

Providing Restricted Access to Mental Health Archives within Government Archives: The Subject Stakeholder

Patricia Galloway

ABSTRACT

Since 2010, the author has been part of the Central State Hospital (CSH) Digital Library and Archives Project to digitize records from the first state psychiatric hospital for African Americans, founded in 1870 in Virginia at the pleadings of the Freedman's Bureau and run by the state since then.¹ Many of the records of this hospital not yet accessioned by the Library of Virginia have now been digitized, and this project is working on a set of tools for lawful access, including one that can be used for automated redaction to protect sensitive data while responding to the needs of different stakeholder groups.

Project participants were especially concerned about understanding the communities that have grown up around state-run psychiatric hospitals, as the project was done at the request of the hospital. The proposed plan is to work with the Central State Hospital and the Library of Virginia to provide the project materials to both. The records that were chosen to be digitized included the minutes of the people who first ran the hospital as well as the registers kept on the patients, which differ over time.² In the past ten to fifteen years, professional discussion about community archives has responded to communities' desires to build their own archives so that they can be treated fairly, especially with reference to records created about them and kept by others, including records found in state archives.

© Patricia Galloway.



KEY WORDS

Community archives; Restricted records;
Medical archives; Government archives; Access

I therefore commend to the particular care of those among you who are associated with local historical societies the daybooks, case records, commonplace and recipe books, and lecture notes, as well as the correspondence and diaries, of selected local physicians; and to the care of archivists the selected records, including some case histories, of hospitals and other institutions, which will help give the historian a picture of medicine as it has actually been practiced.

John B. Blake, National Library of Medicine, 1964³

Community Archives as a Force in American Archivy

The 2017 Annual Meeting of the Society of American Archivists focused on inclusion and especially on community archives; the 2018 Annual Meeting reflected on archival transparency, and, during the meeting, the *Native American Protocols* were endorsed, after many years, with an apology pointing to the lengthy delay in recognizing them.⁴ In short, the archival profession has been reshaping its relationship with community archives.

Efforts made to appreciate the concerns of the *subjects* of archival documents were not new: ever since Gerald Ham's recognition of the need to use the sampling methods of social scientists on the kind of "vast time series" now being kept, and Helen Willa Samuels's proposal of an inclusive documentation strategy, serious discussions have ensued about what archives ought to be doing to equitably represent the history of everyone while understanding a cultural need for restrictions on certain kinds of data.⁵ With the recognition of a kind of archival malfeasance with respect to Indigenous and unrepresented people (in the Caribbean, South Africa, Australia, Canada, and, finally, the United States), the voices of Jeanette Bastian, Verne Harris, Terry Cook, and Randall Jimerson aim at this equitable representation.⁶ In my own teaching, I have seen over the past ten years a growing interest on the part of archival graduate students in "community archives," that is, archives controlled by a community to preserve its identity as a community by making its own decisions as to what to collect and especially how to share it.

Archivists may have to let go of that "archives power" they have built as the makers and arrangers of collections, with the power to choose to destroy as well as to construct. As archivists, we need to share that power with others whose ideas of archival curation and archival access may be different from those built up in Western archival practice for several hundred years.⁷ In working with the Central State Hospital (CSH) records, participants in the project wanted to enable data while protecting privacy—particularly important because most of the patients had no control over their own treatment.

In this review of our work, I will raise several issues. First, to lay the groundwork for the research design of this article, the literature review traces concerns with privacy among archivists going back to the 1970s and also addresses more current concerns with the Health Insurance Portability and Accountability Act (HIPAA) and its Privacy Rule. A sketch of our current understanding of the making of the records at the CSH and those who made them, as well as those about whom the records were made, follows. Our methods also looked at archival practices around state hospital records, for which we developed two questionnaires: one for state archivists, as well as one for the families of patients and for researchers chiefly of the history of psychiatric hospitals. Finally, I summarize our results from the questionnaire, suggesting ways archivists, families, and researchers can agree on the protection of patient identities.

Emergence of Privacy for the Subject Stakeholder

Howard Zinn's lecture to archivists in 1970 about gathering "documentary material about the lives, desires and needs of ordinary people"⁸ is well known, but archivists were already concerned about these issues with respect to medical records. In 1960 Philip D. Jordan, a professor of history, urged archivists not to destroy, but to

bring together in systematic fashion sources which would provide the raw materials for the investigation of Federal and state policies for education, health, and social services. . . . Always it must be remembered that the health of the public is an integral portion of social development and it is interrelated with other social changes in the community.⁹

In 1974, Virginia R. Stewart, field archivist for acquisitions at the University of Illinois at Chicago Circle, called for archives to maintain personal case files from health and welfare services on the basis of a 1973 survey of sixteen archives. The survey pointed to the significant worth of such records for medical research, in spite of the existing tendency to schedule them for destruction once their active need had passed because of the cost of keeping them. Stewart emphasized their value, but also called for a uniform law in the states to protect the privacy of subjects, referring to a document from the Department of Health, Education, and Welfare reporting on the potentially dangerous results of automated data systems.¹⁰ And, in 1983, Ruth Simmons of Rutgers cited Stewart when she spoke of "governmental case files and databases" being generated due to entitlement programs and pointed to

a compelling need to ensure the protection of privacy and limited access and control over these files, . . . The time is over for ad hoc decisions on access,

both for the protection of the repository and for the protection of privacy rights of individuals archivists are ethically and legally bound to uphold.¹¹

Simmons called for repositories to formulate policies for access to restricted records, requiring researchers to provide a statement of need for access and to be held accountable for the use of permitted records. Meanwhile, in 1985, historian Roy Porter of the Wellcome Institute encouraged archivists and medical historians to look at “the patient’s view: doing medical history from below,” offering a research agenda for “sufferers’ history” that would gather records from all periods to enrich medical history.¹²

In 1986, Alice Robbin, head of Data and Program Library Service at the University of Wisconsin–Madison, surveyed the fifty state archives on public policy for personal privacy and the restriction of records from health and social services. She found that most state archives knew little about their statutory position and that nearly all state hospitals controlled their own records.¹³ In the same year, citing Stewart and Robbin, Roland Baumann, chief of the Division of Archives and Manuscripts, Pennsylvania Historical and Museum Commission, conducted a survey of fourteen states’ administration of restricted records and distinguished three approaches to access: legislated; contracted (via intra-agency instruments); and limited (but without written guidelines). Citing several case studies, he offered the Georgia Records Act as a model law, but also urged the Society of American Archivists (SAA) and the National Association of Government Archives and Records Administrators (NAGARA) to act together in pursuit of the then-current *Planning for the Archival Profession: A Report of the SAA Task Force on Goals and Priorities* to develop a model law.¹⁴

We may well ask why the archival world took this opportunity to be concerned with privacy in the 1970s and 1980s. Certainly, hospitals and other medical providers were beginning to make widespread use of databases for medical recordkeeping (as noted by Stewart), even though said databases were mainly for billing patients. But, it may be that archives were also beginning to respond to the Belmont Report, finalized in 1979, which set out the “Ethical Principles and Guidelines for the Protection of Human Subjects of Research” as a result of the National Research Act, passed in 1974. The Belmont Report would, in the following years, become the motivation for Institutional Review Boards whose reviews were requisite for university researchers to receive grants from the National Science Foundation (NSF) or the National Institute of Health (NIH).¹⁵

Another consideration would soon arise, the Health Insurance Portability and Accountability Act (HIPAA), initially passed in 1996 to protect people changing jobs from being denied health insurance for pre-existing conditions. But, by that time, hospitals had finally begun to computerize, and Title II of the act was also designed to underpin the increasing digital transmission of health-care information while, at the same time, guarding a patient’s

privacy. A more specific federal law was also needed, because patient data were being transmitted across state lines. In 2000, the “Standards for Privacy of Individually Identifiable Information” (the Privacy Rule) was created to protect patient data explicitly.¹⁶

The regulations of the Privacy Rule are only imposed on medical professionals, agencies, and businesses like hospitals (called “covered entities”) that provide, bill for, and receive payment for medical care, when protected data already in electronic form are transmitted. Furthermore, if nonelectronic data are stored by a covered entity, they also fall under HIPAA’s privacy regulations. HIPAA compliance has not been adjudicated for state and university libraries, which fall under the category of “hybrid entities,” but, so far, transfer from one entity to another is the key, as Individually Identifiable Health Information (IIHI) is the item being protected under the title of Private Health Information (PHI), defined as IIHI generated by covered entities. PHI must be created or received by providers, must be about an individual, and must potentially allow a third party to identify that individual before it can be put aside. Originally, the Privacy Rule had no time limit: the health information of deceased patients was also protected for fifty years for the benefit of their descendants (as HIPAA was originally intended), who might be subject to a refusal of health insurance.

