



## Journal of Documentation

Taking the long view of medical records preservation and archives  
Lorraine Dong

### Article information:

To cite this document:

Lorraine Dong, (2015), "Taking the long view of medical records preservation and archives", Journal of Documentation, Vol. 71 Iss 2 pp. 387 - 400

Permanent link to this document:

<http://dx.doi.org/10.1108/JD-11-2013-0141>

Downloaded on: 10 November 2016, At: 20:41 (PT)

References: this document contains references to 69 other documents.

To copy this document: [permissions@emeraldinsight.com](mailto:permissions@emeraldinsight.com)

The fulltext of this document has been downloaded 804 times since 2015\*

### Users who downloaded this article also downloaded:

(2015), "The unbearable lightness of participating? Revisiting the discourses of "participation" in archival literature", Journal of Documentation, Vol. 71 Iss 2 pp. 358-386 <http://dx.doi.org/10.1108/JD-01-2014-0012>

(2015), "Data literacy: in search of a name and identity", Journal of Documentation, Vol. 71 Iss 2 pp. 401-415 <http://dx.doi.org/10.1108/JD-02-2014-0026>

Access to this document was granted through an Emerald subscription provided by emerald-srm:563821 []

### For Authors

If you would like to write for this, or any other Emerald publication, then please use our Emerald for Authors service information about how to choose which publication to write for and submission guidelines are available for all. Please visit [www.emeraldinsight.com/authors](http://www.emeraldinsight.com/authors) for more information.

### About Emerald [www.emeraldinsight.com](http://www.emeraldinsight.com)

Emerald is a global publisher linking research and practice to the benefit of society. The company manages a portfolio of more than 290 journals and over 2,350 books and book series volumes, as well as providing an extensive range of online products and additional customer resources and services.

Emerald is both COUNTER 4 and TRANSFER compliant. The organization is a partner of the Committee on Publication Ethics (COPE) and also works with Portico and the LOCKSS initiative for digital archive preservation.

\*Related content and download information correct at time of download.

# Taking the long view of medical records preservation and archives

Medical  
records  
preservation  
and archives

387

Lorraine Dong  
*School of Information, The University of Texas at Austin,  
Austin, Texas, USA*

Received 2 November 2013  
Revised 10 March 2014  
Accepted 1 May 2014

## Abstract

**Purpose** – The purpose of this paper is to present an argument for taking the long view of the retention and preservation of inactive medical records.

**Design/methodology/approach** – Using the theoretical framework of Actor-Network Theory, the author examines medical records, and especially mental health records, as actants that participate in the classification and treatment of patients, and in the development of psychiatry and mental hospitals as social institutions.

**Findings** – The varied and profound roles of medical records demonstrate the ability for records to have multiple “lives” that can touch many individuals beyond a single human lifetime.

**Practical implications** – As the current and future custodians of historical medical record collections, information professionals are in a position to be greater advocates for the increased preservation of and mindful access to these materials.

**Social implications** – Medical records have potential to be cultural heritage documents, especially for emergent communities.

**Originality/value** – This paper articulates the ways in which medical records are an embedded part of many societies, and affect the ways in which illness is defined and treated. It thus suggests that while laws regarding the retention and destruction of and access to medical records continue to be deliberated upon around the world, such records can have enduring value as information artifacts.

**Keywords** Archives, Classification, Theory, Information profession, Health, Information control

**Paper type** Conceptual paper

## Introduction: why medical records matter

Public understanding of mental illness and mental health has become increasingly possible through projects that present the perspectives and lived experiences of mental healthcare consumers and workers. For example, University of College London information studies doctoral student, Anna Sexton, collaborated with the Wellcome Library to launch a digital archive of recovery stories as told by individuals who have experienced mental health difficulties[1]. The Exploratorium in San Francisco, California, held a temporary physical exhibit in 2013-2014 called “The Changing Face of What is Normal: Mental Health” that included patient belongings from a defunct New York state facility, Willard Psychiatric Center, and video-based interviews in order to present the challenges and risks of defining mental illness[2]. The Austin, Texas-based art group, Four Plus Four Equals, attempts to raise awareness about mental health through audio recordings and co-created artwork by artists and people in recovery[3]. While oral narratives and artifacts are the primary informational sources for these three projects, health provider records can provide yet another critical viewpoint into the world of mental illness and institutional care. The accessibility of mental health records, and medical records in general, as archival documents is not always possible, however, dependent upon specific national and state laws and organizational policies.



The predominant discussions among information professionals and legal scholars in the USA about the preservation and archiving of inactive medical records has been focussed on understanding the nuances of constantly shifting laws and codes regarding the retention and disposition of and access to this genre of records in order to implement policy correctly and effectively (Gilliland and Wiener, 2011; Lawrence, 2007; Petrilu, 2000). While these practice-based concerns are by no means widely resolved yet or have straightforward solutions, they are further complicated by their basis in complex questions of institutional accountability and liability, patient privacy, and the purpose and value of medical records over time. In this paper, the author focusses on the last topic in order to elucidate how this particular genre of records, whether as medical or cultural objects, are dynamic participants continually affecting how we perceive the world around us. This investigation into the literature regarding the social role of medical records is part of a larger study by the author that will trace the ecologies of hospital document belonging to a single mental institution over a 150-year span.

