5</td>
<td>Laborer</td>
<td>F</td>
<td>31</td>
<td>M</td>
<td>31</td>
<td>Married</td>
<td>unknown</td>
<td>6</td>
<td>mania</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1875-5-19</td>
<td>improved</td>
</tr>
<tr>
<td>6</td>
<td>Laborer</td>
<td>M</td>
<td>34</td>
<td>F</td>
<td>34</td>
<td>Single</td>
<td>unknown</td>
<td>11 years</td>
<td>mania</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1881-4-10</td>
<td>died</td>
</tr>
<tr>
<td>7</td>
<td>Laborer</td>
<td>M</td>
<td>26</td>
<td>M</td>
<td>26</td>
<td>Single</td>
<td>epilepsy</td>
<td>7</td>
<td>epilepsy</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1890-8-7</td>
<td>died</td>
</tr>
<tr>
<td>8</td>
<td>Laborer</td>
<td>M</td>
<td>36</td>
<td>M</td>
<td>36</td>
<td>Single</td>
<td>unknown</td>
<td>15 years</td>
<td>dementia</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1880-7-21</td>
<td>died</td>
</tr>
<tr>
<td>9</td>
<td>Laborer</td>
<td>F</td>
<td>49</td>
<td>F</td>
<td>49</td>
<td>Single</td>
<td>unknown</td>
<td>2 1/2 years</td>
<td>insomnie</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1891-6-1</td>
<td>died</td>
</tr>
<tr>
<td>10</td>
<td>Laborer</td>
<td>M</td>
<td>40</td>
<td>F</td>
<td>40</td>
<td>Single</td>
<td>unknown</td>
<td>6 years</td>
<td>mania</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1896-8-30</td>
<td>cured</td>
</tr>
<tr>
<td>11</td>
<td>Laborer</td>
<td>M</td>
<td>27</td>
<td>M</td>
<td>27</td>
<td>Single</td>
<td>unknown</td>
<td>6 months</td>
<td>melancholia</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1871-6-14</td>
<td>removed to make room for acute case</td>
</tr>
<tr>
<td>12</td>
<td>Laborer</td>
<td>F</td>
<td>36</td>
<td>F</td>
<td>36</td>
<td>Single</td>
<td>unknown</td>
<td>15 years</td>
<td>insomnie</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1899-11-25</td>
<td>removed to make room for acute case</td>
</tr>
<tr>
<td>13</td>
<td>Laborer</td>
<td>M</td>
<td>30</td>
<td>M</td>
<td>30</td>
<td>Married</td>
<td>domestic troubles</td>
<td>2 years</td>
<td>mania</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1880-11-1</td>
<td>removed</td>
</tr>
<tr>
<td>14</td>
<td>Laborer</td>
<td>M</td>
<td>47</td>
<td>M</td>
<td>47</td>
<td>Single</td>
<td>epilepsy</td>
<td>15 years</td>
<td>epilepsy</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1860-6-12</td>
<td>died</td>
</tr>
<tr>
<td>15</td>
<td>Laborer</td>
<td>F</td>
<td>35</td>
<td>F</td>
<td>35</td>
<td>Single</td>
<td>unknown</td>
<td>7 years</td>
<td>mania</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1866-9-10</td>
<td>died</td>
</tr>
<tr>
<td>16</td>
<td>Farmer</td>
<td>M</td>
<td>23</td>
<td>M</td>
<td>23</td>
<td>Single</td>
<td>blow on head</td>
<td>6 years</td>
<td>dementia</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1872-7-23</td>
<td>died</td>
</tr>
<tr>
<td>17</td>
<td>Farmer</td>
<td>M</td>
<td>38</td>
<td>M</td>
<td>38</td>
<td>Single</td>
<td>religious escape</td>
<td>6 years</td>
<td>insomnie</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1855-7-34</td>
<td>died</td>
</tr>
<tr>
<td>18</td>
<td>Farmer</td>
<td>M</td>
<td>24</td>
<td>M</td>
<td>24</td>
<td>Single</td>
<td>masturbate</td>
<td>many years</td>
<td>mania</td>
<td>NC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1878-6-26</td>
<td>died</td>
</tr>
</tbody>
</table>
1. Name
2. Address (beyond state)
3. Dates (beyond the year) associated with the individual
4. Telephone Number
5. Fax Number
6. Email Address
7. Social Security Number
8. Medical Record Number
9. Health Plan Beneficiary Number
10. Account Number
11. Certification or License Number
12. Vehicle Identifiers
13. Device Identifiers
14. Web URLs
15. IP Address
16. Biometric Identifiers, such as fingerprints
17. Full-face photos
18. Any other unique identifiers, characteristics, or codes
1. Name
2. Address (beyond state)
3. Dates (beyond the year) associated with the individual
4. Telephone Number
5. Fax Number
6. Email Address
7. Social Security Number
8. Medical Record Number
9. Health Plan Beneficiary Number
10. Account Number
11. Certification or License Number
12. Vehicle Identifiers
13. Device Identifiers
14. Web URLs
15. IP address
16. Biometric Identifiers, such as fingerprints
17. Full-face photos
18. Any other unique identifiers, characteristics, or codes
Protected Health Information (PHI) v/s Unrestricted Health Information (UHI)