In 2011, the Department of Health and Human Services (HHS) wanted to extend HIPAA restrictions to protect patients more securely from the revelation of their illnesses as medical providers were using more digital records, but was thwarted by complaints from several groups. Hence, in 2013, HHS modified the Privacy Rule to seemingly remove protection from PHI after fifty years, but it did two things: it let states enact laws to expand protection beyond fifty years, but said nothing about protection of privacy beyond that period; and it permitted covered entities to continue to restrict information *that they retained*.¹⁷ The Central State Hospital wants to maintain its information and not hand it over to the state.

The CSH has already handed over some records to the Library of Virginia, which now has a legal charge to protect them for 125 years from the time of their last presence at the state-run hospital. Furthermore, by Virginia state law, no pre-1913 patient records belonging to state-run hospitals can be destroyed without offering them first to the state archives. Board meeting minutes and annual reports must be kept either by the hospital or by the state archives, and the state must work with state-run hospitals to establish means of detecting and redacting any PHI that might be transmitted as an active record so as to preserve patient privacy.¹⁸ The CSH project was designed from the start to make it possible to redact any PHI so that this privacy can be preserved in the archives as it has agreed with families.

Thus, we have tried to address another concern. HIPAA was initially designed to help workers out in the world and was not concerned with people involuntarily held within mental hospitals. After World War II, scandals surfaced around psychiatric care for the poor in hospitals, relating to electro-shock, insulin shock, lobotomies, and sterilization.¹⁹ Due to the innovations of drug therapies in the 1950s and 1960s, the field of psychiatric care moved to replace mental hospitals with community “centers” where patients could receive one-on-one outpatient care.²⁰ This meant that when HIPAA came along in 1996, it did not concern itself initially with people who were considered incapable of making health decisions but had others making decisions for them. Some documents currently provided by the HHS Office for Civil Rights finally do address mental health explicitly by demanding that patients must name any persons who have the right to look at their diagnoses.²¹

Research Questions

We developed a set of research questions to bring the psychiatric hospital together with the Library of Virginia to consider how the two might agree to preserve the archives while simultaneously working to consider the concerns of the patients and their families, as well as those of the original creators of the records. Jeanette Bastian has spoken about the notion of a “community of records” by making it

... further imagined as the aggregate of records in all forms generated by multiple layers of actions and interactions between and among the people and institutions within a community.²²

Therefore, the following research questions frame this article:

1. Can the notion of “community of records” be used to characterize psychiatric hospitals? I attempt to characterize them by looking at the different tasks of the staff and the records they make.
2. Do different communities around psychiatric hospitals have different concerns about the records created?
 - patients and their families
 - doctors
 - nursing/aide staff
 - recordkeepers
 - administration
 - archives

And perhaps this leads us to what I think may be our final concern:

3. Do the changes in documents hint at an understanding of how records are made and by whom? Have they led to archivists' concerns for patients whose records are made by others without the patients' input?

Archival Concerns for the Subject Stakeholder

Responding to a larger notion of archivists' supporting the agency of the subjects of records, Michelle Caswell and Marika Cifor have argued for archivists adopting an ethics of care, referred to as a feminist "radical empathy" rather than individual rights. This empathy would address not just record creators, record users, and the records community, but also the records' *subjects*, those about whom records have been made, often without their permission. Caswell and Cifor state that archives should make "survivors and implicated communities not just a target group of users, but central focal points of all aspects of the archival endeavor, from appraisal to description to provision of access."²³

This concern is not new to medical sociology. Harold Garfinkel, whose 1967 *Studies in Ethnomethodology* deals among other things with psychiatric records, and points to the importance of how health-care providers read medical files, the skills and experience they have, and how that is likely to vary depending on the reader's relationship to the file. In one chapter of *Studies in Ethnomethodology*, Garfinkel and Egon Bittner point to multiple communities: the record creator, the record subject, the reader's mutual history with both patients and clinic staff, and, not least, an understanding of the organization and operating procedures of the clinic in question.²⁴ Concerned with the specific situations found in psychiatric clinics, Garfinkel and Bittner open up more ideas that our project is interested in: the community of records, multiple communities of records, and archivists' ability to understand such communities.

While HIPAA keeps medical records private from the public for some period of time, it gives patients or their relatives/legal caregivers more access than they have ever had before to their own medical records; it also denies them ownership of these records or the power to constrain their release.²⁵ This means that in thinking about access to records, we need to consider not only the record creators, record users, and record subjects (bearing in mind that all three of these actors were at one time coeval), but also time. Garfinkel pointed to time because of his interest in how medical records are used over their lifespan and how a lack of mutual history or of understanding of the organizational environment in which the records were made can make the records that were produced (and many may not survive) difficult to use for scientific research, or contrariwise,

all too public. Hence, with Caswell and Cifor (as well as Bastian, Cook, Harris, Jimerson, and many others), we need to raise the question of who controls the record, of course; but we also need to raise Garfinkel's and Bittner's questions about the environment in which the records were made and how that environment itself developed and has changed over time.²⁶

The CHS Psychiatric Hospital as a Community of Records

As we look at the CSH today, in light of HIPAA, after concerns for individuals who are subjects of records, what do we need to know to protect patient privacy, given that many patients (from 1870 at the beginning of the CSH) are now dead? Clearly, we need to know how the CSH operated. We are lucky that many sociologists have investigated the field and practices of psychiatry—Erving Goffman, Howard Garfinkel, Anselm Strauss, and Andrew Abbott.²⁷ Such studies give us a broad range of ideas about the complex organizations that make up the psychiatric hospital environment, particularly in custodial hospitals, which the CSH has been for most of its life. But, even more, they provide us a better understanding of the multiple communities that make up that environment, although most of this literature comes from the time period coeval with the earliest CSH records with which we are concerned.²⁸ Much of this work indeed focused on how the communities that cluster around such a hospital interact, occupy identities, and participate in care, and the thinking that lies behind it can be useful for making sense of earlier activities.²⁹ Furthermore, Anselm Strauss's work on psychiatric hospitals has led to an understanding of what he called "negotiated order" to describe the way multiple groups with different skills negotiate their actions in the workspace as their relationships and even skills and tools change over time.³⁰

In our project, the Central State Hospital records reflect the activities of a group of communities that has grown and evolved from the creation of the hospital until today. The hospital has always been a state-run institution. As noted, some of its paper records are already lodged with the Library of Virginia; the records that we have had digitized by Crowley Company have not yet been handed over to the state archives; the hospital is reluctant to part with them because it uses them as case studies for teaching, and doctors as well as nurses still consult them. The people involved with the hospital, both as employees and in other roles, fall into several categories, each relating in some way to the creation of the records that survive, and each group bears its own relationship to those records.³¹

From the beginning, **administrators** (referred to as "superintendants" for medicine and "stewards" for management) were responsible for the running of the hospital, the balancing of the books, and the overall provision of care.