The author will review the sociological literature about the hierarchical environments of medical institutions, with a focus on the temporally and culturally inscribed relationships between health records and people. The intent is to demonstrate that medical records are not static objects that will always affect people in the same way across cultures and time. In order to begin considering the full range of potential uses and roles of records, the author proposes employing Actor-Network Theory (ANT) as a theoretical framework in which objects have social agency and the ability to shape people's perceptions and beliefs. According to proponents of ANT, objects have the potential for dynamic social lives and agency, in the sense of having effects over ontological situations (Latour and Woolgar, 1979/1986; Pickering, 1995). Within ANT, which is the "sociology of associations" (Latour, 2005, p. 9), objects have social roles equal to that of humans in affecting situations and making an impact on their surroundings.

The objects that are the focus of this paper – hospital records – are inclusive of "information or data that has been fixed on some medium [and] is used as an extension of human memory or to demonstrate accountability" (Pearce-Moses, 2005). Records, however, do more than represent human actions and memories; they have values or affordances "transcending any single aspect of recordkeeping or use" (Yeo, 2007, p. 330). Records communicate rules, structure daily activities, and serve as intermediaries in human relationships. More implicitly, they can reify beliefs, influence social norms, and maintain structures of power. Besides being reflections of human activities, records actively impart social and cultural assumptions to people associated with the records and connected by them. By following the social lives of records, we can infer not only how they are used in different eras and take form in different media, but also how the ideas that they convey are mutable and socially constructed concepts. The shifting classification schema used by mental health practitioners and institutions is a particularly powerful example of records' multiple and temporally specific roles (Szasz, 1974; Starr, 1982; Rogler, 1997; Bowker and Star, 1999; Foucault, 1961/2006; Metzl, 2009).

By demonstrating the power and roles of mental health records in the past as institutional agents, the author will promote taking the long view of these records' historical value and their emergent potential for future participation within a broader cultural heritage matrix. Mental health records can serve as evidence of the beliefs emerging from and being reinforced by the professional fields of psychiatry and medicine – and implicitly, society at large – at a given time. A conservative approach to the destruction of medical records should be taken because such documents can

---

continue to help us understand and challenge our beliefs about mental illness, mental healthcare, and the purpose of records.

### Medical records as actants

Pragmatist George Herbert Mead, while developing the sociological theory of symbolic interactionism in the early decades of the twentieth century, observed that an individual's social identity and sense of self is shaped by the physical world and the objects around him. This post-humanist argument for the agency of objects and recognition of their impact on our lives is, as sociologist Adele Clarke (2005) calls it, a moment of "conceptual rupture" (p. 56). By viewing language as a social phenomenon, Mead also began a rich line of inquiry into "the continuity between non-human and human communication" (Bernstein, 2010, p. 151). Mead's research on social actions, rather than just human actions, prompted other sociologists to examine the role of objects in dynamic social systems (Puddephatt, 2005; Gross, 2010).

In the early 1980s, Bruno Latour (2005) and fellow sociologists John Law and Michel Callon at the Centre de Sociologie de l'Innovation developed ANT. These initial proponents of ANT took and generalized the term "actant" from literary analysis. An actant can be a single individual, an idea, a technology, a biological entity, or a non-biological thing that has agency because it modifies a state of affairs (pp. 54, 71). According to ANT, all actants are equal participants in a network of associations, and, more specifically, are mediators, meaning that they change any associations that pass through them (pp. 34, 39). Groups (a term Latour prefers to "communities") of actants are always working to define themselves through continual performance, explanation, and rule-setting. Records are non-human actants that are part of networks made up of groups, individuals, activities, ideas, and other objects that are interacting with one another to produce meaning using discourse. Here, discourse encompasses more than written or spoken communication. It includes all the signs and symbols that convey relationships between actors, objects, and other discursive players; for example, discourse includes the gestures used between people, the types of materials used in buildings (e.g. steel and glass compared to pressboard and vinyl siding), and the garments worn.

Within networks of actants, power is not a given, but instead something that must be constantly produced. Day-to-day practices are what create, maintain, and destroy ontologies (Mol, 2002). Latour argues that objects, by becoming carriers of social rules and even delegates of moral authority, can police behavior and determine the power relationships between humans (Dant, 2005). In *Laboratory Life*, Latour and Steve Woolgar (1979/1986) observe the pervasiveness of documents in scientific activities, whether that is the reading, discussion, or production of a "readable trace": "Even the most informal exchanges constantly focussed [sic] on the discussion of documents" (p. 53). They go on to argue that material components are as necessary as intellectual ones for the "production of facts," or the construction of an objective reality, in a laboratory (p. 238).

Beyond the laboratory setting, documents and their movements are integral components in how power is distributed within any professional environments. Max Weber (1948/1991) studied the files and filing systems that make up the internal workings of bureaucracies, and noted that anyone who has internalized these procedures and information to achieve "knowledge of the files" is capable of making optimal bureaucratic decisions (p. 214). In other words, it is the "flows of documents," rather than individuals, that are the "primary mechanisms of managerial control"

(Yates, 1989, p. 20). The documents, while created by human agents, have their own effect on how institutions run; accumulated data from documents have the ability “to classify, to form categories, to determine averages, to fix norms” (Foucault, 1975/1995, p. 190).