**PHI** is: Individually identifiable health information transmitted or maintained in any form or medium (electronic, oral, or paper) by a covered entity or its business associates...excluding information on those individuals who have been deceased for longer than 50 years.

**UHI** is: Medical records featuring any of HIPAA’s eighteen identifiers, maintained in any form or medium (electronic, oral or paper) by a covered or uncovered entity pertaining to individuals who have been deceased for fifty years or longer and are thus exempt from HIPAA regulations. A public record.
HIPAA Loopholes

Federal v/s State

According to Federal Law
• Medical Records containing UHI are public records.

According to State Law
• Medical Records containing UHI are available in some states and not available in others.
• State level restrictions on records containing UHI is changing all of the time.

Result
• There is no one set of best practices that addresses the specific situation of each institution in each state.
• Access Anxiety
Access Anxiety…

But Make It Digital
Methods for Exploratory Study

Research

Resources
- NLM directory of medical history collections
- The Harvey Cushing/John Hay Whitney Medical Library at Yale University

Contact
- Emailed 75 different repositories
- Covered 27 states and the District of Columbia

Response
- 7 participants
- 10 years experience
- Federal level, private and public universities
- 1 covered entity, 6 non-covered
Findings: Conceptions of UHI

7/7 Agree
- Some historical health records are more sensitive than others
- It’s best to err on the side of caution when digitizing materials with UHI
- Digital online formats should be provided with access restrictions
- HIPAA identifiers can be used as a road map for access to UHI

6/7 Agree
- Unrestricted digital online access differs from physical access to collections

5/7 Agree
- Unrestricted digital online access represents a loss of Archival Control

“Those people are dead, but their living relatives are still around and whatever’s found in [a collection] could have implications for them.”
Findings

7/7 Agree
- Some historical health records are more sensitive than others
- It’s best to err on the side of caution when digitizing materials with UHI
- Digital online formats should be provided with access restrictions
- HIPAA identifiers can be used as a road map for access to UHI

6/7 Agree
- Unrestricted digital online access differs from physical access to collections

5/7 Agree
- Unrestricted digital online access represents a loss of Archival Control

“It’s important that archivists follow what the law is and not impose their own moral understandings of what is sensitive or not...archivists get into trouble when they stray from legal definitions and get into their own personal ethical considerations.”
Findings

7/7 Agree
- Some historical health records are more sensitive than others
- It’s best to err on the side of caution when digitizing materials with UHI
- Digital online formats should be provided with access restrictions
- HIPAA identifiers can be used as a road map for access to UHI

6/7 Agree
- Unrestricted digital online access differs from physical access to collections

5/7 Agree
- Unrestricted digital online access represents a loss of Archival Control

Data presented online “is available just by searching. It is highly retrievable and sortable and indexable…[digitized online data]…is less mediated in most cases…If someone comes into the reading room…they might sign something [and] we might be having a face to face conversation…that might dictate how they meet these materials.”
Findings

**7/7 Agree**
- Some historical health records are more sensitive than others
- It’s best to err on the side of caution when digitizing materials with UHI
- Digital online formats should be provided with access restrictions
- HIPAA identifiers can be used as a road map for access to UHI