The institution began as the Howard's Grove Hospital for Confederate Soldiers, which was quickly reworked in between 1868 and 1870 at the request of the Freedmen's Bureau to house former slaves from other hospitals and prisons, and even those suffering from homelessness (at first, the hospital had "123 insane persons and 100 paupers, not insane.")³² In the earliest days, some board members were African American, and an attempt was made to hire an African American matron. In 1873, Dr. Randolph Barksdale was elected superintendent; he had studied in Paris, was a surgeon in the Confederate Army, and had experience on the wards for the insane of the Blockley Hospital in Philadelphia.

No purpose-built building existed until 1885, when the hospital was transferred to Petersburg and built on the Kirkbride plan for "moral management" that aimed to provide healthy food and exercise and set work schedules for the inmates as a part of the treatment, as suggested by Barksdale.³³ In his 1896 report, he mentioned that the CHS was using some mechanical restraints and hypnotics were given freely.³⁴

Dr. William Francis Drewry served first as a psychiatrist in 1886, but then, from 1896 until 1924, he took over administration of the hospital and was required to supply monthly reports to a board.³⁵ In 1897, he began to use a modern system of clinical charts, and, in 1899, he received the surgical room and a pathological lab that he had asked for, as well as his first trained nurse.³⁶ He admired the "moral management" plan and was said to have been meticulous with the budget and kind to the inmates, borne out by his provision of a chapel, as well as separate wards for patients depending on their diagnoses, along with recreation and humane treatment as it was known at the time.³⁷ In 1907, he led the CHS to adopt Emil Kraepelin's "dichotomy" to diagnose patients, which was manic depression as opposed to dementia praecox (schizophrenia), each of which targeted a specific pattern of symptoms.³⁸ Superintendents lost rank at the decline of the "moral management" plan and the change in Virginia that placed all asylums under the management of a single state board. Until recently, CSH superintendents have been white.³⁹

From the start there have also been **physicians**, although early on they numbered only one or two. The physicians *were* the researchers into disease and its treatment, with the result that they *and their training* controlled the notions of disease that they acted on. To understand this, we have to look to the reports of the administrators, which include the education of physicians. In the process of "moral management," patients might first be treated with opioids until they fell in line with the routine of the asylum; then the opioids were gradually withdrawn, and patients were given jobs to perform, and rewarded with freedom on the campus.⁴⁰ Physicians' approaches evolved during the next hundred years as the hospital became more crowded: in the 1920s, medical theory promoted such physical treatments as sterilization, insulin and electric shock, and lobotomies,

to be replaced by psychoanalysis in the 1960s.⁴¹ With the further development of psychiatry after World War II, the CSH adopted the use of teams much like those described by Strauss et al. regarding practices in state hospitals before the movement to “community care.”⁴² It is important to consider that the whole discipline of medicine, which had increasing control of asylums, was constantly changing, thus pointing to the value of such records as those of the CSH.⁴³

Nursing and other care staff (the second group, seen as laypersons and often referred to as “aides” or “attendants”), who were especially responsible for the routine services and activities on the wards, provided some records of patient treatment: case files brought in after Drewry were assembled by nurses to whom physicians would give directions.⁴⁴ In predominantly custodial institutions like CSH, we know from later data that only one nurse might be available per ward, assisted by one or more aides.⁴⁵ The nursing staff had specific practices of care that changed with time; and, as Geoffrey Bowker and Susan Leigh Star have pointed out, nurses’ activities in the creation of records and the delivery of care may have been invisible to the physicians and administrators with whom they worked, because they (at least in modern times) did not record everything so that they might retain control of their own work.⁴⁶ We have some data that indicate an effort to fill the position of CSH “matron” (overall head nurse) with a trained Black nurse in 1873, which apparently failed.⁴⁷ Yet, in 1926, white staff members numbered 25 out of the 209 who worked at CSH (including doctors and “trained nurses” and three medical interns).⁴⁸ And, by the time of integration in 1964, CSH had 4,800 patients, having begun as Howard’s Grove with 123 “insane” African Americans.⁴⁹ Aides were more likely to be Black, while nurses were white, but again, that changed with time.⁵⁰ We know the least about these staff members; their habits of recording are nevertheless of greatest interest, especially as reporting forms changed along with recorded information and the records themselves require a good understanding of the practices of the hospital.⁵¹

We also know that there has long been **recordkeeping staff**, mostly white in early days but integrated after 1967. Early in the history of the hospital, registrars recorded the entrance and exit (or death) of patients, and recordkeepers dealt with the expenditures of the hospital (minutes indicate that these elements were discussed frequently in board meetings).⁵² With the introduction of typewriters, typists transcribed doctors’ materials for case studies, and, over time, recordkeeping methods underwent serious reorganizations.⁵³ The CSH recently adopted computers; in spite of installing a Cerner system, its effort has lagged behind other state-run hospitals.⁵⁴ To this day, however, recordkeeping staff are familiar enough with the older records to answer queries about past patients.

In the hospital's earliest history, it is not clear who was responsible for committing patients, as many, after emancipation freed them from enslaved labor, may have been more accurately considered homeless and without resources than actually insane.⁵⁵ From the turn of the twentieth century, however, **families** might have been responsible for the presence of patients in the hospital. It was possible for families to visit patients in the hospital or for the patient to be given a "furlough" to visit their homes.⁵⁶ Few studies have been done about these families themselves, nor do we have much information about any influence they may have had on treatment or about how patients depended on their families' prosperity or lack of same.⁵⁷ But, recent requests for genealogical information and responses to our questionnaire reveal that many families alive today wish to have access to the records of relatives who were patients at the hospital. They are also concerned that access by nonrelatives be restricted.⁵⁸

While **patients** apparently enjoyed differing degrees of freedom based on the theory of treatment at the time, they were also seriously circumscribed in their ability to control their own treatment. We know from photographs and ward schedules that many patients took part in the activities of the institution. They washed clothing and sheets, worked in fields raising food for the hospital, and, apparently, at least some were allowed to indulge in sports and picnics.⁵⁹ In 1967, the hospital began to desegregate and also began to admit patients for "forensic" reasons: they were adjudged criminally insane and were sent to the hospital in the course of criminal justice. So far, the hospital has kept its records (except those transferred to the Library of Virginia), although most of the the case-file records were microfilmed and the paper records subsequently destroyed, making access very difficult.⁶⁰

Among these community groups, only one *appears* to transcend the passage of time: the **families**, whose concern for the patients—and possibly their concern for how the patients' institutionalization reflects on the families themselves—has been continuous and multigenerational. Recordkeeping has also become more important not only for family relationships, but also because of genetic issues. Examples like the experiences of relatives of Black men in the Tuskegee syphilis experiments and the family of Henrietta Lacks, a Black woman whose cancer cells were the first to be "immortalized"—at Tuskegee Institute—and live to this day, can give us hints about how these family issues developed.⁶¹ A recent Associated Press story about the Tuskegee syphilis study voices the concerns of families whose male relatives are mostly long dead and especially their distrust of medicine.⁶² We know that family genealogists have for some time addressed questions to the CSH's recordkeepers, testifying to the extreme concern of families around medical treatments for a family member, even several generations later.⁶³

Lorraine Dong argues for another transcendent element: the **records** themselves can be seen as actors in the larger community of the psychiatric hospital.⁶⁴ The example of CSH shows that records have, in the hands of both hospital staff and the archivists who may follow them, the ability to outlive not only the patients but also their families. This is of course why we have archives; but because the history of mental health care (or any health care) is clearly a process of practices and discoveries, the very practice of medicine, at least in the West, sells itself as a progressive triumph over death. Yet the preservation of treatment records, as noted previously by Roland Baumann, Philip D. Jordan, Roy Porter, Alice Robbin, Ruth Simmons, and Virginia Stewart, has been accorded little attention until recently, with the emergence of electronic medical records systems (EMRs) and more recently, HIPAA and “precision medicine.”⁶⁵ Arguments around these issues are important because they pertain to research and who can have access to medical records.