In terms of the ability for records to classify people, written institutional records can create identities that are difficult to alter, and assist in reinforcing systemic ideologies about race, gender, and other social identities (Mol, 2002). For example, the diagnostic charts used in hospitals are the means through which official and formal patient identities are formed and recalled. These institutional identities are situated in specific cultural eras, resulting in individual profiles that arguably reflect less an individual’s self-identity and more the prevailing conceptions of illness and professional developments at the time. Medical records, as a particular type of institutional document, play a significant role in the shaping of how we understand and perceive what is illness, who is considered ill, and how we treat it.

Medical records and other types of documents can continue to have agency after they are no longer used for their original purposes. Andrew Pickering (1995), a sociologist in science and technology studies, self-identifies himself as being divergent from the ANT developers and other responders in his focus on how material agency is “temporally emergent in practice” (p. 14). For Pickering, the performativity of actants can be as repetitive as that of humans, if not more so (e.g. a machine doing the same operations day after day); therefore, noticeable shifts in material agency can appear slow “on the time scale of human affairs” (Pickering, 1995). The interplay between human agents and material actants across long spans of time, however, can be profound.

Pickering’s conceptualization of objects as having different social interactions with people over time is critical for this paper’s argument to preserve mental institution records for two reasons. First, as the author will attempt to illustrate in the next section, mental health records have been and continue to be powerful agents in helping to create institutional identities for patients, establishing mental disorder diagnoses and classifications, and upholding cultural and social authority. Second, the ways in which historical mental health records could interact with humans in the future as archival resources is unknown and must be constantly revisited. While the societal impact of archival mental health records has largely gone unstudied, archival scholars have discussed institutional records in general as being valuable archival resources, not only as evidence of administrative activities but also as cultural heritage artifacts when appropriated by various communities as part of their cultural memory (Taylor, 1982; Bastian, 2003; Cox, 2009). As Pickering emphasizes, objects have the ability to make social impacts that are very different from the kinds made by human actants, especially in the formers’ ability to exist as both physical and informational objects for longer periods of time and across multiple networks.

### **The work of medical records: professional authority**

Along with human actors, documents support the medical field as a professional discipline and in the disciplining of patients. Paul Starr (1982), a professor of sociology and public affairs whose research focusses on health care reform, alludes to the power of documents when he writes about how medical professionals create legitimacy to ensure their occupation’s success as a cohesive group within society. A group creates a shared body of knowledge and standards, which in turn act as “cultural authority” to outsiders (p. 12). French sociologist Pierre Bourdieu (1991)

observed that professionals strive to create cultural capital that is specific to their field; these shared resources – particular ways of thinking, talking, and acting – allow them to participate in and know the rules of the political game. Bourdieu's former colleague, Robert Castel, focussed on psychiatry as a profession that actively develops specialized, or "expert," knowledge (Ingleby, 1983, p. 160). In turn, the public gives professionals, as a group and as individuals, their trust and, thus, a great deal of political capital and power.

Psychiatrists, like other subgroups, have the potential to gain status within larger groups through the development of cultural authority and social authority (Starr, 1982). Cultural authority resides in objects or ideas, such as medical jargon, white lab coats, and the Hippocratic Oath. Sociologist Andrew Abbott (1982), in his dissertation on the development of American psychiatry, describes the deepening cultural authority of psychiatry as a field through the increase in mental health textbook publishing and in the development of disease categories in state hospitals. Social authority, on the other hand, is based on a hierarchy of individuals (e.g. doctors, nurses, patients) and their actions. The two types of authority are not necessarily dependent on one another; for example, one could trust the information of a medical web site without personally knowing the person who wrote it or his medical credentials. However, the two authority sources often inform each other. In the case of the doctor-patient relationship, Starr asserts that cultural authority generally precedes social authority in creating situations in which patients entrust their health to doctors. Patients often hold an implicit belief that doctors have the ability to read the signs of illness and to diagnose: "By shaping the patients' understanding of their own experience, physicians create the conditions under which their advice seems appropriate" (Starr, 1982, p. 14). Similarly, psychology professor David Ingleby (1983) argues based on his research on health and social care systems in multicultural societies that medical knowledge has valuable cachet as a social ordering tool because it can "regulate morality without seeming to do anything of the sort" (p. 163). Documentation practices and recordkeeping, in part, are tacitly responsible for achieving Starr's "conditions" and Ingleby's "regulat[ing]."

A way in which hospitals and other disciplinary institutions (e.g. governments, prisons, archives) maintain power over the people they oversee and perpetuate the pervading norms and social order is through control over how and what information is transmitted and retained (Jimerson, 2009). Bourdieu (1991) theorized that various forms of speech, including everyday written forms of communication, are a form of "symbolic power" or "symbolic violence" that implicitly marginalizes individuals and perpetuate social hierarchies. The use of classification systems in everyday recordkeeping at disciplinary institutions, and mental hospitals in particular, reveal how records are participants in practices that perpetuate temporally situated social norms and professional goals.

### **The work of medical records: mental health classifications**

Geoffrey Bowker and Susan Star (1999) discuss how categorizations and standardizations are embedded tools developed and shared within infrastructures, and specifically within social institutions. Their primary example of an organizational system is the Nursing Intervention Classification, which is a system used by nurses in their recordkeeping practices and is understood by the more general medical field. The classifications, or labels, applied to patients are often not based solely on the observed individual, but are rather a negotiated compromise of naming that allows

harmony and understanding across a potentially diverse infrastructure (e.g. the US healthcare system). The resulting labels serve as “boundary objects,” a term Star and Griesemer (1989) introduced to describe objects that reside in multiple communities of practice in order to meet some information need (p. 297). While no system of representation entirely embody what it purportedly signifies (Yeo, 2007), medical records in particular are characterized by precision and brevity as substitutes for accuracy and representational work in order to accomplish efficiently the tasks at hand. Abbott (1982) describes “a constant strain between the ideal of complete observation and the doctrine of crucial signs and symptoms” faced by late-nineteenth-century doctors when diagnosing patients with mental illnesses (p. 313). Latour (2005) asserts that social classifications such as race and mental status, which are culturally created and defined, are reified and naturalized by being absorbed into what is considered natural, non-social, and scientific.