**6/7 Agree**
- Unrestricted digital online access differs from physical access to collections

**5/7 Agree**
- Unrestricted digital online access represents a loss of Archival Control
For Standards:

• Uniform application and extension of HIPAA and HIPAA-influenced standards to all potentially identifying medical records
  • For some, includes privacy boards and review processes required of covered institutions
  • For others, strict adherence to restriction periods mandated by the state or institution
• Increased communication between archives and health informatics practitioners, adoption of HIPAA-compliant software
Managing Access:

- **No restrictions**
  - Risk management (handling UHI risk like copyright)
  - Redaction
- **Restrictions**
  - Thorough description at the level of the finding aid
    - Can include an explanation for restriction and/or a link to institutional policies
  - Wait and See approach
  - IRB-approved application process
  - Tiered Access
  - Dark archive

Suggestions

The imposition of standards and managing access
Examples

From institutions in Pennsylvania, Virginia, and Maryland
State Hospitals (14 collections)

Danville State Hospital (PA) County Registers, 1872-1923
This collection contains a register, arranged alphabetically by county, containing the names of persons responsible for a patient’s support. Information includes: name of the responsible person, more

Danville State Hospital (PA) Court Commitment Books, 1884-1924
This collection contains handwritten copies of commitment orders from the Court of Common Sessions which committed patients to Danville State Hospital, and named more

Danville State Hospital (PA) Male Case Index Books, 1880-1920
This collection, arranged alphabetically by name of patient, includes a list of each male patient referencing volume and page number to RG/023/AMEH/DANV/620- Male more

Danville State Hospital (PA) Patient Ledgers, 1872-1921
Records are grouped by account and then arranged chronologically by date of transaction. Records are externally, alphabetically by surname of patient in RG/023/AMEH/DANV/27- Index to more

Dixmont State Hospital (PA) Annual Reports, 1848, 1850-1875
This collection contains annual reports documenting the financial status and activities of the hospital. Information provided includes reports prepared by the superintendent, treasurer, farmer, storekeeper, and
The Central State Hospital Digital Library & Archives Project

Founded in 1870 in Petersburg, Virginia, Central State Hospital (CSH) – formerly Central State Lunatic Asylum for Colored Insane – was the first mental health care facility for African Americans in the country. The collection contains over 100 years of records related to the historic institution; these are the most complete archival records of blacks and mental illness in the United States. Items include board minutes, annual reports, procedural manuals, financial reports, patient registers, photos, newsletters, and monographs.

INFORMATION FOR FAMILIES  ABOUT THE PROJECT

Research

Learn about accessing the materials in the digital archives.

Learn more
Terms of Access and Use

Guiding principles of the Medical Archives advocate open intellectual inquiry as the primary means of advancing new knowledge. Policies are designed to make holdings accessible for use whenever possible, consistent with applicable laws and institutional regulations.

The Privacy Board of the Johns Hopkins Medical Institutions oversees archival policy and procedures for review and adjudication of requests for access to materials protected by privacy laws. Learn more

Categories of materials protected by law

- Patient Records and Identifiable Health Information
- Clinical Trial Data and Records of Research Involving Human Subjects
- Student Records and Information
- Intellectual Property and Copyrighted Material
Two copies, identified and de-identified. Identified is in a dark archive and access is mediated by the PI of the project.

Data is in a secure repository through the The Odum Institute for Research in Social Science.

Detailed description provided in the finding aid, also hosted on the Odum Institute site.

Approached UNC libraries, but they do not have the capacity for the restrictions needed to host online at this time.

What about the Dix Project?
Education
Educates archivists and alleviates access anxiety

Alignment
Promotes ideological alignment within the practice

Communication
Fosters increased communication within the field and across silos

Labor
Reduces labor and effort for smaller institutions
Awareness
Raise awareness of collections

Description
Focus on collection description as chief access point

Advocacy
Advocate for more comprehensive federal and state protection laws
• Dong, Lorrie. “Exploring the Reaches of Privacy and Technology: Central State Hospital Digital Archives Project.” Archival Outlook, August 2016.


Thank you!
salmond@hsc.edu