“External” Groups

As we have already observed, **sociological scholars** contribute much to the study of mental health hospitals, chiefly by observation. Sociologists in particular pay attention not only to observation on active wards, but also to the impossibility of accessing psychiatric notes, the development of hospital records, and ways to use records as evidence of hospital practices.⁶⁶ A relatively new community is **historical scholars**, who have begun investigating hospitals like Central State for their history, the evolution of their treatments, and an understanding of the evolution of concepts around the idea of mental disease or disturbance, especially in the treatment of Black patients. Serious interest exists in how Black hospitals might be compared with hospitals for whites until the 1960s, and whether patient records reflect known schools of nineteenth- and twentieth-century disease theories.⁶⁷ Finally, **medical researchers**, though they may not be interested in what we now consider “historical” medical records, will certainly be concerned going forward with modern digital recordkeeping in psychiatric hospitals in pursuit of “evidence-based” and “precision” medicine as hospital systems gather more and more records.

As I have pointed out already, with the evolution of the notion of “archives power,” **archivists** themselves may be active in the preservation of at least the records of state-run hospitals, which are usually legally bound by retention schedules. Archivists have begun to voice concern about how such records should ethically be used.⁶⁸ Current misgivings around the equitable treatment of all communities involved with hospital records, including patients and their families as well as hospital workers, call into question first, whether universal access should be the only justification for permanent retention, and second,

who might be enabled to control or to codesign the records of communities.⁶⁹ Given the new recognition of records' importance to the survival of communities (notably, Black communities here), in the CSH project, we have been working through how hospital records are preserved and, especially, for whom.

Access to CSH Documents

After CSH documents remaining at the hospital were digitized by the Crowley Company, our aim was to develop a means of handling them so that we could offer to other states as well as to Virginia a way of managing such records by selectively and virtually redacting them without destroying the originals. One member of the team, a lawyer, outlined the legal setting of state hospital records in each state, with the intention of developing a range of policies found in the states. Then we sent a Qualtrics questionnaire to the chief archivists of all the states to gather data (using data from the Council of State Archivists [CoSA]) plus a cover letter to ensure that those who were familiar with practices would be assigned questions.⁷⁰ We were concerned with digital environments among state archives (to be used for our efforts to create a digital ecology for the records themselves), and, relevant to this article, archives' treatment of and apprehension about sensitive records. We achieved a relatively good spread across the United States, with responses from nineteen states representing just under half the population of the country.⁷¹ The segment of the questionnaire discussed here focused on archival usage, including the concerns of archivists for the people by whom and about whom the records were made. We wanted to see whether the archival respondents would reflect the current anxiety regarding the ethical treatment of the communities around organizations like psychiatric hospitals. The presence of such anxiety would mean that we should focus especially on the abilities of our digital tools to constrain access where appropriate and where needed by archives to comply, both with the law and with the wishes of directly involved communities.

Thus, my aim in this portion of the research was to discover what the stance in state archives is regarding legal access to the patient records of the hospital. I hoped to find in the responses to these questions how concerned archivists are to serve the stakeholders discussed earlier: patients and their families; hospital employees including doctors, and also nurses, aides, and recordkeeping staff; and researchers of various kinds. I also wanted to discover whether the growing interest among archivists in community archives, and even the understanding of a state hospital as a congeries of communities who themselves deserve to be served, might manifest itself in a changed focus of consideration, perhaps attributing them to specific roles and in that way becoming a long-term part of the hospital's recordkeeping with respect especially to the patients and their

families. This is especially concerning because HIPAA does not require a uniform term for records to be kept beyond fifty years.

Results from the State Questionnaire on Access

The state questionnaire included questions specific to restrictions on access, habitual visitors to the archives and their requirements, and uses of redaction. (The other portion of the questionnaire asked about digital equipment and programs so that we could tailor our work to what state archives were using.) The relevant questions are listed and discussed here, together with “Yes, other” comments.

Q17 Do you have digital collections that require restricted access (in whole or in part) for some period of time? Choose all that apply. Please add any other restrictions that are not listed.

No (0)

Yes, legal restrictions (state or federal) (17)

Yes, deed of gift restrictions (8)

Yes, institutional policy restrictions (including retention schedules) (9)

Yes, incomplete processing restrictions (8)

Yes, other (3)⁷²

Clearly, legal issues weigh on archivists, thus explaining the “No” response. In the open-ended comments repeated often-rehearsed advice regarding institutional policy, requirements of deeds of gift, and an honest confession of incomplete processing—but, by far the most concerning to archivists seem to be legal issues as framed by states and the federal government: this emerges from state records schedules that we investigated.

Q18 If you could digitally redact, easily, archival materials at the item or textual level in order to provide greater online access, would this enable you to provide better service to potential patrons?

No (2)

Yes (17)⁷³

This element was particularly clear but also abstract, as we offered no elaboration. Still, the answers seem to promise an opening to deal with stakeholders.

Q19 Would it be useful to you to be able to provide access to specific collection elements to designated user groups (e.g., donors of a collection, persons mentioned in a collection) but not to others (e.g., children, the general public)?

No (6)

Yes (13)

These judgments may mirror the previous question as well, in that “yes” may reflect the weighting seen in the previous question, such that the idea of automated redaction may for the majority of archival respondents represent an ethical solution.

Q20 What stakeholder groups do you consider when providing digital services? Choose all that apply. Please add any important constituencies not mentioned.

Government employees (18)

Patrons with professional needs (17)

Academic/scholarly researchers (18)

Teachers (14)

Genealogical researchers (17)

Other (7)⁷⁴

Our responders see state government employees who may have specific access to restricted data (for example, those who work for a state board of health) as equal to academic/scholarly researchers. Furthermore, more state archives offer special outreach to teachers, and have patrons “with professional needs” who are likely lawyers. Genealogists are presumably a version of “families” (who could be relatives) who may also use the records kept by the state. We did not ask whether digital services might depend on the age of the records.

Q21 How do you take stakeholder groups’ interests into account for access? Choose all that apply. Please add any other such procedures that you use.

Provisions in deed of gift (10)

Specifications in retention schedules (12)

Negotiations with stakeholder representatives (11)

Usability testing (7)

Evaluation of use statistics from records of paper collection
use (10)

Evaluation of online analytics related to digital collection use (8)

Other (2)⁷⁵

“Provisions in deed of gift” and “Specifications in retention schedules” are straightforward, as is forecasting via existing statistics, but “Negotiations with stakeholder representatives” might be seen as representing something of the new community leanings on the part of archivists. And, many states chose to give us miscellaneous materials in answer to this question, but it was interesting to see how they were all over the map.