Cognitive linguistic scholar George Lakoff, based on his observations of the language use of scientists and politicians, has written extensively on how different social groups create their own classification systems, or framing metaphors, then present them as the authoritative way of viewing the world (Lakoff, 1987, 2008; Lakoff and Johnson, 1980; cf. Trace, 2002, on police officers socialized in record creation). Psychiatrists have arguably developed their professional authority in part through the “classificatory impulse” (Dandeker, 1990, p. 147). Classification systems are always changing as infrastructures evolve due to cultural changes, technological growth, and time. In turn, classification can affect how individuals within institutions and across institutions interact. For example, Michel Foucault (1961/2006), in tracing the difficulty for eighteenth-century doctors and scientists to classify mental illnesses as they did physical ailments, notes how the names for mental illnesses in this time period were necessarily evocative of “a whole world of symbols and images” (p. 205). Doctors used metaphorical and visually evocative language when speaking of black melancholy, vapors rising from the abdomen, or frayed nerves. During that era, a divide persisted between the arguably more physical realm of medical classifications and the metaphorically oriented classifications used in mental hospitals (p. 393). Then in the late 1800s, general medicine classifications changed from general physiological descriptions, “senility” and “destitution,” for example, to more specific and categorized diagnoses (Rosenberg, 1987, p. 152). The shifts in diagnoses and classifications over time for mental illnesses reflect developments in the psychiatric profession, especially in mental illness epistemology and the profession’s attempts to merge with the general medical field.

In response to Foucault’s 1961 history of mental illness, *History of Madness*, a group of sociologists in the late 1960s and 1970s began to focus on the social history of medicine. One major critique they have of Foucault’s work was that he does not sufficiently address the dynamic social factors involved “in the shaping of the treatments offered for insanity at different periods in different societies” (Melling, 1999, p. 2). Ingleby (1983) and the psychiatry historian and sociologist Andrew Scull (1983), among others, examined the economic, political, and professional sources that in part determined mental illness diagnoses and treatments.

On the extreme end of the spectrum in defining mental illness, a subset of sociologists argues that mental illnesses and the corresponding classifications have been entirely socially constructed in order to control sectors of the population. Thomas Szasz (1974) views mental diseases as entirely metaphorical illnesses that reflect society’s changing norms and need to stigmatize groups through labels of sickness.

Alluding to Ludwig Wittgenstein's language games, Szasz argues that all mental illnesses are a type of game in which both doctors and patients play roles involving culturally constructed impersonation, rules, and signs.

As an example of the "game" of mental illness, Szasz discusses hysteria as a historical disease that was invented by Jean-Martin Charcot and Sigmund Freud, but no longer exists in modern mental disorder classification. Micale (1993) provides an in-depth examination of the "diagnostic drift" (p. 523) in psychiatry and the eventual disappearance of the term hysteria. The mental state that once was labeled hysteria is diagnosed as either a type of dissociative disorder or a somatization disorder in 4th ed. of the *Diagnostic and Statistical Manual of Mental Disorders*, or DSM-IV (American Psychiatric Association, 2000). Interestingly, this edition of the manual recommends psychiatrists take a "cross-cultural perspective" especially when evaluating the former disorder because "dissociative states are a common and accepted expression of cultural activities or religious experience in many societies." Thus, the manual recognizes, for this particular mental condition at least, that cultural factors determine whether it should be called a state or a disorder.

Medical sociologists have investigated the historical and social influences on the increasing complexity and growth of mental disorder diagnoses generally in the *DSM* (Rogler, 1997; Greenberg, 2013) and for specific diagnoses, e.g. homosexuality (Lamberg, 1998), post-traumatic stress disorder (Wilson, 1994), and eating disorders (Parry-Jones and Parry-Jones, 1994). Jonathan Metzl (2009) observes in his examination of schizophrenia in early twentieth century admission records from the Ionia State Hospital for the Criminally Insane in Michigan that "the meanings of diagnostic categories changed even when the names of the categories remained the same" (p. 68). Metzl, currently the Director for Vanderbilt's Center for Medicine, Health, and Society, points to changing social conditions as the driving force behind the shifts in classificatory meaning; earlier, the sociologist Harold Garfinkel (1967/1984) saw minor changes in institutional policies, procedures, personnel, and organizational structures as the reason for fixed clinical terminology becoming ambiguous.

In his discussion of the language "game" of mental illness, Szasz (1974) strongly critiques the existing mental healthcare structure for what he perceives as the systemic victimization of patients, especially those who have been involuntary institutionalized as a result of cultural castigation. He acknowledges, however, the societal need for such rules and metaphorical languages (p. 161). Similarly, Bowker and Star (1999) describe the requirement for classification for functional societies (p. 317) and MIT management Professor JoAnn Yates (1989) views the shift from descriptive to comparative data as a necessity for the systemic management of large organizations (p. 80). According to sociologists and grounded theorists Barney Glaser and Anselm Strauss (1965), the definitional "signs" from social structures inform interactions between actors. Classifications, stereotypes, and norms all serve as pieces of the picture of what people know or assume they know about one another, creating an "awareness context" (p. 274).

In addition to classification systems being a symbolic part of social institutions in that they represent ways of shaping beliefs and maintaining order, they are also part of the built environment (Bowker and Star, 1999, p. 39). Embodied in records, insignias (e.g. uniforms), and manmade structures and landscapes, classification systems are part of the material culture of institutions. Yates (1989) argues that internal organizational records are a necessary component of systematic management because they contribute to "corporate memory" (p. 63). After institutions are gone, such materials can continue to serve as tangible evidence of discipline, control,



and an institutional perspective on controlled populations. They can, for example, be used to trace how records served as organizational managerial tools. Echoing the anatomical metaphor developed by late-nineteenth-century Dutch archivists to describe archival arrangement (Muller *et al.*, 1898/1968), Yates (1989) studies the “skeletal remains of the communication systems that once controlled and coordinated [companies]” in order to deduce the “muscle and flesh” (p. xix). The historian Marc Bloch (1962) has noted that historical documents can become “the evidence of witnesses in spite of themselves” (p. 61). In other words, some documents can persist as the unintended artifacts of past decisions and practices, as seen in Ann Laura Stoler’s (2009) historiographical study of how the Dutch East Indies government’s official records reflect negotiations of colonial power and Michelle Caswell’s (2010) research on the ongoing social lives of Khmer Rouge mug shots as mediators for human rights activism.

### Medical records as cultural heritage

Objects have the distinct ability to impact social activities and viewpoints beyond an individual human’s lifetime. This temporal characteristic is especially powerful when thinking about how the same objects can be present throughout changes in institutional administrations and cultural frameworks. As Pickering (1995) reminds us, the meanings of records in relation to social environments are constantly shifting. In keeping with the fourth, pluralization dimension of the records continuum model in archival studies (McKemmish *et al.*, 2009), institutional records can be part of many social worlds and networks of association over time. Records can serve several functions over the course of their existence; some persist across many human lifespans while others are highly ephemeral and have very short periods of use before being destroyed, never to be seen again or to be used by anyone outside of the institution. As “active” or “in use” institutional records, medical documents can belong to multiple social networks, some of which are based on administrative or “official” workflows while others, such as those Erving Goffman (1961) wrote about in Asylums, are informal and covert. Numerous studies have already shown medical records, in particular, as integral parts of institutional culture (Craig, 1989, 1990; Ngin, 1994; Yakel, 2001a, b; Mol, 2002). Institutions are constantly undergoing administrative changes, shifts in funding and policy, and other transitions, and records accordingly can continue to be utilized for other institutional purposes or be intellectually and/or physically located elsewhere in an archival capacity.

When records become historical artifacts of past institutional functions and cultural practices, they become part of archival networks. Documents take on new meaning when they are no longer used by the institution that created them. As players in these social groupings, records may move from being the implicit components of everyday recordkeeping practices into the foci of project and research discourses. In a postmodern archival framework, record authenticity and reliability are socially constructed concepts; rather than “standing for the facts,” records reflect rational bureaucracies at work (MacNeil, 2001). Thus, instead of being peripheral agents that administrative and staff members utilize to inscribe factual information, records as archival materials can be put on display as proxies or agents in themselves of hegemonic structures and practices. For example, scientific research reports become “historical cultural documents” if preserved over time and made accessible (Clarke, 2005, p. 169). Canadian archivist Hugh Taylor (1982) argues that administrative records can become part of a community’s heritage, and studying how records were managed

can reveal a great deal about the relationship between an institution and the community it serves:

The connection of records management with heritage may seem rather remote. Yet, if the “collective memory” is to be systematically updated to contain not only administrative decisions but also the response of the community to its administrators (and producers in the private sector), operational files must be retained that are appropriate to record linkage and other techniques of quantitative history (p. 126).

Taylor points to the continuing use of institutional records as being part of a “collective memory” that goes beyond institutional recordkeeping or administrative culture. Eric Ketelaar (2005), borrowing the political science term of “community of memory” for archival theory, suggests that “to be a community, a family, [or] a religious community, a profession involves an embeddedness in its past and, consequently, in the memory texts through which that past is mediated” (p. 7). Therefore, records that may serve as the material objects, or the “objectivized culture,” to reinforce corporate memory for a professional community can be “cultivated” again for a different kind of cultural memory for other types of communities (Assmann and Czaplicka, 1995, p. 131).

In summarizing the essays found in Jeannette Bastian and Ben Alexander’s *Community Archives*, Richard Cox (2009) comments on the powerful societal role of archival records and repositories, especially in brokering relationships between a group and the larger society within which it resides. He writes, “[Archival records] perform complicated roles of commemoration, celebration and communication that establish or strengthen communities,” and furthermore, they “serve interesting and complicated roles related to the power of particular groups in any society or culture within that society” (p. 254). Bastian (2003) argues for the importance of retaining administrative records as part of community archives. Such written history “becomes a primary link in the ability to define the community narrative and forge community identity” (p. 47). The records act as “frameworks for interpretation” that can support or contradict individuals’ memories. Archival mental institution records have the potential to be used by emerging communities, such as individuals in recovery, patients’ families, and healthcare workers, all of whom have had their identities shaped by the records themselves as material objects and conveyers of social meaning.