Additional Surveys: Families and Researchers

Clearly these few questions do not provide exhaustive responses to what we need to know about archival records. How does the law of the state work with HIPAA? How much freedom does the state archives, which includes records of hospitals and their interactions with patients, have in its dealings with HIPAA? As long as even paper records were available, patrons would have to be very interested to find relatives. In this age of online genealogical resources such as Ancestry.com and Family Search, researcher expectations are very different than they used to be. Research may be more difficult since the relative may have been at the psychiatric hospital long ago. To serve such patrons requires archivists to develop another set of practices to treat families, patients, and researchers in specific ways, which is why we have been surveying researchers and families about their preferences.

More recently, we have begun surveying families regarding what they think about both their own access to records and the sharing of records with others. In addition, we have queried a sample of “professionals” (most of whom are historians). These surveys are not completed, so I provide just preliminary evaluations. So far, we have queried representatives of thirty-three families and fifty-two “professionals,” eighteen of whom identified themselves as historians. Interestingly, given the large number of genealogists indicated as stakeholders in the state questionnaire, many of the family representatives queried stated one interest as genealogy.

Discussion

In this new century, as archivists have begun to confront the fact that they might want to collect community archives that are significant for our understanding of our world, many have also come to the conclusion, along with Terry Cook, that the new-century archivist may become a facilitator of the preservation of tradition and the past by gathering in archival materials that *may not be immediately shareable*.⁷⁶ What kinds of use cases can justify such collections? Caswell’s “radical empathy”? H. W. Smith’s “cultural diversity competency”? It begins to look as though we need to rethink appraisal theories from the perspective of the long life that archives may accord to the records that they keep—as well as, more specifically, the changes being wrought by electronic health records and their affordances of instant search.

Individual hospital records mark the extreme case of this problem, because, in spite of the use of individual records for medical research, no rules or even “best practices” yet exist that go beyond the Hippocratic assertion that patients’ privacy should be respected. Studies done on the subject are beginning to

concern medical researchers, who are constructing other ways to study bodily harm from infections and diseases. Furthermore, existing law continues to view the facts of a patient's case, at least as recovered by samples from or images of their bodies, as belonging to the hospital or the practice, not to the patient or the patient's family.⁷⁷ Decreasing costs and increasing availability of DNA genomics as well as mobile-captured health data allow more and more health data to be sold and shared.

It is also not clear that medical researchers have made much attempt to include historical records in their longitudinal data series (studies in Seattle [1956 to present], Iceland [its Health Sector Database lasted only from 1998 to 2002], and Ireland [2010–2017, questioning 8,504 persons fifty years or older] would have been happy to have as many as three generations⁷⁸). Perhaps this is because medical practices have changed so much. It may be time to consider how historians can trace the longitudinal history of medical care through detailed patient records of the past. In other words, contrary to the remarks of John Blake cited at the beginning of this article, perhaps we need to go further than “selected records, including some case histories. . . .” The work of multiple medical sociologists and historians has shown that, with more engagement with the language and ontologies implied by historical medical records, it may be possible to reconstruct the evolution of disease and whether it had a physical or social cause—if we do not destroy or, on the other hand, commoditize medical records.

Clearly, the **health benefits** of medical research are easier for people in general to understand than, for example, a historian's efforts to paint a portrait of the formation of groups of people who experience a hospital differently; or a sociologist's analysis of what shapes hospital healing or how it may vary from place to place and culture to culture.⁷⁹ Current efforts to preserve longitudinal historical medical records as we have been doing in our project by digitizing them may lead historians, social scientists, information scientists, and medical researchers to make more of an effort to understand their details. This is especially important in the long period of the growth of state hospitals from the early nineteenth century to the present. With more work with stakeholder groups whose identities are tied up in these records, both medical research and the communities themselves may find new ways to work together.⁸⁰ Our experience in this research shows the need for an appraisal process that recognizes that changes will always take place in state-run hospitals, so that the records kept can reflect the actual experience of illness and the natural histories of disease that may not be possible to trace if archivists fail to keep them. Many records from state asylums have not yet been taken into archival custody, and the importance of the preservation of these older records should be emphasized.⁸¹

Conclusions

Subjects of medical records—and their families, who oversee their affairs as in psychiatric hospitals—deserve to influence how their data are used. Archivists' experiences with community archives offer a new perspective on this issue, but archivists have frequently had concerns about community archives in the past. State archives with which we have spoken are interested in considering how to work within legal restrictions on the sharing of patient data. This is especially important because even if state-run hospitals still retain older records, the burden of making sure that those records remain private according to state law may fall on the state archives. State archives are also interested in the possibilities of using digital redaction to offer better service by making redacted materials, especially from older records, available to researchers. Most archives identified similar stakeholder populations, including families of patients in psychiatric hospitals. Finally, the majority of state archives are interested in according varied access to stakeholder groups given the nature of the groups' relationship to the data to be shared.

These results imply that archival concern for communities is gaining significant importance, along with a serious effort to understand how power relations are involved in the production and control of records: how records are created can offer clues to the powers of their creators. As archivists, we need to be aware that our own practices have changed with time, which makes archival practice something we cannot take for granted. New needs to manage digital research records require new thinking about privacy, unknown in the paper world, where we can see the records and control them. Yet, now, especially with digitized records, we can redact records so that researchers can use the patterns within them and families can remember their relatives. This opens up many more responsibilities for archivists (not least of which is the duty to preserve digital records), but it also opens up the possibilities of working with families in ways that we have seldom done before.

NOTES

- ¹ The principal investigator on this project has been Professor King Davis, with myself, Unmil Karadkar, Victor Obaseki, and Lorraine Dong involved in the project, which for the last three years has been funded by the Andrew W. Mellon Foundation. The Freedmen's Bureau created only two mental hospitals, of which the Central State Hospital is the only one still active. The project was first proposed because the hospital decided that saving the records was important and feared that the Library of Virginia might destroy them. After Dong's work organizing the records, Crowley and Company digitized them. The project is responsible for hosting the materials while negotiations go on with the Library of Virginia.
- ² See Lorraine Dong, "The Institutional and Archival Social Ecologies of a State Mental Hospital's Records, 1870 to Present" (PhD diss., University of Texas at Austin, 2015), 122–156.
- ³ John B. Blake, "Medical Records and History," *American Archivist* 27, no. 2 (1964): 234.
- ⁴ See Society of American Archivists, "SAA Council Endorsement of Protocols for Native American Archival Materials," <https://www2.archivists.org/statements/saa-council-endorsement-of-protocols-for-native-american-archival-materials>, captured at <https://perma.cc/5PLP-9D3T>.
- ⁵ F. Gerald Ham, "The Archival Edge," *American Archivist* 38, no. 1 (1973): 5–13; Helen Willa Samuels, "Who Controls the Past," *American Archivist* 49, no. 2 (1986): 109–24. Interestingly, Samuels points on page 114 to Ham's "three seminal articles," one of which was "The Archival Edge."
- ⁶ Jeanette Bastian, *Owning Memory: How a Caribbean Community Lost its Archives and Found its History* (Westport, CT: Libraries Unlimited, 2003); Verne Harris, *Archives and Justice: A South African Perspective* (Chicago: Society of American Archivists, 2007); Terry Cook, "Evidence, Memory, Identity, Community: Four Shifting Archival Paradigms," *Archival Science* 13 (2013): 95–120; Randall Jimerson, *Archives Power: Memory, Accountability, and Social Justice* (Chicago: Society of American Archivists, 2009). Jimerson attended the Native American Archivists Section to offer congratulations for the acceptance of the *Protocols* in 2018.
- ⁷ Cook, "Evidence, Memory, Identity, Community," in which Cook argued for a sequence of archival paradigms or frameworks, from judicial legacy to cultural memory to societal engagement to community archiving (p. 95).
- ⁸ Quoted in Ham, "The Archival Edge."
- ⁹ Philip D. Jordan, "The Challenge of Medical Records," *American Archivist* 23, no. 1 (1960): 143–51.
- ¹⁰ Virginia Stewart, "Problems of Confidentiality in the Administration of Personal Case Records," *American Archivist* 39, no. 2 (1974): 387–98. The document she quoted from regarding data systems was *Records, Computers and the Rights of Citizens: Report of the Secretary's Advisory Committee on Automated Personal Data Systems*, HEW Publication No. (OS) 73-94, July 1973.
- ¹¹ Ruth Simmons, "The Public's Right to Know and the Individual's Right to Be Private," *Provenance, Journal of the Society of Georgia Archivists* 1, no. 1 (1983): 1–4.
- ¹² Roy Porter, "The Patient's View: Doing Medical History from Below," *Theory and Society* 14, no. 2 (1985): 175–98.
- ¹³ Alice Robbin, "State Archives and Issues of Personal Privacy: Policies and Practices," *American Archivist* 49 no. 2 (1986): 163–75.
- ¹⁴ Roland Baumann, "The Administration of Access to Confidential Records in State Archives: Common Practices and the Need for a Model Law," *American Archivist* 49, no. 3 (1986): 349–69.
- ¹⁵ For the Belmont Report as issued by the Department of Health, Education, and Welfare on April 19, 1979, see <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html>, captured at <https://perma.cc/D84E-6FNS>. For an outline of the Belmont Report for nurses see Vickie A. Miracle, "The Belmont Report: The Triple Crown of Research Ethics," *Dimensions of Critical Care Nursing*, 35, no. 4 (2016): 223–28.
- ¹⁶ An early treatment of HIPAA appears in Menzi L. Behrnd-Klodt, *Navigating Legal Issues in Archives* (Chicago: Society of American Archivists, 2008): 141–47. A more recent treatment, before the 2013 change to the Privacy Rule, was published by Lorraine Dong, "The Ethical and Legal Issues of Historical Mental Health Records as Cultural Heritage," in *Proceedings of the Memory of the World in the Digital Age: Digitization and Preservation*, ed. Luciana Duranti and Elizabeth Shaffer (UNESCO, 2013): 735–44.