Archival records can be used specifically for “liberation historiography,” a form of historical writing by minority communities who were misrepresented or excluded from the official records that once served as the dominant form of historical evidence about those communities (Ernest, 2004). Echoing Benedict Anderson’s (1991) “imagined communities,” Ernest calls for groups who have been defined by and share an identity under systemic inequalities “to work from an understanding of the historical condition of oppression to a vision of [self-determined] historical agency” (p. 18). Such agency can be achieved, he argues, through the construction of historical writing that acknowledges both the “fragments of history” found in archival institutional records and the previously unwritten experiences of their communities (p. 5). The potential for institutional records to become integral fragments of history and memory for communities, and to be part of emergent discourses, depends on both their sustained preservation and accessibility.

### **Conclusion: information professionals taking the long view**

Mental health records can reveal to us a perspective, albeit a partial one, into an institutional environment that is relatively isolated and unfamiliar for much of our society. The accessibility of these medical records, whether currently or in the future,

as data or heritage sources is necessary for the potential creation of new communities and new cultural endeavors (cf. Bastian, 2003; Ernest, 2004). For example, access to archival hospital records can lead to digital archives for hospital staff members or academic researchers, virtual museums on the web about mental institutions, and patient and staff oral narratives contextualized and compared with archival hospital records.

Framing mental hospital records within ANT in order to accommodate the always changing and long-term work that material objects can do is a conceptual start toward thinking about how institutional records with sensitive information should be approached from a legal and ethical standpoint. ANT promotes a dynamic perspective on the relationship between medical records and people over time. Therefore, the laws and codes regarding medical records retention, destruction, and archival preservation and access should be revisited constantly with the following queries: do they balance the need to protect individuals' privacy with the impetus to preserve our cultural record? Do they reflect current opinions and attitudes toward patients' rights and researchers' access needs? Furthermore, ANT helps articulate why the drive for information access must be tempered with the understanding that information interacts with individuals, is contextualized by the situation, and has the potential to be emotionally, economically, or socially impactful if retained and accessed.

Concomitant with the adoption of ANT as a theoretical framework for conceptualizing our relationship with medical records, information professionals can become greater advocates of taking the long view in preserving what may not be viewed as worth saving in the short term, especially in regard to maintaining privacy and confidentiality and assuaging liability. Adopting the stance of long-term preservation helps to justify retaining records even if they may need to remain in a dark archives for an indefinite amount of time. Privacy norms and the laws regarding medical records can and have changed over time. Records of a certain age that are legally restricted or deemed too sensitive for public access by its custodians may no longer be so in the future. Active hospitals must continue to be risk-adverse to allowing record access as it could lead to liability issues or damage to their reputation. However, even if they currently may not want to share their decommissioned records, they could alter their policies in the future or, as seen across the USA, close down and the state archives would eventually allow for those records to become available to the public with less concern about legal repercussions to the hospital.

The uncertainty and potential for changes in legal, ethical, and emotional stances over time toward sensitive records such as of the ones created in mental institutions means that preemptive preservation actions prior to appraisal may be the most prudent solution in practice. According to archivist Mark Greene (Greene, 2002; Greene and Meissner, 2005; Greene, 2010), the archival mission of accommodating future research is a necessarily unknowable one because it is impossible to know what documents or information researchers will want to access. Therefore, Greene advocates that archivists should err on the side of retention and preservation of materials, regardless of current technical or legal impediments. Beyond their daily work practices, information professionals should consider taking on a more proactive role as advocates of the long-term preservation and future access of health records. If future research shows evidence of negative repercussions on the cultural record because of health privacy laws, information professionals will need to work with scholars, researchers, and legal experts to discuss and formulate a response that

addresses the current and proposed restrictions. The response may include best practice recommendations for upholding the preservation and archiving of these records, as well as epistemological arguments for why the records should be preserved for the long term and eventually made accessible.

### Notes

1. <http://mentalhealthrecovery.omeka.net/>
2. [www.exploratorium.edu/visit/west-gallery/whatisnormal](http://www.exploratorium.edu/visit/west-gallery/whatisnormal)
3. [www.4plus4equals.org/](http://www.4plus4equals.org/)

### References

- Abbott, A. (1982), "The emergence of American Psychiatry, 1880-1930", dissertation, University of Chicago, Chicago, IL.
- American Psychiatric Association (2000), *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed., American Psychiatric Association, Washington, DC.
- Anderson, B. (1991), *Imagined Communities*, Verso, New York, NY.
- Assmann, J. and Czaplicka, J. (1995), "Collective memory and cultural identity", *New German Critique*, No. 65, pp. 125-133.
- Bastian, J. (2003), *Owning Memory: How a Caribbean Community Lost Its Archives and Found Its History*, Libraries Unlimited, Westport, CT.
- Bernstein, R. (2010), *The Pragmatic Turn*, Polity, Malden, MA.
- Bloch, M. (1962), *The Historian's Craft*, Knopf, New York, NY.
- Bourdieu, P. (1991), *Language and Symbolic Power*, Harvard University Press, Cambridge, MA.
- Bowker, G.C. and Star, S.L. (1999), *Sorting Things Out: Classification and Its Consequences*, MIT Press, Cambridge, MA.
- Caswell, M. (2010), "Khmer rouge archives: accountability, truth, and memory in Cambodia", *Archival Science*, Vol. 10 No. 1, pp. 24-44.
- Clarke, A.E. (2005), *Situational Analysis: Grounded Theory After the Postmodern Turn*, Sage, Thousand Oaks, CA.
- Cox, R. (2009), "The archivist and community", in Bastian, J. and Alexander, B. (Eds), *Community Archives: The Shaping of Memory*, Facet Publishing, London, pp. 251-264.
- Craig, B. (1989), "Hospital records and record-keeping c. 1850 – c. 1950 part I: the development of records in hospitals", *Archivaria*, No. 29, pp. 57-87.
- Craig, B. (1990), "Hospital records and record-keeping c. 1850 – c. 1950 part II: the development of record-keeping in hospitals", *Archivaria*, No. 30, pp. 21-38.
- Dandeker, C. (1990), *Surveillance, Power and Modernity: Bureaucracy and Discipline from 1700 to the Present Day*, St Martin's Press, New York, NY.
- Dant, T. (2005), *Materiality and Society*, Open University Press, Maidenhead.
- Ernest, J. (2004), *Liberation Historiography: African American Writers and the Challenge of History, 1794-1861*, University of North Carolina Press, Chapel Hill, NC.
- Foucault, M. (1975/1995), *Discipline & Punish*, Vintage Books, New York, NY.
- Foucault, M. (1961/2006), *History of Madness*, Routledge, London.
- Garfinkel, H. (1967/1984), "Good organizational reasons for 'bad' clinic records", *Studies in Ethnomethodology*, Polity Press/Blackwell Publishing, Malden, MA, pp. 186-207.

- Gilliland, A.T. and Wiener, J.A. (2011), "Digitizing and providing access to privacy-sensitive historical medical resources: a legal and ethical overview", *Journal of Electronic Resources in Medical Libraries*, Vol. 8 No. 4, pp. 382-403.
- Glaser, B.G. and Strauss, A.L. (1965), *Awareness of Dying*, Aldine Publishing, Chicago, IL.
- Goffman, E. (1961), *Asylums: Essays on the Social Situations of Mental Patients and Other Inmates*, Anchor Books, New York, NY.
- Greenberg, G. (2013), *The Book of Woe: The DSM and the Unmaking of Psychiatry*, Blue Rider Press, New York, NY.
- Greene, M. (2002), "The power of meaning: the archival mission in the postmodern age", *The American Archivist*, Vol. 65 No. 1, pp. 42-55.
- Greene, M. (2010), "MPLP: it's not just for processing anymore", *The American Archivist*, Vol. 73 No. 1, pp. 175-203.
- Greene, M. and Meissner, D. (2005), "More product, less process: revamping traditional archival processing", *The American Archivist*, Vol. 68 No. 2, pp. 208-263.
- Gross, M. (2010), "The public proceduralization of contingency: Bruno Latour and the formation of collective experiments", *Social Epistemology: A Journal of Knowledge, Culture and Policy*, Vol. 24 No. 1, pp. 63-74.
- Ingleby, D. (1983), "Mental health and social order", in Cohen, S. and Scull, A. (Eds), *Social Control and the State*, Martin Robertson, Oxford, pp. 141-188.
- Jimerson, R. (2009), *Archives Power: Memory, Accountability, and Social Justice*, Society of American Archivists, Chicago, IL.
- Ketelaar, E. (2005), "Sharing: collected memories in communities of records", *Archives & Manuscripts*, Vol. 33, pp. 44-61.
- Lakoff, G. (1987), *Women, Fire, and Dangerous Things*, University of Chicago Press, Chicago, IL.
- Lakoff, G. (2008), *The Political Mind*, Penguin, New York, NY.
- Lakoff, G. and Johnson, M. (1980), *Metaphors We Live By*, University of Chicago Press, Chicago, IL.
- Lamberg, L. (1998), "Gay is okay with APA (American Psychiatric Association)", *Journal of The American Medical Association*, Vol. 280 No. 6, pp. 497-499, available at: [www.soulforce.org/article/642](http://www.soulforce.org/article/642) (accessed December 20, 2011).
- Latour, B. (2005), *Reassembling the Social: An Introduction to Actor-Network-Theory*, Oxford University Press, New York, NY.
- Latour, B. and Woolgar, S. (1979/1986), *Laboratory Life: The Construction of Scientific Facts*, Princeton University Press, Princeton, NJ.
- Lawrence, S. (2007), "Access anxiety: HIPAA and historical research", *Journal of the History of Medicine and Allied Sciences*, Vol. 62 No. 4, pp. 422-60.
- McKemmish, S., Upward, F.H. and Reed, B. (2009), "Records continuum model", in Bates, M.J. and Maack, M.N. (Eds), *Encyclopedia of Library and Information Sciences*, 3rd ed., Taylor and Francis, New York, NY, pp. 4447-4459.
- MacNeil, H. (2001), "Trusting records in a postmodern world", *Archivaria*, No. 51, pp. 36-47.
- Melling, J. (1999), "Accommodating madness: new research in the social history of insanity and institutions", in Melling, J. and Forsythe, B. (Eds), *Insanity, Institutions and Society, 1800-1914: A Social History of Madness in Comparative Perspective*, Routledge, New York, NY, pp. 1-30.
- Metzl, J. (2009), *The Protest Psychosis: How Schizophrenia Became a Black Disease*, Beacon Press, Boston, MA.
- Micale, M. (1993), "On the 'disappearance' of hysteria: a study in the clinical deconstruction of a diagnosis", *Isis*, Vol. 84 No. 3, pp. 496-526.
- Mol, A. (2002), *The Body Multiple: Ontology in Medical Practice*, Duke University Press, Durham, NC.