- ¹⁷ This is the situation that the CSH finds itself in with the records it still has, and because most of its patients have been Black, sickle cell disease is of concern to families.
- ¹⁸ A list of the Library of Virginia's holdings from the Central State Hospital (entitled "A Guide to the Records of the Central State Hospital, 1874–1961") can be found at <http://ead.lib.virginia.edu/vivaxtf/view?docId=Iva/vi00940.xml&d,> captured at <https://perma.cc/LA8D-QFRB>.
- ¹⁹ Gerald N. Grob, *The Mad Among Us: A History of the Care of America's Mentally Ill* (New York: The Free Press, 1994), 178–90.
- ²⁰ Paul Starr, *The Social Transformation of American Medicine* (New York: Basic Books, 1982): 345–65.
- ²¹ See "HIPAA Privacy Rule and Sharing Information Related to Mental Health" at (<https://www.hhs.gov/sites/default/files/hipaa-privacy-rule-and-sharing-info-related-to-mental-health.pdf>) and "A Patient's Guide to the HIPAA Privacy Rule: When Health Care Providers May Communicate About You with Your Family, Friends, or Others Involved in Your Care," https://www.hhs.gov/sites/default/files/consumer_ffg.pdf, captured at <https://perma.cc/34QF-5H5M>, both from Health and Human Services, Office for Civil Rights.
- ²² Jeanette Bastian, *How a Caribbean Community Lost Its Archives and Found Its History* (Westport, CT: Libraries Unlimited, 2003), 5.
- ²³ Michelle Caswell and Marika Cifor, "From Human Rights to Feminist Ethics: Radical Empathy in the Archives," *Archivaria* 81 (Spring 2016): 23–43. In a project I worked with at the Mississippi Department of Archives and History, the Sovereignty Commission Records, the law judged that individuals could blot out their names or offer a statement if they wanted to leave them in. In a sense, the law constructed a community archives.
- ²⁴ Harold Garfinkel and Egon Bittner, "'Good' Organizational Reasons for 'Bad' Clinic Records," in *Studies in Ethnomethodology* (Cambridge: Polity Press, 1984 [originally 1967]): 186–207. Archivists are aware of the need to revise finding aids or at least to date them.
- ²⁵ Access to medical records is not complete: in general, physicians do not reveal to their patients what they really think about their conditions, and psychiatrists cannot be asked to share any of their observational records that are kept separately from standard ward records, even under HIPAA. This may be changing, however, as the Open Notes movement seeks to share physician notes also with patients. But HIPAA, although it offers access, does not offer ownership for the result of any test carried out by the hospital or other service.
- ²⁶ This concern has also emerged from Marc Berg and Geoffrey Bowker, "The Multiple Bodies of the Medical Record: Toward a Sociology of an Artifact," *Sociological Quarterly* 38, no. 3 (1997): 513–37.
- ²⁷ Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (Garden City, NY: Anchor Books: 1961); Garfinkel and Bittner, "'Good' Organizational Reasons for 'Bad' Clinic Records"; Anselm Strauss, Leonard Schatzman, Rue Bucher, Danuta Ehelich, and Melvin Sabschin, *Psychiatric Ideologies and Institutions* (New Brunswick, NJ: Transaction Books, 1981 [originally 1964]); Andrew Abbott, *The System of Professions: An Essay on the Division of Expert Labor* (Chicago: University of Chicago Press, 1988)—Abbott had produced a 1982 Chicago dissertation entitled *The Emergence of American Psychiatry* and used some of his conclusions in the book on pp. 280–314, "The Construction of the Personal Problems Jurisdiction," chapter 10.
- ²⁸ Several 'master's theses and dissertations have been written in the recent past indicating the interest of students in issues around lunatic asylums for Blacks: Kirby Ann Randolph, "Central Lunatic Asylum for the Colored Insane: A History of African Americans with Mental Disabilities, 1844–1885," (PhD diss., University of Pennsylvania, 2003); Adam Metcalfe Reed, "Mental Death: Slavery, Madness, and State Violence in the United States" (PhD diss., University of California Santa Cruz, 2014); Adia Awanata Brooks, "The Politics of Race and Mental Illness in the Post-Emancipation US South: Central Lunatic Asylum for the Colored Insane in Historical Perspective" (master's thesis, University of Texas at Austin, 2014); Caitlin Doucette Foltz, "Race and Mental Illness at a Virginia Hospital: A Case Study of Central Lunatic Asylum for the Colored Insane, 1869–1885" (master's thesis, Virginia Commonwealth University, 2015); Dong, "The Institutional and Archival Social Ecologies of a State Mental Hospital's Records, 1870 to Present" (PhD diss., University of Texas at Austin, 2015); Mary Wingerson, "'Lunacy under the Burden of Freedom': Race and Insanity in the American South, 1840–1890" (senior thesis, Yale University, 2018). What is remarkable about these essays is, aside from Dong's dissertation,

they leaned on the Library of Virginia archives and do not seriously compare what happened at Central State Hospital after desegregation.