- Muller, S., Feith, J. and Fruin, R. (1898/1968), *Manual for the Arrangement and Description of Archives*, The H.W. Wilson Company, New York, NY.
- Ngin, P. (1994), "Recording keeping practices of nurses in hospitals", *The American Archivist*, Vol. 57 No. 4, pp. 616-630.
- Parry-Jones, W. and Parry-Jones, B. (1994), "Implications of historical evidence for the classification of eating disorders: a dimension overlooked in DSM-III-R and ICD-10", *The British Journal of Psychiatry*, Vol. 165 No. 3, pp. 287-292.
- Pearce-Moses, R. (2005), "Record", Glossary of Archival and Records Terminology, available at: [www2.archivists.org/glossary/terms/r/record](http://www2.archivists.org/glossary/terms/r/record) (accessed October 25, 2012).
- Petrila, J. (2000), "Legal and ethical issues in protection the privacy of behavior health care information", in Gates, J. and Arons, B. (Eds), *Privacy and Confidentiality in Mental Health Care*, Paul H. Brookes, Baltimore, MD, pp. 91-125.
- Pickering, A. (1995), *The Mangle of Practice: Time, Agency, and Science*, University of Chicago Press, Chicago, IL.
- Puddephatt, A.J. (2005), "Mead has never been modern: using meadian theory to extend the constructionist study of technology", *Social Epistemology: A Journal of Knowledge, Culture and Policy*, Vol. 19 No. 4, pp. 357-380.
- Rogler, L.H. (1997), "Making sense of historical changes in the diagnostic and statistical manual of mental disorders: five propositions", *Journal of Health and Social Behavior*, Vol. 38 No. 1, pp. 9-20.
- Rosenberg, C. (1987), *The Care of Strangers: The Rise of America's Hospital System*, Basic Books, New York NY.
- Scull, A. (1983), "Humanitarianism or control? Some observations on the historiography of Anglo-American psychiatry", in Cohen, S. and Scull, A. (Eds), *Social Control and the State*, Martin Robertson, Oxford, pp. 118-140.
- Starr, P. (1982), *The Social Transformation of American Medicine*, Basic Books, New York, NY.
- Star, S. and Griesemer, J. (1989), "Institutional ecology, 'translations' and boundary objects: amateurs and professionals in Berkeley's Museum of Vertebrate Zoology, 1907-1939", *Social Studies of Science*, Vol. 19 No. 3, pp. 387-420.
- Stoler, A. (2009), *Along the Archival Grain: Epistemic Anxieties and Colonial Common Sense*, Princeton University Press, Princeton, NJ.
- Szasz, T. (1974), *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct*, Harper & Row, New York, NY.
- Taylor, H. (1982), "The collective memory: archives and libraries as heritage", *Archivaria*, No. 15, pp. 118-130.
- Trace, C. (2002), "What is recorded is never simply 'what happened': record keeping in modern organizational culture", *Archival Science*, Vol. 2 Nos 1/2, pp. 137-159.
- Weber, M. (1948/1991), *From Max Weber: Essays in Sociology*, Routledge, Oxon.
- Wilson, J.P. (1994), "The historical evolution of PTSD diagnostic criteria from Freud to DSM-IV", *Journal of Traumatic Stress*, Vol. 7 No. 4, pp. 681-698.
- Yakel, E. (2001a), "An institutional view of electronic records management: hospitals and teleradiology", *The Information Management Journal*, Vol. 35 No. 1, pp. 26-33.
- Yakel, E. (2001b), "The social construction of accountability: radiologists and their record-keeping practices", *The Information Society*, Vol. 17 No. 4, pp. 233-245.
- Yates, J. (1989), *Control Through Communication*, Johns Hopkins University Press, Baltimore, MD.
- Yeo, G. (2007), "Concepts of record (1): evidence, information, and persistent representations", *The American Archivist*, Vol. 70 No. 2, pp. 315-343.

---

**Further reading**

- Department of Health and Human Services (2011), "Human subjects research protections: enhancing protections for research subjects and reducing burden, delay, and ambiguity for investigators (HHS-OPHS-2011-0005)", *Federal Register*, Vol. 76 No. 143, pp. 44512-44531.
- Department of Health and Human Services (2013), "Modifications to the HIPAA privacy, security, enforcement, and breach notification rules under the health information technology for economic and clinical health act and the genetic information nondiscrimination act; other modifications to the HIPAA Rules (78 FR 5565)", *Federal Register*, Vol. 78 No. 17, pp. 5565-5702.
- Novak, S. (2005), "Testimony for the January 11, 2005 NCVHS Subcommittee on privacy and confidentiality hearings", available at: <http://ncvhs.hhs.gov/050111p5.htm> (accessed February 12, 2010).

**Corresponding author**

Lorraine Dong can be contacted at: [lorrie.d@gmail.com](mailto:lorrie.d@gmail.com)

**This article has been cited by:**

1. Katherine Birkwood, Eric Howard. 2015. Bibliography. *Library & Information History* 31:3, 218-228. [[CrossRef](#)]