- ²⁹ Garfield and Bittner, "'Good' Organizational Reasons for 'Bad' Clinic Records"; Strauss et al., *Psychiatric Ideologies and Institutions*.
- ³⁰ Anselm Strauss, *Negotiations: Varieties, Contexts, Processes, and Social Order* (San Francisco: Jossey-Bass, 1978), 107–22.
- ³¹ The data for this sketch of the different communities of practice is drawn partly from Dong, "The Institutional and Archival Social Ecologies of a State Mental Hospital's Records, 1870s to Present" and partly from my own research.
- ³² Caroline Norris, "A History of Madness: Four Venerable Virginia Lunatic Asylums," *Virginia Magazine of History and Biography* 125, no. 2 (2017): 158.
- ³³ "Moral management" was first seen in France (Pinel) and Britain (Tuke) and then in America, where it was championed by Thomas Kirkbride among others. See Grob, *The Mad Among Us*, 25–29.
- ³⁴ William Francis Drewry, "Central State Hospital, Petersburg, Va.," in *The Institutional Care of the Insane in the United States and Canada*, vol. 3, ed. Henry Mills Hurd (Baltimore: Johns Hopkins Press, Baltimore, 1916), 744–58.
- ³⁵ William Francis Drewry was born in 1860 and in 1884 graduated from the Medical College of Virginia. He was assistant physician at Central State Hospital from 1886 to 1896, when he took over the superintendency, which he held to 1924. He was city manager of Petersburg, where the hospital was situated, until 1929, when he became the head of the Mental Hygiene Department of the Public Welfare Division of the State of Virginia. He died in 1934. (Data taken from the *American Journal of Psychiatry*, 1935, 957–59.) People who have studied the CSH owe much to Drewry, as he contributed to *The Institutional Care of the Insane in the United States and Canada*.
- ³⁶ Drewry, "Central State Hospital," 759–60.
- ³⁷ Norris, "A History of Madness," 161. Her testimony is based on Drewry's annual reports and his *Historical Sketch of Central State Hospital* from 1905 as well as Drewry's reports to the board members, as represented in the Library of Virginia's holdings. She also had experience as a wellness rehab specialist at Southwest Virginia Mental Health Institute.
- ³⁸ Drewry, "Central State Hospital," 768.
- ³⁹ Our evidence for this is based on photographs, which are especially important for doctors, aides, and recordkeepers.
- ⁴⁰ Drewry, "Central State Hospital," 768.
- ⁴¹ Starr, *Social Transformation of American Medicine*, 73–77, 345–65; Abbott, *The System of Professions*, 294–308.
- ⁴² Strauss et al., *Psychiatric Ideologies and Institutions*, part 3. A segment in this book addresses the Chicago State (public) Hospital, which is in a sense the continuation of the 1870s Central State Hospital, as the chapters first link "Laymen in the State Hospital," then "Treatment Services in the State Hospital," "Professionals in Their Organization of Work," and finally "Patient Fates on the Treatment Services." This is because, although the Chicago State Hospital was observed in the 1960s, when teams (consisting of a psychiatrist, a psychologist, a social worker, an occupational therapist, student nurses, and one or two aides) were beginning to work actively with patients, many patients continued to be relegated to "chronic" wards, which dominated CSH.
- ⁴³ Berg and Bowker, "The Multiple Bodies of the Medical Record, 513–37.
- ⁴⁴ See Strauss et al., *Psychiatric Ideologies and Institutions*, chapter 5, "Laymen in State Hospitals."
- ⁴⁵ In 1877, the ratio of nurses to patients was one to eight, Drewry, "Central State Hospital," 746.
- ⁴⁶ Geoffrey C. Bowker and Susan Leigh Star, *Sorting Things Out: Classification and Its Consequences* (Cambridge, MA: MIT Press, 2000); also Berg and Bowker "The Multiple Bodies of the Medical Record." A 1994 article by Phyllis M. Ngin, "Recordkeeping Practices of Nurses in Hospitals," *American Archivist* 57, no. 2 (1994): 616–30, provides a glimpse of nursing practice in the 1990s, when nurses had forms to fill out but kept notes, some of which they transcribed to the forms and then discarded at the end of shift—this was before digital practices had taken over nursing.

- ⁴⁷ Drewry, "Central State Hospital," 751. Dong, "The Institutional and Archival Social Ecologies of a State Mental Hospital's Records" has recovered quotations from the matron's arguments to keep her job (212–13).
- ⁴⁸ Dong, "The Institutional and Archival Social Ecologies of a State Mental Hospital's Records," 212–16.
- ⁴⁹ Norris, "A History of Madness," 159.
- ⁵⁰ Again, this is evidenced by photographs and differing uniforms.
- ⁵¹ See Garfield and Bittner "'Good' Organizational Reasons for 'Bad' Clinic Records." Lorraine Dong, who has been involved in this project from its inception, carried out interviews with former caregivers which, given the fact that these staff members learned from those who went before them, amounts to a possible three generations of care observed in the project. From Dong's research, it seems that aides were most proud of their work with the patients and took pride in their wards as entities.
- ⁵² Library of Virginia, "A Guide to the Records of Central State Hospital, 1874–1961."
- ⁵³ See Barbara Craig, "Hospital Records and Record-keeping, c. 1850–1950, part 1," *Archivaria* 29 (1990), 57–87; part 2, *Archivaria* 30 (1990): 21–38; Craig, "Confidences in Medical and Health Care Records from an Archive Perspective," in *Privacy and Confidentiality Perspectives: Archivists & Archival Records*, ed. Menzi L. Behrnd-Klodt and Peter J. Wosh (Chicago: Society of American Archivists, 2005), 246–56. For forms used at CSH, see Dong, "The Institutional and Archival Social Ecologies of a State Mental Hospital's Records," 122–55.
- ⁵⁴ At the moment they are installing a Cerner system, one of the most respected systems today.
- ⁵⁵ Drewry, "Central State Hospital," 735–42.
- ⁵⁶ Drewry was concerned about "After-Care" in his 1910 report (p. 10), citing "the many furloughs returned."
- ⁵⁷ For community care through the nineteenth and twentieth centuries in Britain, see Peter Bartlett and David Wright, *Outside the Walls of the Asylum: The History of Care in the Community, 1750–2000* (London: Athlone Press, 1999).
- ⁵⁸ In our Families questionnaire, the families did not want identifiable access accorded to news media.
- ⁵⁹ Drewry's reported to the board the work that was done by the patients: some might not perform them, or performed them part-time, but many did perform labor—for women, washing clothes, cleaning the wards; for men, actual farming, and one of the most important staff at the asylum was the farmer. Drewry wrote in his Report of the Superintendent for 1910, under "Occupation," that "An average of about seventy per cent of our patients are employed daily at some manual work. . . . Everywhere about the hospital . . . may be seen every day groups of men and of women whose hands have found something to do. In that way their minds are made more contented and the results are better physical and mental conditions, to say nothing of the financial gain to the institution." Then for "Diversion," "As far as our limited resources permit, we provide entertainments and pleasure, in various ways, for our patients. . . . To Dr. Banks belongs the credit for inauguration of this mode of amusement"—that is, "field Sports Days" consisting of baseball played against teams from the town of Petersburg (all from "After-Care," p. 12).
- ⁶⁰ Our project has not worked with case-file records, but they still exist at the hospital in microfilm, although they are not sorted except chronologically—and at any rate, case files were not kept until the turn of the twentieth century. Dong has managed to discover something of what belonged in the case files through interviews with former staff at the hospital, who were able to elaborate on the kinds of records they kept—as mentioned before, they not only made records, but had to deal with records of patients who had come long before they were hired by the hospital. See Dong, "The Institutional and Archival Social Ecologies of a State Mental Hospital's Records, 1870s to Present," 146–53.
- ⁶¹ For the Tuskegee syphilis experiments, see Allan M. Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States since 1880* (Oxford: Oxford University Press, 1987), which outlines the racist setup of the "experiment" that ran from 1932 to 1972 without treating the "sample" of men even when treatment was possible. For the story of Henrietta Lacks's cancer and its exploitation, see Rebecca Skloot, *The Immortal Life of Henrietta Lacks* (New York: Broadway

- Books, 2011), which provides an interesting portrait of Lacks's family's desperate efforts to understand what had happened to her.
- ⁶² For this ongoing issue from an archival point of view, see Tywana Whorley, "The Tuskegee Syphilis Study: Access and Control over Controversial Records," in *Political Pressure and the Archival Record*, ed. Margaret Procter, Michael Cook, and Caroline Williams (Chicago: Society of American Archivists, 2005), 109–17.
- ⁶³ One feature of the project's studies has been to create questionnaires for living relatives of patients as well as researchers who might want access to the records.
- ⁶⁴ Lorraine Dong, "Taking the Long View of Medical Records Preservation and Archives," *Journal of Documentation* 71, no. 2 (2015).
- ⁶⁵ The growth of digital recordkeeping in state-run hospitals will make the care of the records very challenging. See Kish Hawthorne and Lorraine Richards, "Personal Health Records: A New Type of Electronic Record," *Records Management Journal* 27, no. 3 (2016): 286–301; Alessandro Blasimme, Marta Fadda, Manuel Schneider, and Effy Vayena, "Data Sharing for Precision Medicine: Policy Lessons and Future Directions," *Health Affairs* 37, no. 5 (2018): 702–9; Jennifer Kulynych and Henry T. Greely, "Clinical Genomics, Big Data, and Electronic Medical Records: Reconciling Patient Rights with Research when Privacy and Science Collide," *Journal of Law and the Biosciences*, January 15, 2017: 94–132; Robert Gellman and Pam Dixon, "The Precision Medicine Initiative and Privacy: Will Any Legal Protections Apply?," *World Privacy Forum*, May 18, 2016; Robin N. Fiore and Kenneth W. Goodman, "Precision Medicine Ethics: Selected Issues and Developments in Next-Generation Sequencing, Clinical Oncology, and Ethics," *Current Opinion in Oncology* 28, no. 1 (2016), <https://doi.org/10.1097/cco.0000000000000247>; Susan Bull, Nia Roberts, and Michael Parker, "Best Practices for Ethical Sharing of Individual-Level Health Research Data from Low- and Middle-Income Settings," *Journal of Empirical Research on Human Research Ethics* 10, no. 3 (2015), 302–13.
- ⁶⁶ For the evolution of records, see Craig, "Hospital Records and Record-keeping"; and Garfinkel and Bittner, "'Good' Organizational Reasons for 'Bad' Clinic Records," for the use of hospital records to chart the environment of the hospital.
- ⁶⁷ Keith Wailoo, *Dying in the City of the Blues* (Chapel Hill, NC: University of North Carolina Press, 2000), *How Cancer Crossed the Color Line* (Oxford: Oxford University Press, 2010); Julie Livingston, *Improvising Medicine, An African Oncology Ward in an Emerging Cancer Epidemic* (Durham, NC: Duke University Press, 2012); as well as the list of theses and dissertations cited above.
- ⁶⁸ Dong, "The Institutional and Archival Social Ecologies of a State Mental Hospital's Records, 1870s to Present," 230–75.
- ⁶⁹ For a sample of treatments of community archives and the powers of the archivist, see the early part of this article as well as Jeannette Bastian and Ben Alexander, *Community Archives: The Shaping of Memory* (London: Facet, 2009); Mary Caldera and Kathryn Neal, eds., *Through the Archival Looking Glass: A Reader on Diversity and Inclusion* (Chicago: Society of American Archivists, 2014); and for a further step, Andrew Flinn and Anna Sexton, "Research on Community Heritage: Moving from Collaborative Research to Participatory and Co-designed Research Practice," (CIRN Prato Community Informatics Conference, 2013), <https://www.monash.edu/it/hcc/dedt/prato-conferences/prato-cirn-2013/prato2013papers>.
- ⁷⁰ See Cover Letter to Archivists, from Alabama, Arkansas, California, Colorado, Connecticut, Georgia, Kentucky, Louisiana, Minnesota, Mississippi, Nebraska, New Mexico, North Carolina, Tennessee, Texas, Vermont, Virginia, Washington, Wyoming.
- ⁷¹ The states were the above list.
- ⁷² Question 17: County auditors (recording offices) select levels of online access for recorded documents transferred to archives [WA]; restriction imposed by legislators on their own records [TX].
- ⁷³ Question 18: We redact sensitive information from the access copies of digital records [AR].
- ⁷⁴ Question 20: While we have specific stakeholder groups we strive to make materials accessible to anyone, even those not necessarily part of one of the groups [VA]. General Public [VT]. Patrons/donors, decision makers (legislators, departmental administrators) [NC]. IT [CT]. Many [NM]. General Public—anyone who requires records [TX]. Middle and High School students completing History Day projects [GA].

- ⁷⁵ Question 21: Currently working on obtaining an OASIS system. Project is ongoing [CA]. The issue of access to historical mental health records is timely for us as well. A researcher has been seeking full access to Civil War veterans' mental health records here in Connecticut [CT]. The bill has been raised again this year in the Connecticut General Assembly to open all health records 50 years after an individual's death in line with HIPAA regulations [CT]. Remote patron correspondence with staff (email or online requests for information) [NC]. NEHS is beginning the process to discuss digitization efforts and access to electronic records. We are looking at possible services, but need to review our IT infrastructure. Our servers are 15 years old [NE]. Redaction software already exists—we use Adobe Acrobat and the tool Bulk Extractor (from the BitCurator suite)—both tools allow for keyword, number, string searching. The problem is that even when we locate names, numbers, email addresses, we still need to know that context (are they public or private). We also have restrictions that require human review and cannot be automated [TX]. Needs of donor agencies; ease of item level indexing [WA].
- ⁷⁶ Cook, "Evidence, Memory, Identity, Community," 113–16.
- ⁷⁷ Bull, "Best Practices for Ethical Sharing of Individual-Level Health Research Data," 302–13.
- ⁷⁸ K. Warner Schaie and Sherry L. Willis, "The Seattle Longitudinal Study of Adult Cognitive Development," *ISSBD Bulletin* 57, no. 1 (2010): 24–29; David E. Winickoff, "Genome and Nation: Iceland's Health Sector Database and Its Legacy," *innovations* (Spring 2006); "The Irish Longitudinal Study on Ageing (TILDA)," Trinity College Dublin, "New TILDA Report on Ageing in Ireland Launched Today," March 7, 2017, <https://tilda.tcd.ie/news-events/2017/1702-w3-key-findings>.
- ⁷⁹ Starr, *The Social Transformation of American Medicine*, 1982; Annemarie Mol, *The Body Multiple: Ontology in Medical Practice* (Durham, NC: Duke University Press, 2003); Strauss et al., *Psychiatric Ideologies and Institutions*
- ⁸⁰ Jimerson, *Archives Power*.
- ⁸¹ Here in Austin we have the Austin State Hospital (ASH) which is facing a serious makeover to partner with the University of Texas's new medical school; the ASH has myriad records. In Mississippi, the state archives has digitized nineteenth-century asylum records and has discovered newly found records from a transfer of many records to another asylum in the early twentieth century.

ABOUT THE AUTHOR

Patricia Galloway worked as a medieval archaeologist in Europe in the 1970s and then became involved with humanities-oriented computing, which she supported in the Computer Unit of Westfield College of the University of London, where her primary interest was text analysis. From 1979 to 2000, she worked at the Mississippi Department of Archives and History (MDAH), where she was an archaeological editor and an electronic records program director. From 1997 to 2000, she directed the NHPRC grant-funded project at MDAH to create an electronic records program for the state of Mississippi. Since coming to the School of Information at the University of Texas, Galloway has developed a suite of courses designed to prepare students to become capable of managing and maintaining digital cultural objects.